SERVING PEOPLE WITH INTELLECTUAL DISABILITIES:
A COMPARATIVE INVESTIGATION OF THE PERCEPTION
OF FAMILY CAREGIVERS AND KANSAS MINISTRY
NETWORK CREDENTIAL HOLDERS

A PROJECT SUBMITTED TO THE
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ABSTRACT

In recent years, church leaders have struggled to integrate persons with disabilities and their family caregivers into the regular life of the church. A misunderstanding of the disability culture combined with a lack of resources and volunteers effectively curtail ministry efforts for successful integration and inclusion for persons with disabilities.

This comparative investigative study of both clergy and family caregivers of persons with intellectual disability provides an initial foundation for clergy to envision effective ministry in mutual relationship. This project surveyed eighty-four Assemblies of God Kansas Ministry Network credential holding clergy members as well as thirty-six adult family caregivers of persons with disability. The survey also asked each group to predict the response of the other.

The research suggests the following: (1) clergy members have little awareness of their discrepancies between claimed theology and supportive practice, (2) both clergy and caregivers require additional opportunities to develop mutual understanding, (3) very few churches attempt inclusionary practice or intentional targeted outreach in comparison to the prevalence of disability, (4) congregations can successfully implement some level of disability ministry despite their size or status, and (5) churches would benefit by collaborating with existing local social agencies.

Local pastors can build bridges alongside those within the disability community to further inclusion and create co-laborers for the work of the gospel.
ACKNOWLEDGMENTS

Let me begin by acknowledging the countless persons with disabilities and their family caregivers. Your desire to be active and included in the local congregation has provided insight and stamina in this journey. I am particularly grateful to Richard Goens and his mother who provided an early example of what could be. We still dream!

A number of people walked alongside me in this journey. Many thanks to Rev. Bill Gaventa for leading the academic disability community and to Ginny Thornburgh for tirelessly advocating churches to include persons with disability. I am indebted to Dr. Jeff & Kathi McNair, Dr. Julie Lane, and Dr. Michael Hoggatt for shaping my approach to special education and disability ministry during our NACSPED years. Dr. Erik Carter gave me countless tips over lunches, at conferences, and in airplanes. I remain humbled by the late Nella Uitvlugt of Friendship Ministries who showed me firsthand how ability ministry with empowered volunteers can transform individuals, congregations, and denominations. I am forever grateful to the leadership of Rev. Charlie Chivers and the Special Touch team for introducing and faithfully executing disability ministry within the Assemblies of God.

I am especially indebted to the leadership of Dr. Amos Yong, project adviser, from our first conversation on disability in 2005, to his input on this final project. Without Dr. Johan Mostert, I would still be lost in statistics—thank you for helping me
design the action research chapters. I have also appreciated the biblical insights Dr. Doug Oss, biblical adviser, has given me as I have poured over disability texts.

Special thanks to the leadership of Connie Zienkewicz and Lesli Girard of Kansas Families Together and Dr. Terry Yancey of the Assemblies of God Kansas Ministry Network. Their endorsements of this project led to higher than anticipated response rates.

I am deeply grateful for the constant encouragement of the Doctor of Ministry team at AGTS. Dr. Ava Oleson, AGTS D.Min. Program Coordinator, and Dr. Cheryl Taylor, AGTS D.Min. Program Director, provided support and inspiration every step of the way. Dr. Lois Olena, AGTS D.Min. Project Coordinator, somehow kept me on track over many, many years. I am thankful for the outstanding editorial gift of Dr. Stephanie Nance, who spent countless hours correcting my grammar. Without their tender mercies this project would still be languishing.

Finally, thank you to my wife Teresa—who has steadfastly stood by my side during the turns and twists of this endeavor. To my children, Marissa and Lillian, thanks for letting papa get his work done.

“Now to him who is able to do far more abundantly than all that we ask or think, according to the power at work within us, to him be glory in the church and in Christ Jesus throughout all generations, forever and ever. Amen.”—Ephesians 3:20-21 (ESV)
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CHAPTER 1: INTRODUCTION

The Context

The local church serves as the touchstone for my varied experiences in business, education, and other disability related organizations. Since late 2014, I have served as the bi-vocational lead pastor of a small rural church in Wellington, Kansas. During the workweek, I am employed as a full-time permanent special education substitute teacher for elementary students in Haysville, Kansas. With my passion for integrating people with disabilities into the community at large and the church in specific, I also accepted an appointment as Chair-Elect of the Kansas Special Education Advisory Council (SEAC).

During the previous decade, I served as an associate pastor and head of Christian schools at two churches, first in the urban Los Angeles, California, area and then in Wichita, Kansas. During my time in those roles, my primary duties included administration and development of the church day school, including facilitating accreditation processes and laying the foundation for inclusive Christian special education services. My secondary duties gave me opportunity to offer pastoral counseling, develop spiritual formation projects, and preach on a semi-regular basis.

While serving at Palm View Assembly of God in Whittier, California, I began a family and adult Sunday school class for adults with intellectual disability (ID). The class provided a forum for adults with ID ranging in age from fourteen to fifty-four to attend a session specifically for them. Several older parents of children with ID also attended the class with their child. The class size varied from six to fourteen persons in attendance on
a weekly basis. Through an interactive poster presentation at the May 2007 meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD) entitled “The Role of the Religious School in Developing Spiritual Supports in the Local Faith Community: A Case Study,” I presented the process of utilizing the Christian day school and Sunday religious education to foster mutual inclusion within the disability community.

While serving at Bethel Life Church in Wichita, Kansas, my daughter with Down syndrome participated in the Unforced Rhythms special needs disability class. During this time, I also received approval from the mission committee to lead a team of adult volunteer caregivers to serve at the 2011 Special Touch Summer Getaway in the Oklahoma District of the Assemblies of God.

The context of this project will fall under the auspices of Special Touch Ministries, an Assemblies of God U.S. Missions compassion ministry serving the concerns of people with disabilities. Special Touch is active in numerous states and districts with their trademark Summer Getaway, community based chapters, disability friendly church certifications, and training seminars. Special Touch, founded by Rev. Charlie Chivers in 1982, remains the largest national disability ministry in the Assemblies of God. Since 2005, I have served as a volunteer caregiver at several Summer Getaways, led small mission teams of caregivers, and represented Special Touch in the Southern California Network of the Assembly of God.

I have remained active in leadership roles for several national Christian disability organizations. As the executive treasurer of Friendship Ministries from 2008 to 2015, I oversaw the finances of an international organization devoted to developing inclusive
spiritual formation curriculum for those with intellectual disabilities in both the English and Spanish languages; Friendship Ministries is an independent ministry operating under the umbrella of the Christian Reformed Church North America (CRCNA). As a past president and member of the steering committee for the National Association of Christians in Special Education (NACSPED), I was recently named president of the Faith-based Schools and Organizations Caucus within the Council for Exceptional Children (CEC).

The Problem

Since the passage of the landmark Americans with Disabilities Act (ADA) in 1990 and the reauthorized Individuals with Disabilities Education Act of 2004 (IDEA), more people with intellectual disabilities (PWID) have experienced inclusion in the regular educational and social lives of the community. Parents and peers have acclimated to seeing children, youth, and young adults engage in social and educational settings. Public structures and institutions have altered facilities and programming to meet unique needs of persons with disability. The same is not true in the local church, in large part due to the wary perceptions of many persons with disabilities towards in response to the evangelical communities’ successful opposition to disability legislation. Prior to the passage of ADA in 1990, the NAE successfully argued that the freedom to practice religion trumped a government requirement to provide compassionate accessibility to religious services.¹ In December of 2012, the evangelical movement successfully lobbied against the U.S. Senate ratification of The United Nations Treaty on the Rights of Persons

with Disabilities.² Both of these uncompassionate actions have created an indelible and formidable gap between many faith communities and those within the greater disability community. In the most recent 2010 National Organization on Disability (NOD) survey, people with disabilities attended religious services at least one time per month – seven percent less than persons without disabilities did.³ Churches that seek to be missional in compassionate disability outreach must increasingly be intentional.

Although a few larger urban churches have ministries in development, many pastors and churches have limited financial and human resources, inadequate knowledge, and undiscovered skill sets in order to undertake this mission. Whether resulting from an insufficient theological understanding of disability, uninformed of a significant number of new resources, a lack of friendships with people with intellectual disabilities, or misconstructions on the relationship between disability and healing, pastors often find it easier to seek intentionally other missional initiatives, consequently overlooking an ever-growing need that cuts across all age and demographic lines. The continued rise of people-first advocates challenges the Christian community to invest fully the same level of energy in spiritual formation, discipleship, and hospitality among this significant population. Pastors and churches must learn new paradigms, discover innovative strategies, and expand their concept of ministry to embrace a person with disability over the course of a lifespan.


³ Kessler Foundation / NOD, The ADA, 20 Years Later., 2010.
The Purpose

This research project will investigate, compare, and contrast the perceptions of intellectual disability between pastors of the Assemblies of God Kansas Ministry Network (AGK) churches and family caregivers in order to raise awareness, promote understanding, facilitate integration and expand services. Utilizing those findings, this project will recommend AGK district interventions to guide pastors and churches in developing contextualized missional strategies to include PWID as ministry partners by overcoming perceived barriers, embracing unique theological perspectives, addressing structural evils, and collaborating with other secular and faith based organizations in the community.

Definition of Terms

*Ableism*—Discrimination or prejudice against persons with disabilities.

*Accommodation*—Removing structural or psychological barriers to allow access.

*Collaboration*—Working together across disciplines to create positive outcomes.

*Disability*—The consequences of physical or mental impairments that substantially limit major life activities.

*Handicap*—A socially constructed disadvantage as a result of disability.

*Impairment*—A physiological loss of normative functioning or form.

*Intellectual Disability*—“a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.”

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Modification—Changing the established rules to allow alternative pathways for
success.

Normate—The socially constructed ideal image people represent themselves as
definitive humans.5

Normate Hermeneutic—The means by which scripture is interpreted so that it
complies with and reinforces a particular culture’s bias toward the socially constructed
norms.6

Supports—Resources that allow those with identified needs to pursue positive
outcomes.

Description of the Proposed Project

Scope of the Project

The Survey: Local Church Edition

I will create a comprehensive survey questionnaire utilizing Qualtrics and make it
available in both online and paper format to administer to all AGK churches in early July
2014. At the end of July 2014, I will collect the survey data and will co-relate it to the
completed 2013 ACMR data report.

The instrument will consist of one quantitative section. I will collect information
in the following domains: the number of people with intellectual disabilities attending at
least one time per month including gender and age range, the type of programs offered

5 Rosemarie Garland-Thomson, Extraordinary Bodies: Figuring Physical Disability in American

6 Kerry Wynn, “The Normate Hermeneutic and Interpretations of Disability within the Yahwistic
Narratives” in This Abled Body, Semeia Studies, Vol. 55, edited by Hector Avalos, Sarah J. Melcher, and
specifically for people with ID and family caregivers in the church, any programs co-sponsored by the church in the community for PWID or their family caregivers, and any involvement of PWID engaging in ministry or service.

_The Survey: Credential Holder Edition_

I will create an anonymous comprehensive survey questionnaire utilizing Qualtrics and make it available using unique identifiers in both online and paper format to administer to all AGK credentialed ministers (certificated, licensed, and ordained). The survey will be distributed in early April 2014 to coincide with the annual AGK Ministry Network meeting and will be closed in June 2014. The instrument will consist of three major sections:

1. **Background demographic data**—I will collect information on age, gender, academic level attained, years of ministry experience, years in current position, pastoral staff portfolio (lead, executive, youth, music, children, etc.) and church size.

2. **Quantitative section**—I will develop a series of questions informed by the literature reviews. These inquiries could include several domains: structural barriers, theology, attitudes, current disability ministry offerings, and reasons for lack of disability ministry. Queries will include beliefs on the relationship of disability and sin (culpability), disability and healing, and on PWID engaging in ministry.

3. **Qualitative section**—I will elicit responses from ministers to relate any positive or negative experiences, feelings, and situations with PWID or their family caregivers who were either disruptive to the church setting or meaningful in congregational life.
The Survey: Family Caregiver Edition

I will create an anonymous comprehensive survey questionnaire utilizing Qualtrics and make it available in either online and paper format for administration to PWID or their primary family caregivers in AGK churches (sovereign, district affiliated, and parent-affiliated). In order to protect privacy issues, AGK ministers will be requested to identify PWID or their primary family caregivers from among their congregation and provide them access to either online portals or paper survey instruments provided by me to the AGK ministers. To ensure additional participation, public social service organizations will alert their clients to the survey. The survey will be conducted from early April 2014 through June 2014. The instrument will consist of three major sections:

1. Background demographic data—For all participants with intellectual disability, I will request the PWID or their family caregiver to provide information on age, gender, grade level attained, type of disability, years involved in church, and frequency and type of church volunteerism. For children (under 21 years of age) with intellectual disability, I will request the primary family caregiver to provide their own information on age, gender, academic level attained, years involved in church, and frequency and type of volunteerism.

2. Quantitative section—I will develop a series of questions informed by the literature reviews. These inquiries could include several domains: structural barriers, theology, attitudes, current disability ministry offerings, and potential reasons for lack of disability ministry for churches within the AGK. Queries will include beliefs on the relationship of disability and sin (culpability), disability and healing, and on PWID doing ministry.
3. Qualitative section—I will elicit responses from PWID and their primary family caregiver to relate any positive or negative experiences, feelings, and situations with PWID or their family caregivers that were either disruptive to the church setting or meaningful in congregational life.

**Evaluation of Data**

I will group the survey responses into the three current AGK regions (East, Central, and West) and further divide them into their respective average membership sizes (0 to 79, 80 to 200, >200) to align with the current nine-presbytery model. According to 2012 ACMR reports, the AGK currently has 137 churches with 17,494 average Sunday morning attendees. The Network has twenty-eight churches in the western region with 2,119 attendees, forty churches in the central region with 5,556 average Sunday morning attendees, and sixty-nine churches are in the eastern region with 9,819 attendees. I will then analyze and compare the survey results to the ACMR, current disability U.S. census data of the county, and the special education services report of the local public school district.

**Presentation of Data**

Utilizing the analyzed survey results, I will make strategic recommendations to AGK district personnel regarding future development of specific interventions at the August 2014 AGK district presbytery meeting and the AGK church ministry conference in February 2016. The survey findings will be posted in online forums for discussion and feedback. Finally, I shall create a report that will be helpful to both clergy and family caregivers for achieving mutual ministry by communicating needs, desires, and expectations with each other.
Limitations

This research is limited in scope to persons already involved in some capacity, either past or present, within a local Assembly of God Kansas congregation. Although the project will examine perceptions of ID, it will not create any curriculum or theological training aids for pastors or churches. This research is also limited to evaluating perceptions of PWID and their family caregivers; it will not investigate perceptions of people with physical disabilities only.

Phases of the Project

The project design will include five stages of mutually informed development, including research, planning, implementation, evaluation, and writing. Much of the research for the biblical-theological review and general literature review will occur prior to the actual implementation of the survey project and will inform the content of the survey questions. Additional research and writing for the biblical theological review will be done after the survey results are compiled in order to address questions raised within the survey.

Research

The first stage of this project will involve research into the current social science perspectives of disability ministry practice and its relationship to the disability movement in general. The second stage will examine the biblical theological underpinnings of disability understanding and disability ministry.
General Literature Review

The general literature review will explore research published in the last decade that identifies self-reported needs of people with intellectual disabilities (PWID) and their family caregivers. The study will examine the corresponding systems of services and supports and their efficacy in affecting desired outcomes. Chapter 3 will also explore the relationships and failures that exist between those needs and the systems of supports provided by a network of collaborative organizations across the lifespan. This chapter, utilizing resources from where the special educational community, the intellectually and developmentally disabled community, and the faith-based community converge, will seek to explore various models of service and spiritual support partnerships to maximize mutually beneficial outcomes.

Biblical-theological Review

Chapter 2 will begin by exploring differing hermeneutical approaches taken with common disability texts. This in-depth study, utilizing a disability informed lens, will consider First Testament holiness codes in Leviticus and Deuteronomy, the eschatological understanding of disability in Isaiah and Jeremiah, and the question of disability suffering contained in the writings of Job. The study will also take into account New Testament passages exploring the relationships between disability and sin, disability and healing, and disability and body ministry.

Preparation

This project will require the development of a survey instrument utilizing Qualtrics. It will also require the identification of all credentialed ministry holders in the AGK ministry network, as well as a sufficient number of parent caregivers of persons
with intellectual disabilities involved in congregations within Kansas. The data will be analyzed to discover distinctive perceptions among clergy and caregiver populations.

*Implementation*

The identification of AGK ministry credential holders and network churches will begin in February 2014. The identification of parent caregivers of persons with intellectual disabilities will begin in March 2014 with the assistance of existing statewide community organizations. The survey instruments will be available for participants to complete between April 2014 and July 2014.

*Evaluation*

Upon conclusion of the surveys, the project will continue with both qualitative and quantitative analysis of the comparative data during July and August 2014. The resultant findings will inform future strategic options which both the local church and the AGK ministry network can create to increase disability ministry alongside caregivers and persons with intellectual disability.

*Writing*

The writing of this project will occur during several major periods during 2014 and 2015, reflecting the realities of bi-vocational ministry. The contemporary literature review (chapter 3) will conclude during early 2014 and will highly influence the survey project design. The analyzed findings of the project (chapter 4) will transpire in the fall of 2014. These findings will help inform the final draft of the biblical theological review (chapter 2) in the fall of 2015. A summary reflection of the entire project experience
(chapter 5) will be concluded in December 2015. I will write the project introduction (chapter 1) in December 2015.

**Conclusion**

The presence of families, caregivers, and persons with intellectual disability remain either conspicuously absent or relatively hidden in the local church. A fresh biblical understanding of the role of persons with disability within the story of the people of God will provide a foundation for the local church to pursue actively mutually beneficial ministry among those with disabilities, utilizing collaborative techniques already emerging within other disability focused disciplines. Churches intentionally implementing collaborative supports and services which allow persons with disability to fulfill their calling witness a holistic model of the kingdom of God.
CHAPTER 2: BIBLICAL-THEOLOGICAL

LITERATURE REVIEW

Introduction

The faithful people of God embrace His active participation in the created world, where He reconciles everyone back to Him. The contemporary church hearkens back to the events of the day of Pentecost (Acts 2:17-18) where binaries of exclusion were broken (Gal. 3:28). The new community of believers rejected the prevailing social construct and explicitly welcomed those considered weak: the elderly, the female, the poor, and the foreigner. Although no specific mention is made of persons with either physical or intellectual disability within the list of Acts or Galatians, they too are implicitly included. Unfortunately, the portal for full participation and flourishing within the community of faith often remains inaccessible to persons with disability.

This biblical literature review will examine several foundational writings on disability throughout the unfolding redemptive history of the Scriptures. The passages were chosen as representative of perspectives within the covenantal eras and comprehensive of many types of disabilities. This analysis will consider the holiness codes contained within Leviticus, the utopian prophecies of Isaiah and Jeremiah, the suffering of Job, and the interaction among Jesus and persons with disability portrayed within the Gospel of John.
Hermeneutical Approach

The American rediscovery of the power of Pentecost during the early twentieth century brought a renewed understanding of God’s work in healing, the work of mutual ministry among the local church, and the role of the individual. The first generation of Pentecostal scholars adopted a hermeneutic derived from the Bible Reading Method common to American fundamentalism.\(^1\) Harmonizing prevalent theological and cultural norms with Pentecostal experiences resulted in an increased pursuit of divine healing for functional and sensory impairments without rejoicing in the potential ministry contributions of persons with intellectual or permanent physical impairments.

The focus on the events at Pentecost (Acts 2) and its foreshadowing (Joel 2:28-29) at times did not take into consideration other passages prophetically inclined toward the utopic eschatological future which considers persons with disabilities crucial. The contemporary church, continuing in Pentecostal pursuits, must rekindle a fresh understanding of the necessary vitality and contributions of persons with disabilities as agents in mutual ministry. The editors of one treatise on disability suggested that the ignorance of the non-normate\(^2\) contexts of scriptural texts, particularly on the relationship of sin, disability, and exclusion, have distorted Christian thought and practice.\(^3\) This naturally leads to an exploration of hermeneutical approaches.

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\(^2\) *Normate* is defined as the socially constructed ideal image people represent themselves as definitive humans. See Chapter 1 for an extended footnote.

The Four Questions

Several interpretative models of disability concurrently prevail in American society and consequently in local pastors and churches. Depending upon the denominational influences and even career backgrounds of volunteer staff, a local church special needs ministry may have leaders with various understandings of disability. Each model lends itself to reflecting theologically about a different question.

In all of ancient religious history, people understood impairments and disabilities as either the direct or indirect action of a supernatural being. Supernatural causality did not recognize any natural occurrences of impairment. The covenantal promises recited in Deuteronomy linked the failure of God’s people to follow his injunctions with curses that would produce conditions favorable to disability. John Christopher Thomas’ examination of the New Testament authors revealed that each of them, with the possible exception of Mark, attributed infirmities to God.\textsuperscript{4} The Augustinian doctrine of sovereignty placed the existence of persons with disability squarely on the whims of God demonstrating his power.\textsuperscript{5} In the popular mindset, people linked God’s sovereignty and disability as God’s punishment for sin. Supernatural causality often results in the question, “Who sinned?”

The scientific revolution slowly chiseled away at the direct causation of impairments. Today, the dominant social construct of disability perceives the world through a modern medical or functional ideal. This model identifies the lack of an individual’s functional abilities and focuses on the quest to achieve a cure, through either

\textsuperscript{4} John Christopher Thomas, \textit{The Devil, Disease, and Deliverance: Origins of Illness in New Testament Thought} (Cleveland, TN: CPT Press, 2010), 310.

medical approaches or divine healing, in order to restore a person into a fully able-bodied normate state. A functional model assumes normal is the state of being in which the maximum amount of economic productivity occurs. This perspective labels negative outcomes of productivity as “suffering.” The dominant question is that of theodicy: Why does God allow suffering?

The rise of disability studies during the last generation advanced a liberation model. In a reaction against ableism, Nancy Eiesland succinctly argued the social construct of disability discriminated against persons with physiological impairments, reducing them to valueless entities instead of contributive people. Her identification of Jesus as the disabled God-man upon the cross who sought to bring liberty to the poor resulted in the shifting emphasis to advocate for the change of unjust systems in the socio-political realm as well as in ecclesiastical communities. The Liberation model seeks to free persons with impairments from the effects of their disability within the greater society. In essence, this approach asks, “Who should be made equal?”

The limits paradigm sought to address critiques of the liberation model—which did not seem to take the physiologically impairments seriously enough. The limits model asserts finitude is a necessary aspect of humanness. Furthermore, it recognizes ever changing webs of conditional relationships across time and space define limits; the fluidness of fluctuating impairments recognizes God’s sovereignty and the fallen world in

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the present lived condition of infirmity.\textsuperscript{8} Theological reflection in the limits model asks, how can we be mutually supportive to one another in our present yet changing reality?

Each of these four approaches provide valuable insight to the biblical foundation for reconciling persons with disabilities into their rightful role as mutual ministers within the Christian community.

Disability Terms and Imagery

The biblical text uses several terms for physical disabilities—usually translated “lame” or “crippled.” In the First Testament the Hebrew word \textit{pissēaḥ} is used for “lameness” fourteen times.\textsuperscript{9} The New Testament uses the Greek adjective \textit{paralytikos} and its cognates ten times in reference to either congenital conditions or injuries to the arms, legs, and spine (Matt. 4:24; 8:6; 9:2,6; Mark 2:3-5, 9). The majority of instances used are during the healing ministry of Jesus.\textsuperscript{10} The noun \textit{chōlos} is also used fourteen times, referring to a non-ambulatory or crippled person (Matt. 11:5, 15:30, 31; 18:8, 21:14, Mark 9:45; Luke 7:22; 14:13, 21; John 5:3; Acts 3:2, 8:7, 14:8, Heb. 12:13).\textsuperscript{11}

The Hebrew word \textit{ʿāwar} and its cognates are used to refer to blindness thirty-five times in the First Testament. Similarly, the Greek word \textit{typhlos}, used fifty times in the New Testament, refers to a person who is unable to see—either physically blind or

\begin{thebibliography}{99}


\bibitem{Ibid} Ibid., 496.

\bibitem{Ibid2} Ibid., 389.
\end{thebibliography}
spiritually darkened. When both the words for lame and blind are used together, this synecdoche represents the entire range of disabilities.

But one must understand disability also as a social construction of Hebrew anthropology in the distinction between clean and unclean. Although no specific word for disability in our current contemporary understanding exists, the Hebrew word mûm may come close. Mûm occurs twenty-one times in the Old Testament. It translates as blemish, spot, or injury. Although not an exhaustive term to describe various ailments, it often refers to obvious visually identifiable disabilities such as blindness or lameness, yet not for those who are deaf, mute, or leprous. The use of mûm is primarily in reference to cultic participation for priests (Lev. 21:17ff) and for animals (22:20). It is often coupled with personal morality (Job 11:15) and righteousness before God.

On several occasions outside the cultic realm it refers to ideally perfect human specimens: Absalom (2 Sam. 14:25), the Shulamite woman (Song of Sol. 4:7) and the Hebrew men in Babylonian exile (Dan. 1:4).
The Levitical injunctions focusing on the priests’ wholeness when coupled with the curses found in Deuteronomy 28 give credence to divine supernatural-causality. The Levitical injunctions primary focus is on the holiness code—that which must be done in order to keep the covenant intact. When read together, the consequential curses of breaking the covenant includes numerous physical ailments and impairment which often yield a disabling condition.\textsuperscript{19} Disease and disability could be synonymous. A normate reading would assume that these injunctions, if good for the priests, would hold true for the entire population.

Another perspective of the holiness codes, however, offers a redemptive aspect. The cleanliness codes kept the unclean persons or objects the furthest away from that which is the most holy—the holy of holies.\textsuperscript{20} Specific limitations only increased with a higher risk factor. Only the high priest had to be the most ritually clean when entering the Holy of Holies.

To have a better understanding of the impact of blemish in the holiness codes, one must understand the relationship of \textit{mûm} (blemish) with its antonym \textit{tāmîm} (perfect). The Hebrew Bible uses \textit{Tāmîm} ninety-one times,\textsuperscript{21} with the majority of occurrences in Leviticus.\textsuperscript{22} The author uses the verbal interplay to indicate contrast and thus reveal the spectrum of tensions between the two words. Read together within a theocentric

\begin{footnotes}
\item[19] Amos Yong, \textit{Theology and Down Syndrome: Reimagining Disability in Late Modernity} (Waco, TX: Baylor University Press, 2007), 23.
\item[21] Mounce, 754.
\end{footnotes}
framework of ritual purity and cleanliness, *mûm* is often assigned to persons and items as impure, unclean, or defiled.

The Levitical codes designated certain animals and foods by their nature as either clean or unclean (Lev. 11). People and objects had a fluid relationship with uncleanness. (Lev. 11,15). Ways to become unclean ranged from anything involving bodily fluids to contact with death\(^\text{23}\)—the ultimate disability.

Uncleanness did not only affect the individual. The prophets used the metaphor of uncleanness theologically to describe cultural immorality and idolatry. Priests offered different prescriptions for those who needed to become physically clean, but moral uncleanness required cleansing mediated only by God.\(^{24}\)

Leviticus 5 set out two major categories of uncleanness for both animal and human. Becoming unclean is a part of the human condition. Ignoring the leakiness of bodies, Creamer writes, “misses the full richness of the experience of disability.”\(^{25}\) No one can stay ritually clean at all time. Even the best often unintentionally and unaware become unclean. Since the acts involved in daily life would result in some uncleanness, purification rituals were established. Furthermore, anything that made them unclean would reset at sundown where the priest could then partake in the normal communal life. Violations occurred when a person did not perform the purification rituals in proper manner and time, at that time he was subject to penalties.\(^{26}\) The law also provided for

\(^{23}\) Ibid, 350.

\(^{24}\) Ibid, 351.

\(^{25}\) Creamer, 28.

\(^{26}\) Yamauchi, 350.
persons who encountered the unclean without their knowledge, which made them unclean. Since the Day of Atonement served as the sole time all omissions have a chance to become rectified, the cult crafted particular methods and restrictions to ensure it be the most clean of all days. Although there was no way to repair the original offense, the sacrificial offerings would make up for the sins of omission and solve the problem of temple contamination.²⁷

Christian tradition depends upon the Judaic customs and teachings from which it emerged. The First Testament recounts numerous instances of disability. Narrative and didactic texts offer knowledge of attitudes and practices toward persons with disability. Upon a closer examination, many characters within the biblical texts also exhibit infirmities, debilitating conditions, and disabilities. These heroic characters present a contrast to a popular perspective, which rests on one interpretation of the Levitical codes. Yet neither may be exclusionary.

**Disability in the First Testament**

This section will review Leviticus 21:16-23 in its particular historical context and the immediate implications it had upon persons with disability in priestly service. Particular attention will highlight the cultural background, literary context, disability terms, and disability imagery.

**Leviticus**

Longstanding tradition holds that the Mosaic community authored Leviticus, while critical scholarship has attempted to identify strands of various groups of redactors

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²⁷ Ibid, 350.
in differing time periods within it.\textsuperscript{28} Although the final compilation may have originated in the Persian period of post-exilic,\textsuperscript{29} traditional Jerusalem elements remain which indicate its origins date to the second millennium BC during the time of Moses and the Exodus.\textsuperscript{30} Roy Gane concludes that the dates of multiple redactors are not as critical as its internal claim to divine authorship.\textsuperscript{31} John Kleinig further posits that Leviticus contains idealized principles unbounded by time as it was “unlikely that the law of Moses was every fully implemented at any period in Israel’s history.”\textsuperscript{32} The implication on a disability-nuanced interpretation is evident: idealized principles may only exist in the realized eschaton.

Leviticus principally concerns itself with ritual processes in an emerging culture. Anthropology is subordinated to a theological ideal of holiness, establishing God as the theologically central focal point of reference.\textsuperscript{33} This layering creates a connective tension between the human actions of daily living in a fallen world and the call to spiritual holiness. The normate interpretation reverts to an equivalent understanding—that which is unclean is profane; that which is clean is holy. In order to redeem disability passages, one must untangle that statement to allow the theocentric focus to emerge—all human

\begin{thebibliography}{99}
\bibitem{r29} Erhard Gerstenberger, \textit{Leviticus} (Westminster John Knox Press, 2003), 11.
\bibitem{r31} Roy Gane, \textit{Leviticus, Numbers}, The NIV Application Commentary (Grand Rapids, MI: Zondervan, 2004), 28.
\bibitem{r32} Kleinig, 18.
\bibitem{r33} Ibid., 7.
\end{thebibliography}
disability experience points toward the Creator. An examination of disability terms and imagery illustrates this effectively.

The Challenge of Exclusion and Priestly Defects

The simple reading of Leviticus 21:16-23 in the face of tradition relies upon the normate position. Although this passage did not limit priests with blemishes from serving in regular duties, it did exclude them from the most holy of duties. In this passage, a list of defects presented disqualify a person from the priestly class from priestly service. The twelve items listed in the negative attempt to identify an obvious typical ideal specimen. Most defects were visible to the eye, asymmetrical, long lasting (chronic), or produced a physical impairment. The first two defects, blindness and lameness, become synonymous with and representative for all disabilities. Later rabbis expanded this list to include 142 different items.34

The primary priestly duty is to perform sacrificial offerings of worship. A casual contemporary reader often reads the description of the blemished sacrificial animals back into Leviticus 21 as an expansion of what defects might exclude priests. Just as defective animals were considered polluted, impure, ugly and abominable, defective priests were similarly rejected.35

Commentators take several approaches to these problematic texts. The first approach leaves it intact as part of that covenantal era and does not attempt to justify it. Another approach rejects that text as an interpolation from later prevalent culture. A third


35 Olyan, 30.
approach finds an element that points towards possible future redemption within the unfolding covenants of redemptive history.

Saul Olyan points out that a defect, which disqualifies a priest from holy service, does not necessarily mean that the priest would do something to intentionally profane the temple, but that his potential to possibly profane the sanctuary is greater than others.\(^{36}\) Although this contributes to a stigmatized and marginalized culture, it does not automatically make him unclean.

Gane interprets this text as merely a list of job qualifications—only perfect people can have special access to God.\(^{37}\) With no attempt to wrestle with this passage, he individually spiritualizes it and concludes that ultimately ministers hold responsibility for their own actions.\(^{38}\) Although Nubuyoshi Kiuchi rejects that this passage does not equate physical normality with holiness or qualifications for priesthood, he does so by claiming disability is extremely uncommon. He then contradictorily asserts that this passage intends to take the focus off the external physical appearance of the priest and focus on inner holiness.\(^{39}\)

Erhard Gerstenberger suggests that the actual priestly practice does not indicate these regulations were characteristic of the priesthood, but seem to reflect the holiness codes for animals and sacrifices while simultaneously aligning with other oriental cultic

\(^{36}\) Ibid., 31.

\(^{37}\) Gane, 374.

\(^{38}\) Ibid., 378.

\(^{39}\) Kiuchi, 397.
practices not typical to the practitioners of the Yahweh religion. He redeems this passage as a call for congregational responsibility, purity, and cultic identity.  

Roger Cotton places these disqualifying defects within the context of the fall and a reminder that the presence of God requires purity and wholeness, conjoining both the theological and anthropological into one ethic; he then attempts to reconcile it with the notion that for the Christian believer, physical wholeness does not rely upon personal holiness. Mark Rooker, noting the ultimate impossibility of the perfection of both the priest and the sacrifice, suggests that both ideals culminate in the singularity of Jesus Christ—the High Priest and sacrificial lamb. This passage then serves as a reminder that no one qualifies to be without blemish except Christ.

Kleinig expands even further upon this by recognizing the spatial distances in relation to cleanliness and suggesting that the priest with a disability, while having limits, could still participate in much of the temple tasks while residing in its sacred spaces. In fact, even with the social marginalization among his non-priestly disabled peers, Olyan suggests the priest still enjoys prestige others do not have. A disability critique, however, seeks to examine if the theological spirituality, when uncoupled from the anthropological reality, results in marginalization or stigmatization.

40 Gerstenberger, 318.


42 Rooker, 276.

43 Olyan, 31.
Implications of the Torah

A cursory examination of the Hebrew Bible indicates that society did not value persons with disabilities. Taking their cue from the normate rendering of Leviticus 21, the prevailing culture placed persons with disabilities with other marginal persons, including the poor, the widow, and the alien. Their contributions were devalued and insulted. Actions by the larger community to insult foreign Gods often had the people of Israel mirroring disabilities on idols by cutting of the head, hands, and feet—symbolic of a loss of power and agency.44

As these injunctions were placed into popular culture, the marginalization was even more severe for the common person. This practice is recorded in 2 Samuel 5:8, which cautions “anyone blind or lame shall not enter the house.” Exclusion from the sanctuary is a serious religious disadvantage.45

Several commentators have explored whether the Levitical codes ensured communal participation in light of the fact that those with disabilities typically had negative social experiences in the larger community. The tribe of Aaron may have offered a model to the rest of the nation of Israel on how to treat those with disabilities (Lev. 21:22). Kleinig examines table fellowship as a communal aspect of the priests. He suggests that the Lord makes the blemished priest holy, when he eats the ration of holy food.46 Although ineligible to present offerings, the imperfect priest can become perfect again by residing in the presence of God. Likewise, a baptized believer in Christ, who

44 Ibid., 44.

45 Ibid., 32.

46 Kleinig, 459.
shares in the new body and blood of Jesus, qualifies again for ministry and service.\textsuperscript{47}

Although this table fellowship did not afford reconciliation in the practices of the ancient culture, it foreshadowed the future utopian and eschatological visions of persons with disabilities returning from exile and welcomed to God’s banquet.

Disability in the Prophetic Vision

After the destruction of Jerusalem and the ravages of the exile, the effects of disability upon the population was undoubtedly greater. The prophetic writings indicate a shift in perspective during this time. The prophetic writings of Jeremiah and Isaiah, recognizing that the nation of Israel is itself now disabled, relax some of the restrictions on persons with disability and suggest additional access to cultic worship.\textsuperscript{48} This section will examine one passage from Jeremiah and two passages from Isaiah.

\textit{Jeremiah}

The writings of Jeremiah are set in the decades before and after the fall of Jerusalem in 587 BC.\textsuperscript{49} The finalized book, completed by Jeremiah’s contemporaries, functioned to reflect on the past, make changes in the present, and pray for the future.\textsuperscript{50} Jeremiah’s underlying message is both impending judgment and forthcoming

\textsuperscript{47} Ibid., 461.

\textsuperscript{48} Olyan, 81.


\textsuperscript{50} J. Andrew Dearman, \textit{Jeremiah and Lamentations}, The NIV Application Commentary Series (Grand Rapids, MI: Zondervan, 2002), 20.
significant themes include the restoration of the covenant and the return to the land. Within the greater book of Jeremiah, two major divisions are delineated. The first section, chapters 1-25, focuses on judgment, while the second section, chapters 26-52, is a collage of materials united around deliverance.

The Book of Consolation (Jer. 30-33) serves as a reminder: even in the middle of judgment deliverance is already being prepared. Hope for recovery of both the land and a relationship with the Lord is possible, even though it would appear that the debilitating injury is incurable (30:13). Yet God promises to be the healer of that disability and the mitigator of exclusion (v. 17).

The poetic oracle of Jeremiah 31:7-9 extends the promise to those northern tribes in exile. Jeremiah focuses on restoring the people’s relationship to the creative Father. God redeems the path of exile, once the road to pain and death (Jer. 6:21). Now even persons with disability and the weak can return home safely. The word picture evokes

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52 Ibid., 24.

53 Fretheim, 19; Dearman, 22.

54 Fretheim, 413.

55 Martens, 186; Dearman, 267.


57 Martens, 190.


59 Fretheim, 431.
memories of the disabled nation of early Israel, subjugated to the physical scars of bondage from their Egyptian captors, who also fled in the original exodus.60

In Jeremiah’s description of the remnant returning, he lists categories of persons who typically cannot undergo long journeys due to physical conditions: the blind, the lame, expectant mothers, and women in labor.61 In a similar context to Jeremiah 6:21, the synecdoche—the blind and lame—represents persons with disabilities. Although God made access to the pathway and inclusion on the journey easier, He did not change their underlying conditions. Olyan suggests that God intended to show that no one gets left behind.62 Their listed presence with women in general and expectant mothers in particular adds to the normate rendering of cultural stigmatization directed towards unproductive members of the remnant in rebuilding Jerusalem. Pamela Scalise interprets the phrase “traveling as a great throng” as representing an inclusive environment: qualifying factors of mutual aid and relationship override concerns of productivity and function. The warriors assist the disabled; the clean support the unclean — together they make one united journey home.63 Jeremiah highlights these particular excluded ones as being representative of the new birthed kingdom. The imagery of expectant mothers symbolizes new life in a restored order that includes all.64

60 Ibid., 428.

61 Longman, Jeremiah, Lamentations, 205.

62 Olyan, 82.


64 Fretheim, 431.
Isaiah

Scholars have proposed numerous hypotheses regarding the date and authorship for Isaiah. Most center around First Isaiah (ch 1-39) and Second Isaiah (ch 40-66). Dating ranges from the pre-exilic period of the eighth century BC or the post-exilic period as last as the fifth century BC. Several modern commentators have accepted Isaiah as it stands as one united work. They argue that part of the prophetic task is to look forward into the unfolding story of God and write what will come. For the purposes of examining the disability texts, whether it is a future prediction or a near event makes no difference; shifting perceptions of persons with disability occur as the situation changes.

The proclamation of victory contained within the vision of Isaiah 33:17-24 introduces the coming king of salvation. Whereas previous leaders had been impure and the surrounding the nations had assembled against Israel, God kept His covenantal promise. God redeemed and restored His people. In this new ethic of return, while disabilities still exist, persons are no longer stigmatized because the setting they were in changed. As Olyan writes, “It is their situation and status that are now transformed.” The new utopia does not perceive disabilities as anything but a normal part of the spectrum.

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67 Motyer, 262.

68 Olyan, 84.
Where before the term for perfect beauty had been used in tension with marginalized defects in the Levitical passages, they are now no longer polar opposites. Beauty does not just replace the disfiguring branding of an exile (Isaiah 3:24), but being redefined as part and parcel of the characteristic of the Messiah, paralleling Psalm 45:2, and hinting at the disabled suffering servant images in Isaiah 53. God fulfills His promises with the reign of the promised Christ. The scars of branding remain, but are now defined as beautiful. Isaiah also links the presence of the beautiful king to the land; for the once branded, disfigured, and disabled ones, returning to this land promises freedom from marginalization and access to worship. The blind and lame, representative of all those with disabilities, are now included among the spoilers who have been restored and can provide for their families as God provides for them.

The vision’s conclusion again couples sin and sickness (Isaiah 33:24). In this new Messianic reign, both physical sickness and spiritual sin are erased. Far from seeing persons with disabilities receiving new access in the new age, Watts interprets this passage through a stigmatizing lens of pity, which rejoices in the new prosperity at the expense of those with disabilities.

Stanley M. Horton links divine health to forgiveness

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69 Goldingay, 190.
70 Motyer, 267.
71 Schipper, Disability and Isaiah’s Suffering Servant, 30.
72 Oswalt, 380.
73 Motyer, 267.
74 Olyan, 84.
of sin.\textsuperscript{76} Similarly, Oswalt, rejoicing in the place of spiritual and physical health, unfortunately identifies the yet remaining presence of the physical impairment as an effect of sin.\textsuperscript{77}

John Goldingay nuances Isaiah 33:24 better by interpreting it as even those who have physical impairments can rightfully assert they are no longer ill (or with defect) since their societal status has changed through forgiveness of sins.\textsuperscript{78} J. A. Motyer’s interpretation suggests that this couplet should be seen in opposition to the presence of disability. When sin is not present, neither exists the disabling social aspects of a physical illness, impairment, or infirmity.\textsuperscript{79} Olyan rejoices that the Lord is exalted because it is His Messianic Kingship that “makes the normalization of a disabled person possible.”\textsuperscript{80}

The passage of Isaiah 56:3-7 examines the return of privileged access in the new utopia for priests with a disability. This passage resides in a unique juncture in Isaiah, traditionally known as the beginning of Third Isaiah by several scholars.\textsuperscript{81} Even for those who see Isaiah as one unit, this section certainly begins with a new emphasis. These chapters reconcile the dual thematic approaches of God’s people keeping righteous in First Isaiah (chapters 1-39) and God keeping his people righteous in Second Isaiah


\textsuperscript{77} Oswalt, 381.

\textsuperscript{78} Goldingay, 191.

\textsuperscript{79} Motyer, 268.

\textsuperscript{80} Olyan, 84.

\textsuperscript{81} Goldingay, 315.
(chapters 40-55) by pointing to the climax of the Jerusalem as the utopian light of the world as revealed in a chiastic structure of Third Isaiah (chapters 56-66). 82

This text stands in direct contrast to the longstanding tradition that forbade men with crushed testicles from serving as priests (Lev. 21:20; Deut. 23:1). It also appears in stark opposition to the conclusion of First Isaiah, the only other time Isaiah records the term eunuch (Isa. 39:7). The maimed eunuch exemplifies a faithless, sin-filled Israel who God could no longer use. 83 This interpretation stands in direct co-relation to one of the major covenantal blessings promised to Abraham—the increase of offspring to those faithful to the covenant. 84 This defect is what provided the basis of social stigmatization and limitation on roles.

Although contemporary governmental structures may have highly regarded eunuchs, they were not allowed at the temple (Lev. 21:20, Deut. 23:1-2). 85 As once defective Jerusalem is restored to its theocentric role in worship, so too once defective priests are restored to their previously forbidden duties. The only qualification a eunuch needed to reverse his social predicament was the same requirement as everyone else: to “bind himself to God as an act of love, service, and worship.” 86

The elimination of socially stigmatizing qualification offers a radical shift toward inclusion. God declared the eunuch’s familial name would never be cut off; but

82 Oswalt, 606.
83 Goldingay, 317.
84 Horton, 407.
86 Oswalt, 608.
memorialized eternally within the temple. In so doing, God did not alter the eunuch’s disabling condition—but greatly transformed his social status. Furthermore, the text reiterates that the eunuch can dwell in the presence of God.\textsuperscript{87} The usage of eunuch here also functions symbolically as representative for all excluded persons, marginalized and forgotten as their family lines died out.\textsuperscript{88} Olyan points out that this passage neither stigmatizes nor romanticizes disability, but focuses on providing access.\textsuperscript{89} Amos Yong therefore suggests since persons with disabilities can now serve in the priesthood, similarly, all persons with defects and blemishes have access to worship in the new utopian covenant.\textsuperscript{90}

Disability in the Writings

The book of Job, arguably one of the most ancient works in the Bible, addresses the themes of suffering and disability in the context of God’s sovereignty and grace. This timeless book has had dates assigned to it ranging from the first century BC to the seventh century BC.\textsuperscript{91} Both Norman Habel and Tremper Longman conclude that a precise date is not only impossible, it is not important for interpretation.\textsuperscript{92} The

\textsuperscript{87} Motyer, 466.
\textsuperscript{88} Goldingay, 317.
\textsuperscript{89} Olyan, 85.
\textsuperscript{90} Amos Yong, \textit{The Bible, Disability, and the Church: A New Vision of the People of God} (Grand Rapids, MI: Wm. B. Eerdmans, 2011), 68.
introductory throne room scene clearly identifies a relationship between suffering and God’s sovereign purposes.\(^{93}\)

The context of Job 29:12-17 immediately follows the central theme of Job—The fear of the Lord is the beginning of Wisdom. Job articulates his argument of innocence by recounting his status in a legal appeal.\(^{94}\) He presents himself as someone who has administered past justice for the suffering—vulnerable, poor, and disabled—as a basis for why he should not suffer now.\(^{95}\) His societal respect had risen as he took on the role of a righteous ruler—comforting those in need.\(^{96}\) The use of clothing imagery foreshadows how Christ clothes the believer in righteousness.\(^{97}\) He takes upon Himself the role of father to the fatherless, known and unknown, both within and outside his area of jurisdiction.\(^{98}\) For persons with disability, he became their caregiver, their limbs, and their eyes, becoming their agent, and doing what they could not do.\(^{99}\) Job placed them upon an equal pedestal and offered justice.\(^{100}\)

Job’s theological error was in assuming that his care for others would eliminate him from ever requiring care from others. Elihu spoke to this false supernatural causality and fixed compensation theology without connecting it to any past personal sins as some


\(^{94}\) Habel, 408.

\(^{95}\) Ibid., 410.

\(^{96}\) Longman, *Job*, 337.

\(^{97}\) Ibid., 339.

\(^{98}\) Habel, 411.

\(^{99}\) John E. Hartley, 391.

\(^{100}\) Habel, 411.
of the other dialogues argued. Job’s suffering is a preventative measure, which kept Job from perpetuating theology incongruent with God’s purpose.\textsuperscript{101} Even the righteous ruler has a tendency to become arrogant and assume disability never happens to them. Those who have not subscribed to the prosperity gospel often assume falsely that righteousness offers a life without suffering to those who serve God.\textsuperscript{102} Job learned that efforts as a righteous ruler to people with disabilities could not be hierarchal in nature, but must take place out of mutuality. Suffering, even undeserved, exists as a natural part of humanity; God’s repurposes suffering as a demonstration of His grace and humanity’s faith.\textsuperscript{103}

**Disability in the New Testament**

The New Testament Scriptures build upon the substance of disability already established by introducing the realized eschatological nature of Jesus’s ministry. The tradition of the First Testament has already shown that the people of the covenant can move beyond marginalization and pity toward a changing structural social system so persons with disability are welcomed and have access to worship and communal life. A simplistic reading of healing passages can lead to an inaccurate conclusion that Jesus ministry was limited to instantaneous physical cures. Healing, however, has multiple dimensions. The next section will examine theological principles derived from selected disability texts.


\textsuperscript{102} Longman, *Job*, 342.

\textsuperscript{103} Waters, 125.
John 9 — “Who Sinned?”

Johannine literature records several accounts of Jesus’s interactions with persons with disabilities. John’s Gospel emerged in the late first century, most likely partially dependent upon the Synoptic Gospels in its final version. Major themes identified within John include a focus on revelation and redemption within a framework of Christology. The miracle stories within John serve to reveal Jesus as the redeemer. The relationship between revelation and redemption is highlighted in the juxtaposition between disability and sin found in the story of the blind man’s healing.

The normative interpretation views this passage as part of the overarching framework of John: Following the previous chapters where Jesus announced He was the light of the world at the Feast of the Tabernacles (Sukkot), now Jesus opens eyes to reveal He is indeed the Messiah. Four interrogations confirm the finished work of the healing. Each investigation addresses particular concerns: the neighbors verify the blind man’s identity, the Pharisees confirm the event was performed on the Sabbath, concluding Jesus is a sinner, the parents protest possible exclusion from community, and the man formerly blind concludes only the Messiah can heal. The passage continues with a discussion between the Pharisees and Jesus using blindness as a metaphor for spiritual

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106 Burge, 276.

unawareness, but concludes with Jesus providing inclusion to the one excluded from the local synagogue.\footnote{Burge, 275.}

Several items within this normative rendering of this narrative are problematic for disability theologians: the usage of a body metaphor for a spiritual condition, the connection between sin and congenital disability, and the idea God created individual disability in order that Jesus might be glorified.

Jennifer Koosed and Darla Schumm, writing from a distinctively Jewish tradition, point out that the Bible does not record any blind disciples. The conclusion thus drawn is this: “physical restoration is a necessary component of their entry into the community.”\footnote{Jennifer L. Koosed and Darla Schumm, “Out of Darkness: Examining the Rhetoric of Blindness in the Gospel of John,” in Disability in Judaism, Christianity, and Islam: Sacred Texts, Historical Traditions, and Social Analysis, ed. Darla Schumm and Michael Stoltzfus (New York, NY: Palgrave Macmillan, 2011), 85.} A person born physically blind is symbolic of a person spiritually blind.\footnote{Thomas, 101.} Because spiritual blindness is often associated with arrogant ignorance,\footnote{Carson, 378.} a danger exists in associating those who are physically blind as also mentally and spiritually incapable.\footnote{Koosed and Schumm, 86.} Our ableist assumptions conjoin blindness and darkness as aberrant.\footnote{Yong, The Bible, Disability, and the Church, 55.} The metaphor used can often shape attitudes and acceptance into the faith community, as broken bodies may hinder spiritual insight and understanding.\footnote{Koosed and Schumm, 88.} Eiesland suggests the disabled body is
a much more powerful witness within the celebration of rites such as the Eucharist or the laying on of hands, as it demonstratively argues against this prevailing metaphor.115

Another problematic area is the connection between disability and sin that materializes with the disciples’ question, “Who sinned?” Within the cultural context, the root of all disability and suffering, including blindness from birth, emerged from sin. Supernatural causality of sin and sickness was prevalent throughout all ancient cultures. Judaism pointed to First Testament Scriptures, which supported this idea (Ezra 18:20; Ps. 89:33).116 Eye disease and resulting blindness were common as an age related dysfunction.117 Cultural traditions held that children born with disabilities either sinned in utero, or were the consequences of their parent’s sin.118

Thomas points out that the disciples’ question could have arisen from a belief that unborn babies already have souls (Jer. 1:5; Ps. 139:15-16) and therefore have the potential to sin prior to birth; another possibility he presents is God had foreknowledge an unborn child would have a sinful destiny.119 Jesus’s answer to this question differs from His response to the paralytic in John 5, causing some commentators to suggest Jesus overturns the supernatural causality linkage to sin, while others disagree.120 Sin and disability’s relationship is seemingly simultaneously supported, yet contradicted.121 D. A.

116 Barrett, 356.
117 Burge, 272.
118 Barrett, 356.
119 Thomas, 105.
120 Koosed and Schumm, 80.
121 Eiesland, The Disabled God: Toward a Liberatory Theology of Disability, 72.
Carson notes the partial accuracy of the disciples’ question. Generalized theological statements of the origins of sin and working out the implications of the Fall lose force when applied in singular instances. Although disabilities could direct result from individual sinful acts, not all of them necessarily do.122

The third problematic area engages a primary focus of John’s Gospel—the work of Christ. The works of Jesus are the embodiment of the works of the Father and cement Jesus’s identity.123 Yet the interaction of those two persons of the Godhead creates difficulty. A final question arises: does God specifically cause disability to glorify Jesus? Thomas follows a plain reading hermeneutic and reaches a normate conclusion: that God is responsible for the disability in order that the healed one might glorify God.124

The interpretation hinges on reading the clause, “That the works of God might be displayed in his life,” as either a purpose or a result. Either interpretation would fit within John’s idea of God’s sovereignty.125 Gary M. Burge offers a disability friendly suggestion when suggesting the clause should apply to the next line, following four of the eleven instances of the Greek transition bina. This in effect shifts the focus from God making a person blind, to God sending Jesus to do works of glory.126 The tightening of the fall’s effects on singular individuals loosens and Jesus’s role of doing God’s works

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122 Carson, 361.


124 Thomas, 113.

125 Carson, 362; Barrett, 356.

126 Burge, 272.
emphasized. The purpose is so all people, with disabilities or without, can perceive the revealed works of Jesus as a fulfillment of the prophetic vision.\textsuperscript{127}


The Lukan account of Jesus’s ministry includes particular attention to disenfranchised, poor, and disabled persons.\textsuperscript{128} The author wrote and disseminated the dual work of Luke-Acts as a historical account around the destruction of the temple in AD 70.\textsuperscript{129} Luke purposes to establish Jesus as the Messiah through his demonstration of power.\textsuperscript{130} The necessary corollary is that the Messiah reigns in the utopian vision as expressed in Jeremiah and Isaiah.

Within the context of Jesus’s early ministry, Luke sets two miracle passages in chapter 5. The first relates the story of the man healed from leprosy while the second retells of the paralytic both healed and forgiven of his sins. They unite in several elements, yet disparate in others. Both follow the standard structure of a miracle story: need awareness, petition, healing, confirmation of healing, and testimony.\textsuperscript{131} Both also forced access: the man with leprosy left his stigmatized home and came to Jesus\textsuperscript{132} and

\begin{itemize}
\item \textsuperscript{127} Thompson, 117.
\item \textsuperscript{130} Ibid., 39.
\item \textsuperscript{131} Bock, 470.
\item \textsuperscript{132} Ibid., 473.
\end{itemize}
the four friends carved a hole in the roof for the paralytic. Several differences also emerge.

In the first, the man’s uncleanness was a result of temporary illness. The presence of liturgical remedies for confirmation of curative healing reinforced the notion that symptoms of leprosy could be mitigated through ceremonial cleansing, even if priests were not expected to perform the healing. Jesus bids the leper to follow the ceremonial laws enforced by the priest and does not address any notion of personal sin as an aspect of supernatural causality. The Early Church, adopting the liturgy of Judaism, would have understood Jesus performing spiritual cleansing—in effect removing both uncleanness and sin. John Nolland correctly cautions that Luke does not make this link precisely clear.

In contrast, the only incident of a paralytic shared among the Synoptic Gospels ends with both a declaration of forgiveness of sin and a curative healing. Sin and disability link in apparent irony, in a rhetorical effort to highlight the nature of Christ being, but linked nevertheless. Many casual readers with a normate perspective note that the curative healing came subsequent to a declaration of forgiveness.

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134 Bock, 473.

135 Marshall, 207.


137 Ibid., 232.

138 Yong, *The Bible, Disability, and the Church*, 60.
Marshall is representative of this thought by suggesting Jesus executed healing only to prove His claim to divinity and would not have offered healing except for that purpose.\textsuperscript{139} Bock suggests that Jesus addresses the paralytic individually.\textsuperscript{140} Stein reminds the act of forgiveness is best considered a corporate declaration of Jesus’s authority rather than individual absolution of sin.\textsuperscript{141} This interpretation releases some space between the relationship of the paralytic condition and sin, which the persistent background of covenantal curses and supernatural causality often conjoin.\textsuperscript{142} Although the primary purpose of this passage establishes Christological authority, Grant contends it has also historically “served as proof of the moral imperfection of people with illness or disabilities.”\textsuperscript{143}

Another distinct difference between these two pericopes is the social setting in which they occurred. The greatest debilitating stigma was the social ostracism that came along with a diagnosis of leprosy and its resulting association with sin.\textsuperscript{144} The leper approached Jesus in a social setting of a Galilean city\textsuperscript{145} as an individual. By curing the individual with leprous skin disease, Jesus allowed the now former leper to return to be

\textsuperscript{139} Marshall, 215.
\textsuperscript{140} Bock, 481.
\textsuperscript{141} Stein, 176.
\textsuperscript{142} Yong, \textit{The Bible, Disability, and the Church}, 61.
\textsuperscript{144} Bock, 473.
\textsuperscript{145} Ibid., 472.
included in the greater society. The greater healing may be the acceptance of the one once excluded.

In contrast, a group of four friends brought the paralytic to see Jesus—there was no social stigma that forbade them association; on the contrary, the Lukan account singles out their character and assigns them great faith. Stein suggests a Lukan thematic thread connects the “works” of cutting the roof with the “faith” ascribed to them by Jesus. Stein suggests a Lukan thematic thread connects the “works” of cutting the roof with the “faith” ascribed to them by Jesus. Nolland, extending this reasoning deeper, notes that faith is “attributed to those who act decisively.” This interpretation becomes problematic for those persons with disability who are accustomed to the loss of agency. The onus of faith lies upon the friends taking action and not upon the one who required healing.

The normate reading of this text accepts without question the Christological claim of authority of the unfolding realized eschatology. Jesus follows the script laid out in Isaiah and Jeremiah and exalts persons with disabilities above the teachers of the law. Yet the contemporary question persists if one must be physically healed or able bodied to be part of the new kingdom. Undeniably a sincere question, Luke answers it with silence. What he does make clear is the availability of salvation through Jesus Christ in this world and the next.

146 Ibid., 481.
147 Stein, 176.
148 Nolland, 235.
149 Stein, 180.
150 Grant, 77.
1 Corinthians 12 — “Diversity in the Body”

Paul established the church in Corinth during his second missionary journey in AD 50 (Acts 18) and subsequently sent a number of letters to address manifested concerns.\(^\text{151}\) Both epistles had to re-establish Pauline authority as continued theological errors and social actions created a church divided.\(^\text{152}\) Paul wrote 1 Corinthians as a response to a previously sent first letter referenced in 1 Corinthians 5:9-13.

As one of his themes, Paul spoke to the issue of diversity within the church in particular context of spiritual gifts—one of which is healing. Using the metaphorical image of a body, he describes what an embodied church should be by using the Greek noun \textit{melos}. This term is used thirty-four times in the New Testament with a range of meanings from member, part, or limb—most often by Paul discussing the relationship of Christians within the church.\(^\text{153}\) By utilizing body imagery in his metaphor, the context tends to lend itself to addressing those with inferior or broken bodies, not just those wishing to be a member of the faith community. Thomas connects this with the preceding passage on the proper participation in communion—the failure of the church is not violating the act of communion, but the act of mutual fellowship.\(^\text{154}\)

Paul speaks to those who feel they are inferior to retake agency over their assigned bodily function or organ. Paul also addresses those who are dominant and suggests they both cause and receive harm when not accepting the role of the perceived


\(^\text{153}\) Mounce, 446.

\(^\text{154}\) Thomas, 37.
inferior members of the body. While acknowledging different manifestations of the Spirit’s gifts distributed upon the congregation, he rejects any insistence of hierarchy of persons within the church—no one is intrinsically more valuable than any other. Paul’s explicit theme indicates how diversity, united in the body of Christ through a conversion experience, must act in unity to function in mutual and reciprocal health. Paul uses a series of rhetorical questions to indicate the absurdity of neglecting needed organs of the body and presses that imagery onto the body of Christ. Anthony C. Thiselton argues the final conclusion of this passage places the emphasis on unity with evidence of mutual concern over the mere presence of diversity. All are welcome if united with the Spirit and receiving the paradoxical essential inferior members of the body.

Although no binary lists reside in this passage, the fact that it presents embodiment imagery exalting the weak has enabled numerous disability discourses. Horne argues God gives power to persons with disability precisely when people exercise

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156 Ibid., 675.


158 Thiselton, 674.

159 Ibid., 675.

160 Fee, 1007.
mutual concern. The Greek term *merimna* used in 1 Corinthians 12 is often used to describe an anxiety that distracts. Yet paradoxically, in this case it binds and connects.

Reynolds proposes that vulnerable personhood already fundamentally links us together. He further suggests when we empower persons with disabilities to celebrate their gifts within the church and contribute to its life, the body of Christ achieves its true purpose—becoming a place of redemption for all. Eiesland also indicates the great struggle of the church is for it to represent essential diversity, even while hating the differences that make each indispensable to the other.

Hans Reinders takes this argument one step farther in exploring Pailin’s rejection of the contributory view of worth. He does not fully accept Pailin’s claim that some members (limbs) of the body purpose to function improperly in order that an opportunity exist solely for others to show mutual care and respect. He does, however, concede the worth of a person with severe intellectual disabilities may lie in the fact they teach humanity how to receive friendship from both God and themselves in order that humanity has the capacity to share it to others. Then persons with disability also have a role in

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162 Mounce, 130.


164 Ibid., 245.


167 Ibid., 225.
the body of Christ and should be included in the all whom are baptized in one Spirit, transcending any binary divisions common in contemporary culture of Jew-Gentile, male-female, slave-free.\footnote{168 Fee, 998.}

2 Corinthians 12 — “The Thorn in the Flesh”

Paul penned the second recorded epistle to the Corinthians to address the continuing rift between the culture of Corinth and the culture of the cross. Paul made his case that just as the power of God worked through Christ in weakness and suffering, so the power of God must work through the church through weakness and suffering.\footnote{169 Garland, 32.} Yong challenges the reader to view Paul as a disability influenced theologian who understands weakness.\footnote{170 Yong, \textit{The Bible, Disability, and the Church}, 89.}

One passage that stands out in disability literature arises from Paul’s usage of the Greek term \textit{skolops}, often translated as “thorn.” Used only once in the New Testament, it has a traditional meaning of a sharpened stake to use for defensive siege battle replete with imagery of a defeated head on a post, or a festering splinter.\footnote{171 Colin Brown, “Skolops,” in \textit{New International Dictionary of New Testament Theology}, ed. Colin Brown (Grand Rapids, MI: Zondervan, 1986), 726.} Although the first image can connote torture resulting in disability, the second image also can be understood as a chronic impairing event. Lengthy lists have emerged as to what physical ailment Paul suffers from and if in fact any of those impairments are related to sin and moral
temptation. The role of Satan and sin complicate this account. Paul identifies Satan as fundamentally linked to the disability, yet recognizes God’s sovereignty and control in a manner similar to Job; he recognizes God as the passive agent behind the messengers of Satan. Belleville suggests the thorn serves as a physical reminder of a divine encounter, similar to the one Jacob received after wrestling with God. For the point of this discussion, the origin of the thorn is not as important as the tormenting result. For Paul, this affliction kept him humble and informed his concept of power in weakness. The context of 2 Corinthians 12 ultimately reveals triumph over disability.

Paul argues that his natural inclination would be to boast in his apostolic calling, yet his disability stays his arrogance. From this he concludes, divine action is only possible in the presence of the humble, a principle carried over from the tenets of Judaism and reinforced by the death of Christ on the cross. Yet the excruciating pain was so great, that despite its effect on keeping him humbled, he prayed regularly to have the stake removed as he believed it hindered the effectiveness of his ministry. His three


176 Brown, 727.

177 Belleville, 167.

178 Garland, 521.
petitions resonate with the prayers of Christ in the garden before crucifixion.\textsuperscript{179} As with Christ, there came a time when Paul had to accept his current condition as part of the sovereign will of God.\textsuperscript{180} Paul realized, even with his limitations, that his vocational ministry was not over, just as Christ’s ministry had not ended at the crucifixion. With his assertion that God’s grace is sufficient for him, Paul introduces finality to the question.\textsuperscript{181} In a paradox reminiscent of Jesus in the healing of the blind man in John 9, the very thing that substantiated Paul’s apostolic authority disqualified him from the perspective of his critics.\textsuperscript{182} Yet Paul affirms that God’s power is perfected in weakness, not necessarily in overcoming weakness.\textsuperscript{183} Furthermore, exaltation of disability and weakness does not honor either God or the person with a disability.\textsuperscript{184} When a person, with or without disability, embraces their own weakness, they learn to welcome the weakness found in others.\textsuperscript{185} Dependency on God is not just a character trait for persons with disability, but a desired trait for all created beings following Christ.

\textbf{Conclusion}

In the previous pages, several selected disability texts offer insight on key principles of disability theology. Representative of different periods of Jewish and

\begin{itemize}
\item \textsuperscript{179} R. Kent Hughes, 2 \textit{Corinthians: Power in Weakness}, Preaching the Word (Wheaton, IL: Crossway Books, 2006), 213.
\item \textsuperscript{180} Barnett, 571.
\item \textsuperscript{181} Belleville, 308.
\item \textsuperscript{182} Hughes, 212.
\item \textsuperscript{183} Belleville, 311.
\item \textsuperscript{184} Yong, \textit{The Bible, Disability, and the Church}, 97.
\item \textsuperscript{185} Reynolds, 117.
\end{itemize}
Christian thought development, each passage contained several recurring themes. First, although sinful people may commit sinful actions resulting in conditions of disability, Scripture does not support narrow assignments of divinely caused disability assigned to specific persons; Scripture addresses the question of who sinned specifically with a negative, since all have sinned. Second, although suffering is part of being human, God provides the necessary grace needed to endure and to prevent incongruent theology, which exalts an individual righteous person over the work of God. Third, God provides everyone with equal access as part of the eschatological vision. When the church accepts the calling to be an inclusive and welcoming environment, gathered weakness liberates God’s power celebrated in corporate worship. Finally, God requires the church as the body of Christ to support each other mutually within limited knowledge and abilities.

Although the themes thread throughout all the passages examined, another perspective can see the unfolding plan of God revealed through the emphasis of the various Scriptures. The Leviticus passages provide awareness of disability. Prophetic passages preview the access people with disabilities receive in the eschatological future. Job’s writings intimate simple justice and care is not enough. Healing stories in the gospels narrate the integration of people with disabilities back into regularly social community. The Pauline epistles show how persons with disabilities must be actively engaged in body ministry as co-laborers for the church to be maximally effective.

The goal of a Pentecostal church is to move along this continuum in order that all persons with disabilities actively engage in both receiving and giving mutual ministry out of their weaknesses.
CHAPTER 3: GENERAL LITERATURE REVIEW

Introduction

The faith community has had a long history supporting the poor, disenfranchised, and disabled. Many religious organizations in the United States have developed homes and institutions, which have provided care for people with intellectual disabilities for well over one hundred years.\(^1\) The last several decades, however, have seen a shift in social policy resulting in the rapid deinstitutionalization of people with intellectual disabilities and their reintroduction into American community life. Despite the advances made in supported job environments and some social institutions—brought in part by legislation—the American church has had a more difficult time integrating people with intellectual disabilities into their communal worship expressions.

The main body of this chapter explores literature published between 2001 and 2013 that identifies self-reported needs of people with intellectual disabilities and their family caregivers. Furthermore, this chapter explores the relationships and failures that exist between those needs and the corresponding systems of services and supports provided by a complex network of collaborative organizations. This chapter concludes with the possibilities of an emerging model that establishes joint collaborative partnerships between faith based and community organizations. As disability and

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spirituality research moves in furtive fits, this review does include some key research older than ten years since it remains current in the field.

Identifiable Needs of Persons with Intellectual Disability and Identifiable Needs of Their Family Caregivers

Needs Identification through Family-centered Practice

Family-centered practices place the onus on the consumer to self-direct supportive services that facilitate an identified need. In the early years of life, supports exist for both a young child and other family member caregivers. Whenever possible, the individual with the disability directs his or her own supports. Over the last several decades, this transition to self-directed care has emerged as people with disabilities moved from self-contained institutions and reemerged into the community at large. Carl J. Dunst, Carol M. Trivette, and Angela G. Deal created a model that identified clusters of needs within the disability community. They categorized needs across twelve broad definitions: economic, physical, food/clothing, medical, employment, transportation/communication, adult education, child education, childcare/respite, recreation, emotional, and social.\(^2\)

Dunst, Trivette, and Deal also identified several major determining factors that cause families to seek outside support in meeting those needs: life cycle changes, family systems, value systems, and community contexts.\(^3\) The typical life cycle from birth to death has normative changes contained within, such as marriage, childbirth, schooling, and retirement. Non-normative events such as death, accidents, and job loss create stress


\(^3\) Ibid., 93.
and increase need requirements. The definition of family structure evolves in constant flux between remarriages, adoptions, and multiple income earners. Differences in assimilated cultures, values, and spiritual beliefs require needs assessments to take into account cultural expectations and biases, resulting in varying families possessing different sets of dominant needs. The community context, replete with varying state laws and differing implementation of federal legislation within local townships, also alter the need requirements.

Needs versus Concerns

Dunst, Trivette, and Deal differentiate between family concerns and needs. Concerns reflect gaps and discrepancies between what currently exists and what could exist. Fundamentally, a concern indicates the presence of an awareness, which necessitates a course of action. Needs are expressed desires for resources in order to achieve outcomes for a particular measurable outcome or goal.\(^4\) Dunst, Trivette, and Deal also unveil four conditions present in the transformation of a concern into a need: (1) an awareness of a discrepancy, (2) a value judgment that the concern will have an impact, (3) an awareness of a potential solution, and (4) an awareness of how to procure a solution.\(^5\)

One shortcoming of relying on a behavioral model is the assumption that consumers who self-identify a concern will consequently express it and correspondingly

\(^4\) Ibid., 94.

\(^5\) Ibid., 95.
receive supports; often, however, they do not. Dale Yeatts, Thomas Crow, and Edward Folts, introduced a practice-oriented approach that focuses on three sets of factors: knowledge, access, and intent. Knowledge represents the information given to the consumer about the existence of a supportive service that would benefit him or her in satisfying a need, as well as the practical steps required to enroll in those services. Access removes barriers from achieving those supports, whether transportation, availability, or financial. The desirability of the support, the compatibility of cultural similarity, and the perception of the attitudes from those individuals providing the support unite to influence intent. This model allows for service providers to proactively encourage consumers or clients to engage in support services.

Misidentification of Needs

Some researchers indicate apprehension that disability professionals identify and determine needs that the family or person with disability does not consider concerns. Pamela H. Epley, Jean Ann Summers, and Ann P. Turnbull illustrate that the joint determination of needs are vital to successful outcomes, yet warns most needs assessments are completed without sufficient family input.


8 Montoro-Rodriguez, Kosloski, and Montgomery, “Evaluating a Practice-Oriented Service Model to Increase the Use of Respite Services Among Minorities and Rural Caregivers.,” 917.

carefully clarify that a difference often exists between what clients may want and perceive as need and with what organizations and service delivery systems can offer.\textsuperscript{10} Epley, Summers, and Turnbull also posits an additional criticism of professionals who determine need based upon the ability of support resources, in essence manufacturing needs that can be met while overlooking legitimate needs that require supports.\textsuperscript{11}

\textbf{Needs Domains}

The Family Needs Scale emerged from Dunst, Trivette, and Deal’s work. Utilizing this standardized forty-one question assessment, social workers design a family’s supports needed for the immediate future. By interpreting responses from this scale and others, social agencies provide appropriate supports to achieve the desired outcome. In 2004, the American Association of Intellectual and Developmental Disability (AAIDD) released the Supports Intensity Scale (SIS), which classified seventy-three specific needs into three major categories: support, advocacy, and medical. Six central themes organize support needs: home living, community living, life-long learning, employment, health and safety, and social activities.

The need assessment of participation in the community includes church attendance as just one example among other activities.\textsuperscript{12} Neither of these assessments, however, included spiritual or congregational supports as an intentional separate


\textsuperscript{11} Epley, Summers, and Turnbull, 204.

The Religion and Disability subcommittee of AAIDD later developed a Supplemental to the SIS. This document did examine congregational supports and called for an integrated, holistic vision. The next section will examine the literature utilizing this taxonomy of identified needs.

**Home Living**

For adults, home living includes everything from toileting, hygiene, clothing, and meal preparation in addition to basic food and shelter. For families expecting a typical child and suddenly experiencing early onset disability, these expected living tasks amplify, requiring additional support. In the 1986 reauthorization of the Individuals with Disability Act (IDEA), part C deemed both infants and their families eligible to receive early intervention services. Epley, Summers, and Turnbull studied seventy-seven Kansas families of young children with disabilities. Families indicated their perception of the range and severity of their own needs. Forty-one families specified more than five areas of needs, while six families designated more than ten discrete needs. Of those families, 31 (40.3 percent) of the respondents identified early intervention services, 33 (42.9 percent) indicated service coordination, 19 (24.7 percent) desired parent training, and only 7 (9.1 percent) requested respite care as their dominant needs. At times,

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14 Epley, Summers, and Turnbull, 201.

15 Ibid., 208.
families may not recognize their need. Dunst, Trivette, and Deal suggest the observation of a family’s home environment can serve as a discussion starter for need identification.\(^{16}\)

Mark B. Dekraal, Denise J. Bulling, Nancy Shank, and Alan J. Tomkins identify independent living skills, affordable housing, and the development of a financially sound economic plan as critical needs when children with a disability move into adulthood and the family caregiver becomes less involved.\(^{17}\)

*Community Living*

The Americans with Disabilities Act (ADA) in 1990 guaranteed the right for accessibility and participation in activities for people with disabilities. Needs categorized in community living include recreation, transportation, accessibility to public services and community events, shopping, and participation in community events, including religious services. Yet Mark B. DeKraal et al reveal that transportation outside urban areas remains limited, creating a cascading effect and exasperating other employment, financial, and medical needs.\(^{18}\) Epley, Summers, and Turnbull reported that five participants also indicated a lack of adequate transportation as a predominant need.\(^{19}\) The level of education, persistence of poverty, and the prevalence of disability also impact the local community setting.

\(^{16}\) Dunst, Trivette, and Deal, 101.


\(^{18}\) Ibid., 261.

\(^{19}\) Epley, Summers, and Turnbull, 208.
David Ehrenkrantz et al researched disability prevalence in Kansas. The findings indicated 9.8 percent of households contain at least one child with a disability who requires need-based services.\textsuperscript{20} The rate of prevalence did decrease as the educational level of survey respondents increased. This corresponds with the survey results of Carla Peterson et al. Their survey indicated poverty factors increased risk for disability. Poverty limited access to transportation, medical care, and other government and education intervention services. It also reported ethnic minorities most at risk were least likely to take advantage of early intervention.\textsuperscript{21}

\textit{Life-Long Learning Activities}

The needs of life-long learning apply to both the person with a disability and the family. The family as caregivers must learn new skills. For adults with disabilities, continuing adult education on how the world works proves vital for successful inclusion in daily activities. Life-long learning activities include interacting with others, utilizing problem-solving strategies, incorporating technology in daily living, and performing simple function tasks such as counting money or reading signs.\textsuperscript{22}

\textit{Employment}

While several social safety nets exist to aid persons with disabilities, employment does not exist just for economic status. The ability to live a structured life similar to productive citizens of the larger community plays an important role in the self-identity of


\textsuperscript{21} Carla Peterson et al., “Meeting Needs of Young Children at Risk for or Having a Disability,” \textit{Early Childhood Education Journal} 37, no. 6 (April 2010): 513.

\textsuperscript{22} Thompson, 50.
an adult with a disability and serves as a major goal of many people with individual support needs. Many adults with disabilities do not wish to continue working in sheltered workshops and instead explore competitive employment at minimum wages. This desire for inclusion results in additional needs, which must receive attention in order for them to succeed. Grace Francis et al report the additional economic freedom that comes with a regular job allows for greater peer relationships, independence, and a higher quality of life.23

*Health and Safety*

Many children and adults obtain needed health and dental services provided through federal or state sponsored programs such as the Kansas Department of Health and Environment’s KanCare.24 This domain also includes learning how to make balanced diet decisions and avoid household hazards.25 The number of families requesting counseling services and support groups serves as evidence of the growing demand.26 Counseling and chaplaincy services are important for adults with intellectual disability, especially to process grief and other change of life events.27

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24 Ehrenkrantz et al., 50.

25 Thompson, 50.

26 Epley, Summers, and Turnbull, 208.

Social Activities

The category of social activities includes community recreation, leisure activities, volunteerism, and friendships. In the childhood years of disability, the initial set of social support activities involved the entire family. Parents often find social settings and recreation events that occur in a supportive environment with like peers for their child.

Religion and Spirituality

This review considers religion and spirituality distinct from other social activities. The AAIDD’s position statement of 2010 indicates spirituality plays an important part of human experience; evaluators should consider it as part of the needs assessment.

Melinda Jones Ault, Belva C. Collins, and Erik W. Carter point out both corporate religious participation and individual spiritual experiences serve as important factors in determining quality of life.

Services Provided by Community Agencies

Each educational or social service agency tasked with providing support services to both families and persons with disabilities attempt to do so by staying family focused.

28 Thompson, 26.
29 Dunst, Trivette, and Deal, 93.
participant directed, and community based. Successful support services recognize the need for strong collaboration and multi-pronged partnerships to ensure appropriate attention to needs, successful inclusion, positive measurable outcomes, and a high quality of life.

Defining Support

While exploring a research agenda, Kathleen B. Kyzar et al studied the literature and determined no common definition of support utilized existed. Based upon the review, they articulated four types of support and their definitions:

1. Emotional support—assistance related to improving psychosocial functioning in terms of reducing stress and improving a positive orientation of feelings.
2. Physical support—assistance related to improving physical health or daily living skills of the family member with a disability.
3. Material/instrumental support—assistance related to improving access to adequate financial resources and the completion of necessary tasks.
4. Informational support—assistance related to improving knowledge from verbal or written materials presented either online, through print, or video that leads to improved decision making.

Support Service Induction

Point of Entry

Families suddenly thrust into the need for support services often do not know how to begin the journey. Depending upon their initial exposure and entry point, service delivery patterns vary greatly. After reviewing literature on needs assessment, Diane Hiebert-Murphy, Barry Trute, and Alexandra Wright discovered the patterns of entry into support services could hold substantial implications in meeting the family’s prioritized

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needs for a child with a disability. Their longitudinal study conducted in Manitoba, Canada, of forty-three mothers and twenty-nine fathers yielded three factors important to service entry: recognition of a problem, a formal diagnosis, and linkage (referral) to services.34

The identification of atypical development is categorized into three groups along an activity continuum: (1) parents who took a proactive role in seeking help after problem recognition, (2) parents who actively sought help for their child for other health related issues, and (3) by healthcare officials where parents took an inactive role. Following a healthcare diagnosis, all parents took an active role in discovering supports, even if they experienced a negative relationship with the healthcare provider. No correlation exists, however, between parents’ reactions, either positively or negatively, and the level of activity each played in identifying the eventual diagnosis. The study did note the referrals, or the lack thereof, to community based support services directly correlated with the experience and knowledge of disability by the healthcare professionals.35 This directly affected the patterns of entry into the support services system.

Pattern of Entry

Four entry patterns emerged from Diane Hiebert-Murphy, Barry Trute, and Alexandra Wright’s study: early entry, prompt entry, delayed entry, and atypical entry. The later a child entered the support services system, the higher the parent’s level of


concerned urgency and critical advocacy.\textsuperscript{36} The authors concluded the following: (1) natural supports of extended family and friends in conjunction with public education can help parents determine if a child needs intervention, (2) healthcare professionals function as natural gatekeepers of support services in the community and must receive education on how to serve in this role effectively, and (3) parents and families with delayed or atypical entry points may require more intensive critical emotional supports and faster response times in order to help stabilize the family dynamics.\textsuperscript{37} These findings contain important implications for appropriately measured pastoral responses as well.

Families who have entered social service delivery models find not all are alike. King and Meyer differentiate between service integration and service coordination, present an outline of three approaches of support services, and offer implications for planning and policy-making.\textsuperscript{38}

**Service Integration and Coordination**

Service integration purposes to lend a holistic macro perspective while shaping a seamless continuum of care, ensuring all needs get met. King and Meyer define service coordination as the logistical micro process that forges different efficient services together.\textsuperscript{39} Integration and coordination of support services can take one of three different approaches within a singular conceptual framework: geographically based, agency based, or participant/family directed. The design of each model often depends upon local

\textsuperscript{36} Ibid., 428.

\textsuperscript{37} Ibid., 431.

\textsuperscript{38} King and Meyer, 477.

\textsuperscript{39} Ibid., 489.
factors, existing legislation, collaborative partnerships, and resource availability. King and Meyer suggest apt attention to all three approaches increase the likelihood of the services integration and coordination.

By clarifying the roles and scopes of seemingly competing organizations, stakeholders understand the respective roles and deescalate frustrating situations. King and Meyer conclude this framework by suggesting families will continue to need service coordinators, multiple points of access and entry into the system, and the option to use multiple approaches to meet support needs.\(^{40}\)

**Service Delivery Models**

*Agency Based*

As families navigate between agency-based and family-directed supports, the agency-based service provider plays a key role. Carla Wood Jackson, Randi J. Traub, and Ann P. Turnbull studied parents’ experiences with childhood deafness and concluded reactions to diagnosis fell roughly in-line with the earlier findings of Heibert-Murphey, Trute, and Wright. They discovered universal implications for the role of service providers even after an early entry point into the service coordination system.\(^{41}\) This study’s implications reiterated the need for more responsive serve providers to the needs of the families and called for a collaborative partnership in service decisions. Specific recommendations include:

- Creating family-centered supports in addition to the child’s.

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\(^{40}\) Ibid., 477-490.

• Empowering the family’s decision-making and advocacy skills.
• Facilitating network opportunity and support groups for family members.
• Exercising caution when involving parents as primary implementers of intervention strategies.
• Developing action plans that include respite care, counseling, and other resources.
• Establishing trust and respect through collaborative partnerships.  

*Geography Based*

Peterson discussed similar suggestions in exploring the implications of early intervention in geographically based Early Head Start educational programs. Early educators received encouragement to refer quickly for coordinated disability related services, to collaborate with the health care community, to focus on intervention strategies, and to provide services and supports to the families as well as the child.

*Participant Directed*

While service providers and educational interventionists all play key roles in providing support for needs, the participant/family directed model also relies on the decision-making skills and choices of a person with a disability or his or her chosen surrogate. Judith M. S. Gross et al conducted a case study of family caregivers of persons with severe intellectual disability who utilized participant-directed Medicaid waiver funds to steer their own service, supports, and provider management. The research inquiry sought to examine how experiences influence caregiver decisions in directing

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42 Ibid.

43 Peterson et al., 510.
services. The recurring theme revealed parents recognizing their customized direction as a means directly linking toward and achieving an end goal of desired outcomes.\textsuperscript{44}

Caregivers perceived correlations in the following areas: individualized supports with independent behavior, independent budget with health and safety, and increased caregiver responsibility with increased social inclusion.\textsuperscript{45} The reasons family caregivers turned to participant-directed services cluster in several areas, including negative experiences when dealing with the existing service delivery system and the difficulty of finding supports in rural regions.\textsuperscript{46}

Model Support Service Programs in Kansas

\textit{Positive Behavior Supports}

Rachel Freeman et al recognized behavior supports as one of the primary needs of families. The Kansas Institute for Positive Behavior Support training program (KIPBS) sought to build a common statewide approach in regards to behavior across human service organizations. The stated goals of the program include training regional KIBS facilitators, providing Kansas organizations with free access to resources, and implementing statewide positive behavior support (PBS) programs. The twelve-month-long ongoing training program creatively took into account the regional differences

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45 Ibid.

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between urban eastern Kansas and western rural Kansas. Any human services professional with a bachelor’s degree may participate in the training.\textsuperscript{47}

\textit{Competitive Employment}

Family-caregivers’ goals often include discovering employment opportunities for adults with intellectual or psychiatric disabilities—many cannot work in competitive employment. Erik W. Carter, Diane Austin, and Audrey A. Trainor revealed a family’s expectation of their child’s employment with a disability accounts for an employment rate five times higher than families who do not share the goal.\textsuperscript{48}

Successful employment requires life-long learning skills. Trevor J. Manthey et al examined four types of supportive education models, including the self-contained classroom, local on-site support, mobile support, and freestanding support.\textsuperscript{49} Used in conjunction with supportive employment, each model attempts to give an employee only the amount of support required in order to promote successful independence. Manthey et al discovered that 57 percent of individual placement and support programs already included supportive education as a component and recommended the integration of supported-education and employment services to a greater degree.\textsuperscript{50}


\textsuperscript{50} Ibid., 22.
In 2010, several agencies within Kansas collaboratively developed the Family Employee Awareness Training program (FEAT), designed to create high employment expectations and streamline employment services and resources. During the initial two years, 324 participants, including caregivers and professionals, attended eleven training seminars held in the major population centers of Kansas. Less than fifty participants possessed disabilities requiring an independent support need for employment.

The pilot study sought to measure immediate measurable impacts in four key themes: (1) availability for competitive employment options exists but requires considerable effort to achieve access, (2) limited options due to current economic conditions, (3) limited employment because of negative employer stereotypes, and (4) people with disabilities and support needs require too much support. These findings were even more dominant in rural environments, defined as city centers with less than 25,000 populations. This study revealed that participants perceived education professionals held lower expectations than did the persons with disability and their family caregivers.52

Family Professional Partnerships

The perceived differences in employment expectations illustrate the importance of family-professional partnerships in obtaining necessary supports. As Jean Ann Summers et al point out, collaborative efforts between disability families and professionals fall

51 Major population centers of Kansas include the eastern region cities of Kansas City, KS (146,000), and Topeka (127,000), and Lawrence (88,000); the central section city of Wichita (382,000); and the western section cities of Garden City (27,000) and Hays (20,000). Population figures are from the 2010 US Census Bureau.

52 Francis et al., 45-54.
short of the ideal. Martha Blue-Banning et al recognized the inequality of power exhibited between the relationships of professionals and the disability families serves as a major challenge to successful partnerships. Entry point early intervention services should not just focus on immediate needed supports, but also prepare parents to develop into effective partners with the various agencies their child encounters when reaching adulthood.

**Characteristics of Successful Partnerships**

Blue-Banning et al’s qualitative study sought to identify characteristics of successful caregiver-professional partnerships. By conducting thirty-three focus groups with English language parents in Kansas, North Carolina, and Louisiana, as well as thirty-two interviews with non-English language speaking parents located in Kansas, the study identified key indicators that would lend to productive partnerships. Six dominant themes emerged from dozens of indicators: communication, commitment, equality, skills, trust, and respect.

Positive, frequent, tactful, and honest sharing of information efficiently serves as critical keys to effective communication. Both parents and service providers wanted to see commitment and loyalty shown to each other as people, not as case numbers. Each wanted to know the other actively pursues important goals identified for the child and the

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55 Ibid., 168.

56 Ibid., 174.
family. Empowering behaviors and social validation that remove equity imbalances and allow for exploration of options proves essential for creating a harmonic sense of mutual equality. Safety, reliability, and discretion produce a trusted assurance of dependability on the others within the partnership.

Both sides of the partnership desired the other to respect their competencies and skills as a professional or a parent while maintaining high expectations. In their findings, they also discovered some partnerships reached an impasse when parents sought to blur the lines between professionalism and friendship, while professionals worried about enabling co-dependent behavior. Blue-Banning et al suggest the study’s implications are relatively inexpensive to implement. Furthermore, study participants indicated the quality of partnership directly correlated to overall quality of life.57

*Partnership Outcomes: Measurement Tools*

Summers et al used these findings to develop a psychometric pilot instrument to measure achievable outcomes. Available in both English and Spanish, the Family-Professional Partnership Scale reconfigured the six dominant domains into two categories: child focused relationships and family focused relationships. Of the six domains, the themes of commitment and competency dominate the child relationship category, while the family relationship category stresses communication and equality. Respect and trust are common to both. Taken together, both subscales yield a complete picture of the family professional partnership. This abbreviated eighteen-point scale model serves useful not just for agency or school wide implementation, but also in

57 Ibid., 181-182.
discovering areas of strengths and weaknesses in other programs that impact quality of life.\textsuperscript{58}

\textit{Quality of Life Measurements}

Those with needs that require assistance to meet a minimum quality of life receive support services. Several surveys and concepts have attempted to measure quality of life by assessing life satisfaction. The five domains of the Beach Center Family Quality of Life Scale (FQOL) include family interaction, parenting, emotional well-being, material well-being, and disability related supports; it does not include any spiritual indicators.\textsuperscript{59} Family outcomes that result from disability supports impact the scale either negatively or positively. Quality of Life measurements allow for both agencies and individuals to assess the outcomes of current services prior to making decisions to change protocols.\textsuperscript{60}

\textbf{Outcomes: The Relationships of Needs and Services}

Jean Ann Summers, Janet Marquis et al explored quality of life questions further by examining the interrelationship between family quality of life and family-professional partnerships in a sample of 180 predominantly female parent (98.8 percent) respondents. The study required a 75 percent completion rate of three items: a services inventory, the family-professional partnership scale, and the FQOL.\textsuperscript{61}

\textsuperscript{58} Summers et al., “Measuring the Quality of Family—Professional Partnerships in Special Education Services,” 75.


\textsuperscript{60} Ibid., 781.

Services Inventory

The services inventory explored the percentage of need along with an adequacy rating of the supports provided. Of the 180 respondents, 176 identified child-oriented support needs and 124 identified family oriented support needs.\textsuperscript{62}

\textit{Child-Focused Support Needs}

In the child-oriented support needs component, 163 respondents (91 percent) indicated the greatest need existed in speech and language services, with only five indicating they received inadequate support services. Conversely, they deemed the areas of behavior support, self-care training skills, transition services, and counseling as the highest without adequate support in child-oriented services. Of the fifty-seven (32 percent) respondents who indicated need for behavior support, only twenty-three reported adequacy of service. Similarly, of the fifty-six (31 percent) who indicated the need for self-care skills training, only twenty-five reported receiving enough support. Of the thirty (17 percent) who indicated a need for transition services, from high school into adulthood, only fifteen reported enough support, and of the twenty (11 percent) who indicated the need for counseling services, only eight reported enough support.\textsuperscript{63}

\textit{Family-Focused Support Needs}

In Summers, Marquis et al, a considerably lower amount of families indicated need for family-focused than child-focused support services; those who did however,

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\textsuperscript{62} Ibid., 328.
\textsuperscript{63} Ibid., 326.
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indicated a sharply negative satisfaction rating in all categories.64 While the query regarding gaining information about services for the child had the highest amount of need with seventy-three (41 percent), only seventeen respondents perceived enough service adequacy; of the forty-six (26 percent) who needed service groups, twenty-six received no support; of the thirty-five (19 percent) who indicated counseling needs, nineteen received no support; and of the twenty-seven (15 percent) who requested respite care, eighteen received no support.65

The lower need for family services is consistent with Barry Trute, D. Hiebert-Murphy, and A. Wright’s study on outcomes of services provided to new mothers of children with a disability in areas of personal self-esteem, parenting skills, and family adjustment. While the identified needs from mothers remained constant during the sixth to the eighteenth month after an entry point into family support services, the need for family oriented support services tapered off, eventually reducing over time. B. Trute, D. Hiebert-Murphy, and A. Wright suggest this results from successful family centered service coordination.66

Services Satisfaction

In Summers, Marquis et al study on family quality of life, the family-professional partnership scale results indicated the highest satisfaction level correlated with the friendliness of the service provider, while the lowest satisfaction level reflected the

64 Ibid., 328.

65 Ibid.

parents’ inability to obtain needed information for a child’s needs. Furthermore, the FQOL revealed Emotional Well-being as receiving the lowest satisfied in contrast to Physical Well-being receiving the highest satisfaction rating.\textsuperscript{67}

When correlating all three surveys together and developing a conceptual model, the researchers found adequacy ratings served as a significant predictor of family quality of life and of partnerships. Researchers also discovered that successful collaborative relationships partially mediate the ill effects of inadequate services. As such, cultivating family-professional partnerships early proves crucial to long-term success. The lower Emotional Well-being rating coupled with inadequate ratings for needs in care-delivery models (care groups, counseling service, and respite care) suggest the need for the development of additional support tools, such as promoting faith communities as another avenue for supportive services.\textsuperscript{68}

**The Role of Faith Communities: A Brief History**

Faith communities exist as ubiquitous support networks in the community at large. Yet they have not taken on a leading role welcoming people with disabilities into full worship inclusion and social participation. To a large degree, the American church resembles the dominant culture. During much of the twentieth century, those with disabilities were institutionalized and did not live in local neighborhoods. While many denominations established chaplain ministries in state institutions, few, if any, churches made overtures to include people with disabilities in the regular rhythm of church life.

\textsuperscript{67} Summers et al., “Relationship of Perceived Adequacy of Services, Family-Professional Partnerships, and Family Quality of Life in Early Childhood Service Programmes,” 329.

\textsuperscript{68} Ibid., 333-335.
From Institutionalization to Integration

Institutional chaplains were among the first to advocate for the church to include persons with disabilities. Their voices emerged in the early 1990s at the time of the passage of the Americans with Disabilities Act (ADA) and focused on the Christian education of young children. Brett Webb-Mitchell, writing about his experience as a chaplain in a Florida residential facility, declares, “Developmentally disabled young people are ready to hear the good news of God’s grace, and to see it extended to them through the church.”

Webb-Mitchell acknowledges past practices make children with intellectual disabilities wards of the state, removing them from a chance to experience God’s grace in a faith community. Not content to place sole responsibility on the state institutions, he also called both the Christian family caregivers of persons with disability and the church to account: families feeling awkward, ostracized, and embarrassed had stopped attending services. Congregational representatives, who felt unprepared to minister alongside those with disability, often encouraged families to attend another church. By these actions, Webb Mitchell suggested that the church as a worshiping community loses an opportunity to experience transformation from compassionate ministry mediated in authentic relationships.


70 Ibid., 981.
Traditional Barriers to Accommodation: Architecture, Angels, and Attitudes

Although architectural and financial issues tend to loom as the major barriers for church committees, Albert A. Herzog reports that many American mainline denominational churches had aggressively moved to make their older facilities more accessible, but more loosely organized networks had not done so yet. Writing from a South African context, Erna Möller identifies hindrances in attending communal worship services. Inaccessible doors, pulpit areas, seating arrangements, slopes of auditorium floors, and even restroom facilities remain common, particularly in rural and underdeveloped areas.

Webb-Mitchell posits several excuses churches routinely utilize to discourage persons with disabilities to participate in congregational worship. Some theological presuppositions regard persons with intellectual disability as angel-like and sinless. Others hold reason and cognitive assent to doctrine as essential to understanding and receiving grace. Market-driven and seeker-sensitive churches developed alternate services that hid people with disabilities from the larger congregation. Möller reports on the propensity in many primitive or Pentecostal contexts to regard disability as a sign of sinful oppression that requires healing or fixing.

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74 Möller, 159.
Yet, even without the presence of physical and potential theological barriers, persons with disability and their family caregivers tend to cite attitudes within the church as the largest hurdle. One disability ministry assessment begins with an inquiry into the attitudes of the congregation regarding people with disabilities prior to its extensive list of questions regarding facilities. Ault found the following when comparing available and helpful accessibility features: first ranked, the helpful features of welcoming attitude (90 percent), followed by additional participatory supports (67.3 percent), accessible materials (46.3 percent), long before accessible facilities (46.3 percent). Nearly inversely, churches focused on accessible facilities (89.3 percent), welcoming attitudes (81.8 percent), and additional supports (40.2 percent).

Ginny Thornburgh, director of the Interfaith Initiative at the American Association of People with Disabilities, recognizes changing attitudes and “extending the sacred gift of friendship—the body of Christ, one on one” as key to creating community. Nella Uitvlugt, in a 2008 article for *Exceptional Parent* magazine, acknowledges many congregations do not automatically know what to do—yet encourages the parent and family caregivers to strategize along with the congregation to create awareness and develop mutual welcoming and respect. Parents should hold reasonable expectations of the congregation, and the congregation can begin with a

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welcoming attitude that seeks friendship. Dialogue with those at the margins reveals congregations’ shortcomings.

**Religious and Spiritual Needs Identified**

This section will focus on identified religion and spirituality needs and the supports offered within the context of the worshiping community. In the context of the literature, religion and spirituality exist as two separate loci that have various levels of overlapping influence. While spirituality is common to all peoples and plays an important part in a person’s holistic makeup, religion serves as the institutionalized patterns of ritual and doctrine that help shape one’s spirituality. As spirituality gives meaning to all aspects of life, including disability, a church’s expression of religious theology, attitudes, and rituals can either support or shun people with disability.

**Identified Religious Needs by Parents of Children with Disability**

Several studies have examined the role of religion in families with children with disabilities. Debra G. Skinner, Vivian Correa, and Martie Skinner focused primarily on Latino parents residing in Arizona, North Carolina, Florida, and Massachusetts, Denise J. Poston and Ann P. Turnbull interviewed urban parents in Kansas, and Carol Pitchlyn, 79 Ibid., 47.


Brenda Smith-Myles, and Virginia Cook examined perceptions of families in Louisiana, North Carolina, and Kansas. Each of the studies reported identifying similar needs and purposes for religious supports.

The study on Latino families insightfully cautioned against generalizations of any one ethnic group as variations within the sample reflected differing expressions of religion and culture. The differences in ethnic approaches also reflect in the varied approach between the American white church and the black church experience—African American churches accepted and reintegrated people with disabilities long before the predominantly white denominations considered inclusion.

Skinner, Correa, and Skinner examined the role of religion for families with disabilities in Latino communities. Of the 250 parents surveyed, 92 percent expressed being very religious and 69 percent identified as Roman Catholic. This study most aptly revealed the discrepancy between average church attendance, less than once a month, and personal faith ranking high—a 4.1 on a scale of one, very little, to five, a lot. Parents reported some religious institutions as providing necessary supports in worshiping, emotional support, practical aid, prayer, and education. The study revealed, however, the

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84 Skinner, Correa, and Skinner, 311.


86 Skinner, Correa, and Skinner, 304.

87 Ibid.
churches’ ability and willingness varied greatly, due in large part to most churches being ill equipped.\textsuperscript{88}

In a limited study of eight African-American and eight white parents, Pitchlyn Smith-Myles, and Cook examined the role of organized religion in the families of children with disabilities. While the majority of respondents thought clergy was supportive, many respondents agreed the church did not take an active role as much as other community agencies. Overwhelmingly, they recognized their personal spiritual beliefs as a coping mechanism.\textsuperscript{89} Pitchlyn, Smith-Myles, and Cook concluded an urgent need exists for the religious community to intentionally seek and embrace the families of persons with disability.

Poston and Turnbull expanded a previous study on family quality of life and examined the impact of spirituality on seventy-eight families with children with a disability. Focus groups conducted in three locations, including Kansas City, Kansas, revealed that many regarded spiritual beliefs and participation in religious communities as essential for surviving the challenges related to dealing with disability. Half of the families utilized their faith to make sense of the disability. While many respondents reflected acceptance in a religious community, others faced difficulty and expressed concern that their children were not fully accepted. The study reports families look for three things in a religious community that will help their quality of life: first and

\textsuperscript{88} Ibid., 306.

\textsuperscript{89} Pitchlyn, Smith-Myles, and Cook, “Urban Parents’ Perceptions about the Role of Organized Religion and Spiritual Beliefs in Their Family Life,” 11.
foremost, welcoming acceptance of their child; second, spiritual and emotional support for themselves; and third, inclusive supports for their children during worship services.\footnote{Poston and Turnbull, 101-103.}

MaLesa Breeding and Dana Kennamer Hood’s qualitative findings after interviews with parents from one Texas ministry reflected Poston and Turnbull’s three findings. The parents offered insights about churches, suggesting religious institutions must move from beyond merely tolerating their children toward embracing their presence. In their concluding remarks, Breeding and Hood recognize choosing to serve families and children with disability necessitates a church to make a long-term commitment toward children throughout adolescence and into adulthood.\footnote{MaLesa Breeding and Dana Kennamer Hood, “Voices Unheard: Exploring the Spiritual Needs of Families of Children with Disabilities,” \textit{Christian Education Journal} 4, no. 2 (September 1, 2007): 289-291.}

Amy Elizabeth Jacober’s qualitative study of seventeen families of teenagers with disabilities across five states explored their religious experiences. Many families, while grateful for the religious community’s initially acceptance of their young children eventually felt a gradual abandonment from the church’s formal programs as their child entered adolescence. While some families had completely abandoned attending worship services, the majority did not blame the religious institutions—already resigning themselves to the fact that evangelical churches did not differ from the culture.\footnote{Amy Elizabeth Jacober, “Ostensibly Welcome: Exploratory Research on the Youth Ministry Experiences of Families of Teenagers with Disabilities,” \textit{Journal of Youth Ministry} (October 1, 2007): 73.}

Responses echo recurring themes of desiring welcome, acceptance, and friendship. Parents also indicated they did not feel comfortable going to clergy for guidance on their
Furthermore, they identified specific needs that if addressed would serve as a starting point: a safe environment, an intentional effort by a youth minister to build relationship, and something occasionally organized around their child’s reality.94

Identified Religious Needs by Caregivers of Adults with Disability

Carol A. Minton and Richard A. Dodder examined the participation of people with developmental disabilities in religious services by conducting a comparative qualitative study with four residential home managers, six church leaders, and twenty-five adults in group homes. The results suggested while persons with intellectual disabilities indicated a desire to attend worship services, negative stereotypes hindered their ability.95 While most residents were able to attend services, a recurring theme of continued isolation emerged—limited pastoral visits, phone calls, or opportunities to participate in church social activities.

Painfully aware of the lack of inclusion, group home managers perceived churches as only minimally welcoming. Interviews with church leadership indicated a wide range of acceptance. One commented on the effort it took to accommodate persons with disabilities and indicated no place existed for them in the church. A Pentecostal pastor, however, admitted the receptivity of his church’s worship style and indicated that his staff worked proactively to make both the residents from the group home and the

93 Ibid., 78.


congregation comfortable. Unsurprisingly, the majority of negative perceptions of the caregivers and persons with disability correlated with the less accommodating church.96

Minton’s research concluded several findings: (1) a majority of adults with developmental disabilities express a desire to attend worship services, (2) agency staff needs trained on how to facilitate integration, (3) local church leaders and congregations possess little awareness and training in disability issues, and (4) most impressively, residents who developed friendships with people in the congregation developed a sense of community and welcome.97

Research conducted by Carter indicated that while having an intellectual disability was not a correlative predictor of the importance of spirituality, it did impact the congregational participation opportunities made available. Yet in his study of nearly 450 youth and young adults with intellectual disability, he discovered the creative ways in which they expressed their spirituality.98 Carter suggests state agency support staff may unintentionally overlook expressions of spirituality that differentiate from their own while congregations may reject legitimate expressions of faith that appear disruptive.99 Somewhere in between those poles spirituality longs for support.

**Religious and Spiritual Supports Addressed**

The recurring themes that echoed throughout most studies summate into three major needs the church can address within the context of its weekly worship expression:

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96 Ibid., 434.
97 Ibid., 436.
98 Carter, 67.
99 Ibid.
a place of welcome, a place of support for the family, and a place of inclusive friendship for the child or adult with a disability.

A Welcoming Ethic

A welcoming ethic encompasses more than the identification of needs and support services offered. A welcoming environment allows mutual ministry to occur. Christianity Today’s 2005 “Where We Stand” editorial addresses fearful stereotypes and elevates the need for mutual ministry when proclaiming, “the disabled need the church—almost as much as the church needs the disabled.” Pressing the issue even farther, J. Daniel Salinas critiques predominant church structure focused on growth strategies as having bought into the secular utilitarian ethic that devalues persons with disabilities who exist on the margins.

By placing value on production instead of being, the church has copied the environment of the world. Salinas suggests the first step to developing a welcoming space is to reclaim the compassionate mission of Christ and actively seek those with special needs to function as part of the church. Webb-Mitchell calls for the return of persons with disabilities as active participants in the regular worship service as a reminder that God calls all people, not just ones with good works or average intelligence. The change process begins by creating awareness.

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100 “Fear Not the Disabled: We All Benefit When People with Disabilities Are Valued in Our Churches (Where We Stand),” Christianity Today (November 1, 2005): 29.


A spirit of welcoming involves more than accessible facilities; it intentionally promotes people with disabilities into the worship forum. When writing about autism, Mary Beth Walsh lists several ways clergy can develop awareness and a welcoming space in the congregation by utilizing existing structures: public prayer, congregational publications, outdoor signs, social media, preaching, inclusive religious education, service projects, and respite outreach. Kristin Peterson suggests the average parishioner can make a worship experience easier for family caregivers by offering simple smiles and words of encouragement. The key to sustaining awareness, however, rests squarely upon lead clergy who choose whether or not to model awareness through their actions and support. Megan M. Griffen et al report that the clergy’s commitment to inclusive practices served as a strong predictor of the congregation’s reaction.

Support Services Provided

Many congregations provide several types of supports during the weekly worship rituals, whether it utilizes liturgical aids replete with repeated phrases, colors, and scents, offers trained peer buddy systems, or uses lighting and technology displays.

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108 Jacober, 175.
appropriately.\textsuperscript{109} Other congregations have developed faith-based socio-emotional support groups for families.

Cynthia Tam and Vincent H. K. Poon analyzed the efficacy of a church-based support group of Chinese Canadians in Toronto. Interviewed respondents included seven families of children with a disability, three members of the organizational committee, and two pastoral staff members. Five positive themes emerged from the study that confirmed the pastoral staff’s perspective that the group was meeting its targeted need: security, communication, emotional growth, knowledge, and hope.\textsuperscript{110} The support group also had secondary impacts upon the children and attracted new families to the church. This study discovered immigrant families and those without extended families in the immediate geographical area need more extensive support.\textsuperscript{111}

In the early years after de-institutionalization, many churches adopted a segregated ministry program model,\textsuperscript{112} often perceived as a glorified babysitting service.\textsuperscript{113} Although it gave a place to people with disabilities, it did not allow a space for mutuality of ministry and full participation in the life of a congregation. Parents are more interested in finding a worshipping community that fully supports their child with a

\begin{footnotesize}
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\item \textsuperscript{109} Möller, 165.
\item \textsuperscript{111} Ibid., 348.
\item \textsuperscript{113} Andrea Bailey, “Welcoming the Little Ones: Children with Disabilities and Their Families Find Joy at a Herndon, Va. Church (From the Front Line),” \textit{Outreach Feb 2007} (February 1, 2007): 124.
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disability.\textsuperscript{114} In the last decade, churches sensitive to disability ministry have moved away from supporting segregated ministry programs toward now promoting integrated inclusive ministry.

Pursuing Holistic Inclusion and Mutuality

The inclusion model seeks to integrate persons with disabilities into the full life of the congregation. Similar to inclusion programs within local school districts, this model places value on every person, with or without disability, as having God-given gifts and graces that the person must express for the benefit of the church. Educational research indicates inclusion provides benefits to both the person with disabilities and those without: both groups increase in active participation, cognitive development, language acquisition, positive behavior, and social relationships.\textsuperscript{115}

Inclusion allows all parties to focus on personhood and be reminded of the \textit{Imago Dei}, the image of God imprinted upon every created human being.\textsuperscript{116} Thomas Pak calls clergy to focus on the personhood of everyone with a disability; he also reminds congregations that disability ministry is family centered.\textsuperscript{117}

People with disabilities possess unique gifts essential to the church.\textsuperscript{118} Ministry offered by persons with disabilities to others in the congregation reveals the

\textsuperscript{114} Barnes, 81.

\textsuperscript{115} Ibid., 85.

\textsuperscript{116} A discussion of the \textit{Imago Dei} is too complex to address in this literature review. For a comprehensive review of the \textit{Imago Dei} as it relates to persons with disabilities, see Ben Conner’s \textit{Amplifying our Witness}.

\textsuperscript{117} Bailey, 124.

\textsuperscript{118} “Welcome the Exceptional: Churches That Embrace People with Disabilities Do More than They Imagine,” 59.
unconditional love of God. When a church embraces people with disabilities, the congregation soon realizes they discover the presence of Christ and receive ministry themselves. By allowing those with disabilities to participate with their gifts and talents in a public liturgical venue, the church creates a welcoming space and sets a trend in place.

Implementing inclusive ministries can take time. Dennis and Murdoch utilized thirty participants in disability focus groups to research ways to sustainably increase inclusion of people with disabilities in parishes and then implemented a pilot model. After two years, they concluded the model worked well by creating awareness within the parish, drafting volunteers to offer ongoing supports, and changing attitudes toward participation with the sacraments.

Similarly, Collins and Ault examined the development of two inclusive disability ministry programs within large churches: one averaged 1000 congregants per week and the other 3500 per week. After researching the impetus for their development, the impact of their program, and the budgets allocated to the programs, Collins and Ault have several suggestions for churches wanting to model similar programs. Their key point differentiates between inclusive practices and inclusive community. Inclusive practices serve as the structures, procedures, and supports, which allow all persons to participate in

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119 Kim Tame, “And Finally … Special in Church,” *Expository Times* 119, no. 10 (July 1, 2008): 520.

120 Brad Jersak, “Guides to the Kingdom: Why Our Church Attends to Prodigals, Children, the Poor, and Those with Disabilities,” *Leadership* 28, no. 4 (September 1, 2007): 32.

121 Peterson, 31.

122 Dennis and Murdoch, 55.
non-segregated worship. However, an inclusive community, the more elusive goal, accepts and welcomes the differences of people and remains committed to them. Collins and Ault warn if an inclusive philosophy does not reside at the core of a ministry, even with inclusive practices implemented, it will never achieve full participation in the community.\textsuperscript{123}

**Outcomes: Parent Perceptions, Recommendations, and Congregational Benefits**

Ault, Collins, and Carter conducted a study of 416 parents\textsuperscript{124} of children with disabilities, inquiring about perceptions of congregational participation across thirteen spiritual domains. This study came to a six-point conclusion:

1. Parents report participating regularly in an average of four domains while their children with disabilities participate in an average of two.
2. Three-fourths of children participate in some regular inclusive activities. Yet a full 20\% are not involved in any activities.
3. A great percentage of parents indicate adequate supports are not fully available.
4. One third of respondents report changing their primary place of worship after being prevented from attending a church event.
5. Families able to participate at a greater level find congregations more supportive.
6. Families indicate that the attitude of faith communities plays an important role in participation.\textsuperscript{125}

Mothers of children with autism echoed similar concerns. Erica J. Howell and Melinda R. Pierson reported on a survey of four mothers involved in four different churches, sizes ranging from 6000, 4000, 500, and 100, who all agreed congregations can

\textsuperscript{123} Collins and Ault, 128.

\textsuperscript{124} The 416 parents consisted of 364 mothers, forty-one fathers, and eight legal guardians.

\textsuperscript{125} Ault, Collins, and Carter, 57.
generally receive more education about disability concerns. As each one participated as a member of varying congregational sizes, evident difference in satisfactory outcomes existed. The larger churches with developed programs generally functioned more inclusively, while the smallest church had the least supportive environment. General shared concerns remained: none of their children interacted with church peers outside of regularly scheduled church services; each parent thought the church held some responsibility to include children with disabilities; and the parents wanted their children to develop their own unique faith expression.

Linda L. Treloar interviewed thirty adults with disabilities or their family caregivers about the impact disability, faith, and the church played on their spiritual lives. She concluded that their existing belief system influenced their experiences and helped determine meaning for their disability. Participants in the study desired for the church to allow them to serve as the subject of ministry, not just the object. They posited several recommendations for the church:

1. Promote a theological understanding of disability. Only two participants had ever heard a sermon related to a positive construction of disability, resulting in an incomplete scriptural basis.
2. Develop a continuing ministry model. By implementing parish nursing and respite care, congregations can provide meaningful ongoing religious support.

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127 Ibid., 162.

Pitchlyn, Smith-Myles, and Cook echo this theme by suggesting clergy make congregants aware of support services available to persons with disabilities in order to increase parent involvement.\textsuperscript{129} Mark Pinsky examined a declining congregation in New Jersey that embraced disability ministry. While initially only purposing to include a specific fifty-year-old man, the church eventually embraced more people and started a network of groups, welcoming all into the church and reversing its decline.\textsuperscript{130}

Intentional focus is critical for the development of mutually inclusive ministry.\textsuperscript{131} The same story has repeated itself many times in various congregations.\textsuperscript{132} The Chinese Canadian church received more families into their congregation and recognized family systems within the congregation changed positively when presented an opportunity to share in mutual love and care with others in the faith community.\textsuperscript{133}

\textbf{Toward A Mutual Collaborative Support Framework}

All participants in the disability support framework have come to the realization it takes everyone working together to accomplish full inclusion and mutuality in the church and society. Jeff McNair joined Stanley Swartz and then Eric Carter advocating for the creation of natural networks of support from members within the congregation who possess expertise in disability matters or special education and has called for social

\textsuperscript{129} Pitchlyn, Smith-Myles, and Cook, 14.

\textsuperscript{130} Mark I. Pinsky, \textit{Amazing Gifts: Stories of Faith, Disability, and Inclusion} (The Alban Institute, 2011).

\textsuperscript{131} Anderson, 80.


\textsuperscript{133} Tam and Poon, 348.
service providers to reach into the congregation.\textsuperscript{134} Linda L. Treloar, emerging from the nursing profession, called upon interdisciplinary professionals to promote group networking in communities.\textsuperscript{135}

Carter formulated a simple framework that binds together the collaborative efforts of families, faith communities, and service systems to meet the support needs of individuals with disabilities.\textsuperscript{136} DeKraal et al requested faith communities to partner in behavioral care management by constructing a collaborative model of integrated faith-based and community organizations.\textsuperscript{137} These two independently developed models allow some flexibility in developing a holistic person-centered plan that takes into account supports needed for full participation while allowing the person’s gifts to flourish in an inclusive community.

\textbf{Person Centered Collaborative Framework for Flourishing Individuals}

Carter suggests his intersecting circular framework of families, faith communities, service systems, and individuals with disabilities represent four core areas where research and policy must still take place. He holds particular interest in their overlaps and intersections. He asserts that only when all stakeholders work together in concerted effort do additional opportunities emerge for individuals with disabilities to flourish. He further


\textsuperscript{135} Linda L. Treloar, “Disability, Spiritual Beliefs and the Church: The Experiences of Adults with Disabilities and Family Members,” \textit{Journal of Advanced Nursing} 40, no. 5 (December 2002): 601.

\textsuperscript{136} Carter, 66.

\textsuperscript{137} DeKraal et al., 259.
suggests individuals given a chance to engage in mutual ministry within the religious circle will also increasingly thrive in the other three domains.\textsuperscript{138}

**Collaborative Service Model Option for Faith Organizations**

The collaborative service model holds two necessary presuppositions: (1) inclusion of faith based organizations are critical for effective response, (2) faith communities can provide effective service options to fill in existing gaps, particularly in rural areas. DeKraal et al acknowledge, however, the unawareness of faith organizations concerning the importance of their role and their value in linking formal and informal systems of care together and developing coalitions.\textsuperscript{139}

Faith groups interested in addressing society’s behavioral health issues may benefit from a model that describes service delivery in terms that have relevance to traditional roles religious groups have assumed in social service provision. A model would enable congregations, faith-based organizations, and community ministry groups to match their strengths, or callings, to a service that can effectively support people with behavioral health problems in the context of the larger behavioral health system of care.\textsuperscript{140}

The value of this model for adaptation to the disability system of supports is readily seen. Similar to the pyramid shaped multiple tiered systems of support (MTSS) used by special educators and positive behavior intervention specialists, it recognizes the universal ability to design 80 percent to 90 percent of interventions and supports across all functions of the environment (i.e., general education environment, organization, or

\textsuperscript{138} Carter, 68.

\textsuperscript{139} DeKraal et al., 256-257.

\textsuperscript{140} Ibid., 258.
congregation). With appropriate training, only 10 percent to 20 percent of support needs tend to require specialized or licensed support or treatment.  

The tip of this three-tiered pyramid model of supports comprises of residential treatment and crisis intervention. These roles tend to be predominantly clinically based and administered by accredited agencies, perhaps including some religiously based vendors (i.e. Lutheran or Catholic social service agencies).

The middle tier of the pyramid includes areas in which both social service agencies and church networks can develop collaborative initiatives. They are not unique to disability supports since many churches and para-church ministries already involve themselves to some degree in one or more of these areas:

- Affordable housing
- Independent living skills
- Service management / Wraparound
- Employment
- Education / Support groups
- Financial assistance
- Transportation
- Social / Recreational
- Mentoring / Respite Care

When churches recognize what they are already doing, they can then target and tailor their services in collaboration with available social service agencies to increase participation in both the congregation and community. Not every church in the community will accomplish everything in all areas; however, by working together, they will address every domain.

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141 Freeman et al., 113.
142 DeKraal et al., 259.
143 Carter, 71.
The base of the pyramid comprises of information and referrals, basic or complex. Every pastor should know what agency or church supports a specific need domain. Dekraal et al suggest faith networks develop a common language and classification of support services available in their region. At the minimum, every congregation should openly discuss disability with a welcoming attitude.\textsuperscript{144}

**Conclusion**

This literature review examined the taxonomy of needs that persons with disabilities and their caregivers identify, as well as the tools utilized with which to identify them. Furthermore, it explored the current services provided and the measurement of satisfactory outcomes in achieving person-centered goals. The programs in Kansas and in rural areas received special attention. A further examination of supports that faith communities offer revealed extensive gaps remaining in the intersection of secular and spiritual supports. Finally, this review examined several theoretical collaborative models that, if implemented, could yield promise in achieving full participation and mutual ministry of people with intellectual disabilities in their spiritual and religious practices.

\textsuperscript{144} DeKraal et al., 263.
CHAPTER 4: DESCRIPTION OF FIELD PROJECT

Introduction

The previous chapter reviewed literature pertaining to the needs of persons within the disability community and the corresponding support services by community agencies. Chapter 4 discusses the preparation, execution, and results of a survey project utilizing comparative analysis across several categories between Assemblies of God Kansas Ministry Network (AGK) clergy members and family caregivers of children with intellectual and development disability (IDD). The survey project sought to answer the following questions:

1. To what extent do theological perceptions of disability between clergy and caregivers inform inclusive praxis?
2. To what extent do clergy and caregivers perceive congregations as a supportive community?
3. To what extent do clergy and caregivers perceive accommodations as necessary to ensure full participation in the worshipping community?
4. To what extent do the local AGK ministry network churches serve the current population of people with disabilities in Kansas communities?

Preparation

Selection of Kansas Ministry Network

As a former AG Christian school administrator and current full-time special education substitute teacher in one of the larger unified school districts in the Wichita, Kansas area, I have heard firsthand reports from parents rejected from a church setting. I have also heard narratives from clergy members who expressed a desire—but faced their own inability—to minister with persons with disabilities and their caregivers. I realized
that both parties often approached disability from different theological perspectives and
were unable to communicate needs and provide mutual ministry service to one another
effectively.

I designed the project to compare two distinct populations and sought the
participation of an undetermined sample size of caregivers active in any churches,
particularly those located in Kansas. First I obtained the latest Kansas Department of
Education (KSDE) report that reflected the 2012-2013 academic school year enrollment,
listing the numbers of students (ages six to twenty-one) with disabilities on
Individualized Education Plans (IEP) in the Least Restricted Environment (LRE).¹ I then
acquired the 2012 Disability Status Report: Kansas, which primarily reports on the
numbers of non-institutionalized working age adults (twenty-one to sixty-five) with
disability.²

Understanding that I would have difficulty identifying congregants with
disabilities through the AGK directly, I turned to Connie Zienkewicz, administrative
director of Families Together, the designated state agency for family caregivers.
Zienkewicz offered to publicize the survey in their organization’s weekly electronic
newsletters throughout the state.

I also sought the participation of at least 20 percent of AGK clergy members
currently residing in Kansas. Terry Yancey, superintendent of the AGK Ministry
Network, offered the assistance of the network office in conducting the survey among

1. Kansas Part B State Annual Performance Report for FFY 2012 (Topeka, KS: Kansas
Department of Education, February 1, 2014).

Cornell University Employment and Disability Institute, 2014).
clergy members. He provided a letter of recommendation that urged all AGK ministers to participate, gave me opportunity to introduce the survey at the April 2014 AGK district council, and offered me a slot at an August 2014 presbytery meeting to report the findings.

The AGK also provided the 2012 and 2013 Annual Church Ministries Report (ACMR) information, an electronic database of 494 clergy members and 139 churches, and printed mailing labels for all clergy members and churches. Of the 494 clergy members licensed in Kansas, I excluded those not currently residing in the state due to missions’ appointments or academic assignments. The final clergy panel\(^3\) contained 368 unique members, and the final AGK church panel contained 136 unique churches.

Creation of Survey Instruments

**Clergy/Caregiver Perception Instruments**

I designed the Internet-based assessments utilizing Qualtrics. Questions originated from several sources discovered in the literature review, including the Support from Religious Organizational and Personal Beliefs Scale-Revised (SROPBS)—utilized by Carol L. Pitchlyn, Brenda Smith-Myles, and Virginia H. Cook\(^4\)—and the congregational participation survey reported by Melinda Jones Ault, Belva C. Collins, and Erik W. Carter.\(^5\) Each survey began with a required informed consent page. The instrument

\(^3\) A panel is a database of pre-selected survey respondents meeting selected criteria. In Qualtrics, the panel feature tracks the distribution of and responses to the survey.


contained three major sections: demographic, quantitative, and qualitative. I divided each section into smaller themed sub-sections. The demographic section consisted of seventeen questions. I divided the quantitative section of thirty-six questions into five themed sub-sections. I wrote some questions in the first person for clergy and appropriately modified them into the third person for the caregiver. In the first three sub-sections, I provided a four-point Likert Scale for participants to evaluate their reaction: strongly disagree, disagree, agree, and strongly agree. The fourth sub-section consisted of ranking nine items from lowest to highest. For the fifth sub-section, I provided a three-point Likert Scale: Yes, No, I don’t know. The survey closed with a qualitative section of three open-ended questions.⁶

Subsection 1: Theology and Pastoral Practice.

- People identified with IDD are created in the image of God
- Places of worship should pray regularly for persons with IDD to be made normal.
- Parents of children with IDD are especially blessed.
- Children with IDD may be a result of a parent’s sin
- Persons with IDD may NOT need to experience God’s saving grace.
- Healing is the primary need for people identified with IDD.
- I allow persons with IDD to receive communion.
- My place of worship allows people with IDD to become members.
- I would celebrate the birth of a child with IDD through public infant dedication.
- I would baptize a person with IDD.
- I am comfortable officiating a legally approved wedding of an adult with an IDD.
- I make personal phone calls and pastoral visits to persons with IDD on a regular basis.
- People with IDD should be allowed to exercise their spiritual gifts.
- Persons with IDD can receive the Baptism of the Holy Spirit with the initial physical evidence of speaking in tongues
- Places of worship should allow persons with IDD to serve in ministry roles.
- I have been adequately trained in ministering to people with IDD and their caregivers.

⁶ See Appendix A, “Creation of the Survey Instrument.”
Subsection 2: Clergy Members as Supportive Partners.

- I am helpful to families when their child is identified with an IDD.
- I am satisfied with the availability of religious education programs our place of worship provides for children with IDD.
- Caregivers of children identified with an IDD are more active in the church now than before.
- When families have problems with their children with an IDD, they would seek help from our place of worship.
- Our place of worship is just as supportive of caregivers of persons with IDD.
- Most of the social activities of families with IDD involve members of the church community.

Subsection 3: Envisioning Cooperative Disability Ministry in the Community.

- Places of worship should provide or arrange transportation to worship services / church social events for persons with IDD.
- Our place of worship provides age appropriate accommodations for youth with IDD at youth group activities.
- Very few persons with IDD live in the local area near our place of worship.
- It takes a lot of money for a place of worship to begin a ministry program for persons with IDD.
- Places of worship should work with persons with IDD to find affordable housing.
- Places of worship should offer financial assistance to members with IDD if needed.
- Places of worship should work together with other agencies to support people with IDD.

Subsection 4: Ranking of Needed Supports.

I asked participants to rank on a scale of 1 to 9 in descending order what they believed would be best for persons with disabilities and their caregiver to fully participate in congregational settings. The nine items were:

- Respite care
- Welcoming attitudes toward people with disabilities
- Additional supports to participate in religious activities
- Accessible transportation
- Accessible facilities
- Parent support groups
- Accessible materials
- Counseling sponsored by faith communities
- Special programs designed for people with disabilities
Subsection 5: Congregational Supportiveness.

- I am supportive of including children with IDD in religious activities.
- Are you aware of any family ever leaving the church because their child with IDD was not included or welcomed?
- Are you aware of any family member ever not participating in religious activities because their child with IDD was not included?
- Are you aware of any persons with IDD unable to participate in a religious activity because support was not provided?
- Have you ever asked parents to stay with their child with IDD at a religious activity so the child could participate?
- Have you ever asked a family the best way to include their child with IDD in religious activities?

Qualitative Section

- Please describe any positive or negative experience you personally have had with a person with intellectual disability and their caregiver.
- Please describe any contribution or disruption that people with IDD and their caregiver have made in your congregation.
- Please share any questions or concerns you may have about including people with IDD and their caregivers into full participation in your congregation.

ACMR Supplemental Survey Instrument

Utilizing Qualtrics, I developed an Internet-based instrument and divided the ACMR Supplemental Survey into three sections. The first section consisted of seven congregational demographic questions, the second section sought to determine demographic data of persons with disability attending services for an ongoing regular basis during the past year, and the third section sought to determine the extent of disability ministry and full participation by people with disabilities within the church. Participants could check multiple boxes of supplied responses or write in additional options.

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7 See Appendix A, “Creation of the Survey Instrument.”
Execution of the Project

Participants and Setting

Clergy

A total of eight-four AGK credential-holding clergy participated, representing 23 percent of the clergy panel. Respondents reflected a cross section of the AGK district. As expected, the majority of respondents were Caucasian, married males. Fifty-eight percent had attained ordination with an equal amount of 18 percent achieving the licensed and certified credential levels. Lead pastors represented 57 percent of respondents.

While two-thirds served in full-time paid positions, 20 percent were in paid bi-vocational or part-time assignments. With experience levels evenly ranged, 54 percent reported over 16 years of pastoral experience. Sixty-five percent of participants had earned a bachelor’s degree, while 29 percent had completed a graduate level program.8

Of the AGK clergy respondents, 88 percent served AGK churches while the remainder served other non-denominational or independent churches. Church size evenly ranged among the respondents: 35 percent of respondents participated in small churches, 30 percent in medium sized churches, and 36 percent in large churches. Respondents also reflected across the three geographic presbytery regions of Kansas: 40 percent in the east, 37 percent in the central, and 23 percent in the western region.9


9 See Appendix C, “Characteristics of Clergy Respondents’ Church Settings,” for statistical breakdown.
Caregivers

A total of thirty-six family caregivers participated in the survey. Only eleven resided in Kansas. The majority of respondents were Caucasian married females. Two-thirds were between the ages of 35 and 54. Seventy-eight percent of respondents were mothers. Sixty-one percent of respondents had earned a bachelor’s degree, and just over a quarter had completed a graduate level program. Eighty percent of respondents indicated they attend regularly scheduled religious services at least once a week with their child with an intellectual disability. Church size evenly ranged among the respondents: 28 percent served or attended small churches, 25 percent in medium size churches, 39 percent in large churches, and 8 percent in super churches. The eleven Kansas respondents were scattered across the three geographic AGK presbytery regions. Five of the respondents identified with the Assemblies of God, although only one resided in Kansas.  

Respondents indicated care for nineteen males and seventeen females. The ages of the children with disability ranged widely, but 83 percent were under 25 years of age. Of the thirty-six children listed, one was married. None have attended any college level courses, while nearly a third have graduated from high school. Caregivers identified 42 percent of children with Autism and another 42 percent with other developmental delays.


ACMR Supplemental Survey

A total of sixteen AGK churches returned valid, completed survey responses, representing 12 percent of AGK congregations. Every respondent indicated the presence of someone with a disability within the congregation. Sixty-nine percent of respondents listed lead pastor tenure over eleven years. All responding churches identified themselves as General Council of the AG affiliated. Church size evenly ranged among the respondents: 31 percent small churches, 38 percent medium size churches, and 31 percent large churches. Respondents were scattered among the three geographic presbytery regions of Kansas: 63 percent in the eastern, 25 percent in the central, and 13 percent in the western regions.\textsuperscript{12}

Pilot Study

I created a test panel of several clergy members and caregivers and invited them to participate in a pilot study of the survey instruments. The pilot study revealed several errors in the survey flow, accessibility, and ease of distribution via email. I simplified the clinical definitions of different categories of disability and repeated them every major section rather than just in the introduction. I also grew concerned at the number of emailed survey invitations ending in junk mail or spam filters. This led to a decision to create www.abilitysurvey.org as an anonymous portal containing links to the survey, an explanation of the informed consent statement, and updates on the progress of the project. It also led to the decision to send out mailers and create Facebook forum posts to alert AGK ministers of emailed invitations.

\textsuperscript{12} See Appendix F, “Characteristics of Supplemental ACMR Respondents,” for graphs indicating statistical results.
Distribution and Collection

I timed the clergy instrument launch coinciding with the annual AGK council. I sent the first email blast on April 6, 2014. The AGK allowed me to make a short presentation during the council on April 9, 2014, where I discussed the need for new strategies to reach persons with disability (including IDD) and requested clergy members’ participation in survey instrument. I sent out a follow-up email blast on April 10, 2014. On May 5, 2014, I mailed a letter via USPS to all AGK clergy members with information requesting the completion of the survey. The last recorded survey entry was on June 3, 2014. I closed the survey on June 22, 2014.

Of the 368 members of the panel\textsuperscript{13}, I received 120 electronic participant surveys and one completed paper survey. Because several of the 121 surveys had not completed major sections, I excluded thirty-seven from analysis, totaling eighty-four valid responses.

I initially distributed the caregiver instrument through Families Together, who featured it in newsletters on April 28 and May 5, 2014. Utilizing a snowball method, I continued to promote this instrument on several disability Facebook sites. The survey also gathered interest outside of the state. I closed the survey on June 22, 2014. Respondents submitted fifty-four surveys. As major sections of many surveys were incomplete, I excluded eighteen from analysis, totaling thirty-six valid responses.

Finally, beginning July 8, 2014, I distributed the ACMR Supplemental instrument using a Qualtrics panel to 136 AGK churches and closed the survey on July 28, 2014. I

\textsuperscript{13} A panel is a database of pre-selected survey respondents meeting selected criteria. In Qualtrics, the panel feature tracks the distribution of and responses to the survey.
received eighteen surveys, two of which were incomplete, leaving a total number of sixteen valid survey responses.

**Results of the Project**

**Introduction**

The survey instruments\(^ {14} \) indicated that disability ministry both within worshipping congregations and the local community has a potentially transformational future. The results illustrated that both caregivers and clergy members begin with similar agreement on theological value suppositions. Significant differences, however, emerged among several factors. First, caregivers and clergy indicate passionate differences between levels of agreement, with clergy age, clergy education, and proximity to those with IDD as factors. Second, clergy’s posited support of theological claims often does not correspond with their own actual practices of ministry. Third, caregivers’ perceptions of clergy’s opinions often do not correspond to clergy’s actual beliefs. The following section presents the quantitative clergy and caregiver comparative results within the framework of the Five Stages of Disability Attitudes.

**Awareness: Moving from Ignorance to Pity**

From the youth pastor who informed young parents that a demon possessed their four-year-old child with IDD, to another who confused becoming normal and healing, commenting, “let’s just pray God heals this baby,” or others who claim that the cost of ministry is too high, caregivers reported interactions with clergy that illustrate the lack of foundational perspectives on theology, disability, and ministry practice.

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\(^ {14} \) See Appendix A, “Creation of the Survey Instrument.”
Normalizing Image Bearers of Christ.

Many clergy members have a difficult time recognizing people with IDD as image-bearers of Christ. One parent wrote:

My son … “scares” my “pastor” my [sic] son loves God with all his heart and doesn’t understand why people treat him so poorly. I too feel a great deal of anger when the ‘pastor’ preaches how we need to love each other the same and we are all made in God’s image and what have you. What he means is if you are made in God’s image, as long as it is like him.

The pairing of two related questions illustrates the discrepancy between assertive believe and congregational praxis. Clergy’s unanimous support of the statement, “Persons identified with IDD are created in the image of God” was similar to the caregivers’ predictive score of clergy response of 86 percent. Yet only 56 percent of clergy opposed the statement’s inverse: “Places of worship should pray regularly for persons with IDD to be made normal,” sharply contrasting with the 89 percent of caregivers opposed:15

When filtering the open-ended clergy comments by those who disagreed with the statement, several results emerged. Although only shifting slightly in the subjective questions, the open comments provided the dramatic evidence. Clergy who perceived persons with IDD as normal and created in the image of God overwhelmingly recited numerous contributions and few disruptions.

Affirming Particular Blessing

Seventy-one percent of clergy supported the statement, “When asked whether parents of children with IDD are particularly blessed” as compared to 56 percent of

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15 See Appendix G, “Image of God, Normalization, and Healing” for graph indicating statistical results and additional analysis.
caregivers. This result indicates that many of the 95 percent of clergy members who affirm that disability is not a result (curse) from sin, also hold the opinion parents possess stronger moral fortitude in which to handle a burden given to them. Many parents do not believe themselves more blessed or cursed than anyone else. A correlation exists between the extent to which clergy feel their supportive engagement as necessary and clergy who believe God is already working in caregivers as exemplified by their endurance of perceived suffering. A perception of particular blessing hinders the collaborative supportive ministry necessary.

*Primacy of Salvation or Healing*

Caregivers predicted that 25 percent of clergy would support the statement, “Healing is the primary need for people identified with IDD.” They also predicted 30 percent of clergy would support this statement: “Persons with IDD may not need to experience salvation.” Caregivers perceived clergy as more concerned about their children’s healing than their salvation. One AG caregiver wrote, “My biggest heartache is that my son is never taught the gospel. As [sic] if he is never expected to receive Jesus or be baptized in the family.” Caregivers’ perceptions were fairly accurate, as 23 percent of clergy indicated healing as the primary necessity and 12 percent of clergy disagreed that persons with IDD needed to experience salvific grace. Ministry role and age were contributing factors. Potential reasons for this discrepancy may lie in clergy’s Pentecostal worldview, making it difficult to assess the receipt of salvific grace outside of either cognitive assent to doctrine or a physical sign of becoming normal.

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16 See Appendix H, “IDD as Curse or Particular Blessing” for graph indicating statistical results.

17 See Appendix I, “Salvation and Healing” for graph indicating statistical results.
Financial Burden

When asked if it takes a lot of money for a place of worship to begin a ministry program for persons with IDD, 28 percent of clergy agreed, juxtaposed to 8 percent of caregivers. Interpreting requests for accommodative support through the lens of a deficit medical model, clergy envision budget draining problems and distractive behaviors instead of potential contributions to the body of Christ. One clergy member used a medical analogy:

If the local hospitals have to refer patients, and some counselors have to refer clients to more equipped professionals for the various IDD cases, then the church may need to recognize its limits as well…we must assess the assets within our congregation and know what the local church organism can and cannot handle.

This is not, however, the motivating factor behind caregivers’ requests; they ask for supports in an effort to offer their friendship and particular gifts to others in a worshipping community.18

Access: Moving from Pity to Care

Social Service Collaboration

Clergy responded to questions on community social services considerably higher than caregivers predicted.19 A large majority agreed places of worship should help persons with IDD find affordable housing, provide transportation to church events, and offer financial resources when needed. Contrary to caregivers’ expectations, clergy were supportive of working collaboratively with other agencies to support persons with IDD.

18 See Appendix J, “Accommodations, Modifications, and Support” for graph and discussion.

19 See Appendix K, “Attitudes towards Social Services,” for discussion and graphs indicating statistical results.
These results rejected caregivers’ widely held perception that places of worship are unwilling to address these initiatives.

*Accessibility Features*

When asked to rank what would be most helpful for persons with disabilities and their family caregivers to participate fully in the congregation in the top five categories, clergy overwhelming placed welcoming attitude toward people with disabilities, followed by accessible facilities, parent support groups, additional supports to participate in religious activities, and special programs designed for people with disabilities. Caregivers also highly desired a welcoming attitude, yet ranked the next four categories in a different order.\(^{20}\) While pew cuts and ramps are architecturally accessible features, they do not solely convey a welcoming attitude. The results suggest caregivers prefer supports focused on allowing them to be more active in the full participatory life of the church. When supportive accommodations are unavailable and with no other place to turn, caregivers and persons with IDD interpret their contribution to the body of Christ as unimportant. Yet clergy who have found ways to accommodate inclusion, report persons with IDD provide “positive experiences” and do not “damage what God was doing.”

*Relational Proximity as a Factor of Pastoral Practice*

Both clergy and caregivers mutually agree over celebratory worship practices of membership and communion, yet each of those requires little intentional interaction between both parties. Public practices requiring greater proximity produce increasingly divergent results. Clergy unanimously agreed they offer infant dedication (infant

\(^{20}\) See Appendix L, “Accessibility Feature Ranking,” for graph indicating statistical results.
baptism) and adult baptism (confirmation) to persons with IDD, yet this sharply contrasted with the caregivers’ predictive score of clergy response of 81 percent for both questions. Eighty-six percent of clergy agreed with the statement that they “are comfortable officiating a legally approved wedding of an adult with IDD,” juxtaposed against the caregivers score of 64 percent. The strength of the differences between the caregivers’ perception of clergy validated the opinion that clergy rarely offer opportunities for public celebrations of spiritual transformation to adults with IDD.\textsuperscript{21}

Practices of pastoral care require even greater interaction and mutual relationship. Caregivers offer mixed reports of pastoral care experiences. One AGK church attender reported, “our pastor is so extremely supportive of our family as a whole which is awesome and has even come to our home as well as to the hospital to pray for my son when he was in the hospital for a week with pneumonia.” Although 40 percent of clergy agreed they made personal contact or phone calls to persons with IDD on a regular basis, caregivers asserted that only 31 percent did.\textsuperscript{22} One caregiver records, “We had one pastor who would visit other parishioners in the hospital at the same time as my son was a patient, but he wouldn’t visit us.”

Integration: Moving from Care to Friendship

Supportiveness as Part of Religious Coping System

When informed their child has an IDD, caregivers often immediately turn first to clergy for support. Clergy reported their role in supportive care by describing their appropriate actions, such as listening to grieving parents for hours or taking care of

\textsuperscript{21} See Appendix M, “Relational Proximity in Public Celebration.”

\textsuperscript{22} Ibid.
immediate needs when sudden onset disability affected a member of their congregation.

Although initial support is critical, ongoing support proves even more crucial. A
caregiver wrote about his experience requesting a “location where a parent support group
could meet, counseling specific for our families; all gone [sic] unresponsive or
disregarded.” Another parent insightfully requests clergy to become even more proactive:

Clergy sometime assume that everything is fine with our family. I have to
say that “assumptions kill relationships.” It would be great to have clergy
that proactively seek to check on our spiritual stamina. As a family of a
child with IDD we want to avoid being seen as “needy”. Therefore, it
would be great if the clergy make the first approach to check on us.

Clergy Helpfulness

Ninety-three percent of clergy agreed, “I am helpful to families when their child is
identified with an IDD,” as opposed only to 53 percent of caregivers affirming clergy
members’ helpfulness. This blunt dissimilarity confirms those actions clergy presume as
helpful that caregivers do not identify as necessarily supportive. The experience with
initial clergy interactions in the early stages of coping with IDD yields a lasting effect
acknowledged by both clergy and caregivers. Sixty-three percent of clergy indicate
caregivers would seek help from places of worship if having problems with a child with
IDD, juxtaposed to only 42 percent of caregivers acknowledging they would seek help
from their clergy member.23 This result confirms caregivers no longer turn to places of
worship for assistance as often as clergy presume.

23 See Appendix N, “Supportiveness as Part of Religious Coping.”
Caregivers’ Participation

Many caregivers desire clergy to be more aware of their new normal. One caregiver remarked, “We just have to do things differently now in order to meet our son’s needs.” When asked if caregivers were as active in the place of worship since the identification of a child with IDD, an even 50 percent of clergy indicated agreement, yet only 28 percent of caregivers agreed. This result confirms the difficulty of caregivers and their children with IDD in maintaining active church integration. Dissatisfaction with religious educational programing factors into the reduced participation. Fifty-three percent of caregivers perceive clergy members contented with the current range of religious education options provided for those with IDD, while in reality actually only 23 percent of clergy are pleased. Compounding this perception, clergy and caregivers actually are in mutual agreement on this point, yet they do not recognize their extreme joint dissatisfaction of current religious education programs.

Comparison of Supportiveness

When asked if places of worship are as supportive to caregivers as other social agencies, 62 percent of clergy indicated agreement, differing from the actual caregiver score of 42 percent. When friendships within congregations no longer offer support, caregiver’s social activities decline. Only 57 percent of caregivers supported the statement, “most of my social activities involved members of my place of worship.” This result suggests many places of worship do not function as strong centers of supportive, inclusive community for people with IDD.

24 See Appendix O, “Participation and Religious Education.”

25 Ibid.
Supportiveness as Part of Integration Process

When asked to describe experiences with faith communities, caregivers narrated various anecdotes on the level of support given to them and their child with IDD. Some had never encountered an exclusive environment, sharing stories where churches built sidewalks, offered respite care, hired special needs staff, or included them on building facility committees. Others, however, never felt welcomed, recounting times when “I was told if my child comes with me we will be forced to sit in the balcony” or the VBS coordinator informing another that “they weren’t equipped to help her [child].” One caregiver recounted her experience:

I had to line up my own “buddies” and pay for them ourselves when my son was younger, if I wanted to attend a service … Our pastor kept having events at his home, which was not wheelchair accessible. My son uses a wheelchair. Our experience is that if a disability ministry gets going, it’s because of us, not the pastor.

A full 96 percent of clergy agreed with the statement, “I am supportive of including children with IDD in religious activities,” yet only 41 percent provided accommodations at youth group activities. When asked if any family ever left the church because their child with IDD was not included, only 19 percent of clergy as compared with 56 percent of caregivers indicated they were aware. Although 21 percent of clergy acknowledged persons with IDD were unable to participate in a religious activity when support not provided, only 14 percent of clergy grasped the fact that some family member was unable to participate in religious activities when a child with IDD was not included. Nearly a third of the clergy had requested parents to remain with their child with IDD at a religious activity so the child could participate, sharply contrasting with two-thirds of the caregivers who reported clergy had asked them to remain. Clergy and caregivers did agree in one area: only 45 percent of clergy ever asked caregivers the best way to include
their child with IDD in religious activities. These results illuminate the vast discrepancy between the perceptions of the clergy and caregivers on the supportiveness of congregational settings, confirming caregivers’ fear they are unwelcomed.

Engagement: Moving from Friendship to Co-Laborers

Opportunities for Empowering Service

Whether an active child with the gift of encouragement, an adult with IDD who volunteers with his or her personal care attendant at the weekly food pantry for an hour, or the daughter whose mere presence “reminds us that God’s creation is full of variety,” some clergy reported that persons with IDD regularly serve in many faith communities as ushers, artists, greeters, and even worship team members. One caregiver, however, regretfully writes regarding her daughter, “she has never been given the opportunity.”

Over 98 percent of clergy supported both statements, “people with IDD should be allowed to exercise their spiritual gifts” and “persons with IDD can receive the Baptism of the Holy Spirit with the initial physical evidence of speaking in tongues.” Yet the support eroded when placed into congregational settings. Only 19 percent of clergy indicated strong agreement that “places of worship should allow persons with IDD to serve in ministry roles” juxtaposed with 53 percent of caregivers. These results confirm the caregiver perception clergy members are not highly desirous of utilizing the ministry gifts of persons with IDD in ministry capacities.

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26 Appendix P, “Congregational Supportiveness.”

27 See Appendix Q, “Empowering Service.”


Necessity of Clergy Education

When asked to share any concerns about including persons with IDD, caregivers reported their frustrations with the overall concern or lack of response for their children’s needs. One caregiver suggested, “educating the church on how to help” would allow ministry to be done more appropriately and effectively. A clergy member similarly inquisitively echoed, “We would do more than we do if we had qualified people; and perhaps if specific training were made available it might empower others willing to provide such ministry?” Yet another clergy member confessed, “I think a big negative experience for me personally is not knowing how to approach people with IDD.”

Only 30 percent of clergy supported the statement, “I have been adequately trained in ministering to people with IDD and their caregivers.” Similarly, only 25 percent of caregivers, perceived clergy had received adequate training yet had predicted clergy response of 45 percent. Many caregivers assume that clergy received training in the pastoral care of persons with disability during their Bible College or seminary course work. Among credentialed clergy holders, 40 percent of the non-lead pastors with graduate degrees reported higher levels of adequate training than 82 percent of lead pastors without graduate work. This result confirms the caregiver perception that clergy members have not received adequate training; however, it highlights the necessity for clergy continuing education while rejecting caregivers’ assertion clergy are unaware of insufficient training.28

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28 See Appendix R, “Clergy Education.”
Disability and AGK Congregations

Thirty-eight percent of clergy indicated that very few people with IDD live near their place of worship. Although the size of the congregation was a factor in this finding, it did not correspond to geographic region. The AGK ACMR supplemental respondents reported a total of 177 persons with some type of disability involved in their congregations, including fifty-six school age children and sixty-eight working-age adults. Only six respondents indicated their faith communities had intentionally targeted ministry for families experiencing disability. Those who did usually provided “buddy” programs or a special needs Sunday school class for children. Persons with disabilities were active in nine of the congregations, mostly serving as ushers. This result suggests that clergy of smaller congregations in less populated western Kansas were more aware of persons with IDD within their communities than those in more populous regions. It also reveals that many opportunities still exist for outreach to persons with IDD and their families. 29

Project Contribution to Ministry

This survey project provided AGK clergy members and adult caregivers of persons with IDD the opportunity to reveal anonymously their approach and concerns on disability ministry in an effort to create additional awareness and understanding with each other. It also quantified the need for disability ministry by comparing the population of persons with disabilities with those currently served by or serving within local AGK congregations. Approaches drawn from the biblical-theological and general literature reviews suggest opportunities to promote inclusive congregations and mutual ministry

29 See Appendix S, “Prevalence of Disability in AGK.”
First, the action research study intended to create awareness of the mutual discrepancies in theology and supportive praxis between caregivers’ shared perceptions of clergy and congregations as a precursor to establishing the necessity of collaborative disability ministry within the local church. The results showed significant disparate perspectives between both parties. These results—some warranted and others not—suggest clergy and caregivers require opportunities to develop mutual understanding through increased communication and understanding.

Second, the project developed the need for disability ministry by quantifying the prevalence of persons within the Kansas disability population and compared it to current disability ministry offerings within AGK congregations. Although several churches attempted inclusive disability ministry practices for current members, intentional targeted outreach remains relatively rare.

Third, the survey revealed that any congregation, regardless of its size or average age spectrum, could successfully implement some level of disability ministry. Factors of clergy age, position, tenure, and congregational size, although contributory toward attitudes on disability and theology, where not necessarily significantly related and could not be utilized as an overarching excuse to avoid disability ministry. This implies that factors of proximal relationship may serve as a stronger indicator of the acceptance of mutual ministry from those within the disability community. These results suggest that specific interventions must focus on opportunities for proximal relationships.

Fourth, this project identified and quantified the need of pastoral candidates to reflect critically upon theological perceptions in light of the lived experiences of disability within congregations and potential church adherents. These results suggest
continuing education and additional training are imperative for pastors in a local church context. Furthermore, seminaries and pastoral preparation programs are in an ideal position to create meaningful cross discipline explorations of ability ministry.

Finally, this project suggests that clergy may be supportive of a ministry model that refocuses on congregant transformational outcomes through the supportive relationships contained within the larger community. This paradigm allows for collaborative efforts between the local church and other social agencies, as well as for intra-congregational supportive relationships.
CHAPTER 5: PROJECT SUMMARY

Introduction

This chapter reflects upon and evaluates the entire process of developing a research action investigation, related project events, and the eventual outcome. While chapter 4 addressed the potential effects of the survey, this chapter focuses on the project’s effectiveness, identifies keys to potential project improvements, offers implications for what this may mean for the future of Pentecostal ability ministry, and provides specific recommendations for the Assemblies of God Kansas Ministry Network and related church organizations. It will conclude with recommendations for others who wish to study disability and further the work of ability ministry.

During the course of this journey, I have diligently listened to the voices of numerous family caregiver stakeholders and clergy. I have had opportunity to discuss every step of my research and development with multiple mentors, inviting them to review carefully any hidden bias and point out flaws in my argument. Numerous nights on retreat or at disability conferences gave me space to reflect upon and strengthen this project’s effectiveness. Primarily, I desired to be a living example for what this project calls the church to do.

Evaluation of the Project

This project uniquely compiled research in the fields of disability studies, special education, religious education, ability ministry best practices, and ministry attitudes. It
also brought together disparate studies from various fields of disability services and created a unified exhaustive research instrument. The premise of this project was that by illuminating the vast openness of the ability ministry field, denominational leaders, human service providers, clergy members, and local congregations will act in unison to develop ability ministry in order to reach a largely unchurched people group.

Keys to Project Effectiveness

Several keys made this project effective: (1) timeliness of need, (2) theological foundation, (3) supportive relationships, (4) space for awareness, (5) technological flexibility, (6) scope of participants, and (7) commitment toward supporting local ability ministry.

First, analysis of other studies on disability issues as well as congregational approaches toward ability ministry uncovered as part of the literature review indicated a rapidly growing interest in this topic. The literature review exposed the range of limited approaches churches have utilized over recent decades, recorded the past painful conflicts between clergy and family caregivers, and offered ways to move forward with reconciliation into the next generation of ability ministry. The number of growing social media platforms, mini conferences, and church training events requesting speakers on ability ministry confirmed the timeliness of the project. Invitations to participate in the survey snowballed rapidly around the country, distributed by similar-minded clergy members among both religious and secular disability groups. Other organizations requested similar studies in their locality. Ability ministry leaders and congregational clergy are actively looking for frameworks to contextualize Holy Spirit empowered ability ministry.
Second, the biblical-theological foundation established a mutual approach toward empowered Pentecostal praxis of ability ministry. Effectiveness of any ministry within an evangelical congregation is intrinsically tied to its biblical mandate and the opportunity for personal spiritual renewal. Research into Hebrew words used to convey “disability” and “blemish” revealed a recurring thread interwoven into covenantal eschatology and the planned redemption of all humankind. Analysis of key healing miracle stories reiterated that the plan of redemption transcended cultural limits and societal norms. The framework laid provided a pathway for local congregations to intertwine empowered witness and service with ability ministry.

Third, the supportive network of relationships developed over the last decade aided this project tremendously. Numerous leaders in the field of ability ministry provided a sounding board on the frustrations inherently involved in the design of the project. Countless family caregivers transparently shared insights learned from past failures of ability ministry in the hopes the survey would instruct the future. A number of leaders provided times of encouragement, understanding, and reflection during the process. A few leaders of both religious and secular organizations made certain that I met the right people in local communities to ensure the prompt distribution and collection of the survey.

Fourth, the action research component of the intervention gave both clergy and caregivers room for self-reflection while forming awareness of the other. The study correctly assumed that many within these two groups have sparse interaction alongside each other. This space gave an opportunity to address issues that persons with disabilities
and their family members continue to encounter on a regular basis. It also allowed family caregivers to understand the framework with which most clergy operate.

Fifth, this project benefited from technological flexibility. Without the resources provided by Internet applications, the geographical scope of this project would have served as its undoing. People in multiple states quickly reviewed and commented on drafts of surveys. Distribution of the survey via email link through other various organizations’ e-newsletters allowed persons in all regions of Kansas to have rapid home access. Tools provided within the survey collection program (Qualtrics) aided in the initial data analysis.

Sixth, the sheer scope of the number of participants makes this project highly effective. During the literature review phase of the project, I realized that many similar studies had relatively small numbers of participants. For this project to make substantive recommendations to larger organizations, it needed to have a significant amount of participants. Due in part to several other keys, networked relationships and technological flexibility, the number of clergy and family caregiver participants exceeded expectations.

Finally, this project succeeded because of long-term commitments to effective ministry in the local church context. Leaders of ability ministry programs have always sought to make the local church more integrated. Local clergy who participated desire to have successful ministry occurring in their congregations and want to explore new ideas.
Keys to Project Improvement

Despite the intense planning, several areas exist which could improve this project in the future: (1) a shortened survey, (2) family caregiver opportunity, and (3) increased church participation.

First, a shortened survey would have increased the participation rate. Although the lengthy survey gave me the exhaustive results desired, it correspondingly reduced the number of participants. Analysis of the data indicated numerous qualified respondents began the survey but did not complete it. I had already reduced the survey by combining some overlapping questions in different domains during the creation of the instrument. A future study would benefit by re-analyzing the questions and determining which ones may be sufficiently redundant.

Second, an increased opportunity for family caregivers to participate in Kansas would also have increased the participation rate. Although Families Together gratefully spread the electronic invitation around Kansas, the lack of in-person contacts in regions across the state resulted in few family caregivers completing the survey. Upon reflection, if survey stations had been set up at advocate training events, disability awareness days, or fundraising walks, a greater number of participants from within Kansas would have participated. Despite pleas for local clergy members to request family caregivers within congregations to complete the survey, few AGK congregant members actually responded. The resulting implication presents both a problem and an opportunity. Either few persons within AGK congregations have disabilities or clergy members are unaware of their presence. The project would have benefited from the development of a church resource kit containing bulletin inserts and other print media, which local clergy could have utilized to develop awareness of the survey.
Third, an increased participation rate from local church ministry offices would benefit the study. Although I obtained higher than anticipated individual clergy participation, the local church version participation was significantly lower than expected. This could be for several different reasons: few local churches have any ability ministry in place so were reluctant to respond, the survey did not reach the correct person within the church organization for completion, or the participants from small churches mistakenly believed the individual pastor survey and the church ministry survey were identical. The timing of the survey rollout may have hindered a greater response rate. Ideally, distribution of the ACMR Supplemental Survey would have occurred in late December, at the same time churches received the regular ACMR. This would have allowed church ministry officials to complete the two documents simultaneously.

**Implications of the Project**

This research project investigated, compared, and contrasted the perceptions of intellectual disability (IDD) between clergy members of evangelical churches and family caregivers of persons with Intellectual disabilities (IDD). The subsequent results revealed both subtle and obvious areas of agreement and dissonance between clergy and family caregivers as they both seek to engage themselves in church life and vocation.

First, the results confirmed the ongoing presence of the clergy and family caregiver divide. Theological constructs built outside of relational exchanges often lead to faulty conclusions. Clergy readily agreed to value statements without being onerously self-aware of one’s own behavior and biases affecting practice of ministry. Many caregivers desire clergy to be more aware of their new normal; in a world filled with
disability, active participation in the work of God necessitates thinking through theological implications of disability.

Second, this project exposed hidden ministry stereotypes. The resulting “moments in the mirror” allowed clergy to see clearly how persons within the disability community often perceive them. Those who allow these discussions to transform their own hidden biases and ministry practices benefit greatly from an increased sense of community when moving from awareness to integration.

Third, this project also revealed ministry opportunities. When not integrated early, caregivers eventually seek out other places beside clergy members and local congregations for support and friendships. When that happens, both the clergy and the congregation are missing out. Clergy who found ways to make accommodations report that persons with IDD provide “positive experiences.”

Fourth, the overall response to the project was positive. The sample size and numerous open comments anonymously shared reiterated the need and concern on this topic. The quality of the answers provided and conversations generated among those who completed the survey indicated this is a pressing topic. The ongoing requests for follow-up consultations, meetings, and training indicate clergy and AGK leadership perceive this as a relevant need in the local congregations.

Fifth, this project offered a model for the integration of persons with disabilities into the life and ministry practices of the local church in the local community. The theological biblical foundation reveals that all persons with disabilities must be welcomed and assimilated into active vocation. This shifts the role of the church from not just a social service provider or a worship center, but into a vibrant community that does
both simultaneously. A fully engaged model allows all members, regardless of ability, to participate fully in the empowering witnessing work of the church.

**Recommendations to the AGK Ministry Network**

The survey revealed the challenges that clergy and local congregations face in developing ability ministry. Some ministry teams may shy away from this task as it appears daunting and overwhelming. Yet the theological foundation of chapter 2 and the best practice models presented in chapter 3 suggest a way forward, which maximizes the often limited within the existing ministry framework. Small shifts of focus and priority can unleash new life.

The local church remains God’s central focus point in communities. Although para-church organizations can increase awareness and provide limited specific opportunities and training, the local church remains the environment for friendship and co-laboring in the gospel. Pastors have the privilege to equip the saints to do the work of the ministry. Teaching congregations to accept ministry from persons with disability, however, requires patience and intentionality of purpose. Ability ministry is not necessarily programmatic, although it can be; at its essence is a worldview valuing everyone’s contribution to God’s unfolding work of redemption. The multi-tiered faith support system (MTFSS) model allows congregations to review what they are already doing through a lens privileged by disability. It also allows for a collaborative system that ensures full participation in both the worshiping congregation and the community at large. Although not every congregation can offer or provide every service or support, every church must find ways to include everyone for corporate worship activities and events.
The survey illuminated three major areas of concern for ability ministry: (1) inadequate training in both foundational theology and practical ministry, (2) limited proximal factors of engagement, and (3) presence of congregational supports.

Training in Ability Ministry

Ministry networks play a significant role in the development of awareness and education of ministry practices within the local congregation and the clergy. The AGK ministry network currently offers multiple training opportunities throughout the year for lay leaders. Incorporating an ability ministry strand at workshops and conferences not only provides practical training for frontline practitioners, but also elevates the awareness of ability ministry. The challenge, however, is not to create another siloed department, but find ways to interweave this strand throughout all other focused training on children, youth, and adult ministry. Networks can also readily identify leadership with ability ministry expertise to serve as coaches or coordinators, allowing easy access for clergy and lay people alike to discover resources to assimilate persons with disability into congregational life.

Like many districts, the AGK also offers a school of ministry for the preparation of clergy. Several valid approaches exist for incorporating ability ministry into the curriculum. The first approach is to review the existing syllabus in order to ensure sufficient intentional focus on an ability perspective exists in theological foundations, scriptural examples, and practical offerings. The second approach advocates for the creation of an ability ministry module as part of the district credential process. This suggested course would provide an introductory biblical foundation and provide simple guidelines on how clergy can engage the local disability community. A third approach
calls for the creation of a certificate in ability ministry as part of a 3-part series of DSOM level courses. Focuses would be on a theological framework for ability ministry, children and youth concerns, and faith based collaboration with the community.

Proximal Relationships

The survey revealed that few clergy members engage persons with disabilities on a regular basis. In order to understand ability ministry within a relational context, clergy are encouraged to participate in a one-week short-term mission trip at a Special Touch Summer Getaway. The experience of serving a person with a disability while simultaneously receiving ministry from them reinforces the potential effect embodied ability ministry can have on a congregation and community.

Congregational Supports

A congregational audit examines both leadership attitudes and congregational practices. The largest determining factor of the success of any ministry is the support it receives from leadership. Family caregivers of persons with disability are keen discerners. As the survey revealed, the most important ministry tool is welcoming leadership. A self-audit allows ministry teams to scrutinize all existing ministry practices and determine what ability ministry is already incorporated in congregational life. Often clergy may be surprised that some components of ability ministry is naturally assumed in other ministry related endeavors. The audit will also reveal multiple areas of potential improvement.

Just as embodied ministry incorporates all members of the congregation into active service and witness, so it also serves as a reminder that the local church does not serve in isolation within the community. Collaborating with other local churches and
social service agencies requires meeting with their respective leadership. Prior to implementing any ability ministry targeted to a niche population, meet with local group home leaders, family caregivers, and persons with disability and intentionally ask what they would need to feel fully supported in your congregation and how they might like to contribute.

Church staff can ensure maximum participation by routinely examining the church calendar of events. If any activity proposed would exclude persons with disabilities from participating, find an alternative or develop accommodations prior to scheduling. Simple solutions may include live streaming worship services and events while providing an online host.

**Recommendations for Future Study**

Disability studies are only beginning to examine the role of the local church in reversing cultural trends of segregation while developing integration and inclusion. This project gave a broad overview of the state of ability ministry, yet it was unable to explore some key interrelationships—particularly in the areas of church health, contemporary youth strategies, and parachurch organizations.

Changing community realities influence church dynamics. Churches also have natural life cycles and periods of transition. One area of future study is in examining the most opportune time to establish ability ministry as reflective of core values in both church plants and in revitalization works.

Although adult ability ministry models have had a generation of experience, youth ability ministry is in incipient form. Much study remains to be done on the impact of youth ability ministry programs, the integration of multiple abilities into one youth group,
and the long-term impact of the trend toward large youth big events, often unintentionally exclude persons with disabilities.

Finally, although ability ministry parachurch organizations have pioneered ministry through camping opportunities, chaplaincy programs, and regional conferences in a segregated environment, the movement toward inclusion and increased local church participation raises questions on their future relationship with the local church. Further study needs to take place regarding the role of parachurch organizations in preventing local churches from developing ministry in the interest of self-preservation or enabling local churches to create ability ministry from within.

**Conclusion**

This project created opportunities for discussion on the challenges normate culture creates on providing full participation for people with disabilities and their family caregivers within the local congregation. The project provided a theological foundation of ability ministry, laid out best practices learned from the experiences of other congregations, took a realistic look at the clergy and caregiver perceptions of each other, and offered a model to follow that gave simple guidelines and recommendations.

Ability ministry—allowing persons with disabilities to participate and contribute their God given talents to the church body—is one of the largest emerging social justice ministry opportunities in the local church today, uniquely uniting all persons across gender, racial, ethnic, and social status lines. Although difficult labor, the rewards for the body of Christ are unlimited and enriching. Without the contributions of persons with disability in our congregations, the church misses the fullness of God’s wonder and grace.
APPENDIX A: CREATION OF THE SURVEY INSTRUMENT

_Clergy/Caregiver Perception Survey_

Utilizing Qualtrics, I designed the Internet-based clergy assessment with three major inquiry blocks. The first block consisted of seventeen demographic questions ascertaining both clergy member background and church placement settings. Questions included county of residence, gender, age, race, marital status, and educational attainment. Further queries included credential level, full time and pay status, years of experience, ministry education, and specific pastoral role. The final section inquired about the congregational setting, including average attendance, geographic region, denomination, and governance structure.

The caregiver survey was similarly designed but with several notable exceptions. Since no panel had been preselected, it contained two preliminary qualifying questions to determine eligibility. The demographic section contained twenty questions, including inquires on state and county of residence, gender, age, race, marital status, educational attainment, household income, and relationship to person with intellectual disability. An additional section sought similar data for the person with an intellectual disability. The final section inquired about the regularly attended congregation, including average attendance, geographic region, denomination, and governance structure.

Survey questions originated from several sources discovered in the literature review, including the use of Support from Religious Organizational and Personal Beliefs Scale-Revised (SROPBS-R) by Carol L. Pitchlyn, Brenda Smith-Myles, and Virginia H.
Cook and the congregational participation survey reported by Melinda Jones Ault, Belva C. Collins, and Erik W. Carter. I created other questions similar to lines of inquiry developed in the *PCUSA Congregational Audit of Disability and Inclusion*. Both Amy Elizabeth Jacober’s research on religious participation of adolescents as well as Carol A. Minton and Richard A. Dodder’s research on participation of adults also informed the question design. The quantitative section consisted of thirty-six questions organized into five separate banks. The qualitative section contained three open-ended questions. I wrote some questions in the first person for clergy and appropriately modified them into the third person for the caregiver. For a complete list of comparative questions, see Table 1 below. I developed the survey to take approximately twenty minutes for the average participant.

Quantitative Section

**Question Bank 1: Theology and Pastoral Practice.** In the first bank of sixteen questions, I asked both clergy members and caregivers similarly worded questions in order to ascertain a) the theological understanding of the relationship of soteriology,

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disability, and sin; b) celebratory congregational inclusive practices; and c) progress toward mutual pastoral care and ministry. I provided a four-point Likert Scale (strongly disagree, disagree, agree, and strongly agree) for participants to evaluate their reactions. I randomized the presentation order so most would not present sequentially.

The first group of six questions sought to determine how parents and clergy perceived children with IDD. These questions established whether their foundational theology of disability anthropology originated in God’s creation or in the aftermath of the fall. I asked questions regarding both pastoral practice and doctrine:

- People identified with IDD are created in the image of God
- Places of worship should pray regularly for persons with IDD to be made normal.
- Parents of children with IDD are especially blessed.
- Children with IDD may be a result of a parent’s sin
- Persons with IDD may NOT need to experience God’s saving grace.
- Healing is the primary need for people identified with IDD.

The second collection of five questions sought to determine expressed attitudes toward congregational participation and inclusion by inquiring about inclusive pastoral practices. Questions focused on celebratory occasions of inclusion in socialized settings, including infant dedication/baptism, adult baptism/confirmation, communion, adult membership, and marriage:

- I allow persons with IDD to receive communion.
- My place of worship allows people with IDD to become members.
- I would celebrate the birth of a child with IDD through public infant dedication.
- I would baptize a person with IDD.
- I am comfortable officiating a legally approved wedding of an adult with an IDD.

The third cluster consisting of five questions sought to examine the attitudes and progress from inclusive practice towards mutual ministry. Questions included inquires on pastoral care practices, spiritual gifts—particularly the classical Pentecostal understanding of the Baptism of the Holy Spirit, and ministry service:
• I make personal phone calls and pastoral visits to persons with IDD on a regular basis.
• People with IDD should be allowed to exercise their spiritual gifts.
• Persons with IDD can receive the Baptism of the Holy Spirit with the initial physical evidence of speaking in tongues.
• Places of worship should allow persons with IDD to serve in ministry roles.
• I have been adequately trained in ministering to people with IDD and their caregivers.

**Question Bank 2: Clergy Members as Supportive Partners.** I designed the second bank of six questions to measure comparative perceptions of clergy in organized religion. I adapted the questions from the *Support from Religious Organizational and Personal Beliefs Scale-Revised* originally developed by Fewell in 1986 for studies of caregivers of children with Down syndrome. This inquiry explored the role of the church and clergy in establishing a supportive and coping environment. I provided a four-point Likert Scale (strongly disagree, disagree, agree, and strongly agree) for participants to evaluate their reactions. Questions specifically included:

• I am helpful to families when their child is identified with an IDD.
• I am satisfied with the availability of religious education programs our place of worship provides for children with IDD.
• Caregivers of children identified with an IDD are more active in the church now than before.
• When families have problems with their children with an IDD, they would seek help from our place of worship.
• Our place of worship is just as supportive of caregivers of persons with IDD.
• Most of the social activities of families with IDD involve members of the church community.

**Question Bank 3: Envisioning Cooperative Disability Ministry in the Community.** The third bank of seven questions sought to evaluate opinion statements

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6 Pitchlyn, Smith-Myles, and Cook, 11.
towards what constitutes disability ministry. Secondarily, it sought to measure the amount of cooperative spirit between the local church as a supportive religious institution and other social service structures available within the local community. I provided a four-point Likert Scale (strongly disagree, disagree, agree, and strongly agree) for participants to evaluate their reaction. Questions specifically included:

- Places of worship should provide or arrange transportation to worship services/church social events for persons with IDD.
- Our place of worship provides age appropriate accommodations for youth with IDD at youth group activities.
- Very few persons with IDD live in the local area near our place of worship.
- It takes a lot of money for a place of worship to begin a ministry program for persons with IDD.
- Places of worship should work with persons with IDD to find affordable housing.
- Places of worship should offer financial assistance to members with IDD if needed.
- Places of worship should work together with other agencies to support people with IDD.

**Question Bank 4: Ranking of Needed Supports.** The fourth bank consisted of one question derived from Ault’s survey on congregational participation.\(^7\) I asked participants to rank on a scale of 1 to 9 in descending order what they believed would be best for persons with disabilities and their caregiver to fully participate in congregational settings. The purpose of this ranking was to determine if the needs identified by caregivers matched the supports offered by clergy. The nine items were:

- Respite care
- Welcoming attitudes toward people with disabilities
- Additional supports to participate in religious activities
- Accessible transportation
- Accessible facilities
- Parent support groups
- Accessible materials

\(^7\) Ault, Collins, and Carter, 54.
• Counseling sponsored by faith communities
• Special programs designed for people with disabilities

**Question Bank 5: Congregational Supportiveness.** I designed the fifth and final bank of six quantitative questions by adapting Ault’s survey on parent’s perceptions of supportiveness of their congregation. This inquiry focused on caregivers’ struggle to become fully included within the worshipping communities. The questions also examined clergy representative’s role in creating or continuing obstacles for those who desire to fully participate within the church. I provided a simple three-point scale (Yes, No, I don’t know) for participants to evaluate their reaction.

• I am supportive of including children with IDD in religious activities.
• Are you aware of any family ever leaving the church because their child with IDD was not included or welcomed?
• Are you aware of any family member ever not participating in religious activities because their child with IDD was not included?
• Are you aware of any persons with IDD unable to participate in a religious activity because support was not provided?
• Have you ever asked parents to stay with their child with IDD at a religious activity so the child could participate?
• Have you ever asked a family the best way to include their child with IDD in religious activities?

**Qualitative Section**

The final section contained three open-ended response questions. These questions provided an opportunity for both clergy representative and caregiver participants to share either positively or negatively on their experience of persons with intellectual disability in congregational settings.

• Please describe any positive or negative experience you personally have had with a person with intellectual disability and their caregiver.

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8 Ibid., 55.
Please describe any contribution or disruption that people with IDD and their caregiver have made in your congregation.

Please share any questions or concerns you may have about including people with IDD and their caregivers into full participation in your congregation.

ACMR Supplemental Survey

I developed an Internet and paper-based survey utilizing Qualtrics and divided the ACMR Supplemental Survey into three blocks. The first block consisted of seven questions identifying the church’s demographic setting, including county, average attendance, denomination, governance, region, and length of current clergy tenure. The second block sought to determine the gender and age range of persons with known permanent disabilities acquired at birth or sudden onset due to a traumatic incident who attended the local church at least one time per month on an ongoing regular basis during the past year.

I requested participants classify persons with disability by gender and age group (birth-5 years, 6-12 years, 13-18 years, 19-24 years, 25-34 years, 35-54 years, and 55+ years) into the one most applicable category of disability:

- Limited mobility (i.e. using a wheelchair or other assistive device)
- Severe visual impairment (i.e. legally blind in one or both eyes)
- Severe hearing impairment (i.e. deaf culture - communication primarily through sign language or the use of cochlear implants)
- Severe behavior disorder (i.e. diagnosed psychological/emotional disorder)
- Intellectual and developmental disability (i.e. Down Syndrome/Autism/Cerebral Palsy)

The third block sought to determine the extent of disability ministry and full participation by people with disabilities within the church. I provided participants with the option of checking multiple boxes of supplied responses. Participants also had the opportunity to write in additional options not listed. Specifically, I asked:
- During the past year, did your congregation have any intentionally targeted ministries for families, children, or adults with intellectual or developmental disabilities?
- During the past year, did your congregation co-sponsor intentionally targeted ministry for families, children, or adults with intellectual or developmental disabilities?
- Identify what ministry opportunities those with any disability served in during 2013.
- Identify what ministry opportunities those with IDD served in during 2013.

Table 1. Questions on Foundational Perspectives

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<tr>
<th>Question #</th>
<th>Clergy question</th>
<th>Caregiver question</th>
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<tr>
<td>5.2</td>
<td>People identified with IDD are created in the image of God.</td>
<td>People identified with IDD are created in the image of God.</td>
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<tr>
<td>5.9</td>
<td>Places of worship should pray regularly for persons with IDD to be made normal.</td>
<td>Places of worship should pray regularly for persons with IDD to be made normal.</td>
</tr>
<tr>
<td>5.4</td>
<td>Parents of children with IDD are especially blessed.</td>
<td>Parents of children with IDD are especially blessed.</td>
</tr>
<tr>
<td>5.5</td>
<td>Children with IDD may be a result of a parent’s sin.</td>
<td>Children with IDD may be a result of a parent’s sin.</td>
</tr>
<tr>
<td>5.6</td>
<td>Persons with IDD may NOT need to experience God’s saving grace.</td>
<td>Persons with IDD may NOT need to experience God’s saving grace.</td>
</tr>
<tr>
<td>5.8</td>
<td>Healing is the primary need for people identified with IDD.</td>
<td>Healing is the primary need for people identified with IDD.</td>
</tr>
</tbody>
</table>

Table 2. Questions on Celebratory Practices of Inclusion

<table>
<thead>
<tr>
<th>Question #</th>
<th>Clergy question</th>
<th>Caregiver question</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.10</td>
<td>I allow persons with IDD to receive communion.</td>
<td>Clergy representatives allow persons with IDD to receive communion.</td>
</tr>
<tr>
<td>5.13</td>
<td>My place of worship allows people with IDD to become members.</td>
<td>My place of worship allows people with IDD to become members.</td>
</tr>
<tr>
<td>5.3</td>
<td>I would celebrate the birth of a child with IDD through public infant dedication.</td>
<td>Clergy representatives offer the sacrament of infant baptism or the ordinance of baby dedication to children with IDD.</td>
</tr>
<tr>
<td>5.7</td>
<td>I would baptize a person with IDD.</td>
<td>Clergy representatives offer the sacrament of confirmation or the ordinance of adult baptism to persons with IDD.</td>
</tr>
<tr>
<td>5.12</td>
<td>I am comfortable officiating a legally approved wedding of an adult with an IDD.</td>
<td>Clergy members are comfortable officiating a legally approved wedding of an adult with an IDD.</td>
</tr>
</tbody>
</table>
Table 3. Questions on Progress toward Mutual Ministry

<table>
<thead>
<tr>
<th>Question #</th>
<th>Clergy question</th>
<th>Caregiver question</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.16</td>
<td>I make personal phone calls and pastoral visits to persons with IDD on a regular basis.</td>
<td>Clergy members make phone calls and pastoral visits to persons with IDD on a regular basis.</td>
</tr>
<tr>
<td>5.11</td>
<td>People with IDD should be allowed to exercise their spiritual gifts.</td>
<td>People with IDD should be allowed to exercise their spiritual gifts.</td>
</tr>
<tr>
<td>5.18</td>
<td>Persons with IDD can receive the Baptism of the Holy Spirit with the initial physical evidence of speaking in tongues.</td>
<td>N/A</td>
</tr>
<tr>
<td>5.14</td>
<td>Places of worship should allow persons with IDD to serve in ministry roles.</td>
<td>Places of worship should allow persons with IDD to serve in ministry roles.</td>
</tr>
<tr>
<td>5.15</td>
<td>I have been adequately trained in ministering to people with IDD and their caregivers.</td>
<td>Clergy representatives have been adequately trained in ministering to people with IDD and their caregivers.</td>
</tr>
</tbody>
</table>

Table 4: Questions from Support from Religious Organizational Scale—Adapted

<table>
<thead>
<tr>
<th>Question #</th>
<th>Clergy question</th>
<th>Caregiver question</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1</td>
<td>I am helpful to families when their child is identified with an IDD.</td>
<td>My clergy representative was helpful when my child was identified with an IDD.</td>
</tr>
<tr>
<td>6.2</td>
<td>I am satisfied with the availability of religious education programs our place of worship provides for children with IDD.</td>
<td>I am satisfied with the availability of religious education programs provided for my child with IDD.</td>
</tr>
<tr>
<td>6.3</td>
<td>Caregivers of children identified with an IDD are more active in the church now than before.</td>
<td>I am more active in my place of worship now since my child was identified with IDD.</td>
</tr>
<tr>
<td>6.4</td>
<td>When families have problems with their children with an IDD, they would seek help from our place of worship.</td>
<td>If I have problems with my child with IDD, I would seek help from my place of worship.</td>
</tr>
<tr>
<td>6.5</td>
<td>Our place of worship is just as supportive of caregivers of persons with IDD.</td>
<td>My place of worship is just as supportive of me as other social agencies.</td>
</tr>
<tr>
<td>6.5</td>
<td>Most of the social activities of families with IDD involve members of the church community.</td>
<td>Most of my social activities involve members of my church community.</td>
</tr>
</tbody>
</table>
Table 5. Questions on Establishing Cooperative Disability Ministry in the Community

<table>
<thead>
<tr>
<th>Question #</th>
<th>Clergy question</th>
<th>Caregiver question</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1</td>
<td>Our place of worship provides age appropriate accommodations for youth with IDD at youth group activities.</td>
<td>Our place of worship provides age appropriate accommodations for youth with IDD at youth group activities.</td>
</tr>
<tr>
<td>7.2</td>
<td>Very few persons with IDD live in the local area near our place of worship.</td>
<td>Very few persons with IDD live in the local area near our place of worship.</td>
</tr>
<tr>
<td>7.3</td>
<td>It takes a lot of money for a place of worship to begin a ministry program for persons with IDD.</td>
<td>It takes a lot of money for a place of worship to begin a ministry program for persons with IDD.</td>
</tr>
<tr>
<td>7.4</td>
<td>Places of worship should work with persons with IDD to find affordable housing.</td>
<td>Places of worship should work with persons with IDD to find affordable housing.</td>
</tr>
<tr>
<td>7.5</td>
<td>Places of worship should offer financial assistance to members with IDD if needed.</td>
<td>Places of worship should offer financial assistance to members with IDD if needed.</td>
</tr>
<tr>
<td>7.6</td>
<td>Places of worship should work together with other agencies to support people with IDD.</td>
<td>Places of worship should work together with other agencies to support people with IDD.</td>
</tr>
</tbody>
</table>

Table 6. Perceptions of Congregational Supportiveness

<table>
<thead>
<tr>
<th>Question #</th>
<th>Clergy question</th>
<th>Caregiver question</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.1</td>
<td>I am supportive of including children with IDD in religious activities.</td>
<td>Have you found places of worship to be supportive of including your child with IDD in religious activities?</td>
</tr>
<tr>
<td>8.2</td>
<td>Are you aware of any family ever leaving the church because their child with IDD was not included or welcomed?</td>
<td>Have you ever changed your place of worship because your child with IDD was not included or welcomed?</td>
</tr>
<tr>
<td>8.3</td>
<td>Are you aware of any family member ever not participating in religious activities because their child with IDD was not included?</td>
<td>Have you ever refrained from participating in religious activities because your child with IDD was not included?</td>
</tr>
<tr>
<td>8.4</td>
<td>Are you aware of any persons with IDD unable to participate in a religious activity because support was not provided?</td>
<td>Have you ever kept your child with IDD from participating in a religious activity because support was not provided?</td>
</tr>
<tr>
<td>8.5</td>
<td>Have you ever asked parents to stay with their child with IDD at a religious activity so the child could participate?</td>
<td>Have you ever been asked or expected to stay with your child with IDD at a religious activity so he or she could participate?</td>
</tr>
<tr>
<td>8.6</td>
<td>Have you ever asked a family the best way to include their child with IDD in religious activities?</td>
<td>Have you ever been asked by your clergy representative the best way to include your child with IDD in religious activities?</td>
</tr>
<tr>
<td>Question #</td>
<td>Clergy question</td>
<td>Caregiver question</td>
</tr>
<tr>
<td>------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>9.2</td>
<td>Please describe any positive or negative experience you personally have had with a person with intellectual disability and their caregiver.</td>
<td>Please describe any positive or negative experiences with clergy representatives and/or places of worship regarding your child with IDD.</td>
</tr>
<tr>
<td>9.3</td>
<td>Please describe any contribution or disruption that people with IDD and their caregiver have made in your congregation.</td>
<td>Please describe any contribution or meaningful experience that your child with IDD has made in your place of worship.</td>
</tr>
<tr>
<td>9.4</td>
<td>Please share any questions or concerns you may have about including people with IDD and their caregivers into full participation in your congregation.</td>
<td>Please share any questions or concerns which have not been addressed.</td>
</tr>
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APPENDIX B: CHARACTERISTICS OF CLERGY RESPONDENTS

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Valid %</th>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>85.7</td>
<td>72</td>
</tr>
<tr>
<td>Female</td>
<td>14.3</td>
<td>12</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-25 years</td>
<td>1.2</td>
<td>1</td>
</tr>
<tr>
<td>26-34 years</td>
<td>14.3</td>
<td>12</td>
</tr>
<tr>
<td>35-44 years</td>
<td>23.8</td>
<td>20</td>
</tr>
<tr>
<td>45-54 years</td>
<td>21.4</td>
<td>18</td>
</tr>
<tr>
<td>55-64 years</td>
<td>25.0</td>
<td>21</td>
</tr>
<tr>
<td>65 years and over</td>
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<td>12</td>
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<td>Divorced</td>
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<td>Single</td>
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<tr>
<td>Educational Attainment</td>
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<tr>
<td>Less than High School</td>
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<td>1</td>
</tr>
<tr>
<td>High School</td>
<td>1.2</td>
<td>1</td>
</tr>
<tr>
<td>Some College</td>
<td>21.4</td>
<td>18</td>
</tr>
<tr>
<td>Associates Degree</td>
<td>11.9</td>
<td>10</td>
</tr>
<tr>
<td>Bachelor degree</td>
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<tr>
<td>Graduate degree</td>
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<td>24</td>
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<tr>
<td>Ministry Credential Level</td>
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<tr>
<td>Ordained</td>
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<td>48</td>
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<tr>
<td>Licensed</td>
<td>21.4</td>
<td>18</td>
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<tr>
<td>Certified</td>
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<td>18</td>
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<td>Assignment Type</td>
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<td>Full-time paid</td>
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<td>54</td>
</tr>
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<td>Bi-vocational paid</td>
<td>15.5</td>
<td>13</td>
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<tr>
<td>Part time paid</td>
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<td>Unassigned/unpaid</td>
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<td>Years of Experience</td>
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<td>Less than 5 years</td>
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<td>6-10 years</td>
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<td>11-15 years</td>
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<td>10</td>
</tr>
<tr>
<td>16-20 years</td>
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<td>5</td>
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<tr>
<td>20-25 years</td>
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<td>10</td>
</tr>
<tr>
<td>25-30 years</td>
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<td>10</td>
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<tr>
<td>More than 30 years</td>
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<td>21</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Valid %</td>
<td>n</td>
</tr>
<tr>
<td>------------------------</td>
<td>---------</td>
<td>----</td>
</tr>
<tr>
<td><strong>Leadership Role</strong></td>
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<tr>
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<td>48</td>
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<td>Other</td>
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<td>Associate pastor</td>
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<td>6</td>
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<tr>
<td>Chaplain</td>
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<td>4</td>
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<tr>
<td>Worship/Creative Arts pastor</td>
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<td>4</td>
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<tr>
<td>Missionary</td>
<td>3.6</td>
<td>3</td>
</tr>
<tr>
<td>Children’s pastor</td>
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<td>3</td>
</tr>
<tr>
<td>Teaching pastor</td>
<td>2.4</td>
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APPENDIX C: CHARACTERISTICS OF CLERGY

RESPONDENTS’ CHURCH SETTINGS

<table>
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<th>Characteristic</th>
<th>Valid %</th>
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</thead>
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<tr>
<td><strong>Church Region</strong></td>
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</tr>
<tr>
<td>West</td>
<td>22.6</td>
<td>19</td>
</tr>
<tr>
<td>Central</td>
<td>36.9</td>
<td>31</td>
</tr>
<tr>
<td>East</td>
<td>40.5</td>
<td>34</td>
</tr>
<tr>
<td><strong>Average Sunday AM Attendance</strong></td>
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</tr>
<tr>
<td>Less than 80 people</td>
<td>34.5</td>
<td>29</td>
</tr>
<tr>
<td>80-200 people</td>
<td>29.8</td>
<td>25</td>
</tr>
<tr>
<td>200-1000 people</td>
<td>35.7</td>
<td>30</td>
</tr>
<tr>
<td><strong>Church Affiliation</strong></td>
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<td></td>
</tr>
<tr>
<td>AGK General Council affiliated</td>
<td>76.1</td>
<td>64</td>
</tr>
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<td>AGK District Council affiliated</td>
<td>11.9</td>
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</tr>
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<td>Non-denominational</td>
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<tr>
<td>Other</td>
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</table>
### APPENDIX D: CHARACTERISTICS OF CAREGIVERS

<table>
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<th>Valid %</th>
<th>n</th>
</tr>
</thead>
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<td><strong>Gender</strong></td>
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<td></td>
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<tr>
<td>Male</td>
<td>13.9</td>
<td>5</td>
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<tr>
<td>Female</td>
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<td>31</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-25 years</td>
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</tr>
<tr>
<td>26-34 years</td>
<td>2.8</td>
<td>1</td>
</tr>
<tr>
<td>35-44 years</td>
<td>36.1</td>
<td>13</td>
</tr>
<tr>
<td>45-54 years</td>
<td>30.6</td>
<td>11</td>
</tr>
<tr>
<td>55-64 years</td>
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</tr>
<tr>
<td>65 years and over</td>
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<tr>
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<tr>
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<td>Caucasian</td>
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<td>31</td>
</tr>
<tr>
<td>African American</td>
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<td>1</td>
</tr>
<tr>
<td>Hispanic</td>
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<td>3</td>
</tr>
<tr>
<td>Native American</td>
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<td>1</td>
</tr>
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<td>Other</td>
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<tr>
<td><strong>Education</strong></td>
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<td></td>
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<tr>
<td>Less than High School</td>
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<td>High School</td>
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<td>Associates Degree</td>
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<td>Bachelor degree</td>
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<td>Graduate degree</td>
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<tr>
<td><strong>Annual Household Income</strong></td>
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<td>$20,000 - $23,999</td>
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</tr>
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<td>$42,000 - $54,999</td>
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<td>5</td>
</tr>
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<td>$55,000 - $64,999</td>
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<td>$65,000 - $74,999</td>
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<td>Greater than $75,000</td>
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<td>Decline to state</td>
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<td>Characteristic</td>
<td>Valid %</td>
<td>n</td>
</tr>
<tr>
<td>---------------</td>
<td>---------</td>
<td>-----</td>
</tr>
<tr>
<td>Relationship to Child with IDD</td>
<td></td>
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</tr>
<tr>
<td>Father</td>
<td>13.9</td>
<td>5</td>
</tr>
<tr>
<td>Mother</td>
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<td>28</td>
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<td>Grandmother</td>
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<td>Daughter</td>
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<td>Other</td>
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</table>
### APPENDIX E: CHARACTERISTICS OF CAREGIVERS’ CHILDREN WITH IDD

<table>
<thead>
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<th>Valid %</th>
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</tr>
</thead>
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<td><strong>Gender</strong></td>
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<tr>
<td>Male</td>
<td>52.8</td>
<td>19</td>
</tr>
<tr>
<td>Female</td>
<td>47.2</td>
<td>17</td>
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<tr>
<td><strong>Age</strong></td>
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<tr>
<td>Birth-6 years</td>
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<tr>
<td>7-10 years</td>
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<tr>
<td>11-14 years</td>
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<td>5</td>
</tr>
<tr>
<td>15-18 years</td>
<td>16.7</td>
<td>6</td>
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<tr>
<td>19-25 years</td>
<td>16.7</td>
<td>6</td>
</tr>
<tr>
<td>26-34 years</td>
<td>8.3</td>
<td>3</td>
</tr>
<tr>
<td>35-44 years</td>
<td>8.3</td>
<td>3</td>
</tr>
<tr>
<td>45 years and over</td>
<td>0.0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Marriage Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>2.8</td>
<td>1</td>
</tr>
<tr>
<td>Single</td>
<td>97.2</td>
<td>35</td>
</tr>
<tr>
<td><strong>Ethnic Heritage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>72.2</td>
<td>26</td>
</tr>
<tr>
<td>African American</td>
<td>2.8</td>
<td>1</td>
</tr>
<tr>
<td>Hispanic</td>
<td>8.3</td>
<td>3</td>
</tr>
<tr>
<td>Native American</td>
<td>5.6</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>2.8</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>11.1</td>
<td>4</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>69.4</td>
<td>25</td>
</tr>
<tr>
<td>High School</td>
<td>30.6</td>
<td>11</td>
</tr>
<tr>
<td><strong>IDD Identification</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>41.7</td>
<td>15</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>13.9</td>
<td>5</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>11.1</td>
<td>4</td>
</tr>
<tr>
<td>Developmental Disability</td>
<td>5.6</td>
<td>2</td>
</tr>
<tr>
<td>Emotional/Behavioral Disability</td>
<td>5.6</td>
<td>2</td>
</tr>
<tr>
<td>Other IDD</td>
<td>22.2</td>
<td>8</td>
</tr>
</tbody>
</table>
APPENDIX F: CHARACTERISTICS OF SUPPLEMENTAL ACMR RESPONDENTS

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Valid %</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average Weekly Sunday AM Attendance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 80</td>
<td>31.3</td>
<td>5</td>
</tr>
<tr>
<td>Between 80 and 200</td>
<td>37.5</td>
<td>6</td>
</tr>
<tr>
<td>Between 200 and 1000</td>
<td>31.3</td>
<td>5</td>
</tr>
<tr>
<td><strong>Geographic Region</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>West</td>
<td>12.5</td>
<td>2</td>
</tr>
<tr>
<td>Central</td>
<td>25.0</td>
<td>4</td>
</tr>
<tr>
<td>East</td>
<td>62.5</td>
<td>10</td>
</tr>
<tr>
<td><strong>Lead Pastoral Tenure</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 3 years</td>
<td>6.3</td>
<td>1</td>
</tr>
<tr>
<td>Between 4 and 10 years</td>
<td>25.0</td>
<td>4</td>
</tr>
<tr>
<td>Between 11 and 20 years</td>
<td>37.5</td>
<td>6</td>
</tr>
<tr>
<td>More than 20 years</td>
<td>31.3</td>
<td>5</td>
</tr>
<tr>
<td><strong>Governance Structure</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General Council</td>
<td>100.0</td>
<td>16</td>
</tr>
<tr>
<td>District Affiliated (DA)</td>
<td>0.0</td>
<td>0</td>
</tr>
<tr>
<td>Parent Affiliated Church (PAC)</td>
<td>0.0</td>
<td>0</td>
</tr>
</tbody>
</table>
When asked if persons identified with IDD are created in the image of God (question 5.2), the clergy report (100%, mean = 4.33), the caregivers’ predictive score of clergy response (86.1%, mean = 4.19), and the caregivers’ score (94.4%, mean = 4.53), indicated a consensus of strong agreement.

When asked if places of worship should pray regularly for the normalization of persons with ID (question 5.9), the clergy report (56.0%, mean = 2.96) was inconclusive,
sharply contrasting with the strength of disagreement (Table 8) indicated by the caregivers’ predictive score of clergy response (83.3%, mean = 1.89) to the actual caregivers’ score (88.9%, mean = 1.75).

Analysis determined extreme significant difference between the strength of the clergy report (mean = 2.96, SD = 1.25) and the caregivers’ score (mean = 1.75, SD = 1.18); \(t(118) = 4.94, p = 0.00\). Further evaluation found extreme statistical difference between the caregiver predictive score of clergy response (mean = 1.89, SD = 1.14) and the actual clergy report (mean = 2.96, SD = 1.25); \(t(118) = 3.74, p = 0.00\).

Table 8. Strength of Disagreement on Prayers for Normalization

<table>
<thead>
<tr>
<th>Population</th>
<th>General disagreement (%)</th>
<th>Strong disagreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>51.2</td>
<td>4.8</td>
</tr>
<tr>
<td>Caregivers’ prediction of clergy</td>
<td>36.1</td>
<td>47.2</td>
</tr>
<tr>
<td>Caregivers</td>
<td>33.3</td>
<td>55.6</td>
</tr>
</tbody>
</table>

Lead pastors (58.3%) disagreed similarly as other credential holders (52.8%).

Further investigation (Table 9) found lead pastors under 55 years old (63.0%) also disagreed similarly as other credential holders under 55 years old (62.5%). However, lead pastors over 55 years old disagreed at a higher rate (52.4%) than other credential holders under 55 years old (33.3%)

Table 9. Clergy Disagreement on Prayers for Normalization

<table>
<thead>
<tr>
<th>Population</th>
<th>(n)</th>
<th>Age: 18 - 54 years (%)</th>
<th>Age: 55 years and over (%)</th>
<th>All Ages</th>
</tr>
</thead>
<tbody>
<tr>
<td>All clergy</td>
<td>84</td>
<td>62.8</td>
<td>45.5</td>
<td>56.0</td>
</tr>
<tr>
<td>Lead pastors</td>
<td>48</td>
<td>63.0</td>
<td>52.4</td>
<td>58.3</td>
</tr>
<tr>
<td>Non-lead pastors</td>
<td>36</td>
<td>62.5</td>
<td>33.3</td>
<td>52.8</td>
</tr>
</tbody>
</table>

Additional investigation determined extreme statistical significance on the clergy report between healing (mean = 4.33, SD = 0.95) and the normalization (mean = 3.04, SD = 1.25), \(t(166) = 7.53, p < 0.0001\). This result confirms caregivers’ perception that prayers for normalization refute the affirmation of persons created in the image of God.
Yet when filtering the clergy survey by those who disagreed with the statement “Places of worship should pray regularly for persons with IDD to be made normal,” many results changed. Although only shifting slightly in the subjective questions, the open comments provided the dramatic evidence. Clergy who perceived persons with IDD as normal and created in the image of God overwhelmingly recited numerous contributions and few disruptions.

Table 10. Clergy Comments Based on Prayers for Normalization

<table>
<thead>
<tr>
<th>Result</th>
<th>Contributions</th>
<th>Distractions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agreed</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Disagreed</td>
<td>18</td>
<td>3</td>
</tr>
</tbody>
</table>
APPENDIX H: IDD AS CURSE OR PARTICULAR BLESSING

When asked whether parents of children with IDD are particularly blessed (question 5.4), clergy (71.4%, mean = 3.54) indicated agreement, while the caregivers’ predictive score of clergy response (55.6%, mean = 3.22), and the caregivers’ score (55.6%, mean = 3.14) were both inconclusive. Analysis determined graduate education as a factor influencing caregivers’ belief in particular blessing, $\chi^2 (1) = 7.1$, $p < 0.05$. Caregivers’ results substantially differed between those with graduate education (80.0%) and those without (30.8%).

Figure 16. IDD as Curse or Particular Blessing
Table 11. Education Levels of Caregivers and Particular Blessing

<table>
<thead>
<tr>
<th>Education</th>
<th>Agree (%)</th>
<th>Disagree (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Graduate Degree</td>
<td>30.8</td>
<td>69.2</td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>80.0</td>
<td>20.0</td>
</tr>
</tbody>
</table>

When asked if children with IDD may be a result of a parental sin (question 5.5), the clergy report (95.3%, mean = 1.44), the caregivers’ predictive score of clergy response (94.4%, mean = 1.39), and the caregivers’ score (97.2%, mean = 1.22) indicated consensus of negative agreement.
When asked if persons with IDD may not need to experience salvation (question 5.6), clergy (88.1%, mean = 4.12) overwhelmingly disagreed. Their response resembled the caregivers’ actual score (77.8%, mean = 4.03), but was dissimilar from the caregivers’ predictive score of clergy response (69.4%, mean = 3.72).

Analysis determined ministry role influenced differences (Table 12). Lead pastors (93.8%, n = 48) agreed more than other credentialed ministers (80.6%, n=36). Although a large majority of lead pastors over the age of 55 agreed (95.2%, n=21), fewer non-lead
pastors under the age of 55 indicated agreement (75.0%, n=24). Conversely, more
caregivers under the age of 55 agreed (80.8%) than those over the age of 55 (70.0%).

Table 12. Salvation as Necessity

<table>
<thead>
<tr>
<th>Population</th>
<th>18 - 54 years old (%)</th>
<th>55 years and over (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead pastors</td>
<td>92.6</td>
<td>95.2</td>
</tr>
<tr>
<td>Non-lead pastors</td>
<td>75.0</td>
<td>91.7</td>
</tr>
<tr>
<td>Caregivers</td>
<td>80.8</td>
<td>70.0</td>
</tr>
</tbody>
</table>

When asked if healing is the primary need for people identified with IDD
(question 5.8), clergy indicated substantial disagreement (77.3%, mean = 3.62)
corresponding to the caregivers’ predictive score of clergy response (75.0%, mean =
3.81).

The caregivers’ score (83.3%, mean = 4.22), however, exhibited stronger
disagreement (Table 13). Analysis determined the extreme significance between the
strength of the clergy report (mean = 3.62, SD = 0.96) and the caregivers’ score (mean =
4.12, SD = 1.24); t(118) = 2.87, p = 0.00. This confirms many caregivers’ perception
clergy members do regard healing as a primary necessity for persons with IDD.

Table 13. Healing as Primary Necessity: Levels of Disagreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General disagreement (%)</th>
<th>Strong disagreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>69.0</td>
<td>8.3</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>36.1</td>
<td>38.9</td>
</tr>
<tr>
<td>Caregivers</td>
<td>22.2</td>
<td>61.1</td>
</tr>
</tbody>
</table>
Financial Resources

When asked if it takes a lot of money for a place of worship to begin a ministry program for persons with IDD (question 7.6), the clergy reported disagreement (72.6%, mean = 2.52). This outcome corresponded to the caregivers’ predictive score of clergy response (63.9%, mean = 2.58). It differed substantially, however, from the caregivers score (89.7%, mean = 1.78). The levels of strong disagreement varied across all participants (Table 14).
Table 14. Disability Ministry as Financial Burden: Levels of Disagreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General disagreement (%)</th>
<th>Strong disagreement (%)</th>
<th>Total disagreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>69.0</td>
<td>3.6</td>
<td>72.6</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>41.7</td>
<td>22.2</td>
<td>63.9</td>
</tr>
<tr>
<td>Caregiver</td>
<td>52.8</td>
<td>36.9</td>
<td>89.7</td>
</tr>
</tbody>
</table>

Analysis determined extremely significant difference between the clergy report (mean = 2.52, SD = 0.93) and the caregivers’ score (mean =1.78, SD = 0.69); \( t(118) = 4.29, p = 0.00 \). Further investigation also revealed an extreme statistical difference between the strength of the caregivers’ score (mean =1.78, SD = 0.69) and the caregivers’ predictive score of clergy response (mean = 2.52, SD =1.34); \( t(70) = 3.18, p = 0.01 \).

One clergy member validated this perception inquiring, “How far do I go to provide an integrated worship/discipleship experience for someone with IDD when…the resources to do so can be so much more costly (sic).” The accuracy of the caregiver’s predictive score of clergy response combined with the dramatically different caregiver’s score, confirmed the caregivers’ perception clergy believe disability ministry does require extreme financial resources.

**Transportation**

When asked if places of worship should provide or arrange transportation to worship services or church social events for persons with IDD (question 7.1), the majority of clergy indicated agreement (84.5%, mean = 3.80). This outcome did not correspond to the caregivers’ predictive score of clergy response (69.5%, mean = 3.44), as analysis determined a slight difference between it (mean = 3.44, SD = 1.23) and the clergy score (mean = 3.80, SD = 0.83); \( t(118) = 1.87, p = 0.06 \). The actual caregivers’ score (83.4%) however, corresponded to the clergy report (84.5%). This result suggested
clergy, when aware of persons with IDD in the local area, were willing to provide transportation to worship services.

**Age Appropriate Activities**

Integration is crucial as a child with a disability ages. One caregiver reported supports ended as her daughter aged out of the middle school special needs classroom. Another wisely remarked, “inclusion is not something that occurs organically; our community has to be intentional about it.”

When asked if our place of worship provides age appropriate accommodations for youth with IDD at youth group activities (question 7.3), the clergy report (59.5%, mean = 2.75) and caregivers’ score (58.3%, mean = 2.69) indicated consensus of negative agreement. The caregivers’ predictive score of clergy response (41.6%, mean = 3.19) was indecisive, yet differed from the clergy report. This result confirmed caregivers’ perceptions youth with IDD are not welcome with their peers at youth group activities.
When asked if our place of worship should work together with other agencies to support people with IDD (question 7.10), the clergy report (96.5%, mean = 4.21) and caregivers’ score (91.7%, mean = 4.39) indicated consensus of agreement. This outcome differed substantially, however, from the caregivers’ predictive score of clergy response (72.2%, mean = 3.67).
Analysis determined extremely significant difference between the caregivers’ predictive score of clergy response (mean = 3.67, SD = 1.20) and both the clergy report (mean = 4.21, SD = 0.62); \( t(118) = 3.25, p = 0.00 \) as well as the caregivers’ score (mean = 4.39, SD = 0.87); \( t(70) = 2.91, p = 0.00 \).

This result rejects the caregivers’ perception places of worship are unwilling to work jointly with other social service agencies.

**Financial Assistance**

When asked if places of worship should offer financial assistance to members (question 7.8), the clergy report (81.0%, mean = 3.68) and caregivers’ score (72.2%, mean = 3.50) indicated consensus of agreement. This outcome differed substantially, however, from the caregivers’ predictive score of clergy response (47.2%, mean = 2.92).

Analysis determined extremely significant difference between the caregivers’ predictive score of clergy response (mean = 2.92, SD = 1.13) and both the clergy report (mean = 3.68, SD = 0.85); \( t(118) = 4.05, p = 0.00 \) as well as the caregivers’ score (mean = 3.50, SD = 1.13); \( t(70) = 2.18, p = 0.03 \).

This result rejects the caregivers’ perception places of worship are unwilling to offer financial assistance to members with IDD when necessary.

**Housing Assistance**

When asked if places of worship should work with persons with IDD to find affordable housing (question 7.7), the clergy report (76.2%, mean = 3.63) and caregivers’ score (61.1%, mean = 3.33) indicated consensus of agreement. This outcome differed substantially, however, from the caregivers’ predictive score of clergy response (38.9%, mean = 2.69).
Analysis determined extremely significant difference between the caregivers’ predictive score of clergy response (mean = 2.69, SD = 1.17) and both the clergy report (mean = 3.63, SD = 1.08); t(70) = 4.26, p = 0.00 as well as the caregivers’ score (mean = 3.33, SD = 1.26); t(70) = 2.23, p = 0.03.

This result rejects the caregivers’ perception that places of worship are unwilling to work with persons with IDD to find affordable housing.
When asked to rank what would be most helpful for persons with disabilities and their family caregivers to participate fully in the congregation (question 7.11), in the top five categories, clergy overwhelming placed welcoming attitude toward people with disabilities (98.8%), followed by accessible facilities (78.6%), parent support groups (57.1%), additional supports to participate in religious activities (54.8%), and special programs designed for people with disabilities (51.2%). Caregivers indicated the same top five categories but ranked them in a different order (Table 15).

Table 15. Ranking of Accessibility Features

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Caregiver</th>
<th></th>
<th>%</th>
<th>Clergy</th>
<th></th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcoming attitudes</td>
<td>1</td>
<td>2.53</td>
<td>88.9</td>
<td>1</td>
<td>1.54</td>
<td>98.8</td>
</tr>
<tr>
<td>Additional supports</td>
<td>2</td>
<td>4.06</td>
<td>77.8</td>
<td>4</td>
<td>5.23</td>
<td>54.8</td>
</tr>
<tr>
<td>Accessible facilities</td>
<td>3</td>
<td>4.14</td>
<td>69.4</td>
<td>2</td>
<td>3.81</td>
<td>78.6</td>
</tr>
<tr>
<td>Special programs</td>
<td>4</td>
<td>4.81</td>
<td>55.6</td>
<td>5</td>
<td>5.35</td>
<td>51.2</td>
</tr>
<tr>
<td>Parent support groups</td>
<td>5</td>
<td>5.31</td>
<td>50.0</td>
<td>3</td>
<td>5.08</td>
<td>57.1</td>
</tr>
<tr>
<td>Accessible materials</td>
<td>6</td>
<td>5.33</td>
<td>55.6</td>
<td>6</td>
<td>5.49</td>
<td>51.2</td>
</tr>
<tr>
<td>Counseling</td>
<td>7</td>
<td>6.14</td>
<td>38.9</td>
<td>8</td>
<td>6.20</td>
<td>34.5</td>
</tr>
<tr>
<td>Respite Care</td>
<td>8</td>
<td>6.14</td>
<td>33.4</td>
<td>9</td>
<td>6.58</td>
<td>29.8</td>
</tr>
<tr>
<td>Accessible Transportation</td>
<td>9</td>
<td>6.56</td>
<td>30.6</td>
<td>7</td>
<td>5.73</td>
<td>44.0</td>
</tr>
</tbody>
</table>

Caregivers ranked welcoming attitudes toward people with disabilities (88.9%), followed by additional supports to participate in religious activities, (77.8%), accessible facilities (69.4%), special programs designed for people with disabilities (55.6%), and parent support groups (50.0%).
Analysis determined extremely significant difference between the caregivers’
ranking (mean = 2.53, SD = 2.43); and the clergy ranking of welcoming attitude (mean =
1.54, SD = 1.23); $t(118) = 2.96, p = 0.00$. Further investigation also determined extremely
significant difference between the caregivers’ ranking (mean = 4.06, SD = 2.14); and the
clergy ranking of additional supports (mean = 5.23, SD = 2.38); $t(118) = 2.54, p = 0.01$.

These results suggest caregivers desire supports focused on allowing them to be
more active in the full participatory life of the church.
APPENDIX M: RELATIONAL PROXIMITY AND PUBLIC CELEBRATIONS

Worshipping communities celebrate the ongoing work of God through corporate celebratory practices of baptism, confirmation, and membership rituals. A parent reported her frustration of when a clergy member asked her son to read a long paragraph as part of a confirmation service. Another caregiver reports on a meaningful moment involving her daughter with IDD. The differences between these experiences reflect relational proximity clergy have with caregivers and their families.

Communion and Membership

Communion

When asked if clergy allow persons with IDD to celebrate communion (question 5.10), the clergy report (100%, mean = 4.43), the caregivers’ predictive score of clergy response (91.7%, mean = 4.31), and the caregivers’ score (91.7%, mean = 4.42) indicated agreement.
When asked if my place of worship allowed persons with IDD to become members (question 5.13), the clergy report (95.3%, mean = 4.21), the caregivers’ predictive score of clergy response (97.2%, mean = 4.47), and the caregivers’ score (97.4%, mean = 4.39) indicated agreement.
Infant Dedication/Baptism

When asked if clergy offer infant dedication or baptism to children with IDD (question 5.3), clergy indicated overwhelming agreement (100.0%, mean = 4.71). This outcome differed substantially in strength from the caregiver’s predictive score of clergy response (80.6, mean = 4.19) as well as the caregivers’ actual score (83.3%, mean = 4.25). Although the rate of strong agreement corresponded across all three populations (
Table 16), the rate of general agreement was not similar.
Table 16. Infant Baptism: Levels of Agreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General agreement (%)</th>
<th>Strong agreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>28.6</td>
<td>71.4</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>11.1</td>
<td>69.4</td>
</tr>
<tr>
<td>Caregiver</td>
<td>13.7</td>
<td>69.4</td>
</tr>
</tbody>
</table>

Analysis determined an extreme statistical difference between the strength of the clergy report (mean = 4.71, SD = 0.45) and the caregivers’ score (mean = 4.25, SD = 1.38); t(118) = 2.75, p = 0.01. Additional evaluation discovered an extreme statistical difference between the caregiver predictive score of clergy response (mean = 4.19, SD = 1.43) and the actual clergy score (mean = 4.71, SD = 0.45); t(118) = 3.02, p = 0.00. These results confirm the caregivers’ perception that clergy, despite their affirmations, do not persistently offer infant dedication or baptism to children with IDD.

Adult Baptism/Confirmation

When asked if clergy representatives offer adult baptism/confirmation to persons with IDD (question 5.7), the clergy (100%) report indicated unanimous agreement, including those clergy (11.9%) who were unsure if salvation was necessary. This outcome differed substantially in strength from the caregivers’ predictive score of clergy response (80.6, mean = 3.94) and the caregivers’ score (80.6%, mean = 3.97). The strength of ratings varied across the population (Table 17).

Table 17. Adult Baptism: Levels of Agreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General agreement (%)</th>
<th>Strong agreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>45.2</td>
<td>54.8</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>38.9</td>
<td>41.7</td>
</tr>
<tr>
<td>Caregivers</td>
<td>36.1</td>
<td>44.4</td>
</tr>
</tbody>
</table>

Analysis determined an extreme statistical difference between the strength of the clergy report (mean = 4.55, SD = 0.05) and the caregivers’ score (mean = 3.97, SD =
Further examination discovered extreme statistical difference between the caregivers’ predictive score of clergy response (mean = 3.94, SD = 1.29) and the clergy report; \( t(118) = 3.74, p = 0.00 \).

These results confirm the caregivers’ perception of clergy, who despite their affirmations, do not persistently offer baptism to adults with IDD.

**Marriage and Pastoral Care**

![Figure 22. Marriage and Pastoral Care](image)

**Marriage**

When asked if clergy members are comfortable officiating a legally approved wedding of an adult with an IDD (question 5.12), the clergy report (85.7%, mean = 3.83) indicated agreement. This outcome differed substantially from the caregivers’ predictive
score of clergy response (66.6, mean = 3.50) and the actual caregivers’ score (63.8%, mean = 3.36), primarily in their strength of agreement (Table 18).

Table 18. Officiating Weddings: Levels of Agreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General agreement (%)</th>
<th>Strong agreement (%)</th>
<th>Total agreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>71.4</td>
<td>14.3</td>
<td>85.7</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>47.2</td>
<td>19.4</td>
<td>66.6</td>
</tr>
<tr>
<td>Caregivers</td>
<td>44.4</td>
<td>19.4</td>
<td>63.8</td>
</tr>
</tbody>
</table>

Analysis determined a slight variation between the clergy report (mean = 3.83, SD = 0.45) and the caregivers’ predictive score of clergy response (mean = 3.50, SD = 1.21); t(118) = 1.65, p = 0.10. Further evaluation discovered an extreme difference between the strength of actual clergy report (mean = 3.83, SD = 0.90) to the caregivers’ score (mean = 3.36, SD = 1.36; t(118) = 2.23, p = 0.00.

This result confirms caregivers’ perception: clergy members are hesitant to discuss marriage and family concerns among persons with IDD.

Pastoral Care

When asked if clergy members make personal phone calls and pastoral visits to persons with IDD on a regular basis (question 5.16), the clergy report (59.5%, mean = 2.81), the caregivers’ predictive score of clergy response (63.9%, mean = 2.61), and the actual caregivers’ score (69.4%, mean = 2.39), indicated consensus in disagreement. This result confirms the caregivers’ perception that clergy do not provide pastoral care to persons with IDD on a regular basis.
APPENDIX N: SUPPORTIVENESS AS PART OF RELIGIOUS COPING SYSTEM

Clergy Helpfulness

Figure 23. Clergy Helpfulness

Initial Clergy Helpfulness

When asked if clergy representatives were helpful when a child was identified with an IDD (question 6.1), clergy (92.8%, mean = 4.08) indicated agreement (Table 19). This corresponded to caregivers’ predictive score of clergy response (77.8%, mean =
3.78). The actual caregiver score (52.8%, mean = 3.06) however, sharply contrasted to the clergy score.

Analysis determined the extremely significant difference between the clergy score (mean = 4.08, SD = 0.71) and the caregivers’ score (mean =3.06, SD = 1.66); \( t(118) = 4.73, p = 0.00 \). Additional evaluation validated the significant difference between the strength of the caregivers’ score (mean =3.06, SD = 1.66) and the caregivers’ predictive score of clergy response (mean = 3.78, SD =1.20); \( t(70) = 2.11, p = 0.04 \).

This result confirms actions that clergy presume as helpful but caregivers do not identify as necessarily supportive.

**Ongoing Clergy Helpfulness**

When asked if caregivers would seek help from places of worship if having problems with a child with IDD (question 6.4), clergy (63.1%, mean = 3.29) indicated agreement (Table 19). This corresponded to caregivers’ predictive score of clergy response (58.3%, mean = 2.61). The actual caregiver’ score (41.7%, mean = 2.61) however, sharply contrasted to the clergy score.

Analysis determined an extremely significant difference between the clergy score (mean = 3.29, SD = 1.07) and the caregivers’ score (mean =2.61, SD = 1.55); \( t(118) = 2.77, p = 0.01 \). Further investigation validated the extremely significant difference between the strength of the caregivers’ score (mean =2.61, SD = 1.55) and the caregiver predictive score of clergy response (mean = 3.44, SD =1.23); \( t(70) = 2.52, p = 0.01 \).

This result confirms caregivers do not turn to places of worship for assistance as often as clergy presume they do.
Table 19. Participant Response to Scale Items on Organized Religion

<table>
<thead>
<tr>
<th>Scale Item</th>
<th>Strongly agree (%)</th>
<th>Agree (%)</th>
<th>Disagree (%)</th>
<th>Strongly disagree (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My clergy representative was helpful when my child was identified with IDD.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clergy Response</td>
<td>22.6</td>
<td>70.2</td>
<td>7.1</td>
<td>0.0</td>
</tr>
<tr>
<td>If I have problems with my child, I would seek help from my place of worship.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4.8</td>
<td>58.3</td>
<td>34.5</td>
<td>2.4</td>
</tr>
<tr>
<td>I am more active in my place of worship since my child was identified with IDD.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.2</td>
<td>48.8</td>
<td>42.9</td>
<td>7.1</td>
</tr>
<tr>
<td>My place of worship is just as supportive of me as other social agencies.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>10.7</td>
<td>51.2</td>
<td>32.1</td>
<td>6.0</td>
</tr>
<tr>
<td>I am satisfied with the availability of religious education programs provided for my child with IDD.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.4</td>
<td>20.2</td>
<td>59.5</td>
<td>17.9</td>
</tr>
<tr>
<td>Most of my social activities involve members of my place of worship.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.2</td>
<td>53.6</td>
<td>45.2</td>
<td>0.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale Item</th>
<th>Strongly agree (%)</th>
<th>Agree (%)</th>
<th>Disagree (%)</th>
<th>Strongly disagree (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>My clergy representative was helpful when my child was identified with IDD.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Response</td>
<td>27.8</td>
<td>25.0</td>
<td>19.4</td>
<td>27.8</td>
</tr>
<tr>
<td>If I have problems with my child, I would seek help from my place of worship.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13.9</td>
<td>27.8</td>
<td>22.2</td>
<td>36.1</td>
</tr>
<tr>
<td>I am more active in my place of worship since my child was identified with IDD.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5.6</td>
<td>22.2</td>
<td>36.1</td>
<td>36.1</td>
</tr>
<tr>
<td>My place of worship is just as supportive of me as other social agencies.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>22.2</td>
<td>19.4</td>
<td>33.3</td>
<td>25.0</td>
</tr>
<tr>
<td>I am satisfied with the availability of religious education programs provided for my child with IDD.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>11.1</td>
<td>22.2</td>
<td>25.0</td>
<td>41.7</td>
</tr>
<tr>
<td>Most of my social activities involve members of my place of worship.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13.9</td>
<td>33.3</td>
<td>36.1</td>
<td>16.7</td>
</tr>
</tbody>
</table>
APPENDIX O: ACTIVE PARTICIPATION AND RELIGIOUS EDUCATION

Active Participation

When asked if the caregiver was as active in the place of worship since the identification of a child with IDD (question 6.3), clergy (50.0%, mean = 2.94) indicated agreement (Table 19). This corresponded to caregivers’ predictive score of clergy response (41.7%, mean = 2.69). The actual caregiver’ score (27.8%, mean = 2.25), however, sharply contrasted to the clergy score.

Figure 24. Active Participation and Religious Education
Analysis determined a significant difference between the clergy score (mean = 2.94, SD = 1.12) and the caregivers’ score (mean = 2.25, SD = 1.32; t(118) = 1.87, p = 0.06. This result confirms the difficulty of caregivers and their children with IDD in maintaining active church integration.

When asked if most caregivers’ social activities involved members of my place of worship (question 6.6), clergy (54.8%, mean = 3.11) indicated agreement (Table 19). This corresponded to both the caregivers’ predictive score of clergy response (61.1%, mean = 3.31), and the actual caregiver score (57.2%, mean = 2.92). This result suggests many places of worship are not strong centers of inclusive community for people with IDD.

**Religious Education**

Lack of active participation is correlative to lack of adequate religious education programming. When asked if satisfied with the availability of religious education programs places of worship provide for children with IDD (question 6.2), only a few clergy members (22.6%, mean = 2.30) indicated agreement (Table 19). This did not correspond to caregivers’ predictive score of clergy response (52.8%, mean = 3.14), as analysis determined an extremely significant difference in the lack of consensus between it (mean = 3.14, SD = 1.27) and the clergy score (mean = 2.30, SD = 1.06); t(118) = 3.74, p = 0.00. Further evaluation validated another extremely significant difference between the caregivers’ score (mean = 2.61, SD = 1.55) and the caregivers’ predictive score of clergy response (mean = 2.36, SD = 1.50); t(70) = 2.38, p = 0.02. The actual caregiver’s score (33.3%, mean = 2.36) however, corresponded to the clergy score. This result refutes the caregivers’ perception of clergy satisfaction with the current availability of religious
education. It also suggests caregivers and clergy do not recognize their extreme joint
dissatisfaction of current religious education programs. Increasing the quality of religious
education programming may result in increased active participation.
Both clergy and caregivers responded to six questions on perceptions of congregational supportiveness (Table 20). When asked if clergy are supportive of including children with IDD in religious activities (question 8.3), the clergy (96.4%) overwhelming indicated in the affirmative, sharply contrasting with the caregivers’ score (63.9%). Analysis determined a significant difference between the clergy report (mean = 4.93, SD = 0.14) and the caregivers’ score (mean = 3.67, SD = 1.85); t(118) = 6.24, p = 0.00.
When asked if any family ever left the church because their child with IDD was not included (question 8.4), some clergy (19.1%), as compared with most caregivers (55.6%), indicated they were aware. Analysis determined a significant difference between the clergy report (mean = 2.07, SD = 1.60) and the caregivers’ score (mean = 2.78, SD = 2.02); \( t(118) = 2.05, p = 0.04 \).

When asked if any family member not participating in religious activities because their child with IDD was not included (question 8.4), even less clergy (14.3%), as compared with most caregivers (69.4%), indicated they were aware. Analysis determined a significant difference between the clergy report (mean = 2.00, SD = 1.47) and the caregivers’ score (mean = 3.78, SD = 1.87); \( t(118) = 5.59, p = 0.00 \).

When asked if any person with IDD was unable to participate in a religious activity because support was not provided (question 8.5), a minority of clergy (21.4%), as compared to caregivers (80.6%), indicated they were aware. Analysis determined a significant difference between the clergy report (mean = 2.24, SD = 1.64) and the caregivers’ score (mean = 4.22, SD = 1.61); \( t(118) = 6.09, p = 0.00 \).

When queried if clergy ever requested parents to remain along with their child with IDD at a religious activity in order the child could participate (question 8.6), nearly
a third of the clergy (31.0%) indicated they had. This contrasted sharply with the majority of caregivers (66.7%) who reported clergy had asked them to remain. Analysis determined significant difference between the clergy report (mean = 2.43, SD = 1.83) and the caregivers’ score (mean = 3.78, SD = 1.94); \( t(118) = 3.72, p = 0.00 \).

When queried if clergy had ever asked caregivers the best way to include their child with IDD in religious activities (question 8.7), only nearly half of the clergy (45.2%) and the caregivers (44.4%) indicated they had.

These results illuminate the vast discrepancy between the perceptions of the clergy and caregivers on the levels of support offered in congregational settings. It confirms the caregivers’ belief that they are often not welcomed.
When asked if people with IDD should be allowed to exercise their spiritual gifts (question 5.11), clergy (97.6, mean = 4.27) indicated general agreement. This outcome corresponded to the caregivers’ prediction of clergy response (91.6%, mean = 4.22). It, however, differed substantially from the caregivers’ score (97.2%, mean = 4.75). The levels of strong agreement varied across the three populations (Table 21).
### Table 21. Spiritual Gifts: Levels of Agreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General agreement (%)</th>
<th>Strong agreement (%)</th>
<th>Total agreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>64.3</td>
<td>33.3</td>
<td>97.6</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>47.2</td>
<td>44.4</td>
<td>91.6</td>
</tr>
<tr>
<td>Caregiver</td>
<td>13.9</td>
<td>83.3</td>
<td>97.2</td>
</tr>
</tbody>
</table>

Analysis determined an extremely significant difference between the clergy report (mean = 4.27, SD = 0.65) and the caregivers’ score (mean =4.75, SD = 0.73); \( t(118) = 3.57, p = 0.00 \). Further investigation also revealed an extremely significant difference between the strength of the caregivers’ score (mean =4.75, SD = 0.73) and the caregivers’ predictive score of clergy response (mean = 4.22, SD =1.03); \( t(70) = 2.41, p = 0.01 \).

**Baptism of the Holy Spirit**

When asked if persons with IDD can receive the Baptism of the Holy Spirit with the initial physical evidence of speaking in tongues (question 5.18), clergy responded similarly strongly agreed (98.8%, mean = 4.43). As AGK clergy doctrinal understandings of the Baptism of the Holy Spirit and the exercise of spiritual gifts are closely related, these results confirm the caregivers’ perception of clergy members disregarding the relevancy of spiritual gifts exercised by persons with IDD, even after having a Pentecostal experience.

**Ministry Roles**

When asked if places of worship should allow persons with IDD to serve in ministry roles (question 5.14), the clergy report (88.0%, mean = 3.95) indicated agreement. This outcome differed substantially in strength (see Table 22) from both the caregiver’s predictive score of clergy response (75.0%, mean = 3.67) and the caregivers’ score (94.4%, mean = 4.39). The strength of ratings varied across participants (Table 22).
Table 22. Ministry Roles: Levels of Agreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General agreement (%)</th>
<th>Strong agreement (%)</th>
<th>Total agreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>69.0</td>
<td>19.0</td>
<td>88.0</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>50.0</td>
<td>25.0</td>
<td>75.0</td>
</tr>
<tr>
<td>Caregiver</td>
<td>41.6</td>
<td>52.8</td>
<td>94.4</td>
</tr>
</tbody>
</table>

Analysis determined an extremely significant difference between the clergy report (mean = 3.95, SD = 0.82) and the caregivers’ score (mean =4.39, SD = 0.87); $t(118) = 2.64, p = 0.01$. Further investigation also determined an extremely significant difference between the strength of the caregivers’ score (mean =4.39, SD = 0.87) and the caregivers’ predictive score of clergy response (mean = 3.67, SD =1.26); $t(70) = 2.82, p = 0.01$.

Comparative analysis between the strength of clergy responses to questions on spiritual gifts (mean = 4.27, SD = 0.65) and ministry roles (mean = 3.95, SD = 0.82) $t(166) = 2.80, p = 0.006$ determined extreme statistical significance. Further investigation revealed a few clergy (12.2%) who agreed persons with IDD should exercise spiritual gifts while concurrently disagreeing persons with IDD should serve in ministry roles.

This result confirms the caregiver perception that clergy members are not highly desirous of utilizing the ministry gifts of persons with IDD in ministry capacities.
When asked if clergy representatives had been adequately trained in ministering to people with IDD and their caregivers (question 5.15), the majority of clergy (70.2%, mean = 2.42) indicated disagreement. This outcome did not correspond to caregivers’ predictive score of clergy response (55.5%, mean = 2.92), as analysis determined a difference in the lack of consensus between it (mean = 2.92, SD = 1.34) and the clergy score (mean = 2.42, SD = 1.31); $t(118) = 1.90, p = 0.06$. The strength of ratings varied.
across the populations (Table 23). The actual caregivers’ score (75.0%) however, corresponded to the clergy report (70.2%).

Table 23. Adequacy of Training: Levels of Disagreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General disagreement (%)</th>
<th>Strong disagreement (%)</th>
<th>Total disagreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>44.0</td>
<td>26.2</td>
<td>70.2</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>44.4</td>
<td>11.1</td>
<td>55.5</td>
</tr>
<tr>
<td>Caregiver</td>
<td>41.7</td>
<td>33.3</td>
<td>75.0</td>
</tr>
</tbody>
</table>

Additional analysis determined a significant difference between the caregivers’ score (mean =2.31, SD = 1.41) and the caregivers’ predictive score of clergy response (mean = 2.92, SD = 1.34); \( t(70) = 1.88, p = 0.06 \). Further investigation indicated age, credential type, and region were not factors, yet educational attainment levels reduced the strength of disagreement (Table 24). Among credentialed clergy holders, non-lead pastors with graduate degrees (40%) reported higher levels of adequate training than lead pastors (82.3%) without graduate work.

Table 24. Graduate Training: Strength of Disagreement

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>General disagreement (%)</th>
<th>Strong disagreement (%)</th>
<th>Total disagreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All clergy ministry roles</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All Clergy</td>
<td>44.0</td>
<td>26.2</td>
<td>70.2</td>
</tr>
<tr>
<td>Non-graduate degree</td>
<td>48.7</td>
<td>28.3</td>
<td>75.0</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>37.5</td>
<td>20.8</td>
<td>58.3</td>
</tr>
<tr>
<td></td>
<td>Lead pastors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-graduate degree</td>
<td>55.9</td>
<td>29.5</td>
<td>82.3</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>57.1</td>
<td>14.3</td>
<td>71.4</td>
</tr>
<tr>
<td></td>
<td>Non lead pastors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-graduate degree</td>
<td>34.6</td>
<td>30.8</td>
<td>65.4</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>10.0</td>
<td>30.0</td>
<td>40.0</td>
</tr>
</tbody>
</table>
This result confirms the caregiver perception clergy members have not received adequate training; however, it highlights the necessity for clergy continuing education while rejecting caregivers’ assertion clergy are unaware of insufficient training.
APPENDIX S: PREVALENCE OF DISABILITY IN AGK

Figure 28. Prevalence of Disability in AGK

Disability Prevalence

When asked if very few persons with IDD live in the local area near our place of worship (question 7.4), the clergy report (61.9%, mean = 2.96) indicated slight disagreement. Although similar to the predictive score of clergy response (69.4%, mean = 2.50), it sharply contrasted with the caregivers’ score (72.3%, mean = 2.19) as shown by the strength of disagreement (Table 25). Analysis determined significant difference
between the strength of actual clergy report (mean = 2.74, SD = 1.30) and the caregivers’ score (mean = 2.19, SD = 1.35); \( t(118) = 2.10, p = 0.04 \).

Table 25. Persons with IDD in Local Community: Levels of Disagreement

<table>
<thead>
<tr>
<th>Population</th>
<th>General disagreement (%)</th>
<th>Strong disagreement (%)</th>
<th>Total disagreement (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>54.8</td>
<td>7.1</td>
<td>61.9</td>
</tr>
<tr>
<td>Caregivers’ prediction</td>
<td>50.0</td>
<td>19.4</td>
<td>69.4</td>
</tr>
<tr>
<td>Caregiver</td>
<td>30.6</td>
<td>41.7</td>
<td>72.3</td>
</tr>
</tbody>
</table>

The size of the congregation was a significant factor in disagreement, \( \chi^2 (2) = 8.35, p < 0.05 \). This factor of congregational size, however, did not correspond to geographic region: clergy in the least populous western region had the highest level of disagreement (68.4%) while those in the central region had the smallest (58.1%). This result suggests clergy of smaller congregations in western Kansas were more aware of persons with IDD within their communities than others.

**Congregational Census**

Respondents reported a total of 177 persons with some type of disability involved in their congregations (see Table 27). The largest identified age category was those over 55 years old (68), working-age adults (63), and school age children (56). The greatest identified disability in all categories was mobility impairment (72), followed by severe behavior disorder (43), intellectual and developmental disability (34), hearing impairment (21), and visual impairment (7). The majority of the persons with identified disabilities (58.3%) were 55 years or older.
Table 26. Congregation Census of Persons with Disability by Age

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Under age 18</th>
<th></th>
<th>Over age 55</th>
<th></th>
<th>All ages</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F</td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
<td>M</td>
</tr>
<tr>
<td>Mobility impairment</td>
<td>6</td>
<td>12</td>
<td>25</td>
<td>17</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Behavior disorder</td>
<td>6</td>
<td>12</td>
<td>0</td>
<td>0</td>
<td>19</td>
<td>24</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>8</td>
<td>9</td>
<td>4</td>
<td>2</td>
<td>18</td>
<td>16</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>0</td>
<td>1</td>
<td>5</td>
<td>10</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Visual impairment</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 27. Congregation Census of Persons with Disability by Type

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>Mobility Impairment</th>
<th>Behavior Disorder</th>
<th>Intellectual disability</th>
<th>Hearing Impairment</th>
<th>Visual Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>By age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 18</td>
<td></td>
<td>18</td>
<td>18</td>
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Ministry Strategies

Only six respondents indicated their faith community had any intentionally targeted ministry for families experiencing disability. When queried if their congregation and other community organizations had cosponsored any intentionally targeted ministries for families, only two replied affirmative.

Congregations reported the most common ministry strategy utilized included buddy programs (7), transportation assistance (3) and a special needs Sunday school class (3). Several other strategies included support groups, respite care, recreational activity, and social service assistance.
Ministry Roles

Respondents indicated persons with disabilities served in ministry roles in 9 of the 16 congregations during the past year. Serving as an usher was the most frequent role (5), followed by children’s ministry team (3), other (3), deacon (1), elder (1), worship arts (1), tech team (1), and youth ministry team (1). Seven congregations indicated persons with any disabilities did not serve in ministry roles.

Respondents indicated persons with IDD served in ministry roles in 7 of the 16 congregations during the past year. Serving as an usher was the most frequent role (3), followed by children’s ministry team (4), worship arts (1), tech team (1), and other (1). Nine congregations indicated persons with IDD did not serve in ministry roles.
APPENDIX T: EXECUTIVE SUMMARY FOR
FAMILIES TOGETHER, INC.

The following eleven-page report was presented to the executive staff for Families Together, Inc.—the designated parent information and resource center contracted by the Kansas State Department of Education (KSDE).
Serving People with Intellectual Disabilities
A Comparative Investigation of the Perceptions of Family Caregivers and Kansas Clergy Members: Executive Summary

Purpose
This research project investigated, compared, and contrasted the perceptions of intellectual disability (IDD) between clergy members of evangelical churches and family caregivers of persons with intellectual disabilities (IDD). Utilizing those findings, this project recommended denominational interventions to guide clergy and churches in developing contextualized missional strategies to include persons with intellectual disabilities as ministry partners.

Definitions
Collaboration Working together across disciplines to create positive outcomes.
Accommodation Removing structural or psychological barriers to allow access (inclusion).
Supports Resources that allow those with identified needs to pursue positive outcomes (engagement).
Modification Changing the established rules to allow alternative pathways for success (engagement).

Preparation Findings
As of 2012, over 350,000 persons with any disability live in Kansas, including over 129,000 with IDD. Prevalence rate of intellectual disabilities is approximately 4.5%. Poverty rate of persons with IDD exceeds 28%. Kansas school systems serve 18,000 students who are outside of the regular classroom more than 20% of the school day. More than 37,000 students have some supports in other educational areas. A total of 56,000 students are on an IEP (including gifted).²

Survey Participants
A total of 120 valid survey responses were analyzed, including 84 clergy residing in Kansas (representing 22% of panel) and 36 caregivers (30% residing in Kansas). Clergy were

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predominately Caucasian college educated full time male experienced lead pastors. Caregivers were predominantly Caucasian college educated mothers, active in their local church once a week or more.

**Summary of Findings**

While both populations held similar theological presuppositions, significant differences in levels of agreement (represented by means) emerged, seen primarily in clergy age, clergy training, and relational proximity to those with IDD. A large minority of clergy belief value statements often did not correspond with reported practices. Similarly, as perceptions are often created from observed actions and relational friendship, caregivers’ perceptions of clergy opinions did not correspond to clergy’s actual values.

Statements were answered utilizing a 4 point Likert scale (strongly agree, agree, disagree, strongly disagree). The bars on the following charts indicate majority agreeing or disagreeing to statement, while the markers indicate the level of strength in agreement or disagreement (mean).

**Theological Foundations**

Caregivers and clergy, while both overwhelmingly agreeing on two value statements, have a radically different opinion of how their belief impacts their practices, as observed by both the amount of persons agreeing as well as the strength level of their agreement.

The praxis question “Places of worship should pray regularly for persons with IDD to be made normal” was an inverse correlate of the theological question regarding the image of God: the responses should have been identical. There was, however, a significant gap between the two in both frequency and strength of clergy opinion. Caregivers overwhelmingly regard children with IDD created in the image of God as normal, in contrast to the clergy. This can lead to the often reported caregivers’ perception non-normal is equated to “sinful” or “evil”. Clergy’s practices significantly contradict their belief: either clergy have not reflected on the implications of the two, or they may be falsely asssenting to a value statement. A small group of caregivers’, perhaps reflecting their perceptions of clergy opinion, hold a minority position that normalcy is desired.
In part, these discrepancies may result from improper distinction between healing and normalization; healing is the restoration of one to full participation in God’s image (physical, mentally, socially, relationally, and spiritually), while normalization is placing human notions of God’s likeness upon all humanity. People with disabilities also get sick, injured, divorced—they too need healing. Healing appropriated for a person with or without disability, does not alter any persons’ identity as a limited human being created in God’s image.

Most clergy do not see healing as primary necessity, although the strength of their agreement is not strong. Furthermore, a significant amount (23%) do think it is the primary need. The strength between levels of (dis)agreement is significant between caregivers and clergy, to the point that caregivers are accurate in their perception clergy’s primary goal is to see their child healed. In addition, the primacy of healing seemed to supplant the necessity of salvific grace. Based upon clergy’s inactive expressions, caregivers tend to conclude just the opposite of clergy’s actual values.

Not every clergy member indicated the necessity of salvific grace for people with IDD. Perhaps it is due to how soteriology is often interpreted in the Christian community as cognitive assent to doctrinal statements. Twenty-five percent of caregivers perceive clergy believe healing is as high a priority as salvific grace. This united combination of healing and salvation tends to further the perception that grace is only extended to those experiencing healing.

Social Services Collaboration and Referrals
Recognizing the church does have a role in community social services, clergy overwhelmingly rely on referral to resources of outside agencies. Not as many clergy are supportive of helping persons with IDD find financial or housing assistance. Significant gaps also exist between the caregivers’ perception of clergy opinion and clergy’s actual report. Despite strong agreement among clergy, caregivers do not see the clergy’s beliefs placed into action. This may be due to the evangelical community’s tendency of separating worship from the core of everyday life. As both clergy and caregivers have substantial agreement in actual opinion, this suggests more formal successful collaborative dialog and action is highly feasible.
Accessibility Feature Ranking

Questions were derived from the work of Ault, Collins, and Carter on caregiver perceptions. In this survey, both Clergy and Caregivers identified **Welcoming Attitudes** as the top feature in creating a hospitable environment. The next four were the same, but differed in ranked order. Clergy predicted architectural accessibility and support groups as primary needs. Caregivers preferred additional accessible supports and special programs. As many churches are now much more accessible than the past, caregivers desire more supports to ensure personal interaction with other congregants. Both clergy and caregivers ranked the five remaining features as similar low priorities.

![Accessibility Feature Ranking - Top 5](chart)

Clergy ranked accessible transportation higher than caregivers. In part, that may because family caregivers often provide transportation. Persons without family caregivers and without transportation have expressed higher concerns on accessible transportation to congregational worship services and events.

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Accommodations, Modifications, and Supports

Monetary Resource
Caregivers overwhelmingly do not believe successful disability ministry requires extensive monetary resources. They accurately perceived the clergy’s perceptions, however, that ministry could result in extensive cost. Caregivers recognize earlier than many, ministry is about friendships and presence, not just facilities and programs.

Transportation
While the Accessibility Feature ranking showed transportation was the ranked least, it remains a significant concern. While the same amount of clergy members and caregivers agreed, the strength of agreement was significantly stronger for the caregivers. Caregivers, however, expected clergy and churches to be more proactive about helping people get to services.

Accommodations for Youth
While most churches accommodate children with IDD through buddy systems, youth are often not included. Despite what some clergy and youth ministers might realize, youth with IDD still have feelings of depression, sexuality, concern over stability of life, etc., just as others their age. Less than half of clergy and caregivers recognize that few supports are provided in youth groups. Caregivers do not realize clergy agree with them; many perceive clergy as believing sufficient supports are already provided.

Adequate Training
Over two-thirds of clergy acknowledge they have not been adequately trained to minister to persons with IDD. This insufficiency of accommodations and supports are due in large part to this lack of training. Ironically, 20% more caregivers actually think clergy were trained, assuming disability ministry was taught in Bible School.

Congregations as Coping Support Systems
Questions were derived from the work of Pitchlyn, Smith-Myles, and Cook. While 93% of clergy rated themselves as very helpful, only 53% of the caregivers concurred with the clergy’s opinion. The caregivers also accurately perceived clergy as thinking they were helpful. This plays into other

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caregiver perceptions. Many clergy may think their job is over after the initial encounter, Caregivers require ongoing support. This affects their decision to later ask for help. While clergy still think caregivers continue to turn them for advice, often they do not.

Church participation becomes difficult. Only 27% reported they are more active in their church than before – yet the survey was on people who still attend at least 1 time per week with 80% attending services four times or more a month. Caregivers accurately perceive correctly that clergy thinks they are still there at same level – not recognizing the new normal. The difference lies not in attendance, but feeling of participation and engagement.

Clergy actually recognize that religious education programming is not adequate for persons with IDD; more so than the caregivers; yet despite their concurrence, caregivers’ report a vastly different feeling projected from the clergy.

These results suggest clergy often do not actualize the value statement (I am helpful) in the ongoing life of a person with disabilities within the congregational setting. While clergy presumed their initial support was extremely helpful, a significant amount of caregivers strongly disagreed. Surprisingly, caregivers did not accurately predict the high level of clergy who thought they were more helpful than they actually were. Over half of the caregivers do not perceive their local congregation as the primary supportive environment, in sharp contrast to the clergy. Caregivers may have had their current experiences back into their initial encounter with clergy, while clergy are basing their answers upon their initial encounter. It would appear, however, nearly two thirds of clergy realize caregivers would not turn to the congregation for ongoing support for their child with IDD.

One concern illustrated within these results is the significant discrepancies between both clergy and caregivers. Caregivers and clergy achieve consensus on only one question; yet in that instance, caregivers perceived clergy to hold a much higher opinion of the efficiency of religious programming than either population actually did. These results seem to confirm caregivers’ perception that clergy and congregations do not provide a supportive, caring environment towards caregivers and persons with IDD.
Proximal Relationships
Several questions were asked regarding typical sacramental and pastoral duties of clergy. The results indicated a pattern: increased interaction with persons with disabilities decreased the comfort-ability level of clergy. While clergy upheld doctrinal value statements, pastoral duties did not reflect the same support. While communion, which requires very little pastoral interaction, reflected high mutual consensus, significant discrepancies emerged in adult baptismal practices, wedding policies, and pastoral visits. A small correlational factor emerged between those who would turn to their clergy for support and those who found clergy making phone calls or visits on a regular basis.

Clergy Awareness of Inclusive Support in Congregation
Questions were derived from Ault, Collins, and Carter.
Clergy indicated overwhelming affirmation for a value statement in support of an inclusive congregation. Yet significant discrepancies emerged between their values and actual awareness of what occurred during congregational life. While small minorities of clergy were aware of families unable to participate fully, this contrasted significantly with caregivers. The most striking question in this subsection indicated less than half of clergy and caregivers communicated needs with each other.

Empowered Service
Clergy agreed people with IDD should be allowed to exercise spiritual gifts. Yet both the frequency of opinion and the strength eroded when applied at the local congregational setting. Caregivers’ perceive a full quarter of clergy do not believe persons with IDD have something to contribute in the worshipping experience. Perhaps contributing to this perception is the common misunderstanding only functional contributions are valid.

Prevalence of Disability in Local Congregations.
The size of the congregation was a significant factor in disagreement. This factor of congregational size, however, did not correspond to geographic region; clergy in the least populous western region had the highest level of disagreement (68.4%) while those in the central region had the smallest (58.1%). This result suggests clergy of smaller congregations in western Kansas were more aware of persons with IDD within their communities than clergy of larger congregations in more urban areas. In urban areas, people with IDD more easily blend into the background and are ignored. Caregivers accurately predicted that clergy did not realize how many people with IDD there are in the community. A large percentage of both caregiver and clergy members surprisingly did agree that very few people with IDD lived in their community. This may be due to the rural settings of a number of respondents.
Of 139 congregations invited to participate in the survey, 18 responded (13%). Two were excluded from analysis as major sections were left blank. Within the 16 validated congregational respondents, a total of 177 persons with disability were reported involved in their congregations. The largest identified age category was those over 55 years old (68), working-age adults (63), and school-age children (56). The greatest identified disability in all categories was mobility impairment (72), followed by severe behavior disorder (43), intellectual and developmental disability (34), hearing impairment (21), and visual impairment (7). The majority of the persons with identified disabilities (53.3%) were 55 years or older. Only 34 persons with IDD were reported, with an even amount under and over 18 years of age.

**Ministry Strategies**

Congregations reported the most common ministry strategy utilized included buddy programs (7), transportation assistance (3) and a special needs Sunday school class (3). Several other strategies included support groups, respite care, recreational activity, and social service assistance. Only six respondents indicated their faith community had any intentionally targeted ministry for families experiencing disability. When queried if their congregation and other community organizations had cosponsored any intentionally targeted ministries for families, only two replied affirmative.

**Ministry Roles**

Respondents indicated persons with any disabilities served in ministry roles in 9 of the 16 congregations during the past year. Serving as an usher was the most frequent role (5), followed by children’s ministry team (3), other (3), deacon (1), elder (1), worship arts (1), tech team (1), and youth ministry team (1). Seven congregations indicated persons with any disabilities did not serve in ministry roles.

Respondents indicated persons with IDD served in ministry roles in 7 of the 16 congregations during the past year. Serving on the children’s ministry team was the most frequent role (4), followed by usher (3), worship arts (1), tech team (1), and other (1). Nine congregations indicated persons with IDD did not serve in ministry roles.
Multi-Tiered Faith Support System (MTFSS) Ability Ministry Model

Worshiping communities remain key social institutions within local communities. While para-church organizations can increase awareness and provide limited specific opportunities and training, the local church remains the better environment for mutual supportive friendship over the lifespan. Clergy have the privilege to equip the saints to do the work of the ministry. Teaching congregations to accept ministry from persons with disability, however, requires patience and intentionality of purpose. Disability ministry is not necessarily programmatic, although it can be. At its essence is a world view which values everyone’s contribution to the worshipping community. The multi-tiered faith support system (MTFSS) model allows congregations to review what they are already doing through a lens privileged by disability. It also allows for a collaborative system that ensures full participation in both the worshipping congregation and the community at large. While not every congregation can offer or provide every service or support, every church must find ways to include everyone for corporate worship activities and events.

Concerns

Three areas of concern emerged from the survey: inadequate ministry training, lack of relational proximity with persons with ICD, and insufficient awareness of needed congregational supports.

Recommendations

Certificate in Ability Ministry
Create a disability ministry certificate as part of clergy continuing education coursework. Foci would be on a theological framework for disability ministry, targeted concerns with children and youth, and faith-based collaboration with the community. Recommended texts include The Bible, Disability, and the Church by Amos Yong, Amplifying Our Witness by Benjamin Corrigan, and Including People with Disabilities in Faith Communities by Erik W. Carter.

Congregational Audit
Using the Multi-Tiered Faith Support System Matrix, examine congregational calendar of events, current ministry offerings, and collaborative efforts. Determine where your congregation currently ranks and then select one goal in each area to improve over the next several years.
Sample goals could include speaking with a local group home administrator or special education coordinator in local school district. Another may be asking parent caregivers and persons with disability what they would need to feel fully supported in your congregation and how they might like to contribute. Developing a committee within the congregation to intentionally look at areas of improving full participation of persons with IDD is a great start.

**Conclusion**

Ability ministry—allowing persons with disabilities to fully participate and contribute their unique talents to the church body—is one of the largest emerging social justice opportunities in the local church today, uniting all persons across gender, racial, ethnic, and social status lines. While difficult labor, the rewards for worshipping communities are unlimited and enriching. Without the contributions of persons with disability flourishing within our worshipping communities, the church is missing out on the fullness of God’s wonder and grace.
APPENDIX U: EXECUTIVE SUMMARY FOR
ASSEMBLIES OF GOD KANSAS MINISTRY NETWORK

The following eleven pages are an executive report developed and presented to the
Kansas Assemblies of God Ministry Network Presbyters at the quarterly meeting of
August 2014.
Serving People with Intellectual Disabilities
A Comparative Investigation of the Perceptions of Family Caregivers and Kansas Ministry Network Credential-holders: Executive Summary

Purpose
This research project investigated, compared, and contrasted the perceptions of intellectual disability (IDD) between pastors of the Assemblies of God Kansas Ministry Network (AGK) churches and family caregivers of persons with intellectual disabilities (IDD). Utilizing those findings, this project recommended AGK district interventions to guide pastors and churches in developing contextualized missional strategies to include persons with intellectual disabilities as ministry partners.

Definitions
Collaboration  Working together across disciplines to create positive outcomes.
Accommodation  Removing structural or psychological barriers to allow access (inclusion).
Supports  Resources that allow those with identified needs to pursue positive outcomes (engagement).
Modification  Changing the established rules to allow alternative pathways for success (engagement).

Preparation Findings
As of 2012, over 350,000 persons with any disability live in Kansas, including over 129,000 with IDD. Prevalence rate of intellectual disabilities is approximately 4.5%, poverty rate of persons with IDD exceeds 28%.\(^1\) Kansas school systems serve 18,000 students who are outside of the regular classroom more than 20% of the school day. More than 37,000 students have some supports in other educational areas. A total of 56,000 students are on an IEP (including gifted).\(^2\)

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Survey Participants
A total of 120 valid survey responses were analyzed, including 84 clergy residing in Kansas (representing 22% of panel) and 36 caregivers (30% residing in Kansas). Clergy were predominately Caucasian college educated full time male experienced lead pastors. Caregivers were predominantly Caucasian college educated mothers, active in their local church once a week or more.

Summary of Findings
While both populations held similar theological presuppositions, significant differences in levels of agreement (represented by means) emerged, seen primarily in clergy age, clergy training, and proximity to those with IDD. A large minority of clergy belief value statements often did not correspond with reported practices. Similarly, as perceptions are often created from observed actions and relational friendship, caregivers’ perceptions of clergy opinions did not correspond to clergy’s actual values.

Statements were answered utilizing a 4 point Likert scale (strongly agree, agree, disagree, strongly disagree). The bars on the following charts indicate majority agreeing or disagreeing to statement, while the markers indicate the level of strength in agreement or disagreement (mean).

Theological Foundations
Caregivers and clergy, while both overwhelmingly agreeing on two value statements, have a radically different opinion of how their belief impacts their practices, as observed by both the amount of persons agreeing as well as the strength level of their agreement.

The praxis question “Places of worship should pray regularly for persons with IDD to be made normal” was an inverse correlate of the theological question regarding the image of God: the responses should have been identical. There was, however, a significant gap between the two in both frequency and strength of clergy opinion. Caregivers overwhelmingly regard children with IDD created in the image of God as normal, in contrast to the clergy. This can lead to the often reported caregivers’ perception non-normal is equated to “sinful” or “evil”. Clergy’s practices significantly contradict their belief: either clergy have not reflected on the implications of the two, or they may be falsely asserting to a value.
statement. A small group of caregivers’, perhaps reflecting their perceptions of clergy opinion, hold a minority position that normalcy is desired.

In part, these discrepancies may result from improper distinction between healing and normalization: healing is the restoration of one to full participation in God’s image (physical, mentally, socially, relationally, and spiritually), while normalization is placing human nations of God’s likeness upon all humanity. People with disabilities also get sick, injured, divorced—they too need healing. Healing appropriated for a person with or without disability, does not alter any persons’ identity as a limited human being created in God’s image.

Most clergy do not see healing as primary necessity, although the strength of their agreement is not strong. Furthermore, a significant amount (23%) do think it is the primary need. The strength between levels of (dis)agreement is significant between caregivers and clergy, to the point that caregivers are accurate in their perception clergy’s primary goal is to see their child healed. In addition, the primacy of healing seemed to supplant the necessity of salvific grace. Based upon clergy’s inactive expressions, caregivers tend to conclude just the opposite of clergy’s actual values.

Concerns
Not every AG clergy member indicated salvation is required for people with IDD. Perhaps it is due to how salvation theology is interpreted in the evangelical/Pentecostal community as cognitive assent to doctrinal statements. Rethinking soteriology may be in order prior to negating its necessity. Caregivers actually perceive clergy think healing as a higher priority than salvation, it may have to do with the clergy focus on normalization/healing, as they do not know how to assess salvation outside of cognitive assent to doctrine. As Pentecostals, we should be much more open to the idea that the spirit residing within each of us is not disabled and can fully engage with the Spirit of God. People with IDD remain moral agents requiring God’s grace.

Social Services Collaboration and Referrals
Recognizing the church does have a role in community social services, clergy overwhelmingly rely on referral to resources of outside agencies. Not as many clergy are supportive of helping persons with IDD find financial or housing assistance. Significant gaps also exist between the caregivers’ perception of clergy opinion and clergy’s actual report. Despite strong agreement
among clergy, caregivers do not see the clergy’s beliefs placed into action. This may be due to the evangelical community’s tendency of separating worship from the care of everyday life. As both clergy and caregivers have substantial agreement in actual opinion, this suggests more formal successful collaborative dialog and action is highly feasible.

Accessibility Feature Ranking
Both Clergy and Caregivers identified Welcoming Attitudes as the top feature in creating a hospitable environment. The next four were the same, but differed in ranked order. Clergy predicted architectural accessibility and support groups as primary needs. Caregivers preferred additional accessible supports and special programs. As many churches are now much more accessible than the past, caregivers desire more supports to ensure personal interaction with other congregants. Both clergy and caregivers ranked the five remaining features as similar low priorities:

![Accessibility Feature Ranking - Top 5](image)

Clergy ranked accessible transportation higher than caregivers. In part, that may because family caregivers often provide transportation. Persons without family caregivers and without transportation have expressed higher concerns on accessible transportation to congregational worship services and events.
Accommodations, Modifications, and Supports

Monetary resource
Caregivers overwhelmingly do not believe successful disability ministry requires extensive monetary resources. They accurately perceived the clergy’s perceptions; however, that ministry could result in extensive cost. Caregivers recognize earlier than many, ministry is about friendships and presence, not just facilities and programs.

Transportation
While the Accessibility Feature ranking showed transportation was ranked the least, it remains a significant concern. While the same amount of clergy members and caregivers agreed, the strength of agreement was significantly stronger for the caregivers. Caregivers, however, expected clergy and churches to be more proactive about helping people get to services.

Accommodations for youth
While most churches accommodate children with IDD through buddy systems, youth are often not included. Despite what some clergy and youth ministers might realize, youth with IDD still have feelings of depression, sexuality, concern over stability of life, etc., just as other’s their age. Less than half of clergy and caregivers recognize that few supports are provided in youth groups. Caregivers do not realize clergy agree with them; many perceive clergy as believing sufficient supports are already provided.

Adequate Training
Over two-thirds of clergy acknowledge they have not been adequately trained to minister to persons with IDD. This insufficiency of accommodations and supports are due in large part to this lack of training. Ironically, 20% more caregivers actually think clergy were trained, assuming disability ministry was taught in Bible School.

Congregations as Coping Support Systems
While 93% of clergy rated themselves as very helpful, only 53% of the caregivers concurred with the clergy’s opinion. The caregivers also accurately perceived clergy as thinking they were helpful. This plays into other caregiver perceptions. Many clergy may think their job is over after the initial encounter. Caregivers require ongoing support. This affects their decision to later ask for help. While clergy still think caregivers continue to turn to them for advice, often they do not.
Church participation becomes difficult. Only 27% reported they are more active in their church than before – yet the survey was on people who still attend at least 1 time per week with 80% attending services four times or more a month. Caregivers accurately perceive correctly that clergy think they are still there at same level – not recognizing the new normal. The difference lies not in attendance, but feeling of participation and engagement.

Clergy actually recognize that religious education programming is not adequate for persons with IDD, more so than the caregivers; yet despite their concurrence, caregivers’ report a vastly different feeling projected from the clergy.

These results suggest clergy often do not actualize the value statement (I am helpful) in the ongoing title of a person with disabilities within the congregational setting. While clergy presumed their initial support was extremely helpful, a significant amount of caregivers strongly disagreed. Surprisingly, caregivers did not accurately predict the high level of clergy who thought they were more helpful than they actually were. Over half of the caregivers do not perceive their local congregation as the primary supportive environment, in sharp contrast to the clergy. Caregivers may have read their current experiences back into their initial encounter with clergy, while clergy are basing their answers upon their initial encounter. It would appear, however, nearly two thirds of clergy realize caregivers would not turn to the congregation for ongoing support for their child with IDD.

One concern illustrated within these results is the significant discrepancies between both clergy and caregivers. Caregivers and clergy achieve consensus on only one question; yet in that instance, caregivers perceived clergy to hold a much higher opinion of the efficiency of religious programming than either population actually did. These results seem to confirm caregivers’ perception that clergy and congregations do not provide a supportive, caring environment towards caregivers and persons with IDD.
Proximal Relationships
Several questions were asked regarding typical sacramental and pastoral duties of clergy. The results indicated a pattern: increased interaction with persons with disabilities decreased the comfort-ability level of clergy. While clergy upheld doctrinal value statements, pastoral duties did not reflect the same support. While communion, which requires very little pastoral interaction, reflected high mutual consensus, significant discrepancies emerged in adult baptismal practices, wedding policies, and pastoral visits. A small correlational factor emerged between those who would turn to their clergy for support and those who found clergy making phone calls or visits on a regular basis.

Clergy Awareness of Inclusive Support in Congregation
Clergy indicated overwhelming affirmation for a value statement in support of an inclusive congregation. Yet significant discrepancies emerged between their values and actual awareness of what occurred during congregational life. While small minorities of clergy were aware of families unable to participate fully, this contrasted significantly with caregivers. The most striking question in this subsection indicated less than half of clergy and caregivers communicated needs with each other.
Empowered Service
AGK Clergy overwhelmingly agreed the Pentecostal distinctive applied equally to persons with IDD. Similarly, they agreed people with IDD should be allowed to exercise spiritual gifts. Yet both the frequency of opinion and the strength eroded when applied at the local congregational setting. Caregivers perceive a full quarter of clergy do not believe persons with IDD have something to contribute in the worshipping experience. Perhaps contributing to this perception is the common misunderstanding only functional contributions are valid.

Prevalence of Disability and AGK Response
The size of the congregation was a significant factor in disagreement. This factor of congregational size, however, did not correspond to geographic region: clergy in the least populous western region had the highest level of disagreement (68.4%) while those in the central region had the smallest (58.1%). This result suggests clergy of smaller congregations in western Kansas were more aware of persons with IDD within their communities than clergy of larger congregations in more urban areas. In urban areas, people with IDD more easily blend into the background and are ignored.

Caregivers accurately predicted that clergy did not realize how many people with IDD are in the community. A large percentage of both caregiver and clergy members surprisingly did agree that very few people with IDD lived in their community. This may be due to the rural settings of a number of respondents.
The 16 AGK congregational respondents reported a total of 177 persons with some type of disability involved in their congregations. The largest identified age category was those over 55 years old (68), working-age adults (63), and school age children (56). The greatest identified disability in all categories was mobility impairment (72), followed by severe behavior disorder (43), intellectual and developmental disability (34), hearing impairment (21), and visual impairment (7). The majority of the persons with identified disabilities (58.3%) were 55 years or older. Only 34 persons with IDD were reported, with an even amount under and over 16 years of age.

**Ministry Strategies**
Congregations reported the most common ministry strategy utilized included buddy programs (7), transportation assistance (3) and a special needs Sunday school class (3). Several other strategies included support groups, respite care, recreational activity, and social service assistance. Only six respondents indicated their faith community had any intentionally targeted ministry for families experiencing disability. When queried if their congregation and other community organizations had cosponsored any intentionally targeted ministries for families, only two replied affirmative.

**Ministry roles**
Respondents indicated persons with any disabilities served in ministry roles in 9 of the 16 congregations during the past year. Serving as an usher was the most frequent role (5), followed by children’s ministry team (3), other (3), deacon (1), elder (1), worship arts (1), tech team (1), and youth ministry team (1). Seven congregations indicated persons with any disabilities did not serve in ministry roles.

Respondents indicated persons with IDD served in ministry roles in 7 of the 16 congregations during the past year. Serving on the children’s ministry team was the most frequent role (4), followed by usher (3), worship arts (1), tech team (1), and other (1). Nine congregations indicated persons with IDD did not serve in ministry roles.

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Multi-Tiered Faith Support System (MTFSS) Ability Ministry Model

The local church remains God’s central focus point in communities. While para-church organizations can increase awareness and provide limited specific opportunities and training, the local church remains the environment for friendship and co-laboring in the gospel. Pastors have the privilege to equip the saints to do the work of the ministry. Teaching congregations to accept ministry from persons with disability, however, requires patience and intentionality of purpose. Disability ministry is not necessarily programmatic, although it can be. At its essence is a world view which values everyone’s contribution to God’s unfolding work of redemption. The multi-tiered faith support system (MTFSS) model allows congregations to review what they are already doing through a lens privileged by disability. It also allows for a collaborative system that ensures full participation in both the worshipping congregation and the community at large. While not every congregation can offer or provide every service or support, every church must find ways to include everyone for corporate worship activities and events.

Recommendations

Three areas of concern emerged from the survey: ministry training, proximal relationships, and awareness of needed congregational supports.

AGK DSOG Certificate in Ability Ministry

The creation of a disability ministry certificate as part of a 3 part series of DSOM level courses, in addition to further training at other AGK events. Focuses would be on a theological framework for disability ministry, children and youth concerns, and faith based collaboration with the community. Recommended texts include The Bible, Disability, and the Church by Pentecostal scholar Amos Yong, Amplifying Our Witness by Benjamin Conner, and Including People with Disabilities in Faith Communities by Erik W. Carter.

Special Touch Summer Getaway

To fully understand disability ministry in context of proximal relationships, participate in a 1 week short term mission trip at either the Oklahoma or Wisconsin Summer Getaway in 2015. By 2017, develop an AGK Special Touch Summer Getaway as part of comprehensive district ability ministry.
Congregational Audit
Using the Multi-Tiered Faith Support System Matrix, examine congregational calendar of events, current ministry offerings, and collaborative efforts. Determine where your congregation currently ranks and then select one goal in each area to improve over the next several years. Sample goals could include speaking with a local group home administrator or special education coordinator in local school district. Another may be asking parent caregivers and persons with disability what they would need to feel fully supported in your congregation and how they might like to contribute. Another useful tool is the Special Touch (AG) Disability Friendly Church Certification.

Conclusion
Ability ministry – allowing persons with disabilities to fully participate and contribute their God given talents to the church body, is one of the largest emerging social justice ministry opportunities in the local church today, uniquely uniting all persons across gender, racial, ethnic, and social status lines. While difficult labor, the rewards for the body of Christ are unlimited and enriching. Without the contributions of persons with disability in our congregations, the church is missing out on the fullness of God’s wonder and grace.

For more information on ability ministry in the AG, contact:
Rev. Marvin J. Miller
Ability Church | Rayne Project Ministries
10808 W. Harvest Lane Wichita, KS 67212
316-765-3145 | mjmiller@abilityed.com
www.abilitychurch.org

Rev. Joe Butler
Ability Tree
P.O.Box 6929, Siloam Springs, AR 72761
479-373-6033 | info@abilitytree.org
www.abilitytree.org

Rev. Charlie Chivers
Special Touch Ministry
P.O. Box 25 Waupaca, WI 54981
715-258-2713 | ministry@specialtouch.org
www.specialtouch.org
APPENDIX V: AGK PRESBYTER POWERPOINT PRESENTATION

The AGK presbytery received a presentation of this project and accompanying recommendations. The following are slides of the presentation from August 2014.

Clergy / Caregiver Perceptions

Serving People with Intellectual Disabilities: A Comparative Investigation of the Perceptions of Family Caregivers and Kansas Ministry Network Credential-holders
Biblical Basis for Ability Ministry

Ephesians 4:14-21
For the body does not consist of one member but of many. \(^{15}\) If the foot should say, “Because I am not a hand, I do not belong to the body,” that would not make it any less a part of the body. \(^{16}\) And if the ear should say, “Because I am not an eye, I do not belong to the body,” that would not make it any less a part of the body. \(^{17}\) If the whole body were an eye, where would be the sense of hearing? If the whole body were an ear, where would be the sense of smell? \(^{18}\) But as it is, God arranged the members in the body, each one of them, as he chose. \(^{19}\) If all were a single member, where would the body be? \(^{20}\) As it is, there are many parts, yet one body.

The Body of Christ

\(^{21}\) The eye cannot say to the hand, “I have no need of you,” nor again the head to the feet, “I have no need of you.” \(^{22}\) On the contrary, the parts of the body that seem to be weaker are indispensable, \(^{23}\) and on those parts of the body that we think less honorable we bestow the greater honor, and our unpresentable parts are treated with greater modesty, \(^{24}\) which our more presentable parts do not require. But God has so composed the body, giving greater honor to the part that lacked it, \(^{25}\) that there may be no division in the body, but that the members may have the same care for one another. \(^{26}\) If one member suffers, all suffer together; if one member is honored, all rejoice together.

- \(^{27}\) Now you are the body of Christ...
Definitions

- **Impairment** — A physiological loss of normative functioning or form.
- **Disability** — The consequences of physical or mental impairments that substantially limit major life activities.
- **Handicap** — A socially constructed disadvantage as a result of disability.
- **Intellectual Disability** — “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.”

Definitions

- **Accommodation** — Removing structural or psychological barriers to allow access. (inclusion)
- **Modification** — Changing the established rules to allow alternative pathways for success. (engagement)
- **Supports** — Resources that allow those with identified needs to pursue positive outcomes (engagement)
- **Collaboration** — Working together across disciplines to create positive outcomes.
Definitions

• Deficit model -- the person with a disability has a deficit which must be corrected.
  - Medical
  - Work Rehabilitation
  - Special Education

• Limits model – Human variations of ability are the norm; experienced in the when, how, and where.

Clergy / Caregiver Perceptions

To what extent do clergy members and caregivers have the same theological understanding of disability?
Journey of Disability Attitudes

Ignorance

• Most people who claim to have disabilities are looking for a handout. The ones who live in group homes should not be allowed in public; their appearance is troubling. They have disabilities because they lack faith or are being punished for sin.

Awareness → Leads to Pity

Adapted from “The Journey of Disability Attitudes” © 2012 Elim Christian Services and Dan Vander Plaats

Journey of Disability Attitudes

Pity

• People who have disabilities are needy people, and it is good to feel sorry for them. But, thank God, no one I know has a disability. Someone should help them and give their lives meaning.

Access → Leads to Compassionate Care

Adapted from “The Journey of Disability Attitudes” © 2012 Elim Christian Services and Dan Vander Plaats
Journey of Disability Attitudes

**Compassionate Care**

- People with disabilities are created in God’s image; for that reason their lives have value. It’s great that our church helps the local group home with yard work and building maintenance.

*Integration → Leads to Friendship*

Adapted from “The Journey of Disability Attitudes” © 2012 Elim Christian Services and Dan Vander Plaats

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Journey of Disability Attitudes

**Friendship**

- As Christians, the Bible teaches us that there is no “us” and “them,” people without disabilities and people with disabilities. God brings many different people into his body, including people with disabilities, and we all benefit as we grow in friendship with each other.

*Engagement → Leads to Co-laborers*

Adapted from “The Journey of Disability Attitudes” © 2012 Elim Christian Services and Dan Vander Plaats
Journey of Disability Attitudes

Co-laborers

• Since God calls each of us to serve and praise him, churches need to encourage people who have disabilities to use their gifts in ministry. Together, we who live with disabilities and we who live without disabilities encourage and equip each other in every good work.

Adapted from “The Journey of Disability Attitudes” © 2012 Elim Christian Services and Dan Vander Plaats
Clergy / Caregiver Perceptions

WHERE DID WE COME FROM

History of the Church and IDD in America

• Church resembled dominant culture
• Not a major issue in worship or work until rise of industrialization and urbanization.
Levels of Feeble-mindedness

History of the Church and IDD in America

- Church resembled dominant culture
- Not a major issue in worship or work until era of industrialization
- Eugenic movement in 1890’s
- Kansas passed sterilization laws in 1913
  - State Home for the Feeble-minded – Winfield, KS
- Fitter Family Days at the Kansas State Fair in 1920
  - Included sermon contests
  - Handed out eugenics certificates authorizing marriages.
Promotion for Fitter Family Contest

Every 15 seconds, $100 go to care of persons with bad heredity

Christian Institutions Established

• As alternative to state schools, the Evangelical Lutheran School established in 1903 in Wisconsin
  • Purpose was to ensure spiritual supports and worshipping community in institutions
  • Led the model for institutional chaplains
  • Now known as Bethesda Lutheran Communities
    • National leader in Christian communities for persons with IDD.
    • Six locations in Kansas
Out of the institutions...

• Willowbrook State School (Staten Island, NY) opened 1947.
• By 1965, home to 6,000 children in facility built for 4,000.
• Abuses exposed by Geraldo Rivera in 1972.
• Willowbrook closed in 1987. As of today, most major institutions have shut down and smaller communities created – group homes.
• Began move back into the community.

Into the schools...

• The Education of the Handicapped Act of 1970
• Section 504 of the Rehabilitation Act of 1973
• The Education Amendments of 1974
• The Education for All Handicapped Children Act of 1975 (P.L. 94-142)
  • The Handicapped Children’s Protection Act of 1986
  • The Infants & Toddlers with Disabilities Act 1986
  • The Individuals with Disabilities Education Act 1990
  • The Individuals with Disabilities Education Act Amendments of 1997 (IDEA) (2004-reauthorized)
...and into local communities.

- While institutional chaplains could support spiritual needs prior to deinstitutionalization the responsibility now rests on the local church.
- Special Touch Ministries (AG) founded in 1982.
  - Initially a 1 week summer Bible camp for those not welcome in church.
- Friendship Ministries founded in 1983.
  - Initially a local Sunday School program.
- American Disabilities Act (ADA), 1990.
- Brett Mitchell Webb, as Florida institutional chaplain in early 1990’s was first major prophetic voice to call for inclusion in churches.

Let the children come...

-“Developmentally disabled young people are ready to hear the good news of God’s grace, and to see it extended to them through the church.”

...into the church.

- Called on the state to stop taking kids away from parents.
- Called for Christian family caregivers to return to church.
- Called for pastors to stop sending persons with IDD and their family caregivers away to find another church.

Excuses churches used to keep people from coming in the 1990’s

- Persons with IDD are angel like – especially blessed (don’t need salvation)
- Only those with full cognitive reason can assent to the doctrines of the church and understand God.
- Persons with IDD lack faith.
- Disability is a sign of sin of person or parents.
- We’re seeker sensitive – a person with IDD might cause disruptions on what God is doing.
How evangelical community has not helped.

- Successfully lobbied against ADA in 1990
- Successfully lobbied against the UN Convention on the Rights for Persons with Disabilities (CRPD) in 2012.
- Created a perception among both unchurched and churched PWD that Christianity is hostile.
- Our passion for the American constitutional right of freedom of religion often exceeds our compassion for those that need the gospel.

*CHURCHES MUST BE MORE INTENTIONAL THAN EVER*

Clergy / Caregiver Perceptions

WHERE WE ARE NOW
Religious Participation (2010)

![Bar chart showing religious participation by frequency and presence of disabilities]

Kansas Populations (2012)

- **All individuals**: 2,844,400
- Persons with disabilities (12.3%): 350,800
- Children (5-15) with disabilities (5%): 22,000
- Youth (16-20) with disabilities (5.4%): 11,300
- Adults (21-64) with disabilities (11.2%): 182,000
- **AGK Sun Am Attendance**: 17,453
Kansas IDD Populations (2012)

- All individuals 2,844,400
- Persons with IDD (4.9%) 129,200
- Children (5-15) with IDD (4.1%) 18,040
- Youth (16-20) with IDD (4.3%) 8,760
- Adults (21-64) with IDD (4.5%) 73,000
- AGK Sun Am Attendance 17,453

KSDE LRE 2012

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<th>Characteristic</th>
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* Source: Data adapted from Part B State Annual Performance Report for FY 2012 (Kansas State Department of Education, Topeka, 2014)
Clergy / Caregiver Perceptions

Interpretation of Survey

Clergy Respondents

- 84 AGK Clergy Members (23% of 368)
  - 86% male
  - 58% ordained, 18% licensed, 18% certified
  - 67% full time paid positions
  - 57% lead pastors (48)
  - 54% over 16 years pastoral experience
  - 65% held a college degree (29% graduate degree)
  - 45% between ages of 35 and 54
Clergy Respondents’ Churches

• Church Size
  • 35% small church (less than 80)
  • 30% medium church (80-200)
  • 36% large church (200+)

• Geographic Region
  • 40% East
  • 37% Central
  • 23% West

Caregiver Respondents

• 36 Caregivers
  • 86% Female
  • 66% Age between 35 and 54
  • 61% college degree (26% graduate level)
  • 80% attend church 1 time a WEEK or more.
  • Only 11 from Kansas
  • 5 AG
  • 1 AGK
Interpretation of Survey

• Caregivers and Clergy begin with similar agreement on theological presuppositions.
• Significant differences emerge
  • Passionate differences on levels of agreement
    • Clergy age
    • Clergy training
    • Proximity to persons with IDD
  • Clergy’s belief claims do not correspond with their practice.
  • Caregivers’ perception of clergy’s opinion do not correspond to clergy’s actual beliefs. – WHY?

Awareness:
Moving from Ignorance to Pity
Welcoming Foundations of Disability and Theology
Image of God

My son... "scares" my "pastor" my [sic] son loves God with all his heart and doesn’t understand why people treat him so poorly. I too feel a great deal of anger when the ‘pastor’ preaches how we need to love each other the same and we are all made in God’s image and what have you. What he means is if you are made in God’s image, as long as it is like him. -- caregiver

Image of God

We are all created in the image of God. There are lots of different images, and God loves them all. Some people need more help than others. We are called to be Jesus to each and every person that comes to us. – clergy member
What are we expecting?

• My biggest heartache is that my son is never taught the gospel. As if he is never expected to receive Jesus or be baptized in the family – AG caregiver
Access:
Moving from Pity to Care
Accommodations, Modifications, Supports, Collaboration
Accessibility Feature Ranking

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Clergy / Caregiver Perceptions

How do clergy members and caregivers perceive congregations as part of a coping support system?
...It destroyed me. I am OK now, but I am not the person I was before my son’s disabilities tore me off my foundation. I am not stronger.

Eventually, I fell into the arms of some parenting support groups (online and in real life) and there, I spilled my tale of woe. Returned to me, finally, was affirmation.

Understanding. Yes, this is awful. So hard. We hear you. We understand you. You are not bad or evil. You are not alone.
There were no **platitudes**.

No “he is here to test your strength” (he is himself, not my test), or “he is here to make you a better person” (he is himself, not my personal self-improvement exercise), or “God never gives you more than you can handle” (he is himself, not God’s telegram by which God’s confidence in me is communicated).

--- Adrienne Jones in “Parents in Pain, Parents Ashamed, BrainChildMag.com Aug 2014
Can we do more?

• We would do more than we do if we had qualified people; and perhaps if specific training were made available it might empower others willing to provide such ministry? – AGK clergy
Integration: Moving from Care to Friendship

Pastoral Care – Negative

We had one pastor who would visit other parishioners in the hospital at the same time as my son was a patient, but he wouldn’t visit us. -- caregiver
Pastoral Care - Positive

• Our pastor is so extremely supportive of our family as a whole which is awesome and has even come to our home as well as to the hospital to pray for my son when he was in the hospital for a week with pneumonia – AG caregiver
Approach me, please!

Clergy sometime assume that everything is fine with our family. I have to say that “assumptions kill relationships.” It would be great to have clergy that proactively seek to check on our spiritual stamina. As a family of a child with IDD we want to avoid being seen as “needy”. Therefore it would be great if the clergy make the first approach to check on us.

-- caregiver
Clergy / Caregiver Perceptions

To what extent do clergy and caregivers perceive necessary accommodations and supports to ensure full participation in the worshipping community?
Opportunities for Empowering Service.
The Role of the Local Church

AGK Congregational Survey
### AGK Churches (n=16, 12.2%)

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<th>Characteristic</th>
<th>Churches</th>
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<td>Under 18</td>
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<td>Over 55</td>
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<td>80 - 200</td>
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<td>&gt; 200</td>
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<td>24</td>
<td>16</td>
<td>11</td>
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### Congregational Strategies (1 of 2)

- Transportation assistance
- Social / Recreational activity assistance
- Housing assistance
- Employment assistance
- Financial training / assistance
- Separate children Sunday School class
Congregational Strategies (2 of 2)

Cosponsored strategies...
Ministry Opportunities – Disability

- Deacon: 1
- Elder / greeter: 1
- Usher / greeter: 5
- Children’s ministry team: 3
- Worship arts: 3
- Tech team: 1
- Youth ministry team: 1
- Other: 3
- NONE: 7

Ministry Opportunities - IDD

- Usher / greeter: 3
- Worship arts: 4
- Children’s ministry team: 4
- Other: 1
- NONE: 9
The Role of the Local Church

Disability Ministry repurposed as Ability ministry
Serving all the people with all the gospel

Role of the Local Church

• The local church remains God’s central focus point in communities.
• Para-church organizations can move people from Ignorance to Compassionate Care, but not usually into Friendship or Co-laborers.
• Church leadership is in the best position to help congregations move from Ignorance to Co-laborers
  • Pastors have the privilege to equip the saints to do the work of the ministry.
• Requires intentionality of purpose
Disability Ministry is not a program...it’s a way of thinking.

- Programs do exist, they can be incorporated into churches, just like any other activity or small group.
  - Danger – it can become segregated.
  - Does not take the place of mutual body ministry & worship.

- Good Programs
  - Friendship Clubs
  - Special Touch Chapters
  - Capernaum Ministry

Collaborative Faith Model

- Faith groups interested in addressing...issues may benefit from a model that describes service delivery in terms that have relevance to traditional roles religious groups have assumed in social service provision. A model would enable congregations, faith-based organizations, and community ministry groups to match their strengths, or callings, to a service that can effectively support people...in the context of the ...system of care. - DeKral
Multi-Tiered Faith Support System

**Residential Supports**
- Group Homes

**Wraparound Supports**
- Collaborative Social Ministries

**Congregational Supports**
- Within your church worship service

**Information & Referral Network**

***Referrals are not an excuse to exclude during worship services.***

Specific Recommendations

Training, Engagement, Congregational Supports Audit
Three major areas of concern

• Inadequate training
  • Fundamental theology
  • Practical ministry
• Proximal Factor
  • Limited Engagement
• Congregational Supports

Create Training Events

• DSOM style class

• 6 week small group or sermon series.

• Introduces theology of disability with a Pentecostal distinctive.
Create Training Events

- DSOM style class

- Engaging youth with IDD in mutual ministry

Create Training Events

- DSOM style class

- Introduces how churches can accommodate and interact with social agencies.
http://bethesdainstitute.org/2014-presentations
Includes speakers:
Dr. Amos Yong
Dr. Ben Conner
Dr. Erik Carter

Among those already committed to appearing at Inclusion Fusion 2014 are...
Joe Butler (of Ability Tree)
Emily Colson (author of Dancing With Max)
Barb Dittrich (SNAPPIN’ Ministries and Key Ministry)
Cameron Doolittle (Jill’s House at McLean Bible Church)
Pam Harmon (Executive Director of Young Life Capernaum)
Amy Kendall (Saddleback Church)
Matt Mooney (author, founder of 99 Balloons)
Barb Newman (author, speaker, educator from CLC Network)

INNOVATION on display November 12 & 13, 2014 at
http://go.mediasocial.tv/keyministry
What are you doing now?

- Look at what you are doing already. You may be very good at some parts of disability ministry already.
- Pick one goal in each area and develop a plan.

Sample Goals

- Meet with local group home leaders and ASK them their needs.
- Put topic on local clergy association agenda and delegate people in the congregations on task force.
  - Intentionally ASK
Sample Goals

- Ask caregivers’ what they need.
- Ask persons with IDD what they would like to contribute.
- Review your church events calendar –
  - If there are things that will exclude people from participating, find an alternative or develop accommodations before scheduling.

Sample Goals

- For those whose needs are so severe they cannot attend church, set up a webstream with a live chat host “pastor.”
- Invite an AG missionary for persons with disability to speak at a service.
AG Special Touch Disability Friendly Church Certification

Special Touch Summer Getaways

- For those who need to increase proximal awareness of persons with intellectual disability.
- One week camp experience, living, eating, worshiping together in Christian atmosphere.
- Short term mission trip for high school students or adults.
- 9 AG Districts
  - Wisconsin
  - Oklahoma
AG Family Ministry

ability tree
HELPING TO GROW ABLE FAMILIES

THE END
SOURCES CONSULTED

Introduction


Biblical-Theological Review


**General Literature Review**


Jersak, Brad. “Guides to the Kingdom: Why Our Church Attends to Prodigals, Children, the Poor, and Those with Disabilities.” *Leadership* 28, no. 4 (September 1, 2007): 31-35.


Tame, Kim. “And Finally...special in Church.” *Expository Times* 119, no. 10 (July 1, 2008): 520-520.


Description of Field Project


