

St. Stephen's College

The Importance of Spirituality in the Lives of Adults with Disabilities (AWDs) and How Church
and Pastors Can Improve Their Ministries To Meet These Spiritual Needs.

by

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ABSTRACT

Spirituality is an integral part of the lives of Adults with Disabilities (AWDs). Sadly, a very few literature have revealed the relationship between the spirituality of AWDs, their quality of life, and general wellbeing.

This research focuses on the gaps that exist in knowledge about how AWDs understand and express their spirituality and how the church recognizes and nurtures this spiritual expression, and what the church and pastors can learn from this research to improve their ministries to meet these spiritual needs. The study uses Community Based Participatory Research (CBPR) with AWDs within the Baptist congregations in Nigeria to investigate these gaps, explore the importance of spirituality in their lives, and addresses these unmet spiritual needs.

This study holds the spiritual needs of AWDs in dialogue with contemporary disability theologians' views on spirituality and disability with deeper reflection on belonging from the *Theology of Inclusion and Belonging* by John Swinton and the *Theology of Prophetic Belonging* by Tom Reynolds. It conducts research interviews with seven research participants from two Baptist congregations of the Nigerian Baptist Convention and elicits responses (voices) from the research participants themselves on how important spirituality is to them, how the church have responded to these unmet needs in their lives. The research participants' expression and experience of spirituality during the research interviews highlight the significance of spirituality in their lives.

The study presents eight implications and some recommendations which, if reflected on and attended to, can enhance the practice of church and Pastors' ministry to

meet the spiritual needs of AWDs in their congregations. The study also provides an exciting opportunity to advance researchers' knowledge on disability studies.

Key Words: Spirituality; Inclusion; Belonging; Intellectual and Developmental Disability; Pastoral Care.

DEDICATION

I dedicate this dissertation to my wife, Abiola Shodipo, and my children, Oluwafunmibi Shodipo, Toluwalase Shodipo, and Mofiyinfooluwa Shodipo. In the first place, my DMin journey would not have been possible if not for my wife and children's encouragement to explore the great opportunity at St. Stephen's College to advance my knowledge about people with disabilities and their spirituality within the Christian community. Their enduring spirit, unwavering support, involvement and engagement in my entire DMin program and process have been phenomenal.

I also dedicate this piece of work to persons and families with disabilities in Baptist congregations in Nigeria who at different times and diverse occasions during my engagement and interactions with some of them, have cheered me up and inspired me all the steps of the way to continue to do the work I am doing. I remember a few of these individuals and families telling me, "*Thank you for doing this for us and with us.*" I feel deeply honoured to be part of your lives, and I dedicate this work to you.

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TABLE OF CONTENTS

Abstract.....	ii
Dedication.....	iv
Acknowledgement.....	v
Table of Contents.....	vii
Introduction and Background.....	1
Rationale for my study.....	7
Research settings.....	8
Definition of Terms.....	12
Scope of my study.....	13
My Research Assumptions and Biases	15
Focus of issues investigated in the study.....	16
Research questions and a sub-question.....	17
Research Outline.....	17
 Chapter 1 Historical Context of Persons with Disabilities in the Church	
and Society	20
Early Perspectives and Treatment of Disability.....	20
The Evolution of Disability Movements.....	25
The Reimagining of Disability Theology.....	30
 Chapter 2 Various Experiences of Adults with Disabilities.....	34
Nature of experiences of AWDs.....	34

Chapter 3	Review of Theologies of Friendship and Inclusion.....	39
	A Theology of Invoking Deep Access by Thomas Reynolds <i>Invoking Deep Access</i> ..	44
	A theology of Friendship by Hans S. Reinders <i>Receiving the Gift of Friendship</i>	48
	A theology of Inclusion by John Swinton <i>From Inclusion to Belonging</i>	52
	A reflection of the interface between access, friendship, inclusion, and belonging....	54
 Chapter 4	 A Deeper Look at the Concept of Belonging.....	 61
 Chapter 5	 Methodology and Method.....	 68
	Choice of Community Based Participatory Approach.....	68
	Main Project Participants	75
	Data Collection.....	77
	Data Analysis.....	81
 Chapter 6	 Findings and Discussion.....	 83
	Expression of Being Close to God.....	83
	Importance of Spirituality and Belonging.....	90
	Feeling Welcomed.....	91
	Feeling Connected.....	95
	Church Supporting Belonging.....	96
 Chapter 7	 Three dimensions of spirituality.....	 99
	What does “life meaning and purpose” mean for AWDs?.....	100

How can AWDs experience meaningful relationship and trust?.....	103
What does “spirituality being connected” mean for AWDs?	109
Conclusion, Implications, and Recommendations.....	113
The Significance of the use of CBPR approach.....	114
The Implications of three dimensions of Spirituality in the lives of AWDs.....	114
The Implications for reconstruction of theology informing attitude and behaviour towards Disabled persons.....	139
Reflection from experiences of AWDs.....	139
Reflection on the work of disabled theologians.....	141
Recommendations provided by the research participants.....	144
Limitations of the study and areas for future research.....	145
The Implications of this study on my practice of ministry and spiritual journey.....	147
 Bibliography.....	 154
Appendix A: Sample of Participants’ Interview Questions.....	165
Appendix B: Research Study: Participants Consent Form.....	167
Appendix C: Research Study: Letter of Invitation Research Partners.....	173
Appendix D: Letter of Confidentiality.....	175
Appendix E: Participants’ Demography.....	176
Appendix F: Activity/Focus of each of the ten meetings.....	177
Appendix G: Analysis Table.....	180

Introduction and Background

Spirituality has long held an important place in the lives of Adults with Disabilities (AWDs)¹ and their families across cultures.² However, in recent times, the varied expressions of spirituality have attracted little but certainly growing attention by scholars in disability studies,³ and clergy, especially those in the pastoral care ministry. Four disability scholars with recent work on disability, spirituality, and faith communities are William C. Gaventa, Amos Yong, Erik W. Carter, and Thomas E. Reynolds. Their main works – William C. Gaventa’s *Disability and Spirituality: Recovering Wholeness*, Amos Yong’s *The Bible, Disability and The Church: A New Vision of the People of God*, Erik Carter’s *A Place of Belonging: Research at the Intersection of Faith and Disability*, and Thomas Reynolds’s *Invoking Deep Access Disability Beyond Inclusion in the Church* - each reveals uncertainty that still exists about how the disabled population experience their own spirituality, how they share that sense of their own spirituality, and how clergy and communities of faith affirm or fail to

¹ Adult with Disabilities has been defined as “a person 18 years of age or older who suffers from a condition of physical or mental incapacitation due to a developmental disability, organic brain damage, or mental illness, or who has one or more physical or mental limitations that restrict the person's ability to perform the normal activities, accessed February 2024. <https://www.lawinsider.com/dictionary/disabled-adult> I have chosen Adult with Intellectual and Developmental Disabilities (AIDDs) for my study because of my professional and ministry experiences with this disability population.

² Erik W. Carter and Thomas L. Boehm, “Religious and Spiritual Expressions of Young People with Intellectual and Developmental Disabilities,” *Research and Practice for Persons with Severe Disabilities*, Vol. 44 (1) 37-52, 2019.

³ Eleanor X. Liu et al., “In Their Own Words: The Place of faith in the Lives of Young People With Autism and Intellectual Disability,” *Intellectual and Developmental Disabilities*, Vol. 52, No. 5, 388-404, 2014.

affirm the spirituality of this population.⁴ Hence, this study aimed to conduct Community Based Participatory Research (CBPR) with Adults with Disabilities (AWDs)⁵ to address gaps in knowledge about how AWDs understand and express their spirituality and how the church recognizes and nurtures this spiritual expression, and what the church and pastors can learn from this research to improve their ministries to meet these spiritual needs.

In Nigeria, people with disabilities can feel that their full humanity is not recognized or appreciated within societies and even among Christian communities. For instance, the church ministry practices and activities in Nigeria do not really reflect the inclusion of persons impacted with disabilities. They are often being treated with neglect and rejection, especially in faith communities. In Nigeria, for example, out of 195 million Nigerians, 29 million are people with disabilities.⁶ Sadly, there is some evidence that many people experience unmet spiritual needs in their congregations. The reason might be how disability is understood and construed, coupled with the way disabled people are treated in diverse cultures. For instance, disability is perceived by

⁴ William C. Gaventa, *Disability and Spirituality: Recovering Wholeness* (Texas: Baylor University Press, 2018); Amos Yong, *The Bible, Disability and The Church: A New Vision of the People of God* (Grand Rapids, MI: William B. Eerdmans Publishing Company), Vol. 5, 2011; Erik W. Carter, “A place of belonging: Research at the intersection of faith and disability,” *Review and Expositor* 113 no. 2 (May 2016): 170, <https://doi.org/10.1177/0034637316637861>; Thomas Reynolds, “Invoking Deep Access Disability Beyond Inclusion in the Church,” In *Dialog A Journal of Theology*, Vol 51, No 3, (September 2012), https://www.academia.edu/12404952/Invoking_Deep_Access_Disability_Beyond_Inclusion_in_the_Church

⁵ Developmental Disabilities have been defined as abilities, qualities, and experiences that differ from the usual in the restrictions they place on free participation and affirmation in the society. Odom S. L. et al., “The Construct of Developmental Disabilities,” in *Handbook of Developmental Disabilities*, (New York, NY: Guilford Press, 2007), 23. I have chosen Adult with Developmental Disabilities (ADDs) for my study because of my professional and ministry experiences with this disability population.

⁶ World Bank Group, “Disability Inclusion in Nigeria, A Rapid Assessment,” In *Social Analysis*, June 2020, <https://elibrary.worldbank.org/doi/abs/10.1596/34073>

the African people to be the result of the activities of unseen powers whose prerogatives have been denied or violated through human omission or commission. For example, in pre-colonial Nigeria a child born with cerebral palsy was ostracized and banished from the community into what was considered at the time “the evil forest” and was left to die. This act was undertaken because such a child was seen as carrying a bad omen or was a victim of punishment resulting from sin. This may also have been the case with a child born without any deformity but who later developed one.⁷

In another context, the victim of physical malformation may be regarded as an incarnation of a deity or a god. An example among the Yoruba of southwest Nigeria is the child born with albinism, a congenital deficiency in skin pigmentation.⁸ Precolonial Yoruba society saw albinos as incarnations of the gods and so treated them with deference. In Yoruba words, they say: *Owo orisa la fi nwo afin*, meaning “We ascribe the reverence of the divinities to the albino.” The Yoruba albino will live a normal life like any other person, but he or she is believed to be *eni orisa*, that is a divine personality.

Although some progress has been made, unfortunately the vestiges of these discriminatory attitudes and beliefs are still visible in Nigeria. Therefore, this research is seeking to transform the way disability is perceived and how disabled people are treated in the church, even in Baptist congregations. This investigation includes examining what the church is doing to meet the spiritual needs of disabled people and what can the

⁷ An example is a child born with complete features but who later became crippled from poliomyelitis.

⁸ Adediran Daniel Ikuomola, “Socio-Cultural Conception of Albinism and Sexuality Challenges among Persons with Albinism (PWA) in South-West, Nigeria,” *IJAH* 4(2), S/No. 14, (April 2015): 203, <https://www.ajol.info/index.php/ijah/article/viewFile/118908/108384>.

church do better or differently to meet these needs, as well as other existential needs of the disabled people.

Early in my ministry, I had sought to carry out pastoral care for people with disabilities, but I was unable to recognize and understand the reality of their spiritual need because it was so different from my experience growing up with my cousin who had cerebral palsy. My experience with my cousin was so compelling because I was inspired by the spiritual support his parents provided him as he navigated through his disability situation. As I engaged in pastoral care ministry in Nigeria and later continued abroad, bringing my theological knowledge from the seminary together with my practical experiences in my ministry encounter with a disability population, I began to recognise and appreciate the value individuals with disabilities place on their spirituality and religious practices.

My observations, interactions, and experiences with AWDs and their families in a church setting in Nigeria, specifically with how AWDs express their own spirituality, and how the church understands and nurtures the expression of that spirituality, have led me to believe that there is a gap. Some authors have maintained that AWDs have the potential to engage their spirituality, although in fact, there are very few studies addressing the spirituality of AWDs. William C. Gaventa affirms, “there have not been many research studies about how young people and adults with intellectual and developmental disabilities define the role of spirituality and faith in their own lives.”⁹ More particularly, there have been even fewer that address the impact of spirituality on the quality of life of adults with disabilities.

⁹ Gaventa, *Disability and Spirituality Recovering Wholeness*, 76.

My ministry work, specifically with Adults with Disabilities (AWDs) over the years, has evolved into exploring the way this population expresses their spirituality, and how this understanding can help reform the pastoral care ministry practices of the church. My quest to know how AWDs relate to their spirituality began when I attended a family workshop in 2004 at Eleekara in Oyo State, Nigeria. It was organised by the Family Life Unit of the Nigerian Baptist Convention and led by the head of the unit, Reverend Mrs. Comfort Ayanrinola, a Baptist missionary who had her theological training in the United States, and whose thinking and writing about families, disability, and spirituality have had a significant influence in my pastoral care ministry to date. Her book titled *Impactive Parenting: God Given Responsibility* reveals the need for people to understand that individuals with disabilities are special people created by God and have spiritual needs among other needs.¹⁰ She shared her ministry experience of how some families of disabled people have used their spirituality and their religious practices such as prayer, scripture meditation, music, and the arts to live their best lives. She emphasizes how important it is for the church to help families with disabilities articulate their spiritual needs and realize their life dreams and aspirations.

The adoption of the term “spirituality” in recent decades by a wide spectrum of cultural societies and belief systems has altered the meaning of the term from its original use “Breath of Life,”¹¹ by the Greek Philosophers. The term has been broadened in some current literature to include the whole of faith as well as the life of

¹⁰ Comfort Ayanrinola, *Impactive Parenting: God Given Responsibility* (Ibadan: Baptist Press (Nig.) Ltd, 2013), 186.

¹¹ Efthymios Tzounis, “Constructing and Deconstructing the Terminology of Spirituality: A Journey Back to the Greek Roots,” *Journal of Traditional Medicine and Clinical Naturopathy*, Volume 248, Issue 6, 2017. Abstract.

the person, including psychological, social, and emotional dimensions.¹² But Weathers et al. see “spirituality” as inclusive of the intimate connection and meaning that are related to human experiences. They view the concept of spirituality more broadly, not just a contemplative awareness of self but also an awareness that involves different experiences and expressions. The key words in Weathers et al.’s description of spirituality are ‘transcendence’, ‘connectedness’, and ‘life meaning.’¹³ In Weathers et al.’s view, transcendence possesses the capacity to transform human lives and situations, and, according to them, is inherent in every human being. For Weathers et al, the connectedness and life meaning both emerge from personal choices people make and experiences they have, and the effect of those encounters on their lives.¹⁴

Joyce Bellous and Margaret Clark offer a broader perspective of spirituality. In their book, *Thick Listening at Thin Moments*, Bellous and Clark opine that every human being is instinctively searching for something that gives them meaning, offers them inner connection and deeper sense of purpose, and improve their general wellbeing. They write that “...spirituality, whether a human capacity or way of life, is healthy only as long as essential spiritual needs are met in community (socially) and in someone’s life (personally)....”¹⁵ Through a closer look at Bellous and Clark’s work, it becomes

¹² Wilfredo Gomez, “When Strangers Read My Body: Blurred Boundaries and the Search for Something Spiritual,” *Tikkun* 29, no.4 (2014):41-42, 68-69. <https://doi.org/10.1215/08879982-2810134>

¹³ Weathers et al., Elizabeth Weathers, Geraldine McCarthy, and Alice Coffey, “Concept Analysis of Spirituality: An Evolutionary Approach,” *Nursing Forum*, Volume 51, Issue 2, 2015, 16. <https://doi.org/10.1111/nuf.12128>.

¹⁴ Weathers et al., 5-13.

¹⁵ Joyce E. Bellous and Margaret B. Clark, *Thick Listening at Thin Moments: Theoretical Groundwork in Spiritual Care Practice* (TallPine Press: Edmonton, 2022), 11-12.

clear that providing inclusive faith communities in which everyone experiences well-being, good condition of health, and general improvement in their quality of life can be a comprehensive vision of inclusion not only for the church, but for all human persons within the society. In fact, my research dissertation has been able to confirm what many researchers and AWDs have been saying, that there is the need for a sense of connection, of being cared for, of being involved and able to participate in activities that can significantly advance their quality of life.

In my view, the idea of spirituality presented by Weathers et al. and Bellous and Clark seems to capture the way people with disabilities express their spirituality which I believed was worth examining. My main research focuses on utilizing the personal experiences of the research participants from the Baptist congregation in Nigeria as well as their personal family stories to understand more about what spirituality mean to them.

Rationale For My Study

This research aimed (1) to explore the importance of spirituality as expressed and experienced by AWDs, (2) to engage the in the entire research project for people to hear their voices, and what the church and pastors can learn from this research to improve their ministries to meet these spiritual needs. (3) to use the findings of this project to better comprehend how AWDs relate to their spirituality within the church, and how the church understands and nurtures the expression of that spirituality (4) to use the result(s) of the data collected to help pastoral caregivers and faith communities understand the implied and inherent attitudes and practices that may make AWDs and

their families to feel unwelcomed within their congregations, and (5) to provide an exciting opportunity to advance researchers' knowledge on disability studies.

I conducted this research through the two Baptist denominations of the Nigerian Baptist Convention (NBC) in Nigeria. The Nigerian Baptist Convention has over 2000 churches, associations and conferences that provide platforms to help people grow and connect with one another, bringing the love of Christ and the justice of God's kingdom to the vulnerable, the marginalized, and the less privileged.

Research Settings

The main research involved individuals with intellectual and developmental disabilities through the two churches of the Nigerian Baptist Convention in Ibadan, Oyo State. I chose the Baptist denominational churches and the two locations because of some documented experiences of the disability population in these faith communities and because of my ministry practices in these locations. This study was an exploration of a Community Based Participatory Research (CBPR) methodology for surfacing spiritual expression and needs from AWDs within Nigerian Baptist congregations, and seven participants participated in this qualitative study. It is possible that through direct participation of the participants, the church care ministry practices can be improved, and church leaders and workers can provide more spiritual support to people with disabilities and their families in the Baptist church ministries. It is also possible that by meeting with participants and providing them with the opportunity to share their personal reflections related to spirituality and belonging, participants can open opportunities for better access to congregational life and feel more connected to the

Divine and others in the church. There is also the possible benefit to participants of finding friends in each other who can be a specific support group beyond the study and may attract new members.

The results of (lessons learned from) the study will be shared at Baptist ministers' gatherings such as Baptist convention, conferences, and associations to improve the way pastoral care ministry towards AWDs is being practiced within the Baptist congregations.

The main project was conducted within Chesire High School, Ibadan via Zoom and audio recorded. The participants chose the location of the meetings and interviews because Annual Baptist Conference and Associational meetings were going on in the two Baptist denominational churches. The location of the school setting was the participants' choice which is one of the prerequisites for conducting CBPR. The main project location was also the choice of the participants to ensure security, utmost confidentiality, privacy, and comfort. The participants expressed personal satisfaction for being involved in what matters to them in their lives, and encouragement that they were able to contribute to research design to improve on how people can better understand how they experience and express their spirituality.

Researcher provided a means of transportation through the research assistant for the participants to aid them from their residence to the meeting venue of their choice. The research assistant picked the participants up from their respective homes and brought them to the research meeting place, and then home again afterwards. I did this to avoid any public ridicule of them while they are using public transport, thus making the place of our research meeting accessible to them. The researcher held a series of meetings

with those who were involved in various ways in the research by Zoom for collaboration and to establish trusting relationships.

Kelly presents the initial steps, the planning, reflection, and action which are the conceptual framework for conducting community based participatory research. Kelly's work does not involve any empirical research, but it provides a more welcoming approach to use for research with AWDs in the church community. Following Kelly's suggested preliminary steps in my pilot project provided ways this marginalised population can be involved in a project that will transform their own lives and the faith communities in which they worship and interact. Even as Kelly addresses critical steps to follow when initiating a research project with community partners, it is also important to address communication and other barriers to their active involvement and participation. Communication may be very important as Kelly acknowledges that "knowledge of an actual community, gained by nurses in their day-to-day work, will determine which of these guidelines will work, which will need modifications, and which will apply."¹⁶ This seems to me that understanding effective communication with AWDs is one of the research techniques to take note of while planning my main research project. According to Barbara Schneider et al., communication can either produce positive or negative experiences with individuals with disabilities. Hence, they suggest that good communication on the part of the researcher is critical to build

¹⁶ Kelly, 2005, 67.

trusting relationship with the disability population for them to have a transformative experience that can contribute to some changes during and after the research process.¹⁷

Also, Hassouneh et al. chose a collaborative approach for dialogue with the disability group (women with physical disabilities) and identification of the research problems for onward investigations. They opted for this type of arrangement probably because of their existing knowledge of and experience with the disability community. It seems that the authors' community relationships with the disability population and their interest in ensuring their full inclusion in research inform their entire research study. Although the study mentions "Self-Empowerment" of , which is an indication of a good working relationship, it does not specify in the study the extent of this relationship (the power dynamics and ownership control of the data and its future implementation) between the researchers and the research subjects. However, it proved to be a good start for research partnership in a community-based participatory research project as "Reflection, Insight, and Self-Empowerment (RISE) and Healing Pathways were born out of this collaboration."¹⁸ Hassouneh et al.'s idea of information gathering process with potential informed my decision to have a series of team meetings with the research participants.

Further in this introduction and background section, I highlight the definition of terms, the scope of the research study, the researcher's assumption and biases, focus of

¹⁷ Barbara Schneider et al. "Communication Between People with Schizophrenia and Their Medical Professionals: A Participatory Research Project" *Qualitative Health Research*, Vol. 14; 562-576, 2004.

¹⁸ Hassouneh et al., *Res Nurs Health*, 2011. 254.

issues investigated in the study, my research questions and a sub-question, and the outline of my study.

Definition of Terms

In this paper, I am using the term AWDs to refer to a group of persons with “conditions due to an impairment in physical, learning, language, or behavior areas.”¹⁹ The term includes impairments caused by a congenital anomaly, impairments caused by disease (e.g., poliomyelitis, bone tuberculosis), and impairments from other causes (e.g., cerebral palsy, amputations, and fractures or burns that cause contractures).²⁰ These conditions can pose significant challenges to individuals who are affected by such disabilities. For instance, Laurie Green et al. refer to such circumstances as “adversity, abuse, trauma, and negative life experiences.”²¹

Also, in this dissertation, the words “adults with disabilities” and “disabled people” are being mentioned. The reason for these two expressions is the preference for how persons affected by disabilities in this study would like to refer to themselves, be called or identified by. The CTV headline, a report of an interview with co-founder of the Disability Justice Network of Ontario Sarah Jama, author and disability activist Amanda Leduc, and Regina-based disability activist John Loepky, says it all. The headline is captioned “why many advocates prefer the term ‘disabled people’ over ‘people with

¹⁹ Centers for Disease Control and Prevention (CDC), *Developmental Disabilities*, accessed March 28, 2022, <https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>

²⁰ Individual with Disabilities Education Act IDEA, <https://sites.ed.gov/idea/regs/b/a/300.8> Accessed May 25, 2018.

²¹ Laurie Green et al., “HELP for behaviours that challenge in adults with intellectual and developmental disabilities,” *Clinical Review*, Vol 64 (Suppl 2) April 2018, 5. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5906788/pdf/0640s23.pdf>

disabilities.”²² In the CTV report, two comments are stated with respect to the use of the words ‘disabled people.’ One, that disability is a reflection of someone’s identity and stories, and disconnecting from it would mean not affirming who they are.²³ Two, the use of the words ‘disabled people’ is an expression of individual strong preference, choice, and autonomy.²⁴

The term “Pastoral care” is used in this dissertation to refer to both the “broad, inclusive ministry of mutual healing and growth within a congregation and its community,”²⁵ as well as “spiritual guidance of human souls.”²⁶ The significance of Clinebell’s idea of Pastoral care which I have applied in this study is the prescribed relationship of partnership and friendship between the physically whole and psychologically fragile, which includes the share-giving of Christian lives for one another.

Scope of the Research Study

The scope of this study is narrowed down to: (a) two churches of the Nigerian Baptist Convention in Ibadan, Oyo State; (b) meeting with the (AWDs) in two selected Baptist churches for conversation and information gathering about their connectedness

²² Jeremiah Rodriguez, “why many advocates prefer the term ‘disabled people’ over ‘people with disabilities’” In *CTV News.ca*, published Wednesday, February 10, 2021, accessed December 6, 2023. <https://www.ctvnews.ca/canada/why-many-advocates-prefer-the-term-disabled-people-over-people-with-disabilities-1.5303797?cache=>

²³ Rodriguez, 2021.

²⁴ Rodriguez, 2021.

²⁵ Howard Clinebell, *Basic Types of Pastoral Care and Counselling: Resources for the Ministry of Healing and Growth*, ed. Bridget Clare McKeever, 3rd ed. (Nashville: Abingdon Press, 2011), 26.

²⁶ Joseph Shiriko, “Disability: Social Challenges and Family Responses,” in *Disability, Society and Theology Voices from Africa*, eds., Samuel Kabue et al., (Kijabe: Kijabe Printing Press, 2011), 170.

and belonging, and the extent to which their spiritual needs are being met; (c) there were seven participants overall.

The study focuses on participants who: a) live with mild to moderate cognitive and communicative disabilities, b) are between 20 to 55 years old, and c) possess expressive language and the ability to understand what is being asked of them, and to communicate clearly in their responses in English. Researchers have seen an observable increase in qualitative research studies involving participants with disabilities with ability to give their consents and express their views in an understandable manner.²⁷

The Researcher's Assumption and Biases

CBPR is an investigative inquiry that is emerging among the marginalised community (AWDs) which incorporates their voice and active participation throughout the research.²⁸ I have worked closely with AWDs from a variety of backgrounds, and in different cultural and religious contexts. I understand the importance of their full participation in the study, which is the main focus of this research. My ability to connect with AWDs in diverse settings is critical to my research.

My assumption. My assumption is that all AWDs are persons (humans) in the

²⁷ Vicki Lloyd, Amanda Gatherer & Sunny Kalsy, "Conducting qualitative interview research with people with expressive language difficulties," *Qualitative Health Research*, (December 1, 2006), 1386-1404, <https://doi.org/10.1177/1049732306293846> ; Barbara Paterson & Shannon Scott-Findlay "Critical issues in interviewing people with traumatic brain injury," *Qualitative Health Research*, 12, 399–409, (March 1, 2002), <https://doi.org/10.1177/104973202129119973> , cited in Kelly D. Coons and Shelley L. Watson, "Conducting Research with Individuals Who Have Intellectual Disabilities: Ethical and Practical Implications for Qualitative Research," *Journal on Developmental Disabilities*, Vol. 19, No. 2, 14-24, (January 2013), <https://www.researchgate.net/publication/273133074>

²⁸ Maria Pontes Ferreira and Fidji Gendron, "Community-Based Participatory research with traditional and indigenous communities of the Americas: Historical Context and Future Directions," in *International Journal of Critical Pedagogy*, Vol 3 (3), 2011, p 153-168.

fullest sense of the term and therefore can articulate their own spirituality. Hence, this study assumed that AWDs are nonetheless part of the human society and have the right to explore their own spirituality.

My biases. I do have positive biases from my background and from my experiences in pastoral care ministry with people with disabilities in Nigeria. I brought my biases into this research.

First, my research population are Adults with Disabilities (AWDs). They could understand for themselves what is hurtful and what is not. They could give their consent. I am aware of the vulnerability of the participants, and I went to the point where I was able to do some things to mitigate their vulnerability.

Second, I made the place of meeting safe by preventing any threat to their security and safety. For instance, I asked ahead of the team meetings via Zoom about what type of support they would need to participate before, during, and after the meeting.

Third, I was flexible with the timeline for preparation meetings via Zoom.

Fourth, to avoid any anxiety or psychological breakdown, participants were: welcomed as valued, full members of the Research Team during introductory preparation meetings; participated in developing questions that were used in the interviews; and got a sample of the questions ahead of time, that enabled participants to have time to consider, reflect on, and review the sample questions before responding in their own interview.

Fifth, I ensured, because of the prolonged contact with myself and the other members of the Research Team, that participants felt that they were not alone

in this experience and have found a community. They would have participated in a group of colleagues who had dealt or are dealing with the same issues. I offered them the chance to find support from each other, not only during my study, but afterwards.

After the study, I provided the opportunities for them to keep meeting each other socially, and to form a support group in each congregation to which they might attract new members. This experience really empowered them to speak out and use their voice to improve their own and others' lives. For instance, after the main interview, they developed more interest in the research process. They were willing to participate in future projects that may promote their social inclusion and spiritual integration not only within the church but also in a wider society. By incorporating the seven participants in the research process and allowing them to share their stories, they were able to provide information that can help to advance changes desired in the church.

Sixth, frequent unscheduled breaks were provided for participants during the preparation meetings, and before and after the interview for self-care purposes.

Focus of Issues Investigated in the study: Having worked closely with AWDs from variety of backgrounds in Baptist congregations in Nigeria for more than two decades, prompted the idea of investigating the importance this group attach to their spirituality and how the church has been responding to the spiritual needs in their lives. Issues examined with the research participants in this study included, the level and depth of faith, the experiences of spirituality within and outside the church, the recognition and acceptance by the church, the feeling of being loved, cared for, supported, and connected, the feeling of belonging, and identifying challenges to meeting spiritual needs.

Research Questions and a Sub-Question

The main research questions that drive the entire investigation are:

- 1) What is the importance of spirituality in the lives of AWDs?
- 2) What are various spiritual experiences of AWDs in the church that need to be understood and respected?
- 3) To what extent do AWDs feel their spiritual needs are being met in their congregational lives, and what would AWDs like to see happen?

The secondary question is: Given the reality of spirituality in the lives of AWDs, how may the understanding of the way AWDs express their spirituality impact the pastoral care ministry practices of the church? These are important questions because they provide some guides to engage the participants on how they express and experience their spirituality and how the church validates or fail to affirm this expression, and what can the church do to meet the spiritual needs of this population in their congregations.

Outline of my study: My dissertation unfolds in seven chapters, followed by a brief conclusion. In chapter One, I look at the historical context of disabled people in the church and society broadly and developmental disabilities more specifically. Furthermore, I consider the evolution of disability movements that has changed disability narratives in the last decades, given rise to medical and social models. This background is followed by the reimagining of disability theology in contemporary Christian community referred to as theological model of disability, examining the works

by Judith Heumann, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*, Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability*, and Samuel Kabue, “Disabled people in Church and Society: A Historical and Sociological Perspective,” in *Disability, Society, and Theology, Voices from Africa*, which have revealed studies on various aspects of disability. Chapter Two then looks at both positive and negative spiritual experiences of AWDs in faith communities in Nigerian cultures. This chapter includes examining the role of spirituality in the lives of AWDs, how the religious practices of AWDs need to be understood and respected, and how the church can nurture the expression of their spirituality, and its implications for Pastoral ministry practices. In chapter Three, I review the literature, looking at disability and spirituality through the lens of contemporary theologians who are disability advocates, and whose works provide a gateway for theological praxis for persons with developmental disabilities in the church and society, particularly their connections to other people and to the community. This part also examined: A Theology of deep access by Thomas Reynolds *Invoking Deep Access: Disability beyond Inclusion in the Church*, A theology of Friendship by Hans S. Reinders *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics*, and A theology of Inclusion by John Swinton *From Inclusion to Belonging: A Practical Theology of Community, Disability, and Humanness*. A reflection of the interface between access, friendship, inclusion, and belonging is considered. Chapter Four reflects learning of new perspectives about friendship and belonging, and how AWDs need no bodily adjustments to belong but are welcome as friends as they are. This chapter also takes up the theology of inclusion and belonging by Swinton and theology of prophetic

belonging by Reynolds; that promote the values of people with disabilities among others and equal participation for all, that God is always interested in those with radically different bodies as friends, which represents the core example of relationship within the church. Chapter Five outlines the methodology. This part of my research focuses on the specific methodology that is used in this research study. It indicates and discusses the reasons for choosing CBPR approach and why it is ideal for my project. Following this, is a description of how my data is gathered and analyzed. Chapter Six is the findings. In this chapter, the themes emerging from the research interview questions and the corresponding responses derived from the analysis of the data collected are described and discussed. The seventh chapter contains the discussion of my findings. This section explores the dialogue of the results that have emerged from the research analysis with the theological and non-theological literature. The last chapter is the conclusion and implications. In this chapter, I undertake some theological and practical reflection on my dissertation, looking at the difference this study will be making in terms of my contribution to Pastoral care ministry, and to my own spiritual development and ministry practice. The conclusion considers the implications for pastoral care practice, making a case for the obvious gap in the disability literature and ministry practice with regards to AWDs, their spirituality, and the need to promote their friendship and belonging in the faith communities. The conclusion and the implication chapter demonstrates how my study can contribute to a reconstruction of Christian theology and religious practices towards AWDs in the church and society.

The next section of this dissertation presents the historical contexts of disabled people in the church and society.

Chapter 1

The Historical Context of Disabled People In The Church and Society

Throughout history, the conceptualizations and treatment of disabilities vary considerably and are quite complex. Marini notes that historically, on one hand, people with disabilities have often been treated with reverence and dignity, and on the other hand, the treatment and attitude toward people with disabilities have been significantly impacted by societal biases, uncertainty, and lack of knowledge regarding disability.²⁹

The next section of this chapter looks at the early perspectives and treatment of disability and various historical contexts of disability.

Early Perspectives and Treatment of Disability

In this work, I look at the concept of disability broadly and developmental disability more specifically. Since 1980s, both Western and African countries have witnessed the emergence of literature in disability history in what is today described as disability studies.³⁰ But prior to this period, the historical contexts of disability lack textual materials. Gaventa admits that the historical resource about disability in the early

²⁹ Irmo Marini, "The History of Treatment Toward People with Disabilities," in *Psychosocial Aspects of Disability, 2nd Edition, Insider Perspectives and Strategies for Counsellors* by Marini Irmo, Graf Noreen M., and Millington Michael, (Springer publishing company: New York, 2017), <https://connect.springerpub.com/content/book/978-0-8261-8063-6/part/part01/chapter/ch01> DOI: 10.1891/9780826180636.

³⁰ Geethu Vijayan, "Disability Studies: A Path Breaking Approach in Literature," in *The Creative Launcher*, Perception Publishing, India, Vol. 5, no. 6, 2021, 16. <https://doi.org/10.53032/TCL.2021.5.6.03>

80s are rare.³¹ However, Philip Ferguson and Emily Nusbaum opine that even though the historical accounts of disability were very scarce yet “there were isolated examples of individual researchers or even entire programs that helped create the foundations of this radically different approach to the study of both the concepts and the experiences of disability.”³² Nonetheless, Kabue points out that for a large part of human history disability was conceived by the society as a liability, and by the early church as a divine retribution from God.³³

Deborah Beth Creamer, a minister, theologian, and a disabled person, in her work, *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*, offers a concise description of the history of the conception of disabilities. In Creamer’s view, disability in the past and perhaps in the present is inevitably connected not only to the ways and degree to which disabled people are perceived and treated, but also the understanding the society has about disability. She argues that “the object of disability studies is most accurately not the person using the wheelchair but rather the sets of social, historical, economic, and cultural processes that regulate and control the way we think about and through the body.”³⁴

³¹ William C. Gaventa, *Disability and Spirituality: Recovering Wholeness* (Texas: Baylor University Press, 2018), 14.

³² Philip M. Ferguson and Emily Nusbaum, “Disability Studies: What Is It and What difference Does It Make?” In *Research and Practice for Persons with Severe Disabilities*, Vol 37, No 2, 2012, 70-80, 71.

³³ Kabue, 8-13.

³⁴ Deborah Beth Creamer, “Disability and Christian Theology: Embodied Limits and Constructive Possibilities,” (Oxford: Oxford University Press, 2008), 16.

During pre-modern times, disabled people were considered invisible in the community.³⁵ This is probably because they were often being treated shamefully by those who were accepted by the society based on the societal beliefs and values about their physical, mental, and physiological body. Most families of disabled people kept them at home for fear of being stigmatized and harassed by the ableist society.

Meanwhile, Victor Berel Finkelstein, a disability right activist and writer, and a pioneer of social model explores disability in the medieval Western capitalist society. He argues that prior to the European industrial revolution, disability was accepted as part of human society.³⁶ But as Western industrial society evolved, the idea of disability shifted from disability participation to disability exclusion because of the way the society was designed; a work-based system that disqualified people with impairments from employment.³⁷ Finkelstein outlines the history of disability in three phases. Phase one is the medieval period with inclusion of people with disability in the main economic activities. Phase two is the age of industrialisation that excluded people with disability because of occupational requirement. Phase three is the transition of people with disabilities to socialism, a system that both medieval period and the age of industrialisation embraces and promotes, which is the idea of social justice, liberation, independence, and equality for all.³⁸

³⁵ Jane Krafft, *The Ministry to Disabled people* (Minnesota: The Liturgical Press, 1988), 17.

³⁶ Victor Berel Finkelstein, *Attitudes and Disabled People: Issues of Discussion*. World Rehabilitation Fund, International Exchange of Information in Rehabilitation, 1980, 6-8. <http://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-attitudes.pdf>

³⁷ Ibid., 6-7.

³⁸ Ibid., 8.

Irina Metzler, a classical and medieval historian, in her historical account of disability from the 5th to the late 15th centuries, explains that the European society conceive disability from neither the health and wellness (medical) or the social standpoint, but rather a position in-between.³⁹ What Metzler means is that disability in Europe was considered as a sickness or disease, a static human condition that requires management by the social institutions instead of society's attempt to understand the lived experiences of people with disabilities. In Metzler's view, this conceptualisation of disability provided the lens through which legal, religious, educational and all other institutions view and treat disabled people up to today.⁴⁰

Until later in the nineteenth century, the idea of disability was scarce from intellectual endeavour. It really did not surface until the concept of "normal" became a subject of academic discourse, one that "examines the meaning, nature and consequences of disability and its effect in the context of social, ethical, political and cultural factors."⁴¹ The conception of developmental disability emerged in the 19th century through a renowned psychiatrist from France named Jean-Etienne Dominique Esquirol.⁴² According to the Minnesota Council on Developmental Disabilities (MCDD), Esquirol categorizes developmental disability into two groups: idiocy and

³⁹ Irina Metzler, "A Social History of Disability in the Middle Ages: Cultural Considerations of Physical Impairment," in Routledge Studies in cultural History Early Twentieth-Century Medical Historians (New York: Routledge, 2013) 5.

<http://web.b.ebscohost.com/ehost/ebookviewer/ebook/bmxlYmtfXzU0NzE4N19fQU41?sid=93c2d06a-23e9-4433-8844-1f6b631d4fee@pdc-v-sessmgr04&vid=3&format=EB&rid=1>

⁴⁰ Metzler, 6.

⁴¹ Vijayan, "Disability Studies: A Path Breaking Approach in Literature," 16.

⁴² The Minnesota Governor's Council on Developmental Disabilities, *Parallel in time: A history of developmental disabilities*, 2021, 2. <https://mn.gov/mnddc/parallels/four/4a/2.html>

imbecility. He refers to idiocy as a term that is used for persons with deficiencies in intellectual functioning. In Esquirol's words, such individuals with intellectual limitations are "incapable of attention, idiots cannot control their senses. They hear, but do not understand; they see, but do not regard. Having no ideas, and thinking not, they have nothing to desire; therefore, have no need of signs, nor of speech."⁴³ But for imbecility, Esquirol notes that individuals are "generally well formed, and their organization is nearly normal. They enjoy the use of the intellectual and affective faculties, but in less degree than the perfect man, and they can be developed only to a certain extent."⁴⁴

The Minnesota Council on Development Disabilities states that these categories of individuals with disabilities were treated with ignominy:

Bound with galling chains, bowed beneath fetters and heavy iron balls, attached to drag-chains, lacerated with ropes, scourged with rods, and terrified beneath storms of profane execrations and cruel blows; now subject to jibes, and scorn, and torturing tricks, now abandoned to the most loathsome necessities or subject to the vilest and most outrageous violations.⁴⁵

By the middle of the 19th century, the tide began to turn for persons with developmental disabilities as many disability reformers began to emerge. Among these reformers was a well-known socialist, Dorothy Dix, who advocated for a better treatment for persons with developmental disabilities, many of whom were living in

⁴³ Ibid., 2.

⁴⁴ Ibid., 2.

⁴⁵ Ibid., 3.

deplorable conditions.⁴⁶ By the late 19th century, the Council states, people began to be much more aware of persons with developmental disabilities.

The Evolution of Disability Movements That Has Changed Disability Narratives In The Last Decades, Given Rise to Medical and Social Models

The reconstruction of disability movements that has shaped disability narratives has been mixed. For much of its history, many aspects of disability models have evolved, which reflect both the Western and African perceptions, beliefs, and experiences. The evolution of these disability movements started with the medical model of disability. This model emerged primarily because of the notion that disability is situated within the individuals.⁴⁷ The theory behind medical model is that disability is the problem of the individual and not the society. The problem was seen as the result of sickness, impairment, or some other health condition, that needed medical care in the form of cure or rehabilitation.

Jason Reimer Greig in his work *Reconsidering Intellectual Disability, L'Arche, Medical Ethics, and Christian Friendship* provides us with a good example of some applications and the implications of the medical model of persons with intellectual and developmental disabilities. Greig, in his book, offers his readers an explorative inquiry into the case of a six-year old Ashley X with profound developmental disabilities.

Ashley X according to Greig requires some therapy, as chosen by her parents, in order

⁴⁶ Ibid., 3.

⁴⁷ Cynthia Lewiecki-Wilson, Disability and Diversity: A Sociological Perspective (review),” *Journal of Literary and Cultural Disability Studies* 5, 2, 2011: 223.

to stop her physical growth because “Ashley’s embodiment includes profound intellectual and physical impairments, along with the continual use of a wheelchair.”⁴⁸

Greig argues that the medical model of disability subjects people like Ashley to ready made labels, rendering them passive recipients of treatment, since they are deemed inadequate and incomplete. He invites medical practitioners and the general public to rethink the use of a medicalized approach as a way to improve the quality of life for persons with intellectual and developmental disabilities. Further, Greig shows that Ashley’s case challenges parents, guardians and other caregivers to tread with caution in decisions to promote greater social participation for their children or clients with severe disabilities without recourse to or consideration of the moral implications their choice(s) could have on the rights of these individuals “to grow into their vocation as truly human persons.”⁴⁹

According to Greig, the decision of Ashley’s parents to carry out medical treatment for their daughter in order to mitigate against the risk of Ashley’s future health complications and possible social exclusion may look justifiable. However, in Greig’s view, the moral questions of “principles, procedures, and permissions”⁵⁰ still inform a much broader discourse on what kinds of ideals, character, and code of conduct a community must possess to support everyone to have the good life and flourish. Greig, therefore, suggests that for disability to be understood by the church and

⁴⁸ Jason Reimer Greig, *Reconsidering Intellectual Disability, L’arche. Medical Ethics, and Christian Friendship*, (Washington: Georgetown University Press, 2015), p. 3.

⁴⁹ Greig., p. 3.

⁵⁰ Greig., p. 2.

society as an experience, there is need for them to look beyond the medical solutions which inhibit disabled people, and consider how these vulnerable individuals can be recognised as friends, which might not only promote them “to ethical significance but also creates the possibility of seeing them as potential teachers and moral exemplars.”⁵¹

Another bad example of a medical model of disability is the descriptive anthropology research by Robert B. Edgerton. Walter R. Gove reflects deeply on the study carried out by Edgerton on individuals with intellectual disability who were hospitalized for a decade at Pacific Hospital, and whose support came through the hospital. According to Gove, these individuals experienced institutionalisation. In his review work of Edgerton *The Cloak of Competence: Stigma in the lives of the Mentally Retarded*, Gove explains that even though the recipients (48 intellectually disabled persons) of treatment at Pacific Hospital for Rehabilitation blended well into the community, yet their experiences did not result in the formation of community relationships that provided a foundation for their independence because of the institutional therapeutic treatment regularly received from their benefactors, “these benefactors assisted in the management of daily affairs and/or crises (which the retardates frequently precipitate) and helped the subjects passed as normal.”⁵² Gove submits that Edgerton’s work not only reveals the failure of the medical intervention of the selected group of intellectually disabled persons but challenges the health care

⁵¹ Ibid., 5.

⁵² Walter R. Gove. Book review: The cloak of competence: stigma in the lives of the mentally retarded. *American Journal of Sociology*, 78(3), 1972, 2.

practitioners to explore an ethical (generous , compassionate, and loving care) and inclusive approach that serve disabled people best interest.⁵³

In my opinion, Greig and Gove's work, one, prioritizes the voice, autonomy, choice, and inclusiveness of persons with intellectual and developmental disabilities. Two, their work also provide researchers with the possibility of reforming and rebranding the medical model that presents vulnerable institutionalized persons as limited and abnormal. These two authors are seeing beyond the boundaries of disability as a medical model.

Following the medical model is the social model. The social model became apparent because the medical model was considered deficient. The contention against the medical model was that it sees disability as the problem of the individual, one that requires medical check and treatments or therapy to function in the best possible way. Greig claims that the foundation of the medical model “ is inherently connected to a person's impairment...their inability to perform certain activities... restricts human functioning, and thus operates as a disabling aspect of their embodiment.”⁵⁴

Many of those who support the social model of disability agree that it mainly focuses on circumstances that hinders persons with disability from full participation in society, such as society's disabling conditions, the environment , and perhaps negative attitudes. According to Chris Shilling, human bodies are perceived as incomplete which are reconstructed through social conditions.⁵⁵ The implication of Shilling's argument is

⁵³ Gove., 3.

⁵⁴ Greig, *Reconsidering Intellectual Disability*.,59.

⁵⁵ Chris Shilling, “The Body as a Project,” in *Sociology Themes and Perspectives* (7th ed) by Micheal Haralambos, (London Harper Collins Publications Limited, 2008), 308.

that the society is responsible for how disabled people feel and think of themselves and how others perceive them. However, Finkelstein writes that disability is a direct result of the development of western industrial society.⁵⁶ He argues that prior to urbanization and industrialisation people with disabilities were not alienated from the society.⁵⁷ He maintains that with the development of industrialisation, people with impairments were offered opportunities to work based on their abilities and skills set. But soon afterwards, according to Finkelstein, industrialization began to create a series of accidents that left some industrial workers injured and occasionally disabled, and disabled people became seen as economic risk because employers would have to pay compensation to injured workers.⁵⁸ Hence, without the right and permission to work, disabled persons became unemployed, seen as abnormal and this situation led to their increasing marginalization and segregation. For Finkelstein, it requires medical care and rehabilitation for them to be fit enough for them to re-enter society and become employable.⁵⁹

In Shilling and Finkelstein's view, the implications of social model thinking is that (1) the social model is liberating, meaning it provides opportunities for AWDs to have their voices heard (2) it is subjective, that is, it creates some sort of human freedom that allows people with disabilities to identify their needs and push against any oppressive structures, and (3) it is more hopeful and enlightened because we can alter social structures and attitudes.

⁵⁶ Finkelstein, *Attitudes and Disabled People*, 6-8

⁵⁷ Ibid, 7.

⁵⁸ Ibid, 8.

⁵⁹ Ibid, 8.

Moreover, the arguments Shilling and Finkelstein have made in support of social model of disability did not go without some criticism. For instance, Finkelstein's description of the accounts of disability has been faulted for its exaggeration. Kabue notes that Finkelstein's analysis has been criticized for being over-optimistic. It is over-simplistic in that it assumes a simple relationship between the mode of production and perceptions of disability. It is too optimistic in its assumption that technological development and professional involvement will integrate disabled people back into society.⁶⁰

It is apparent that the evolution of disability movements that have influenced the paradigm shifts from the medical model of disability to the social model of disability still leaves some room for continuing discourse. In furtherance to this journey, moral questions of relationship and friendship began to emerge. How can a community find the good life for its members? Can the church welcome people with disabilities as potential friends? Is there any possibility of disabled people becoming functional and an integral part of the Christian community? This moral thinking leads us to re-examine the disability theology in contemporary Christian community.

The Reimagining of Disability Theology in Contemporary Christian Community referred to as Theological Model of Disability

The emergence of the theological model of disability is the move by contemporary disability theologians and scholars to take back their voices and stories from those various researchers and scholars who are proponents of the social and

⁶⁰ Kabue, 11.

medical models of disability. This is the result of the disability population feeling subservient to these models. For example, works by Judith Heumann, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*, Nancy Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability*, and Samuel Kabue, “Disabled people in Church and Society: A Historical and Sociological Perspective,” in *Disability, Society, and Theology, Voices from Africa*.” have revealed various aspects of disability championing the voices and perspectives of those with disabilities themselves. For example, Heumann expresses the possibility of self empowerment of disabled people whereby they form a formidable force and are united together to exercise their rights and creative capacity.⁶¹

Through various challenges with medical and social models of disability, it became apparent that the emergence of a new model was necessary, hence the theological model of disability. The theological model is the recent disability movement, which began to emerge in the early twentieth century specifically among the disability theologians. Proponents of the theological model of disability include John Swinton, Nancy Eiesland , and Sharon Betcher. The focus of this model of disability is that it views disability from a scriptural lens and Christian ethical praxis.⁶² Notwithstanding, the model has its own flaws. For instance, the theological model emphasizes self-advocacy which potentially excludes those persons with profound disabilities because of their apparent need for dependence on others for their daily

⁶¹ Judith Heumann, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist* , (Boston: Beacon Press, 2020) p. 3

⁶²Greig, *Reconsidering Intellectual Disability*., 94-95.

routine intensive physical and medical care.⁶³ In chapter three and four of this dissertation, I give much more attention to the views and new perspectives of the disability theologians regarding the theological model of disability, with emphasis on friendship and belonging with a comparative view of theology of inclusion and belonging by Swinton and theology of prophetic belonging by Reynolds.

Certainly, from the examination of Kabue, Creamer, Metzler, and Edgerton's studies, disability history has found its path from objectified representations of the body by the social anthropologists and medical professionals to the way in which people with disability have recently begun to reclaim their lives, history, and experiences, not only in the society but also in the church. There are a few points to note in their various studies: 1) Different disability models have shaped the way people think about disabled people, for instance, the medical, social, and theological models. 2) Disability history has revealed the realities and experiences of people with disabilities either in the past or present, and 3) Whether the experiences of inclusion of disabled people in the church are real or not, there is still a gap in the way the church understands how this population expresses and experiences their spirituality, and the meaning of spirituality to them. William C. Gaventa affirms, "there have not been many research studies about how young people and adults with intellectual and developmental disabilities describe the role of spirituality and faith in their own lives."⁶⁴ Hence, my study explores how understanding the spiritual views of AWDs may change the way pastoral care is provided to enable them to realize their purpose and meaning in life.

⁶³ Ibid., 96.

⁶⁴ Gaventa., 76.

Therefore, in the next chapter I will be looking at various experiences of AWDs who are already incorporating themselves, making use of their abilities and creative capacities, and accepting their roles and responsibilities in faith communities in Nigeria. I will also be looking at some AWDs who are still facing marginalization regarding how they express and experience their spirituality, their personhood and membership in their various religious communities, and the implications of these diverse experiences for pastoral care ministry practices.

Chapter 2

Various Experiences of Adults with Disabilities

The reality of various experiences of AWDs with the church is probably the reason why Christian theologians and other scholars in disability studies have recently begun to invest in new areas and perspectives about the lived experiences of AWDs, with the aim of their full inclusion in the church and wider community. This section of my research dissertation looks at various experiences of AWDs in the church, and the implications for pastoral ministry practices. I have further explored these new experiences of the AWDs in my main research.

Nature of Experiences of AWDs

Understanding spiritual experiences in the lives of AWDs matters. Spirituality is important to millions of individuals across all cultures. It can be difficult to generalize about how AWDs perceive spirituality in their lives because human beings are different in our experiences, and the intersection between nature and nurture in every individual leads to the amazing diversity that we see all around us. However, there are certain common traits and behaviors in AWDs that have their roots in their experiences.⁶⁵ While some AWDs consider spirituality to

⁶⁵ DongDong Zhang and Frank R. Rusch, "The Role of Spirituality in Living with Disabilities," *Journal of Religion, Disability & Health* 9, No. 1 (October 2008): 83-85, https://doi.org/10.1300/J095v09n01_06

be an important component of their healing experiences,⁶⁶ others perceive it as unpleasant, or even confusing, traumatic, and related to great suffering.⁶⁷ Pretorius acknowledges that spiritual experience is not the same for everyone: “for some [spiritual experience] means a mere fabrication of the mind. For others it is pathological and the consequence of psychiatric disturbances and psychological disorders.”⁶⁸

For instance, in Nigeria, Barrister Ayodele Adekanmbi’s story is remarkable. In his stories, I see how his resilience, church connections and family support were vital sources of acceptance, empowerment, meaning making, and self-worth for him.⁶⁹ Adekanmi, a totally blind disability activist and a prominent Nigerian lawyer, who serves in the Oyo State Government as a Special Adviser to the Oyo State Governor on Disability Matters, shares his personal story at a Disability Awareness and Inclusion Conference (DAIC 2022) held at the Conference centre, University of Ibadan. He points out that his church is a place where he feels welcomed and adequately supported. He explains that his experience may be different from others in the church with a disability but comments that AWDs participation in the church and their contributions to economic and social development of the society in Nigeria is still lacking. He

⁶⁶ Bilge Nuran Aydogdu, “Disability and Spirituality,” *Spiritual Psychology and Counseling* 4 No.2 (June 2019): 184-186, <https://doi.org/10.12738/spc.2019.4.2.0072>

⁶⁷ Aydogdu, 188.

⁶⁸ S. P. Pretorius, “Understanding Spiritual Experience in Christian Spirituality” *Acta Theologica Supplementum* 11 (1), 2014, 1.

⁶⁹ Heidi Jenz, “The Things I’ve learned,” *The Bridge, Learning Together* 57, no. 1 (Spring 2016, 3-7), accessed April 4, 2021, http://www.taylor-edu.ca/taylor/pdf/Bridge_2016Spring.pdf

urges the church to model a friendly and inclusive community where people with disabilities can make their own choices without any intimidation, influence decision making process that impact their lives, determine the services they receive, and ultimately become contributing members of the society.⁷⁰

Also, in 2013 during one of our church annual Baptist Conferences in Nigeria, I met a young lady (Esther, not a real name) with a mild autism disorder. During our conversation, she shared that her dominant need was a relief from emotional pain and anxieties. She said she could not make sense out of the world around her, but she acknowledged her pain, and chose her faith through prayer with a church support system (counselors and therapists) to deal with her fears and worries. During our discussion, I observed that her faith was unwavering. She was focused. Her ability to engage her faith in the most powerful circumstances provides a remarkable example of how AWDs use their inner strength, grace, friendship, and the power of their personal choice to accept their disability and adjust to life with disability.⁷¹ These two individuals, Adekanmbi and Esther, see themselves as part of the Body of Christ to which they have something meaningful to contribute.

However, there are a few difficulties that some AWDs experience in their congregations. For instance, Chinonyerem C. Ekebuisi, the Director, Board for Theological Education Methodist Church, Nigeria, is one of the disabled women

⁷⁰ Disability Empowerment Foundation, *Disability Awareness and Inclusion Conference* (DAIC 2022) held at the Conference Centre, University of Ibadan on Thursday, July 21, 2022.

⁷¹ A discussion with and observation of a Baptist member with Autism at Ibadan during 2013 annual Baptist Conference.

ministers who have experienced internalized oppression by the Christian community. She notes that many of the most hostile attitudes and the opposition of many disabled Nigerian women who have the conviction of God's call to join in the ministry of their churches come from the church congregations and the leadership.⁷² Ekebuisi points out that the church still places more emphasis on oppressive physical and social structures and cultural attitudes, rather than acknowledging that AWDs are indwelt by the Holy Spirit and focusing on how best to utilize their spiritual gifts for the enrichment of the Christian community.⁷³ This is the key focus of my study, exploring the possibilities of including the voices of people with disabilities in Baptist congregation in Nigeria.

I close my argument in this section with Gerald Ugo Nwabuisi's perception of future hope for people with disability in Nigeria. Nwabuisi, a Nigerian theologian, argues that one could find very little respite in the struggle for disabled persons' empowerment in Nigeria.⁷⁴ In Nwabuisi's view, the implications of uncertainty that still exists about how AWDs are being treated in their congregations in Nigeria are (1) that disability is perceived as a consequence of sin or perhaps a mysterious act of God, (2) that church theological praxis does not see AWDs as participating members of the Body of Christ, who have rights to express their spirituality and their gifts in it, and (3) that the inbuilt church environment that is inaccessible to church members, who are

⁷² Chinonyerem Ekebuisi, "Persons with Disability and the Worship Life of the Church." in *Perspectives on Disability: A Resource for Theological and Religious Studies in Africa*, ed. Samuel Kabue et al., Ibadan: Baptist Press. 2016, 14.

⁷³ Ekebuisi, 41.

⁷⁴ Gerald Ugo Nwabuisi, "Disability and Nigeria Church: Bridging the gap between Orthodoxy and Orthopraxis," *Trinitarian: International Journal of Arts and Humanities*, Vol. 1, No 1 (2021), 2. https://disability_and_Nigeria_Church_file:///C:/Users/User/Downloads/1693-2363-1-PB.pdf

wheelchair users, is a sign of unwelcoming gesture by the church.⁷⁵ Nwabuisi's work suggests that disabled people need the church to be not just an object of their integration but also a subject encouraging their inclusion and participation.

In my view Ekebuisi and Nwabuisi's stories are testaments to the stereotypes of exclusion, neglect, and marginalisation that AWDs experience within the Christian community and a wider society. Often, the programs and practices of the church do not really represent the hopes and aspirations of the disability theologians for inclusion of this disability population.

This leads us to the next section which looks at disability and spirituality from the lens of contemporary theologians.

⁷⁵ Nwabuisi, "Disability and Nigeria Church," 8-10.

Chapter 3

Review of Theologies of Friendship and Inclusion

This chapter of my paper looks at (1) disability and spirituality in general and (2) disability and spirituality from the perspectives of contemporary theologians who are disability advocates, and whose work provides an approach for practical theology for AWDs in the church and the wider community.

Spirituality and Disability

Questions about disability and spirituality were part of the Christian community of the early church. Nancy Eiesland points out that historically, the Christian treatment of persons impacted with disabilities has been “that disability denotes an unusual relationship with God and that the person with disabilities is either divinely blessed or damned.”⁷⁶ Eiesland offers a reflection of Christian thought and practices that have suppressed disabled people through the ages. Eiesland, through her theology of liberation, invites other theologians to bring to the fore disability discourses associated with human bodies that can possibly transform human experience in the way they view God’s image in themselves and others.⁷⁷

⁷⁶ Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 70-71.

⁷⁷ Eiesland, 111.

Erik Carter, in his reflection on the place and prominence of spirituality and religious expression in the congregational lives of AWDs, ascertains that there is considerable progress made in promoting the social and spiritual inclusion of AWDs. Yet, it is not clear whether much has been accomplished with regards to the full integration and participation of this marginalized group in church life.⁷⁸

Disability affects our day-to-day lives. My experience with my cousin with cerebral palsy, with whom I lived for several years, is still fresh in my memory. I had the opportunity to help care for him. His parents inspired me to love better because of their hearts attitude to care for and serve their son. The reality of various experiences in working with People with Disabilities (PWDs) is probably the reason why Christian theologians and other scholars in disability studies have recently begun to invest in new theologizing and theorizing about disability, with the aim of full inclusion of people with disabilities in the church and wider community.

In discussing historical context of disability narratives within the religious communities, Swinton argues that the beginning of any theological conversation on disability is to acknowledge that people with disabilities experience rejection, marginalization, and alienation from the church ministries.⁷⁹ Swinton agrees that there is a common conception among disability scholars that the church culture

⁷⁸ Erik W. Carter, "Supporting Inclusion and Flourishing in the Religious and Spiritual Lives of People With Intellectual and Developmental Disabilities," *INCLUSION*, Vol. 1, No 1, 2013, 64-66.

⁷⁹ John Swinton, "Who is the God We Worship? Theologies of Disability; Challenges and New Possibilities," *International Journal of Practical Theology* 14, no.2 (February 2011): 274, https://www.researchgate.net/publication/270014936_Who_is_the_God_We_Worship_Theologies_of_Disability_Challenges_and_New_Possibilities

over the centuries needs to disconnect from a medical model of disability that deprives people with disabilities.

Certainly, from Eiesland, Carter, and Swinton, the journey towards the welcoming and integration of individuals with disabilities in the Christian community and the wider society has been a long haul.

Today, important contributions to the area of disability theology are emerging. Theological and anthropological reflections in the theology of liberation as represented by Eiesland, a Christian theology of friendship as explicated by Reinders, a practical theology of disability from inclusion to belonging in the work of Swinton, and the pneumatological reflection by Yong, all indicate how society can be transformed through the Church when love, friendship, and fellowship (Christian doctrines of ecclesiology) are understood from a disability perspective.

In terms of the recent work in the area of disability and theology, I note the influence of Eiesland's *The Disabled God*. Through examining the doctrines of Christology, the imago dei in relation to disability, Eiesland's work on self-representation, subjectivity, and autonomy has taken on new significance in understanding people with disabilities and their spirituality. Her work reveals that individuals with disabilities have rights to express their spirituality and assume their roles as contributing members within their congregations.

I also note, through the work of Reinders, *Receiving the Gifts of Friendship*, that our humanity does not come from our intrinsic value but the realization that we are objects of God's love. God, through His divine love, has

bequeathed to us graciously in Christ Jesus ability to exercise our human rights despite our different cognitive experiences. As Reinders articulates this gift of God that emerges in relationships, he suggests that the inclusion of persons with profound intellectual disabilities in the church is not so much about their access to rights and privileges, but much more their commitments to relationships that evolve from mutuality and friendship.⁸⁰ What Reinders' idea of friendship suggests as I relate it to AWDs is that their disability does not limit or diminish their ability for open and mutual relationships. In other words, they need not do anything to their body to make them acceptable and loved by God and the people. This human philosophy applies to all human beings.

However, in Swinton's work *Inclusion and Belonging*⁸¹, I see a wholistic pastoral care approach that represents the voice, the autonomy, and the full inclusion and participation of people with disabilities in the Christian community. This wholistic approach illustrates how human beings are relational in the way we are created: to love and to be loved, to give and to receive the gift of friendship. Human beings are relational beings, which means we cannot do without one another. Swinton mentions that this relational dimension of human beings has its foundation in a moral virtue (love), bestowed to each person, that allows us to open ourselves to realities and experiences in the world as well as values that we hold about ourselves, others, and God.⁸² I think this is what spirituality is all

⁸⁰ Reinders, 161 & 162.

⁸¹ Swinton, "Who is the God We Worship?"

⁸² Swinton., 15-17.

about: the connectedness with ourselves, with others, and with the Divine. This was part of the experiences of the AWDs during the pilot project: their feeling of being welcomed and connected to the church members and their pastor, and their expression of their relationship with God.

In *Theology of Down Syndrome*, Yong's understanding of humanity as created in the image of God is worth examining. Drawing from the recent narratives of people with disabilities, Yong brings to a theological discourse the need to review the traditional approaches to the doctrines of creation, providence, and of sin, in the wake of recent experiences of people with disabilities.⁸³ He points out that early Christian tradition gave particular importance to sovereignty of God over all things in all its variations and peculiarity including human beings.⁸⁴ Yong argues that if God is all transcendent and at the same time immanent, and is involved in the variation and peculiarity of human creation, then "God is also responsible for...[and] in control of disability."⁸⁵ However, one question that remains unresolved in Yong's view of traditional Christian theology and dogma is the equation of sin to disability, the idea which is still generating a lot of controversies among contemporary theologians.⁸⁶ However, Yong submits that "what is needed is reformulation of the doctrines of sin and the Fall that can provide a more plausible and coherent account for the experience of disability in

⁸³ Ibid., 157.

⁸⁴ Ibid., 158.

⁸⁵ Ibid., 162.

⁸⁶ Ibid., 162 & 163.

our time.”⁸⁷ This is an instance of the man born blind in the Scriptures (John 9: 1-3), a situation in which Jesus attests to God’s immanence in disability. Yong, in his overarching pneumatological perspective, provides us with a dynamic dimension to his theologising in which every person with or without disability is seen to be in a transformative process and also the theological underpinning that under God’s sovereignty all disabilities are part of His plan. In other words, human beings can be transformed in their faith journey regardless of human limitations and boundaries. I believe the notion of AWDs, being God’s image, shows that no two of God’s creatures are alike, yet all show forth His glory and the splendour of His work.

This next section proceeds with looking at disability and spirituality from the lens of contemporary theologians : a theology of Deep Access by Thomas E. Reynolds *Invoking Deep Access*, a theology of Friendship by Hans S. Reinders’s *Receiving the Gift of Friendship*, and a theology of Inclusion and Belonging by John Swinton’s *From Inclusion to Belonging*.

Disability and Spirituality from the Lens of Contemporary Theologians

Invoking Deep Access

The impact of Reynolds’ work *Invoking Deep Access* in theological discourse and in the advancement of inclusive communities, cannot be ignored or undervalued. Reynolds espouses a theology of hospitality with mutuality, an

⁸⁷ Ibid., 164.

ideology that focuses on sharing love with one another and bearing witness to God's unconditional love with one another in the most dramatic and dynamic ways, leading to a more meaningful and life giving connection that ultimately becomes a vehicle through which belonging is genuinely practiced. In his theology of deep access, Reynolds provides a renewed focus on the inclusion and integration of disabled people into full worship life of the church. Reynolds' work is a reflection of how the church has treated disabled people in regard to meeting their spiritual needs in relation to other needs they may have. He challenges the understanding of the church with respect to how it cares for and welcomes people whom society regards as deficient, inadequate, and irrelevant. For instance, in his work on *Prophetic Belonging*, Reynolds brings 1 Corinthians 12; Ephesians 2: 14-15 and Romans 12:4-5, and Romans 12:4-5 to support his argument on our being one body though different members, and suggests to the church, a biblical tradition of hospitality that emphasizes on life sharing with one another "...where all members might give and receive gifts, a place where everyone's participation is assumed as given. All belong. Full stop...."⁸⁸ In his work, Reynolds not only confronted the charitable gestures of the church towards people who are impacted with disabilities, but also invited the church to see the marginalized group within the congregation as part of human society that need to be seen, heard, respected, and supported. Reynolds' work generates a thinking that can possibly move the Christian community from barring and ignoring the presence, potentials, and active participation of vulnerable individuals within their congregations to a truly

⁸⁸ Thomas Reynolds, "Prophetic Belonging.." In *Spiritus*, 52—53.

inclusive church where everyone experiences an open and mutual relationship and friendship , whereby all persons share their gifts and accept each other in collaboration, cooperation and support for one another.

But what does the practice of deep access and receiving gifts with mutual vulnerability mean for the church? The understanding that people have about the church accessibility and mutual vulnerability varies considerably. Kevin Timpe, the founder and president of 22 Advocacy, in his work *Disability and Inclusive Communities*, writes that the church ought to be a place where people are dependent on God and one another, a place where everyone is welcome, celebrated, experience love, and enable others to love and be loved.⁸⁹ For Timpe, the practice of inclusivity and vulnerability of persons in the church is a mutually transformative friendship that is not only peculiar to those with disabilities but available and accessible to all and sundry. Similarly, Samuel Kabue, a visually impaired theologian and member of the UN Committee of Experts on the Rights of Disabled people shares his thought about accessibility and mutual participation of all members. He argues that church accessibility to disabled people is unsatisfactory. He posits that

Fully accesible churches should have programmes for intellectually impaired, some sign language interpreters for the deaf, sitting that can permit wheelchair users to sit with their families and should also assign Sunday readings to blind readers who can read Braille and are willing to do so as a way of encouraging participation.⁹⁰

⁸⁹ Kevin Timpe, *Disability and Inclusive Communities* (GrandRapids: Calvin Press, 2018) p 104 & 105

⁹⁰ Samuel Kabue, “Disabled people in Church and Society: A Historical and Sociological Perspective,” in *Disability, Society , and Theology, Voices from Africa*, eds Samuel Kabue, Esther Mombo, Joseph Galgalo, and C.B. Peter, (Kenya: Zapf Chancery Press, 2011), 15.

For Reynolds, deep access and mutual vulnerability means recognising human uniqueness and limitations, and integrating these virtues and gifts of AWDs in the continuing and everyday life and activity of the churches and congregations. It is not just one event, or activity that happens once, but a way of being and living that just naturally includes people in each and every aspect of church life.

In considering the three responses above, one can see a pattern forming about the AWDs accessibility to the church. Reynolds, Timpe, Kabue all seem to be saying that the Christian community of friendship must go beyond societal norms to accept and welcome everyone as distinctive parts of the larger body of Christ.

Providing deep access and exchanging of mutual vulnerability between the disabled and non-disabled within the church community, as pointed out by Reynolds, Timpe, and Kabue, implies including emotional needs as well. Jean Vanier, a Christian theologian and philosopher, looks at this new dimension of needs from an wholistic approach. Vanier claims that his openheartedness for mutual friendship with AWDs enables him not only to see their giftedness but also their pain, suffering and vulnerability.⁹¹ Vanier's version of spiritual thinking calls us to examine the emotional experiences that individuals with disabilities are going through and how providing spiritual care can make a valuable difference in their lives. Stanley Hauerwas in his book *Suffering Presence* argues that pain and suffering is not peculiar to people with disabilities, it is an inevitable part of life. He states, "we are never quite what we should

⁹¹ Jean Vanier, *Becoming Human* (New York: Paulist Press, 1998), 85.

be until we recognize the necessity and inevitability of suffering in our lives.”⁹²

Hauerwas also highlights the dangers of assuming people with disabilities are suffering based upon normalcy and non-disabled people’s experiences. He urges the church not to see the sufferings and the inabilities of disabled people in their midst as issues to be dealt with, but opportunities for them and the church to encounter God in a new way.⁹³

However, I believe there is an authentic and transformative experience when the theologians reflect more deeply on the place of AWDs in the church and the society, how their gifts might be explored, and their pain and suffering responded to in the most positive way within these environments. I also think that Church can be a place where everyone is valued, where all persons, including the disabled persons, can come to know and have a real, personal and unique experience with God or the Divine, engage meaningfully with members in a spiritual atmosphere of warmth, love, and acceptance. This leads us to examining the theology of friendship as explicated by Hans S. Reinders.

Receiving the Gifts of Friendship

Hans S. Reinders’s work *Receiving the Gifts of Friendship* focuses on intellectual disability. He discovers the value and dignity of humankind in the life and love of God, and in his gift of friendship to all of us through Jesus. Reinders’s theological argument lies in unconditional friendship and fellowship of God with all humanity irrespective of our ability or inability. Reinders argues that our human value emanates first from our ability to receive, rather than our ability to

168. ⁹² Stanley Hauerwas, *Suffering Presence*. (Notre Dame, Indiana: University of Notre Dame, 1986),

⁹³ Hauerwas, 176.

give. As I look at friendship with God as described by Reinders, I begin to question what type of friendship exists in churches and pastoral ministry practices, and how has this type of friendship impacted the way the church treats others including people with disabilities?

While Reinders is cognizant of human variations in our abilities to be friends and to have friends, he emphasizes the need for all humanity to conceive friendship as equality with others “as God’s creatures who share in his economy of salvation,”⁹⁴ knowing that our nature of friendship comes from God’s gift to us. I think what Reinders is probably suggesting is that there is the possibility of reciprocity in authentic friendship with people with profound disabilities even with their supposed limited ability for such relationship. In other words, if we conceive friendship as equality with others as God’s creatures who share in his economy of salvation, then we can also say that we all belong. So friendship with God and belonging are two aspects of being church. I connect this type of friendship with Jesus’s idea of friendship with his own disciples in which he no longer regards his disciples as slaves, but as friends.⁹⁵ Jesus’s invitation for friendship is not limited to just mutual relationships but also provides recipients of this friendship a sense of belonging. Looking at friendship with God through Jesus’s friendship model and Reinders’s ideology of friendship through dedication

⁹⁴ Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids: William B. Eerdmans, 2008), 283.

⁹⁵ John 15:15.

to mutual relationship and fellowship shows that we need many more gifts of friendship to receive from particularly people with profound disabilities.

Reinders's anthropological idea of human significance principally rests not on anything human beings might do to justify God's love for all humanity, but rather the unconditional friendship love of God.⁹⁶ I think what Reinders means here is that the self-giving nature of God is independent of whether we act or respond or make any attempt to approach him. What this means for the church and pastors in our relationship with God and our pastoral care practices with the disabled population in our churches and a wider society is that our responsibility of being God's friend is not a product of what we do or how much we act, but rather begins with how trusting and receptive we are to God. We as church members must pay attention to ways of facilitating that trust and receptivity to God for everyone. Bringing this understanding into our practice of pastoral care ministry with disabled people, we need to regard them as persons and accept them as they are, and not merely as constructs of a medical model of disability.

Many of Reinders's views of friendship connect the theology of friendship with God to the trinitarian relations in which God expresses his perfect love through giving and receiving in communion. Reinders points out that life is a relational gift, not a condition of dependence in relation to others.⁹⁷ According to Reinders, these different individual embodied experiences manifest themselves in the diversity and variety of God's gifts as described by Paul in his illustration of

⁹⁶ Reinders., 212-214.

⁹⁷ Reinders., 238-239.

the Body of Christ: “There are different kinds of gifts, but the same Spirit. There are different kinds of service, but the same Lord. There are different kinds of working, but the same God works all of them in all men.”⁹⁸ According to St. Paul, everyone belongs.

A look at Reinders’s theology of friendship in understanding the humanity and spirituality of people with profound disabilities illustrates, 1) that God’s friendship is consistent regardless of our human condition, 2) that our action or inaction does not alter the divine nature of God’s love for humanity, 3) that our friendship with all people in the world is what makes us stronger and better, and it is in the expression of this friendship that we demonstrate our true spirituality to God and to others.

I think Reinders’s theology of friendship is a call to myself, pastoral caregivers, and to all theologians in disability studies to consider the theology of friendship by focusing on our shared humanity rather than on human differences. His work provides the opportunity to critically reflect on our need to invite people with disabilities for friendship or accept their friendship as they choose us to be friends with them. Is Reinders’ model of friendship with people with disabilities enough to recognise and value them as equal members of the Christian community? In order to be able to make that explicit connection between friendship and belonging, I believe a further examination of friendship in the sense of belonging as discussed by Swinton might need to be explored. In 2000 Swinton wrote a book urging congregations to be more accepting of people with

⁹⁸ 1 Corinthians 12:4-6 (New International Version)

mental health problems called : *Resurrecting the person: Friendship and the care of people with mental health problems*. In 2016 in the context of increasing discussion of the need for policies on Equity, Diversity and Inclusion, Swinton wrote a piece urging further movement from inclusion to belonging in congregations. This leads us to examine Swinton's work *From Inclusion to Belonging* in the next section of this chapter.

From Inclusion to Belonging

In *From Inclusion to Belonging*, Swinton attempts to prescribe a practical theology of belonging. His work invites theologians in disability studies and clergy in pastoral ministry to critically reflect and review how disability is defined and represented in the church and community. He argues that disability inclusion is not just a political ideology, but also a sign of and testament to an authentic Christian community where every member feels a sense of belonging and not just inclusion.⁹⁹ Swinton argues against the politics of disability inclusion and considers it insufficient to describe the term disability.¹⁰⁰ He suggests a fundamental change from politics to love as we transition from inclusion to belonging. Inclusion, in Swinton's view, is to be present and/or to fit into patterns of behaviour or sets of rules within a system. For example, one study that Swinton conducted with Elaine Powrie accounts for variation in inclusion and belonging. Swinton and Powrie find that Kelvin (a man with a profound disability) felt more

⁹⁹ Swinton, "From Inclusion to Belonging," 16.

¹⁰⁰ Ibid., 4.

connected with people outside a local faith community where he felt ignored and insignificant for a period of three months.¹⁰¹ For Swinton, Kelvin was different and not part of the faith community, “was included, but did not belong.”¹⁰² Swinton suggests that inclusion without belonging is not a reflection of Christ church that is shaped by grace and not by appearance.¹⁰³ His view of belonging is better explained in COQUAL’s report on Belonging in Business, which is to feel seen, connected, and supported.¹⁰⁴ I believe this is what AWDs aspire to in their lives as they connect with their faith community, and this is what I investigated further in my research.

I think Swinton is suggesting the fact that inclusion is insufficient to integrate people with intellectual disabilities into the full worship life of the church. He opines that freedom to make choices and decisions is part of belonging and human flourishing in which social and communal relationship is intrinsic.¹⁰⁵

In my view, the idea of inclusion as described by Swinton is not just about the disability language we use, or how accessible my church platform or pulpit is to those with disabilities, but much more. It is about our role as a church in

¹⁰¹ John Swinton and Elaine Powrie, *Why are we here? Understanding the Spiritual Lives of People with learning Disabilities* (London, UK: T&T, 2004), referenced in John Swinton, “From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness,” *Journal of Religion, Disability, and Health* 16, no. 2 (April 2012):175-176, 11.
<https://www.researchgate.net/publication/254374391>

¹⁰² Swinton, 12.

¹⁰³ Ibid., 13.

¹⁰⁴ COQUAL, The Power of Belonging: What it is and why it matters in today’s workplace, Centre for Talent Innovation, Belonging series, Part 1, <https://coqual.org/wp-content/uploads/2020/09/CoqualPowerofBelongingKeyfindings090720.pdf>

¹⁰⁵ Swinton, 5.

helping disability members make sense or meaning of their lives as we walk and minister along side them. But the question is, is inclusion enough for AWDs to belong in the church? This is where Swinton goes further to engage the theologians on the need to transition people with disabilities from *Inclusion to Belonging*. In Swinton's view, people with disabilities should not only be part of the Christian community but must also feel seen for their contribution to the community, connected to other members of the community, feel supported with the community, and be proud of their faith community's values and purpose.

A Reflection on the Interface Between Deep Access, Friendship, and Belonging of AWDs

What does deep access mean for people with disabilities? Are AWDs in the church communities truly and actively involved in their congregational life? What is the meaning of friendship? What is the role of friendships in their involvement? How does friendship with AWDs translate into their belonging and full participation in the church? These are questions that I will be addressing in this reflective section of this dissertation.

Reynolds, speaking from personal experience of caring for a child with disability, challenges the misconception about disability and the treatment of disabled people in faith communities. He suggests that the church should model acceptance and inclusion in a way that is unpatronizing and meaningful.¹⁰⁶ So,

¹⁰⁶ Thomas E Reynolds, "Invoking Deep Access: Disability Beyond Inclusion in the Church," *Dialog: A Journal of Theology*, Vol 51, Number 3, September 2012.
https://www.researchgate.net/publication/263335126_Invoking_Deep_Access_Disability_Beyond_Inclusion_in_the_Church

what does deep access mean for AWDs? According to Reynolds, deep accessibility for AWDs in faith communities means (1) internalising the life and experiences of persons living with disabilities for action (2) eliminating all possible barriers that mitigate against real functioning of disabled people within the congregations, (3) prioritizing the voices and needs of those differently abled with genuine intent and purpose, and (4) paying attention to the designing and deliberate re-designing of church architecture to include accessible entrance, ramps, and rails for wheel chair users and other accessible elements like braille and hearing aids for those with other impariments.¹⁰⁷

This means that people with disabilities have capacity and ability to participate and function like every other Christian in the church, regardless of their disability and vulnerability, if they are provided with space, tools, and safe environment. But I am still not sure Reynolds's theology of deep access and clarion call to the church for a just society represent fully the foundational elements of being in fellowship and spiritual communion, and sharing lives together, especially with those with profound disabilities within the Christian community. As Greig mentions, "the struggle for a just society includes not simply compassionate concerns but also concrete solutions that will enable all people with physical, sensory, and intellectual impairments to participate in society."¹⁰⁸

¹⁰⁷ Reynolds, 2012.

¹⁰⁸ Greig, 105

Certainly, there are key issues worth mentioning here based on my observations and a few conversations with individuals with disabilities and their families in Baptist churches where I attended and, in some cases, served as one of the church leaders. One, apart from the diverse unmet spiritual needs of AWDs, the church has yet to invest in their emotional bank account, meaning building trusting relationship for mutually transformative friendship. Two, some AWDs who are in the church may be welcomed but do not feel accepted and included because nobody seems to understand and respect them for who they are. This deeply ingrained way of thinking about disability and non-chalant attitude towards people with disabilities by the church has deep and grave consequences on the emotional, mental, and physical wellbeing of AWDs and their families in the church. Three, some of the AWDs are disconnected from the church because there is still no authentic conversation and action with respect to their belonging. Others have been ostracised and left the church because they are being traumatized and stigmatised by the name-calling and disability rhetoric that the church members and leaders use against them. Eric Carter's paper refers to a study describing the experience of 12,000 adults with intellectual disability. The report states "that less than half (48%) of these adults reported having attended any type of religious service in the prior month."¹⁰⁹ For me, this report is heart breaking!

AWDs have the right to choose where they want to be, what they want to do, and who they want to be with. I believe promoting their human rights and

¹⁰⁹ Erik W. Carter, "A place of belonging: Research at the intersection of faith and disability," *Review and Expositor* 113 no. 2 (May 2016): 170, <https://DOI:10.1177/0034637316637861>

sense of autonomy can be a way to liberate and include them in the church. We need to invest more time in building and fostering a trusting relationship with them. We need to work alongside them as friends with them, to accept their gifts of friendship, and to understand how they can flourish and be liberated.

What does friendship really mean? The gift of friendship is critical for a Christian community that can only imagine its growing together as a shared giving of one another, in a way that promotes equal participation of everyone which marks the identity of Christian living. While in Nigeria, Esther and her family transferred their membership to our church. When I met Esther, she said she was disabled because of a severe medical condition (polio) during her childhood that left her incapacitated. She said that at the initial stage after her incident everything changed for her. She could not do anything without someone's help, her legs were immobile. Someone had to carry her for her to access places like washroom and other facilities, until she was provided with a wheelchair. She said she learned to train herself to use the wheelchair. She made effort to do things by herself while on the wheelchair. "Being dependent on others for basic day-to-day activities and routine was an emotional trauma for me," Esther said. She felt life was being snuffed out of her as she tried to find her own identity and a place in the world. But she endured and persisted. As she says, "My hope, strength, and peace were trusting in Jesus and asking him to help me."¹¹⁰ Esther is one of the very many vulnerable individuals whose faith in God is

¹¹⁰ A shared experience with AIDDs (Adult with Developmental Disabilities) at Adeoje Baptist Church, Ibadan.

unwavering and whose lives are totally dependent on others not only for personal care and provision but for meaningful and purposeful living .

Within the Interfaith group in Edmonton, Canada to which I belong, the group that enhances the authentic inclusion of AWDs in faith communities, a middle-aged man (Thomas not a real name) with an Attention Deficit Hyperactivity Disorder (ADHD) shared his personal story with the group in one of our monthly meeting sessions. He mentioned how he uses praying, listening to sermons, and quoting Bible passages whenever he experiences sensory overload that leaves him anxious, restless and uncomfortable. He said the love and communion he gets from the members of his congregations, coupled with his spiritual beliefs and practices provide him meaning and bring him to a place of calmness when navigating through complex disability situations.¹¹¹

I give another example in this case to indicate how friendship with AWDs can translate into their inclusion and belonging . In my current place of worship and service, a local Baptist church in Edmonton, I have a family with AWDs with whom I have been friends since I joined the church in 2015. Timothy (not a real name), the young man, has intellectual disability, but he could do absolutely anything. His parents have been incredibly supportive to him, along with the church community support in terms of prayer, visitation, and fellowship. The young man plays drums, a musical instrument, for the church every Sunday and he sees himself contributing to the Body of Christ in which he and his family are members. He has shared his feelings of sense of worth with me in one of a few

¹¹¹ A shared experience with ADHD (Attention Deficit Hyperactive Disorder) at Interfaith Group in Edmonton.

conversations we have had, that he loves what he does for the church because he derives joy and satisfaction in the service. He told me that he finds attending church, interacting with friends, brothers and sisters in Christ and serving God extremely helpful in dealing with his situation and he feels highly esteemed about it. His parents share with me how they are providing support for him for his transition into an independent life in the coming months.¹¹² Friendship and fellowship have great value because they are our rights. They are also human choices that we make in our daily lives. Reinders states that:

People with disabilities have claimed the right – either for themselves, or others have claimed it on their behalf – to speak for themselves rather than being talked about. They have claimed the right to make their own decisions about their own lives. They have also claimed the right to be treated as citizens with the same rights and opportunities that other citizens enjoy.¹¹³

There is a great lesson people like Esther , Thomas, and Timothy could teach those of us who are abled bodied Christians through friendship, that as church members who do not make ourselves Christ followers but rather we are formed through our relationships with others in the Body.

Friendship and belonging informed my entire research work. This is important because both friendship and belonging are fundamental elements of human flourishing. In the next chapter, I will be taking a deeper look at the perspectives offered on friendship, inclusion, and belonging in the theology of inclusion and belonging by Swinton and the theology of prophetic belonging by

¹¹² A shared experience of family with AIDDs (Adult with Developmental Disabilities) at McLaurin Memorial Baptist Church, Edmonton, Canada.

¹¹³ Reinders., 4.

Reynolds. Their work promotes the values of people with disabilities among others and equal participation for all, that God is always interested in those with radically different bodies as friends, which represents the core example of relationship within the church.

Chapter 4

A Deeper Look at the Concept of Belonging

This chapter reflects a deeper look into perspectives on belonging as presented in the theology of inclusion and belonging by Swinton, and the theology of prophetic belonging by Reynolds; (1) that see friendship and fellowship with AWDs beyond just inclusion, (2) that promote the values of people with disabilities among others and equal participation for all, (3) that sees God's love being present with all people, which represents the core example of relationship within the church. Both theologies speak to the shared humanity and common heritage that Christians embody because of the Incarnation (the divine becoming flesh and living among us).¹¹⁴ This type of friendship and belonging reflects Jesus command to receive and share love with others in John 13:34-35, "love one another as I have loved you" and the aspirations and dreams of people with disabilities in the church, that God befriends us and in turn invites us to live in friendship with one another regardless of our human differences.

In this section of my dissertation, I will be exploring (1) what imagining belonging looks like for the church and (2) how the church can practice belonging, from the works of Swinton *From Inclusion to Belonging* and Thomas Reynolds *Prophetic Belonging*.

¹¹⁴ Thomas E. Reynolds, "Prophetic Belonging: Disability, Hospitality, and Being Church Together," *Spiritus: A Journal of Christian Spirituality*, Volume 23, Number 1, Spring 2023, pp. 51-65; John Swinton, "From Inclusion to Belonging: A Practical Theology of Community, Disability, and Humanness," *Journal of Religion, Disability, and Health* 16, no. 2 (April 2012):185-6, <https://www.researchgate.net/publication/254374391>

For Swinton, the starting point for this initiative of belonging is for the church to see the uniqueness in everyone as God sees us, an understanding of sameness and oneness that permeates the entire writing of Jean Vanier's spiritual and philosophical anthropology. Swinton, borrowing from the Vanier's theological insight, argues that "we belong to the same species and share in a common humanity,... held together in all our disparateness...as we share and receive the gifts that we bring to one another that we become one body: a place where we know that we belong."¹¹⁵ Swinton suggests locating our thinking on belonging within God's creation, a reference to Genesis 1:31, which says, "God saw all that he had made, and it was very good," where human beings are not just mere random selection (included) in creation, but are rather significant part (co-creators) within creation.¹¹⁶ I believe the Christian doctrine of creation as accounted for in Genesis 1: 26-27, which says, "God created man in his own image, in the image of God he created him." supports Swinton's notion that human beings are uniquely created. What this means is that this image and likeness of God, as Swinton put it, is reflective in how we look, think, relate, and function as human beings, which is probably different from what can be found in other creatures of God. In other words, we can be seen in each other, belong to one another, and treat each other with dignity, honour, and respect. Paul reiterates this profound insight in his gospel message to the Corinthians as he envisions the church as the body of Christ: "And the parts that we think are less honorable we treat with special honor. And the parts that are unpresentable are treated with special modesty, while our presentable parts need no

¹¹⁵ Swinton, "From Inclusion to Belonging...", 183.

¹¹⁶ Ibid., 183.

special treatment. But God has put the body together, giving greater honor to the parts that lacked it.”¹¹⁷ Swinton echoes Vanier’s thought that “To be included, you just need to be present. To belong, you need to be missed.”¹¹⁸ Looking through people in this way would mean appreciating their worth, value, their gifts and giftedness.

In *Prophetic Belonging*, Reynolds attempts to envision for the church on how imagining belonging might be cultivated as a relational practice. According to Reynolds, “when someone belongs, they are welcomed, noticed, accounted for, heard, seen, accepted, supported, befriended, and valued as a contributor.”¹¹⁹ He claims that thinking about belonging starts with the need to reexamine ourselves, that is, to “explore how divided lines are constructed according to assumptions.”¹²⁰ I think Reynolds’ thought aligns with Paul’s instructions, where Paul charged Christians to watch themselves (to be careful), especially those who seemingly do not see themselves in others, that if they think they are something when they are nothing, they are only deceiving themselves. Paul says, “...But watch yourself, or you may also be tempted. Carry each other’s burdens and in this way you will fulfil the law of Christ. If anyone thinks they are something when they are not, they deceive themselves. Each one should test their own actions...”¹²¹

In fact, Reynolds uses the word ‘provocation’ to describe the extent to which the church should respond to and deal with the issue of, for example, disability assumptions

¹¹⁷ I Cor 12: 23-24, New International Version.

¹¹⁸ Ibid., 179-90.

¹¹⁹ Reynolds., 4.

¹²⁰ Reynolds., 8.

¹²¹ Galatians 6: 1-4, New International Version

that are inimical to our true identity, values, and characters as the body of Christ.

According to Reynolds,

For these provocations can serve as a prophetic call to reexamine how the “we imaginary” functions—how our own communities have been coopted into restrictive imaginaries that build barriers between people and create inequity, preventing and undermining belonging. So a prophetic belonging is one that names, denounces, and resists what distorts belonging. More, it marks a community’s openness to self-examination and critique, confession and repentance.

I believe the provocation Reynolds is referring to in his work *Prophetic Belonging* is not one that steers in us negative emotions, but rather a clarion call, an inspiration, to act for ways to include those who are abandoned and neglected, even those whom society deems the lowest and unworthy, the type that Jesus exhibits towards the Samaritan woman by the well in Samaria. (John 4). According to Reynolds, until there is a radical movement for social reform that is grounded in sincere gestures of shared biblical hospitality, an authentic sense of belonging cannot occur.

So, how can the church practice belonging? For church to practice genuine belonging, Swinton says (1) we must look to Jesus and learn from Him, and (2) we must find community in Jesus. Swinton offers a practice that Jesus prescribes for the church to “love one another as I have loved you.”¹²² Swinton is of the opinion that loving one another is never a product of human imagination, initiative or rationality, but rather the work of the Holy Spirit that is experienced and expressed within the community that Jesus Himself embodies.¹²³ Swinton also points the church to Paul’s irresistible notion of belonging that inspite of our different ethnic nationality, gender, or background, we

¹²² John 15:12, New International Version.

¹²³ Swinton., 184.

still belong to one another and that is where belonging is: “There is neither Jew nor Gentile, neither slave nor free, nor is there male and female, for you are all one in Christ.”¹²⁴ According to Swinton, it is only by seeing the church as people of Christ (Christians) can we begin to understand the idea of belonging. In order for belonging to happen, Swinton argues that the church must be willing to know one another through Jesus.¹²⁵ I think what Swinton is suggesting for true belonging is that the description and qualification of the church that we present as the body of Christ must denote the special, close relationship and communion that exist between Christ and the church. To Swinton this is finding community in Jesus: it is in looking to Jesus and learning to look at one another can we truly find what it means to belong.¹²⁶

Reynolds takes a slightly different twist from Swinton’s worldview on how the church can practice and proceed with belonging. He suggests hospitality that is mutually beneficial to one another: hospitality with and not for.¹²⁷ To Reynolds this type of hospitality is characterized by God’s loving welcome that prioritizes care and love for others, and where “the love of God and neighbour joins.”¹²⁸ I am wondering if Reynolds’ idea of hospitality can be located in Matthew 25: 34- 36 where God’s love is practically demonstrated with others, especially those in the household of faith. Jesus said to his disciples:

Then the King will say to those on his right, ...For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a

¹²⁴ Galatians 3:18, New International Version.

¹²⁵ Swinton., 184.

¹²⁶ Ibid., 186.

¹²⁷ Reynolds., 9.

¹²⁸ Ibid., 9.

stranger and you invited me in, I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me.¹²⁹

In this, hospitality is a practice that Jesus offers to the church to embrace and embody with and for one another. One can see the echoes of the theme of mutual relationship, companionship, and being present in Jesus's exhortation to His disciples. Reynolds notes in Mathew 25:40 that Jesus identifies with the weak and destitute, those in need, as well as others who have nothing to give, such that by receiving them, one receives him.¹³⁰ The attentiveness that comes through the sharing of life together speaks to the centrality of our ecclesiology and moral obligation to one another. I agree with Reynolds that as a church we must learn to embody mutuality through our love for and commitment to one another.

Further to this, Reynolds also invites the church to take a leap of faith to explore all the possibilities of expansive relational connection in their creative response by being vulnerable "open to the messiness of concrete embodied situations that bring the unexpected and surprising, and with it, possibility of failure...to be a learner, to repent, to begin again, and perhaps heal together."¹³¹ Reynolds, viewing the church authentic belonging through the metaphor of dance, concludes his prophetic transformation with an appeal to the church to endeavour to create space and place where everyone can share their vulnerability through dance where, "bodies open to and moving with one another, creating artistic and grace-full time and space together."¹³² I think Reynolds

¹²⁹ Mathew 25: 34-36, New International Version.

¹³⁰ Reynolds., 60.

¹³¹ Ibid., 62.

¹³² Ibid., 63.

suggestion can be quite enriching and spiritually transformative because everyone longs for a spiritual expression, experience, and healing, and the fulfilment of this longing can possibly occur in an atmosphere of oneness in mind, spirit, and body leading to a “dramatic, dynamic, a dialogical encounter between the triune God of the Bible and His people.”¹³³

Overall, I believe that Swinton and Reynolds have provided us with the tools to remodel and reshape our moral and theological thinking for genuine belonging and complete participation of individuals with disabilities in the church’s worship life. This new type of disability theological model captures the idea that AIDDs are human beings (persons) as much as anyone else, an expression of the love and grace of God, and fellow members of the Body of Christ with rights to a mutually beneficial relationship that is hospitable not only to disabled people but also to all persons.

¹³³ Paul Davidson, *Come Let Us Worship* (Ibadan: Baptist Press nig. Ltd), 2002), 2.

Chapter 5

Methodology and Methods

The research methodology for my study is a qualitative approach that utilizes Community Based Participatory Research (CBPR) to understand how AWDs relate to their spirituality and what the pastors and the church can learn to improve their ministries to meet the spiritual needs of AWDs. People with intellectual and developmental disabilities have often been excluded and marginalized within societies.¹³⁴ The whole essence of my CBPR approach is to include the perspective of vulnerable persons (AWDs) and help them have their voices heard for the first time in Nigeria.

There are a few disability studies that have reported the links between spirituality and people with disabilities in Nigeria. Example includes Helen O. Esan's study on the *Impact of African Worldviews on Ministry with Persons with Disability*." The research uses descriptive survey research method to collect information from Baptist Pastors in Ogbomoso, Nigeria, on how they view their ministry towards Disabled people (PWDs). The findings show little or no effect of African worldview on their ministries towards the disability population. However, the research project was not inclusive because the method employed by the researcher only involve the Baptist Pastors' perceptions and

¹³⁴ Chinonyerem Ekebuisi, "Persons with Disability and the Worship Life of the Church," In *Perspectives on Disability A Resource For Theological and Religious Studies in Africa*, eds Samuel Kabue, Helen Ishola-Esan, and Isaac Deji Ayegboyin, (Ibadan: Baptist Press Nig. Ltd, 2016), 41-43.

not those who lived the experiences of unmet spiritual needs.¹³⁵ Olayinka Akande and Adebayo Olorunlana, in their work, *Christianity and Disability in Post-Colonial South-Western Nigeria*, use an ethnography survey and literature to examine the interface of disability and Christianity in the Southwestern Nigeria. The survey was conducted among Christian religious leaders from various denominations and the findings show exclusion of disabled people in the way they are being treated by the Christian community. However, the research does not really represent the voices of the disability population for their inclusion.¹³⁶ Also, Nwabuisi's work, *Disability and Nigerian Church: Bridging the gap between Orthodoxy and Orthopraxis*, demonstrates that Christian theology in the Nigerian church is in sharp contrast with ethical Christian practices in relation to what an authentic and inclusive Christian community should look like.¹³⁷ In my view, none of these disability scholars were able to explore research with AWDs as participants, and how they describe the role of spirituality in their lives.

This is advocacy research meant to further their interests. The benefits of this CBPR approach include: One, within disability literature, CBPR seems to be the best approach because its framework facilitates the full inclusion of the individuals with disabilities throughout the entire research process. Two, my choice of CBPR allows

¹³⁵ Helen Olomu Ishola-Esan, "Impact of the Remnants of African Worldviews on Perception of Pastors Towards Ministering to Disabled people in Nigeria," *Journal of Disability & Religion*, 20:1-2, (2016), 103-118, DOI:[10.1080/23312521.2016.1152940](https://doi.org/10.1080/23312521.2016.1152940)

¹³⁶ Olayinka Akanle and Adetayo Olorunlana, Christianity and Disability in Post- Colonial South-Western Nigeria, *Journal of Environment and Culture* 11 Number 2, (March 2014), 30-44, https://www.researchgate.net/publication/315715577_Christianity_and_Disability_in_Post-Colonial_South-western_Nigeria

¹³⁷ Gerald Ugo Nwabuisi, "Disability and Nigeria Church: Bridging the gap between Orthodoxy and Orthopraxis," *Trinitarian: International Journal of Arts and Humanities*, Vol. 1, No 1 (2021) https://disability_and_Nigeria_Church_file:///C:/Users/User/Downloads/1693-2363-1-PB.pdf

knowledge to be shared between myself and these individuals and create a greater awareness in the church community for reflection and action. Up until recently, the offering of spiritual reflection (interviewing of AWDs and sharing personal and family stories) on the importance of spirituality by researchers during research with disabled people has been limited. Liu et al agree that “spirituality among people with developmental disabilities has long been a neglected area of research.”¹³⁸ Carter and Boehm also maintain that “the place of faith in the lives of youth with intellectual and developmental disabilities (IDD), however is much less clear.”¹³⁹ However, Kovach opines that there is a strong bonding and sharing of knowledge between the researcher and the when they reflect on and share their stories with one another.¹⁴⁰

Looking at spirituality within the background of research, Leslie Gardner, in her paper titled, *Towards a Spirituality of Research*, puts spirituality of research in context of spiritual experience with reflections on the perceptions of researchers and their relationships with other research partners and within their research paradigm. Leslie provides us with a vivid description of what it feels like for a researcher to have his/her own authentic spiritually reflective experiences when conducting research. The four key values and actions that make research spiritual, as Leslie mentions, include: caring, creative, connected, and committed, which according to her are almost identical with

¹³⁸ Eleanor X. Liu et al., “In Their Own Words: The Place of Faith in the Lives of Young People With Autism and Intellectual Disability,” *Intellectual and Developmental Disability*, 52 (5): 401. <http://dx.doi.org/10.1352/1934-9556-52.5.388>.

¹³⁹ Erik W. Carter and Thomas L. Boehm, “Religious and Spiritual Expressions of Young People with Intellectual and Developmental Disabilities,” In *Research and Practice for Persons with Severe Disabilities*, 2019, Vol. 44(1), 37-52.

¹⁴⁰ Margaret Kovach, “Conversational method in Indigenous research,” *First People, Family and Child Review*, 5 (1), 2010, 40-48.

the views of Sophia S Park and Suzanne Mayer as they discuss a Franciscan approach to theological/spiritual reflection.¹⁴¹ Gardner's contribution to spirituality is valid because it calls for researchers to own their spiritual experience and use it as tools to navigate the nuances and challenges that come with doing research.

I agree with Liu et al, Carter and Boehm, Kovach, and Gardner. From my personal experience during the Pilot Project, setting a pace for sharing personal stories and finding connection with participants during research process can be a positive way to engender openness and cooperation. To foster collaboration with the research participants, I first had a pre-meeting discussion via Zoom with them to assure them of my support throughout the entire research process. This discussion included sharing my own personal stories of caring for and supporting my cousin with cerebral palsy. The sharing helped in building a trusting relationship with and instilled confidence in the research participants.

Many of those who support this perspective agree that CBPR prioritises the voice and the experiences of people with disabilities. Greenwood et al. agree by claiming that CBPR not only involves those who are being researched but increase the knowledge and understanding of the situation being studied, creates mutual dialogue, and incorporates this with interventions and change in practices and policy to improve the quality of life for the people being studied.¹⁴² The next section of this chapter takes a look at the reason for my choice of CBPR.

¹⁴¹ Leslie Gardner, *Towards a Spirituality of Research*, A paper presentation at St. Stephen's College, Edmonton on July 13, 2022, 1-9.

¹⁴² M. Greenwood et al., *Hear my voice: old age and disability are not a curse. A community-based participatory study gathering the lived experiences of disabled people and older people in Tanzania*, 2016. Accessed July 9, 2020. <http://www.sightsavers.org/voices-of-the-marginalised/>

Choice of Community Based Participatory Research Approach (CBPR)

I have considered the use of CBPR approach to carry out this main project. My choice of CBPR requires the active engagement and meaningful participation of AWDs throughout the research process. Conversations about developing participatory research approaches for interviewing persons with intellectual and developmental disabilities have begun to emerge. For instance, Jarg Bergold and Stefan Thomas point out that there has been an increased interest in participatory research approaches in recent times.¹⁴³ They write that there had been challenges in getting responses from the marginalised population, the “willingness on the part of the research partners from the life-world under study to enter into the research process, and the necessary knowledge and ability to participate productively.”¹⁴⁴ They mention the difficulties that were being experienced in interviewing the less responsive individuals, however, they opined that this group were gradually being approached by the researchers for their full involvement and participation in research.

Similarly, Saron Kindon, Rachel Pain, and Mike Kesby in their work *Connecting people, participation, and place*, describe the role participatory approach can play in the lives of the marginalised. They mention that the approach does not only provide the opportunity for community representation, but also reflects a fair and just

¹⁴³ Jarg Bergold and Stefan Thomas, “Participatory Research Methods: A Methodological Approach in Motion.” In *Historical Social Research*, (37) 4:191-222, 2012, 2.
<http://dx.doi.org/10.2307/41756482>.

¹⁴⁴ Bergold and Thomas, 12.

process for both researcher and participants contributing and learning together.¹⁴⁵ One of the reasons for using CBPR is that it embraces ethical principles of mutual respect, equality, and collective responsibility. These principles align with my research focus which is to empower and include AWDs in my study to enable them to share their lived experiences and offer their perspectives.

Moreover, Danley and Ellison note that because of the essential skills and knowledge that are necessary for effective participatory research, learning is required.¹⁴⁶ To prepare me for this type of research, one, I took a course *Inquiry, Evaluation and The Search for Knowledge* in 2015 at St. Stephen's college, Edmonton, where I learned about the significance of the qualitative method to research inquiry of which little is known. I undertook a research methodology course to better my understanding of the qualitative (Community Based Participatory Research) methods. Through my knowledge of CBPR, I was able to complete both my Pilot and Main projects respectively. I was able to plan, prepare for, and conduct participatory research with AWDs within the two selected Baptist denominations of the Nigerian Baptist Convention, and provided evidence and knowledge of how spirituality has been impacting AWDs within the Baptist congregations in Nigeria.

Between September 2022 and November 2022, after receiving the approval of the University of Alberta Health Research Ethics Review Board, I carried out a pilot project in the two selected Baptist denominational churches. The pilot project aimed (1)

¹⁴⁵ Rachel Pain, Sara Kindon, and Mike Kesby, "Participatory Action Research: Making a Difference to Theory, Practice, and Action," In *Participatory Action Research Approaches and Methods Connecting People, Participation and Place*, (New York, NY: Routledge, 2007), 29-30. <https://doi.org/10.4324/9780203933671>

¹⁴⁶ Karen Sue Danley and Marsha Langer Ellison, *A Handbook for Participatory Action Researchers*. (Boston: Boston University Center for Psychiatric Rehabilitation, 1999), 2.

to initiate the process of engaging the research participants in the research project, (2) to determine whether the pilot project can result in some modifications of research activities before the main study begins, and (3) to test the chosen methodology and the adequacy for answering the research questions by using a mini version of the main project to identify areas of opportunity and challenge. The learnings from the completed pilot project were very useful for implementing the main study.

For instance, the completed pilot project 1) revealed the shortfalls in the inability to get enough data regarding the participants' family background of church accessibility and participation due to limited number of participants. To this end, in my main research proposal, I did a few things: (1) I expanded the number of my participants, through the guidance and suggestions of my supervisor, to seven to provide more materials. 2) I showed that more knowledge (data) about the participants could be generated through story telling. Further to this, during the main research interview, participants were asked to share their personal and family stories of how they felt close to God. In fact, the data gathered from the story telling provided more information of how-to better support AWDs and affirm their capabilities within which they express their spirituality within and outside the church congregations. 3) I provided an opportunity not only to involve the in the research, but also to understand their new experiences both to conduct interview and to be interviewed.

Nina Wallerstein and Bonnie Duran, in their paper, "The theoretical, historical, and practice roots of CBPR," capture many of the principles of high-quality Community Based Participatory research. They begin with *participation* being one of the core principles in doing CBPR, with some critical questions on what, who, for whom, and to

what extent the people are participating.¹⁴⁷ Wallerstein and Duran are quick to point out that the issue of participation in participatory action research has an antecedent and has been a transformative journey between the academic researchers and the (community members). However, they argue that despite the CBPR's tradition that requires genuine and active participation between researchers and the community members, the practicality of this relationship remains a complex one.¹⁴⁸ This leads us to looking at the participants that constitute the main project.

Main Project Research Partners and Research Participants

The study included three research partners and seven research participants. This research involved participation by two groups of people. The first group, called “research partners” consisted of the Baptist Church Conference leader and the two pastors of the two Baptist congregations. One of the pastors chose to be the research assistant for this project. This group supported my access to research participants and will be important in the dissemination and implementation of the recommendations resulting from the study.

The two pastors helped to recruit the second group, called “research participants” which comprised seven individuals ranging in age between 20 and 55, with mild to moderate intellectual and developmental disabilities, who then worked closely with me to design and carry out the research. The research participants were also chosen based

¹⁴⁷ Wallerstein and Duran, “The Theoretical, Historical, and Practice Roots of CBPR,” In *Community-Based Participatory Research for Health*, (January 2008), 29-30. <https://researchgate.net/publication/306452424>

¹⁴⁸ Wallerstein and Duran, 30.

on their ability to communicate, their capacity to self-consent, and their ability to articulate a preference to participate in a church activity.

The research partners were chosen through a letter of invitation by the researcher via telephone and email (See Appendix C). The research participants were selected by the two participating pastors in the two congregations and recruited by the researcher through an informal letter and consent form (See Appendix B).

Demography- Participants Characteristics

The research participants' demography includes the age, gender, disability, educational background, and church involvement. The demography table indicates that most of the research participants are male, while one person is a female (see Appendix E). Their disability ranges from physical to visual impairments. About two-thirds of the research participants fall within the age 50-59. The educational background column indicates that all the research participants are well educated. All of them reported that they had attained one educational certificate, diploma, or degree. Table 1 also showed their different roles in the church where they attend.

Meetings

The first group meeting was held with the research partners via Zoom on Sunday, September 10, 2023, during which I reviewed the purpose of the research with them. They all agreed via Zoom to continue with their participation and signed the letter of invitation. They verbally indicated their willingness to play their part in the research

process. They provided their support before and during the study. For example, during the meeting sessions with the research, one of the research partners volunteered to be the research assistant and contacting the research participants throughout the research process.

Once the potential participants were selected and indicated their interest in participating, I then scheduled appointment (a first group meeting) with the participants by Zoom on Monday September 11, 2023. I read and reviewed the Information Letter and Consent Form with them individually. Once they agreed verbally and in writing via Zoom, I then asked the research assistant to give them the Consent Form to sign, which commenced the research. Once participants confirmed their participation in the study, a series of group Zoom meetings with time and date were scheduled.

Data Collection

The meeting began on September 11, 2023. Ten meetings were held via Zoom with the research participants, with each meeting lasting more than one hour. (see Appendix F: The table of the activities and focus of the seven participants of each of the 10 meetings.) Rest breaks were provided as required. During the first meeting of the research participants via Zoom, I reviewed the Information letter, and had the verbal consent and written consent form signed. I also gave introductions and explanation about what possible roles the research participants would like to play, followed by the presentation of the sample guided questions for them to develop. The sample questions addressed the topic of, “spirituality as being connected, spirituality as meaningful relationships and trust, and spirituality as life meaning.” Interaction time did not exceed

1hr – 45 minutes on any of the meeting days because of the numbers of participants involved in the research. I used handwritten notes and journal via Zoom for comments made during the meetings. I audio-recorded information via Zoom during the training section with the research team interviewer and one-on-one interview with the interviewer in a separate room. All the interviews were recorded on Zoom by the researcher and transcribed by the research assistant. All the names in the interview were anonymized on the transcript. To ensure reliability of the transcript, I read the transcript while comparing the written transcript to the audio recording of the Zoom session.

During the meetings, I presented the sample research questions to the participants via Zoom with the presence of the research assistant. Next, I offered facilitation support via Zoom as the participants developed main interview questions from the sample questions provided. The sample questions were presented with props to stimulate discussion and for them to share personal and family stories especially with regards to their family background of church accessibility and participation.

Focusing on just three topics, “spirituality as being connected, spirituality as meaningful relationships and trust, and spirituality as life meaning, the research team suggested some ideas during their discussion time and these points were noted on my handwritten note.

The participants suggested that the guided open-ended questions would be more appropriate if questions on their concerns and displeasure about the church could be added to the interview questions. They proposed two additional questions to the guided questions. The questions were adjusted in line with what the research participants offered, and the research participants went over the list of the interview questions for

any changes they would like to see further. After the questions were completed, a copy each was provided for the seven participants via Zoom through the research assistant. After the meetings, I read from the written copy of what each of the participants had said, and I asked if they would like to make any changes to what they had said. They suggested a few changes, and all agreed that there were no more changes they would like to make.

Final Interview Questions

The following were the final interview questions developed by the seven participants:

- 1. Tell me a story about a time when you felt very close to God. (Where were you? What were you doing? Who was there?). How important are times like that to you?*
- 2. What kinds of things or activities help you feel close to God? How does your church help you to do that? What could your church do to make that feeling even stronger?*
- 3. Tell me a story about a time when you felt that people really cared about you, accepted you for who you are, and wanted to be friends with you. (Where were you? What happened? What were you doing? Who was there?) How important are times like that to you?*
- 4. What kinds of things or activities help you feel cared about and accepted for who you are? How do people at your church help you to feel like that? What do people at church do to be your friend? What makes you feel that they are your friends? (What kinds of things do you do together? Can you share good times with them and laugh together? What kinds of things do they do for you if you are feeling sad? How do they show you they care about you?)*
- 5. Tell me a story about a time when you felt that you really belonged to your church. (What was happening that helped you feel that way? What were you doing? Who was there and what were they doing?) How important are times like that to you?*
- 6. What kinds of things or activities help you feel like you belong at your church? What could people at church do to make that belonging feeling happen even more?*
- 7. How well are people with disabilities accepted in the church? Can you tell me a story of when you felt unaccepted?*

8. Tell me a story about a time when you felt uncomfortable with the church. What happened? Who was there? What did they do? What could your church do to prevent such in the future?

Trained Interviewer

Seven qualitative interviews were conducted. This type of interview is described by John W. Creswell as a purposeful sampling for qualitative data collection by the researcher to enhance the understanding of the phenomenon being studied.¹⁴⁹ Training was provided for one of the participants via Zoom on how to ask research questions, and responses were collected to the interview questions from the trained interviewer via Zoom, which were audio recorded. The other research participants agreed to be interviewed by the trained interviewer. The trained interviewer then asked each research participant the interview questions that emerged from the research team meetings in a private session in which the main researcher was present via Zoom for support if needed.

Each interview took place in a separate room in the high school venue that the participants had chosen. Because of the success of the initial meetings via Zoom, as the interview process went on, I observed via Zoom that each of the seven participants felt more comfortable, interacted very well, and shared their feelings and stories about themselves and their lived experiences in the church. Arskey and Knight are of the opinion that researchers who work with participants before the interview are likely to acquaint themselves with their daily routine and ways in which participants communicate to create a more relaxed, friendly, and welcoming environment for the

¹⁴⁹ John W. Creswell, *Educational Research Planning, Conducting and Evaluating Quantitative and Qualitative Research*, (4th ed.), (Upper Saddle River, New Jersey: Pearson Education, Inc, 2012), 287.

participants during the interview.¹⁵⁰ Because of the open communication, most interviews lasted more than 45 minutes.

The trained interviewer interviewed the research team member about what spirituality meant to them, whether they felt loved, cared for, and connected within their congregations, and the changes they will like to see. After the interviews, the audio files were provided to the volunteer transcriptionist who transcribed from audio to written form which form the raw data transcripts for the project. After I received the transcript from the transcriptionist, I checked the content with the audio to be sure what the participants said was what was transcribed. I read from the written copy (transcript) of what each of the research participants had said, and I asked if they would like to make any changes to what they had said. A few corrections and additions were made, and the transcript was reviewed. This step was carried out privately with each participant by myself.

The interviews were concluded on the 9th of October 2023. The interviews were audio recorded via Zoom, filed, and stored in my computer locked with a passcode to prevent unauthorized access.

Data Analysis

The seven research participants became more interested in the research process. During the analysis, I facilitated via Zoom the research participants examining what was said, grouped under each question to identify the main themes per question, as well as themes that appear across questions. I used the pseudonyms that the participants

¹⁵⁰ Hilary Arskey and Peter T. Knight, *Interviewing for Social Scientists: An Introductory Resources with Examples*, (London: SAGE, 1999).

individually chose at the time of this interview. They all worked with me via Zoom to examine closely what each of them said grouped together in response to each of the interview questions asked. I asked them via Zoom to include relevant sections of the transcript that best illustrate the themes for them and to give these themes names. During the analysis stage, the research participants looked at what they had said in response to each of the interview questions and found some common themes. As they discussed the results and the themes, the research participants generated some recommendations for the congregations to help AWDs express their spirituality, name their spiritual needs, and help them get those needs met within the congregations. These recommendations are included in the conclusion and recommendation session of this dissertation. Also included in this analysis are my own reflections and conclusions drawn from the notes and my research journal, held in dialogue with the literature and recent theological perspectives. The review of the transcription has unveiled these emerging themes: (see Appendix G – Emerging Themes/Participant’s Responses).

The task of analysis in this study is not just for the research participants to find out if the themes presented emerge from their shared narratives or responses to the interview questions, but also to see the possibilities of other themes emerging from other stories and experiences they reported. The findings in my study are hereby presented in the next chapter (chapter six) thematically while stating as much of the participants’ original responses as possible. The findings will be followed by a more detailed discussion section in chapter seven.

CHAPTER 6

Presentation and Discussion of Findings

There are five important themes of the findings which emerge from the research team's analysis of the interview transcript data. These include expressions of being close to God and their importance, importance of spirituality and belonging, feeling welcomed, feeling connected, church supporting belonging. I present the findings in this chapter as thematically organized subheadings.

Expressions of Being Close to God and their Importance

The spiritual expression have often been seen through individual family Christian background and religious community thus a person's spirituality "may consist in giving and receiving love or being part of a caring community."¹⁵¹

When asked: "tell me a story about a time when you felt very close to God...", some of the participants' responses reveal their family and religious background, attachment to community of faith, their strong perceptions about God, and how their relationship with God has been a means of survival and coping strategy for them. The research participants already have a solid foundation in the close relationship they already feel with God. This is something that seems to have been established for them

¹⁵¹ William C Gaventa and David Coulter, *Spirituality and Intellectual Disability: International Perspectives on the Effect of Culture and Religion on Healing Body, Mind, and Soul*, (New York: The Harworth Press, Inc, 2001), 2.

because of experience earlier in life. Liu et al. agree by claiming that “faith and spirituality can have an important place in the lives of people with developmental disabilities.”¹⁵²

I was still in secondary school. I had just finished my A' level program. I attended a church camp meeting around 1985 in Lagos. At the end of the program, there was a salvation altar call. I responded because I was moved to tears by the sermon and the song ministrations. I made a confession of my sins. I was led to Jesus. I felt an inner joy that I cannot describe. Times like that are very important to me. Whenever I go through life occurrences and it appears God is far from me, I remember that God is very close to me, and he will never leave me or forsake me.... (Emily)

I am a Polio victim. In my secondary school days, I was a boarder. In form 5, we just resumed on one fateful day, unknowing to us that a colony of bees had invaded a wardrobe filled with bees. A boy disturbed them and they gushed out in large numbers. Others ran, but because I could not run, I fell down and they stung my whole body. It was a near death experience. My whole body and tongue swelled up badly. I was taken to the sick bay, and I recovered. The experience is unforgettable, and it makes me more grateful to God till date.(Abednego)

I was in school. I went to a school fellowship with a friend. The sermon was on end time. That day, the word touched me, and I made a decision to become a better person and to be more committed to God. Times like this are important. My life was changed. (Ultima)

Emily also reveals that her journey of faith in God was rooted in her background from adolescence when she had a divine encounter with God, and how that spiritual experience has been a reference point for her strength, hope, and source of inspiration. The experience of Abednego was that of gratitude and the feeling of the presence and power of God during his awful near-death situation. He shared that his experience of God's miraculous deliverance was an unforgettable one, a divine encounter that had hitherto drawn him closer to God. Ultima's divine encounter, according to him, has had

¹⁵² Eleanor X. Liu et al., “In Their Own Words: The Place of Faith in the Lives of Young People With Autism and Intellectual Disability,” In *Intellectual and Developmental Disabilities* Vol 52. No 5, 401.

significant effect on how he views life in the now and in the future. He believes his decision to respond to a divine call and the feeling of God's presence has greatly influenced the trajectory of his life. Exploring the significance of religiosity and spirituality in emerging adulthood, Barry et al write that there is a strong connection between the role that family, community, and culture play in the forming, nurturing, and and shaping of spiritual beliefs and practices.¹⁵³

I think there is a great communion that family, church, and community can provide to persons with disabilities that validates their experiences of faith and spiritual journey as they transition from childhood to adulthood.

The question then becomes, how can congregations nourish and enhance this relationships? Certainly, the recent literature on spirituality tends to focus on the issue of relationship. David Tacey, in his work, *The Spirituality Revolution: The Emergence of Contemporary Spirituality*, gives credence to the notion that the intrinsic nature of spirituality is relational, one that connects us to the divine, with significant others, and the nature around us.¹⁵⁴ Greig throw more light on this relational spirituality. He argues that church practices allow Christians to be radically dependent on God and one another, to experience God's gift, as well as partake in the sharing of friendship "and

¹⁵³ Carolyn McNamara Barry, Larry J. Nelson, Sahar Davarya, and Shirene Urry, "Religiosity and Spirituality during the transition to Adulthood," In *International Journal of Behavioural Deveelopment*, 34 (4): 11-324, April 1, 2010.
https://www.researchgate.net/publication/240285664_Religiosity_and_spirituality_during_the_transition_to_adulthood

¹⁵⁴ David Tacey, *The Spirituality Revolution, The Emergence of Contemporary Spirituality*. (Hove and New York: Brunner Routledge, 2000), 20.
<https://philosophiatopics.files.wordpress.com/2018/10/david-tacey-the-spirituality-revolution-the-emergence-of-contemporary-spirituality-2004.pdf>

relay this friendship to the world.”¹⁵⁵ What this means for persons with disabilities is that there are spaces for them within the community of faith for them to discern the love and presence of God, develop their own understanding of spiritual identity, and discover their commitments to their faith community.

Importance of Spirituality and Belonging

As a Pastor, I think understanding my role as a leader and mentor in building meaningful relationship, identifying, and affirming everyone’s gifts and engaging each person in ways that best express their spirituality can help foster a place of belonging not just for AWDs but every member of the congregation.

When asked: “what things or activities help you feel close to God...?”, the research participants shared various activities and experiences inside and outside the church that have provided the basis for the understanding and motion of their spirituality and feeling of belonging. They shared, one, that they were able to find life purpose through friendship. For example, Ultima, Howfred, and Emmanuel shared that just having someone to talk to or take interest in their lives makes them think more about what matters to them, their life purpose and meaning. Two, their unique experiences of the church affirming their spirituality and creating platforms to promote their spirituality through various church activities. Here are their personal stories:

In my current church, I got a letter inviting me to address the men’s fellowship, an arm of the church. I was surprised but I accepted it gladly and I prepared for it. I was also made a Sunday School Teacher which is not commonplace in other climes. (James)

¹⁵⁵ Greig, 172.

I was invited to join the church workforce. I was made a children teacher. It was my pastor that came to challenge me to do this. (Howfred)

I was invited to join the church workforce. I was made a children teacher. It was my Pastor that came to challenge me to do this...(Howfred)

I am given the chance to showcase my talent, in-born potential such as singing and also reading the Bible to the church in braille. I also get to play the musical instrument at times. (Emmanuel)

The need to belong is one that we all share, as Reynolds tells us "...When someone belongs, they are welcomed, noticed, accounted for, heard, seen, accepted, supported, befriended, and valued as a contributor. This goes beyond inclusion, of having a right to be there. In belonging, someone matters and is desired, so that, as John Swinton formulates it, when they're absent, they are missed..."¹⁵⁶ This need may come in different forms and can appear in terms of connection to the larger story of the workings of God within the world. It could be in form of finding oneself as part of a welcoming church congregation. Sometimes, this need for connection could just be a desire to find significance and meaning with community associations, friends, or social organisations that are outside of traditional church space.

All the research participants acknowledge that there are still various needs in their lives, and most importantly their spiritual needs: the desire for more connections, the need to feel more significant within those connections, and the need for inclusion that all share. As Ralph Kunz puts it, "the deepest spiritual need of every person is acceptance as a member of the family of God."¹⁵⁷ This assertion is also supported by

¹⁵⁶ Reynolds, 53.

¹⁵⁷ Ralph Kunz, "You have not forgotten us: Towards a Disability-Accessible Church and Society," In *Journal of Religion Disability and Health* (1) 20-33. 24
<http://dx.doi.org/10.1080/15228967.2011.539335>.

Carter who opines that “within the life of a congregational community, faith is formed, shared, and strengthened; relationship are forged and deepened; and gifts are discovered, developed, and dispensed.”¹⁵⁸ However, Carter observes that unfortunately some persons with disabilities are still left out in their experience ‘to grow spiritually, enjoy community and experience relationships.’¹⁵⁹

For instance, when the research participants were asked how the church does provide spiritual help, and what the church can do to make the feeling of spirituality stronger, they mention: spending more time with them, organising special programs to promote their social inclusion and spiritual integration, and providing resource materials such as braille bibles, Sunday school booklets for them to learn and grow socially, intellectually, and spiritually.

Special church programs [can] help me feel close to God, such as Revivals.
(James)

The church can create more time for me for the Bible study. **(Emmanuel)**

The church can make the Bible readable for blind persons like me. **(Steven)**

*The church should see me as a part of the congregations...The church should empower me to be more effective in church activities.***(Howfred)**

*The church can give me a chance to join the choir.***(Ultima)**

I learned that spiritual wellbeing of the participants were very crucial to them, and the church need a new understanding for a theological reorientation that will attend to this spiritual need of persons with disabilities in the church. The importance of

¹⁵⁸ Erik Carter, *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families and Congregations*, (Baltimore, MD: Paul H. Brookes, 2007) 2.

¹⁵⁹ Ibid, 2.

spirituality and belonging to AWDs cannot be over-emphasized. Harold G. Koenig, in his comprehensive and systematic review on the original data-based quantitative research published in peer review journals on the relationship between spirituality/religion and mental/physical health, suggests that there is positive correlation between spirituality and health and wellbeing. He mentions that most participants in the 454 studies carried out and published between 2000 and 2010 gave positive descriptions of how spirituality/religion have sustained them in dealing with various spiritual, physical, emotional, psychological, and mental illnesses.¹⁶⁰ Also, in the 5-Day 2022 Summer Research Workshop on Spirituality and Health I attended as one of the sponsored participants at the Center for Spirituality, Theology & Health, Duke University Medical Center, Durham, NC, between August 15-19, 2022, I had the privilege of engaging with several worldviews on the meaning and significance of spirituality. My takeaway from the discourse on the definition and meaning of spirituality is that spirituality is a very broad inclusive term and therefore should be used and described by individuals themselves so as to maximize connection, engagement, and conversation. However, the general view was that,

Spirituality is distinguished from its consequences – human values, morals, meaning, purpose, peace, connectedness to others, feelings of awe and wonder- by its link to the transcendent. The transcendent is that which is outside of the self, and yet also within the self- and in Western traditions is called God, Allah, HaShem, or a Higher Power, and in Eastern traditions is called Ultimate Truth or Reality, Vishnu, Krishna, or Buddha. Spirituality is intimately connected to religion, and in fact, lies at its core.¹⁶¹

¹⁶⁰ Harold G. Koenig, “Religion, Spirituality, and Health: The Research and Clinical Implications (Review Article),” In *International Scholarly Research Network ISRN Psychiatry*, Volume 2012, 4.

¹⁶¹The Duke Center for Spirituality, *Summer Research Workshop on Spirituality and Health, Theology and Health*, Duke University medical Center, Durham, NC, 2022, 87.

The Importance of Belonging

Friendship and fellowship are key components of belonging. Lorraine Cuddeback shed some light on why this is true. He points out that friendship goes beyond just empowering individuals with disabilities, but rather it is an integral part of inclusion that focuses on “a shared humanity rather than aspects of human differences.”¹⁶² The theme of “the importance to belonging,” was broadly described and experienced by the participants in their respective congregations as shared during the research interview. Carter provides us with how the church can foster belonging. He said the church can represent a place where “faith is formed, shared, and strengthened; relationships are forged and deepened; and gifts are discovered, developed, and dispensed.”¹⁶³

A pertinent question about belonging was raised with the participants, which is, how important is belonging to them? When asked to share : “about a time when you felt that you really belonged to your church,” the participants shared positive experiences of how the feeling of belonging has shaped their identity (who they are), reaffirmed their feeling of being significant, increased their sense of social acceptance, and boosted their self esteem not only within the church but also within their community, as illustrated in the following excerpts. See below the responses of two participants from the research interview.

¹⁶² Lorraine Cuddeback, *Becoming Friends : Ethics In Friendship and In Doing Theology*,” *Journal of Moral Theology*, Vol.6, Special Issue 2, 158-179, 2017, 159.

¹⁶³ Erik Carter, *Including People with Disabiities in Faith Communities: A Guide for Service Providers, Families and Congregations*, (Baltimore, MD: Paul H. Brookes, 2007) 2.

*To my amazement, I was elected as the President of the Fellowship despite my disabling condition. I was surprised despite my activeness. I was not expecting it at all. This made me believe that these people took me for who I was and actually demonstrated true Christianity. I was not discriminated against. Later, I wore a double cap as I emerged the leader of the Choir too after the former choirmaster left and since I was his assistant then. Times like that are spirit-filled times. They are moments of encouragement, knowing that you are not an inconsequential person.***(James)**

*On December 02, 2006, I went to introduce myself to my in-law to-be in Lagos State. They accepted me despite my disability, and I was very excited. My dad, brother, sister, and a friend of mine were there with me. Whenever I remember that day, I am always happy and thankful to God.***(Steven)**

The choice of friendship and fellowship by God's way is explicated in Paul J Wadell's work *Pondering the Anomaly of God's Love: Ethical Reflections on Access to the Sacraments*. He states that "the crucial fact is that God's choice of us precedes and must govern our choice of one another. It is God acting through Christ who constitutes the community of faith, and it is God's actions which shape and determine our own; in short, whoever is acceptable to God must certainly be acceptable to us."¹⁶⁴

I think what Carter and Wadell are saying is that a fully accessible church should allow persons with disabilities opportunities to develop a close relationship and fellowship with the other members: to love and to be loved, to give and to receive, to feed and to be fed with the life of Christ.

Feeling Welcomed

The church should be a place where everyone feels genuinely welcomed despite their diverse abilities and differences. In *Dimension of Belonging*, Carter, Bigggs, and

¹⁶⁴ Paul J Wadell, "Pondering the Anomaly of God's Love: Ethical Reflections on Access to the Sacraments," in *Developmental Disabilities and Sacrament Access: New Paradigms for Sacramental Encounters*, ed. Edward Foley (Collegeville, Mn: Liturgical Press, 1994), 69.

Boehm point out that the feeling of being welcomed is broad in scope. In other words, genuine welcoming transcend just being on a church membership register. They opine that authentic welcoming of persons with disabilities in the congregation involve each member of the congregation accepting their own vulnerability, being openhearted, accepting each other as they are, and providing opportunity for meaningful participation and nurturing for fulfillment.¹⁶⁵

There were mixed reactions in the research participants' responses to feeling welcomed. Most participants expressed that they were welcomed by the church and the pastor. They expressed that they felt a sense of belonging to their church and the sense of connectedness to their pastor and to the church members. For instance, Steven, Howfred and Abednego (not their real names) indicated during the interview one-on-one with the trained interviewer, that the church members were very friendly and showed hospitality, people in the church visited with them and their family, and the pastor also prayed with them.

When I lost my dad, they all came to me, sat with me and encouraged me. They took turns to visit me. I was not alone. (Steven)

When I wanted to pay my 300-level academic tuition, the Pastor discussed with the welfare department after a prior discussion with him, not expecting anything though. After a few weeks, the church sent me #70,000 to cater for the tuition need. (Howfred)

When I moved into my new apartment, not plastered and without a ceiling. The church came visiting notwithstanding and prayed with us there. They check on me whenever I am not around in church. The church has a welfare store where people can take foodstuffs when they do not have. We partake in the church picnics and love feast. They ask after my family and visit me. The Pastor even once visited me in my school (workplace). (Abednego)

¹⁶⁵ Erik W. Carter, Elizabeth E. Biggs, and Thomas L. Boehm, "Being Present Versus Having A Presence: Dimensions of Belonging For Young People With Disabilities and their Families," In *Christian Education Journal*, Series 3, Vol. 13, No.1, 2016, 133.

To Steven, Howfred and Abednego as shared above, the church attitude to welcoming was not with lip service (superficial). It was genuine, practical, and authentic just like Apostle John put it, “Dear children, let us not love with words or tongue but with actions and in truth...”¹⁶⁶ The feeling of being welcomed as experienced and shared by most participants in this study with the example of the two above mentioned seemed very inclusive, an overwhelming sense of being part of a community that “extends beyond being passively present or simply noticed.”¹⁶⁷

However, this observation is contrary to the experience of Steven, one of the research participants. An interview with Steven, one of my research participants, who reveals that some churches still conceive the notion that disabled people need miracle and deliverance for them to be ‘normal’ and acceptable, felt dehumanized and humiliated for being labelled “demon possessed,” by the pastor and some of the church congregation of the church where he was formally attending. Steven shares:

Initially, I attended a church. When they saw me, they said the Pastor requested I come to the podium. I consented. The Pastor said I must receive my miracle, shook my head, and poured water and prayed. When there was no miracle, they concluded I was possessed with evil spirit. (Steven).

The interpretation people in the church give to disability and the understanding they have about disabled people can be very demeaning and damaging. Their perceptions and approach look more patronizing and depersonalising. Kenny, voicing

¹⁶⁶ 1 John 3:18 New International Version.

¹⁶⁷ Carter et al, “Being Present Versus Having A Presence: Dimensions of Belonging,” 7.

her profound concern about seeing her impairment by prayerful perpetrators as “inherently defiant and in need of eradication,”¹⁶⁸ laments,

I am confused by the way people interpret my disability as in need of “fixing” without knowing anything else about me. I am troubled that my body becomes public property they feel they have the right to control. I am indignant that this takes place under the veil of Jesus-following, as though they are the bouncers to God’s table. I am hurt that I must justify my own existence at church.¹⁶⁹

Leonie Reid, in her work, *Giving and Receiving: We Enter a Faith Program Thinking We Are Giving of Ourselves...*, notes that many disabled people have not been given the opportunity by their local church to deepen “their desire for a spiritual ‘connection’ in their lives,”¹⁷⁰ simply because of the unwelcoming attitudes of the congregation. Reid states that where individuals with intellectual disabilities are accepted and included in the congregational life of the church, the experience becomes a life changing one, not only for them but also for their families and the entire faith community.¹⁷¹

Ekebuisi writes that the inclusion of AWDs in the spiritual life of the church is still lacking. Although he claims that more and more churches are becoming aware of and recognizing the importance of ministering to AWDs, yet the church still places more emphasis on patronising prayers and invasive interrogations, oppressive physical

¹⁶⁸ Amy Kenny, *My Body Is Not A Prayer Request: Disability Justice in The Church*, (Michigan: Brazos Press, 2022), 2.

¹⁶⁹ Ibid., 3.

¹⁷⁰ Leonie Reid, “Giving and Receiving: We Enter a Faith Program Thinking We Are Giving of Ourselves...,” in *Journal of Religion, Disability, and Health*, Vol. 8, Issue 1-2, 2004, 126. https://doi.org/10.1300/j095v08n01_10

¹⁷¹ Reid, *Giving and Receiving*, 127.

and social structures, and cultural attitudes, rather than focusing on how best to utilize the spiritual gifts of disabled people for the enrichment of the Christian community.¹⁷²

Carter et al, Kenny, Reid and Ekebuisi reinforce the need for the church to act as an alternative community where disabled people are welcomed and offered a place in the congregations. I believe the church can offer through its theology and praxis the generous welcoming of AWDs and draw each person into a relationship of friendship and fellowship.

Feeling Connected

The church can be positioned to help address the need and desire for AWDs to feel connected to their faith while they provide a safe and supportive place for reflection and spiritual growth. Swinton et al present a communal nature of spirituality through which our feelings and emotions are intertwined with others and our spirituality is being formed within this same community.¹⁷³ I think what Swinton is saying here is that this communal environment can enhance a meaningful relationship for AWDs and may impacts their deep understanding of spirituality and gives meaning to their lives.

For instance during the research interviews, the participants were able to express and experience how they felt about spiritual connection. This includes feeling of love, acceptance, and self worth. Most of the participants mentioned that they felt accepted,

¹⁷² Chinonyerem Ekebuisi, "Persons with Disability and the Worship Life of the Church," in *Perspectives on Disability: A Resource for Theological and Religious Studies in Africa*, ed. Samuel Kabue et al., (Ibadan: Baptist Press, 2016), p. 41.

¹⁷³ Swinton et al, 14 & 15.

valued, and loved. James, Emmanuel, Steven, and Howfred, described how they have been participating in the church through their gifts of teaching and singing respectively. Steven said: “*I was also made a Sunday School Teacher which is not commonplace in other climes.*” And Emmanuel responded that he had the “opportunity to hold microphone to lead praise songs...and to play some of the musical instruments.”

Ana Wansbrough and Nicola Cooper in their work *Recognising all members: The Place of people with Disabilities...*, articulate a tremendous potential for equal participation of disabled people in the church. They opine that every church member has one or more God-given gifts of ministry, and the church needs to recognise, value these gifts, and provide ways these gifts can be exercised by everyone including disabled people.¹⁷⁴ I believe the issue of participation, as mentioned by Carter et al, Wansbrough and Cooper, is simply not only about involving disabled people in the congregational life of the church, but much more ensuring mutuality of God’s love where AWDs are not just seen because of the needs they require, but rather because of the gifts they can contribute.

Church Supporting Belonging

Putting the work of Deborah Cramer in conversation with the experiences of people with disabilities in the church, her article *Including All Bodies in the Body of God: Disability and the Theology of Sallie McFague*, highlights the need for the church to promote belonging for all through the embodied theology (human body experience)

¹⁷⁴ Ann Wansbrough, “Recognising All Members: The Place of People with Disabilities in the Uniting Church in Australia,” In *Journal of Religion, Disability, and Health*, Vol. 8, No. 1-2, September 22, 2004, 148. https://doi.org/10.1300/JJ095v08n01_12

that embraces the relationship of human bodies to God as part of theological reflection and construction.¹⁷⁵

Under the theme ‘church supporting belonging,’ most of the participants shared that despite that people support them in praying, reading the Bible, and socialisation respectively, they still expressed some feeling of dissatisfaction with the church architectural barriers at both social and spiritual levels that keep them at distance in the worship life of the church. For instance, James, Howfred, and Emily’s responses reveal that the church where they attend or visited are not welcoming to people with disabilities in the way the church buildings are structured.

Majorly, I have not been a victim of discrimination in the church. But subtly, I can read that into some omissions in the church. Most churches have altars with steps leading to the altar. I cannot access the altar to pray because of my walking disability. I also travelled from Ibadan to Ejigbo to attend a burial service only for me to be unable to access the church because of its architectural barriers. There were only steps. I could not enter but only stayed back in the car to later join them at the reception venue which was a plain field. (James)

The acceptability is not good enough in Nigeria. There was a day we were dancing forward in church for thanksgiving. Nobody came to assist my mobility until I fell. (Howfred)

Not all categories of disability are well accepted.... Even those with hearing impairment do not seem to be well accepted seeing that many churches do not have interpreters for them. How then do they listen to the sermon? The physically challenged do not also find it easy to access the church buildings because of the stairs. (Emily)

From the participants responses above, there were identifying challenges to meeting their spiritual needs. The biggest challenge is the architectural design of church buildings. These physical and structural barriers constitute major roadblocks to free

¹⁷⁵ Deborah Creamer, “Including All Bodies in the Body of God: Disability and the Theology of SallieMcFague,” In *Journal of Religion, Disability, and Health*, Vol. 9 (4), 2005. 56.

access to worship by disabled people in most of the churches and faith-based communities shared by the participants. Reynolds states “access is not a one-time minimalist achievement, but an ongoing welcoming accommodation to make such participation possible.”¹⁷⁶ Gabriel O. Olaniyan concurs that people with disabilities are not considered in the existing structures in the society whether as church auditoriums or social institutions.¹⁷⁷ He contends that such non-consideration continue to make the disability group insignificant and victims of oppression and exclusion.¹⁷⁸

Also, Swinton argues for an enlarged theology of belonging. He calls on the church community “to move our thinking away from the idea of inclusion towards the experience of belonging.”¹⁷⁹ I think what Reynolds, Olaniyan, and Swinton are trying to advocate for disabled people in faith communities is that while belonging may include connectedness, agents of belonging must include intentional invitation to those unwelcomed through action (praxis), love and acceptance.

This leads us to the next chapter, a further discussion of research findings focusing on three dimensions of spirituality, still in dialogue with my experience with my participants and the literature, including the theological literature.

¹⁷⁶ Reynolds, “Invoking Deep Access...,” 221.

¹⁷⁷ Gabriel Olaniyan, “Societal Responses to People with Disabilities in Africa,” In *Perspectives on Disability: A Resource For Theological and Religious Studies In Africa*, eds Samuel Kabue et al, (Ibadan: Baptist Press, 2016) 86.

¹⁷⁸ Ibid., 87.

¹⁷⁹ John Swinton, “From Inclusion to Belonging a Practical Theology of Community, Disability, and Humanness,” In *Journal of Disability and Health*, Vol. 16 (2) 172 – 190, 182.
<http://dx.doi.org/10.1080/15228967.2012.676243>

CHAPTER 7

Three Dimensions of Spirituality

Dimensions of life meaning and purpose, meaningful relationship and trust, and being connected

This chapter provides a deeper reflection on three dimensions of spirituality as experienced and expressed by the participants. Underpinning the spiritual connection, the social and spiritual support, friendship, acceptance, and self-worth that the research participants have acknowledged in this study, this evidence suggest that spirituality forms a vital part and a valuable source of participants well-being and significance which has provided meaning and direction to their lives and has helped them to deal with the many challenges of life. The expression and experience of participants in this study thus indicate that spirituality can be a significant dimension in their lives. Therefore, this chapter of this study will be focusing on three dimensions of spirituality as relates to AIDDs: life meaning and purpose, meaningful relationship and trust, and being connected.

The place of spirituality in the lives of AWDs is often undermined and misconstrued by the church and pastors. According to Deborah Beth Creamer, the

church has failed to honestly engage with people who have disabilities, to seek out and listen to their stories.¹⁸⁰ Spirituality can be “intensely personal and experiential.”¹⁸¹

The questions that the researcher will be addressing in this section include (1) What does life meaning and purpose mean for AWDs? (2) How can AWDs experience meaningful relationship and trust? and (3) when can AWDs feel the sense of being connected in the church?

What does life meaning and purpose mean for AWDs?

The level of devotion which connotes more the external activities such as (prayer, reading of the Bible, etc) of the participants and the importance they attached to spirituality and belonging constitute life meaning and purpose for them.

Life meaning and purpose come from feeling close to God, especially in times of trial. Interestingly a more suitable definition of spirituality is found in Swinton’s work *Reclaiming The Soul* in which he refers to spirituality as part of human being which drives them into a search for meaning, significance, purpose, meaningful relationship, and connection whether be it on a short term or life term.¹⁸² Others scholars, who agree with this definition suggest that spirituality in the lives of disabled people may not have

¹⁸⁰ Deborah Beth Creamer, *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*, An American Academy of Religion Book (New York: Oxford Academy Press, 2008) <https://doi.org/10.1093/acprof:oso/9780195369151>

¹⁸¹ Thomas G. Plante and Allen C. Sherman, *Research on Faith and health: New Approaches to Old Questions*, In *Faith and Health: Psychological Perspectives*. Ed. Thomas G. Plante and Allen C. Sherman. (New York: Guilford, 2001), 3.

¹⁸² John Swinton, “Reclaiming Soul: A Spiritual Perspective on Forensic Nursing,” In Kettles A, Robinson D eds. *Forensic Nursing and the Multidisciplinary Care of The Mentally Disorders Offender* (London: Jessica Kingsley Publishers, 1999)

been fully explored in general, be it in church or a wider society, but argue that it can be a significant aspect of their lives.¹⁸³ A few times in the interview, some have expressed that the secret of their survival comes from their intimate relationship with God. One said, “*Some years after I lost my sight, and I discovered I still have hope. A man of God ministered to me. I got back home to read the Word of God. I was encouraged to continue my life believing that God is still with me.*” I believe their experiences of spirituality provide the strength and hope for them to cope with life challenges and situations. For instance, most of the research participants shared that their life meaning started when they experienced a divine encounter in a school Christian fellowship or at church retreats and revivals.

As Park and Folkman argue, “finding meaning in such events (aversive or extreme life events) can involve changing one’s fundamental goals, which may entail the development of new world models, drastically altered hierarchies or religious conversions.”¹⁸⁴ This type of spirituality being meaning making venture is further described by Bellous and Clark in their work *Thick Listening and Thin Moment*, in which they argue that “from the perspective of spiritual formation, the human spirit is an agent of communication that accomplishes meaning making; human spirituality is the capacity to make meaning and reflect on the meaning made.”¹⁸⁵

¹⁸³ Amy, Lee Ai and Crystal L Park, “Possibilities of the Positive following violence, and trauma: Informing the coming decade of research,” *Journal of Interpersonal Violence*, 20 (2), 2005: 242 – 249.

¹⁸⁴ Park C., & Folkman, S. “Meaning in The Context of Stress and Coping,” *Review of General Psychology*, 1 (2), 1997, 129.

¹⁸⁵ Bellous and Clark, 32.

A good example of this is my experience with one of my clients while working professionally in a group home in Edmonton, Canada. Jordan, not a real name, liked to share his story with staff a few times. During one of my shifts, he told me he is a lucky guy because God has been so kind to him. He said he could have been dead because he developed anxiety disorder when he was young. He said he grew up not knowing his parents because he started to live in a group home since he was a teenager. I asked him what his relationship with God looked like and what he has learned from his experience with God. He said “I have learned to pray to God for everything, to be kind to myself, and to be kind to others.”¹⁸⁶

Jordan’s experience is one of many experiences of disabled people which are reflective of the relationship AWDs have with God and whose spiritual needs are still yet unmet within a wider society, “...spirituality, whether a human capacity, or way of life, is healthy only as long as essential spiritual needs are met in community (socially) and in someone’s life (personally)....”¹⁸⁷ The church can support individuals struggling with life challenges to overcome their experiences of rejection, despair, fears, and anxiety by providing welcoming and friendly environment and making available spiritual resources with which they can overcome obstacles to fulfilling their dreams and flourishing. Jo-Ann Vis and Heather Marie Boynton state,

A critical component in assisting individuals to move beyond the immediate impact of trauma is the facilitation of spiritual awareness and accessing spiritual resources. The inclusion of spirituality in the post-trauma processes can provide

¹⁸⁶ A shared experience and conversation with one of my clients in a group home in Edmonton, Canada.

¹⁸⁷ Bellous and Clark, 11.

alternatives for positive reconstruction of worldview, coping, and transcendent meaning making.¹⁸⁸

Swinton, Park and Folkman, Bellous and Clark, and the participants, are all proponents of the fact that life meaning and purpose for persons with disability is not just the experiences they go through in life, but rather how the learnings in those experiences have shaped their beliefs about self and the world around them.

How can AWDs experience meaningful relationship and trust?

The idea of friendship conceived by a Christian theologian Jean Vanier as meaningful relationship and trust, whereby persons accept each other for who they are and are being present with each other on the path to fulfilling their dreams and aspirations, presents a future of hope and possibilities especially for the marginalized population. This life of mutual friendship and relationship that disabled people envisioned is replicated in the communities of L'Arche, a place where authentic friendship is embodied and modelled for the church and a wider community. Greig points out that “these communities of people both with and without intellectual disabilities seek to reveal the sacred uniqueness of every person through the simple sharing of daily life together, whereby strangers become friends and the rejected receive their infinite value.”¹⁸⁹

¹⁸⁸ Jo-Ann Vis & Heather Marie Boynton, “Spirituality and Transcendent Meaning Making: Possibilities for Enhancing Posttraumatic Growth,” *Journal of Religion & Spirituality in Social Work: Social Thought*, 27:1-2, 2008, 69-86, DOI:[10.1080/15426430802113814](https://doi.org/10.1080/15426430802113814)

¹⁸⁹ Greig, *Reconsidering Intellectual Disability*, 5.

God's friendship is unconditional and does not require anyone to fit in to be acceptable, but welcomes each one as they are. 1 John 4:10-11, "This is love: not that we loved God, but that he loved us and sent his Son as an atoning sacrifice for our sins. Dear friends, since God so loved us, we also ought to love one another."¹⁹⁰ Just as God welcomes us despite our deficiencies, so the church must open her doors to all and sundry to receive and share this gifted nature of life. Reinders speaks to this more explicitly from the point of view of life being a relational gift. He argues that the goodness of life has nothing to do with our life conditions, but on whether we find peace through our response to the gift of friendship from a loving God.¹⁹¹

Amos Yong, who borrows significantly and explicitly from personal experience of a family member with disability, shares that Christian community is the way people relate to God, a union which informs a mutual and trusted relationship with one another. Yong, in his illustrations, writes that "the church is fully the charismatic fellowship of the Spirit only insofar as she is an inclusive community of hospitality"¹⁹² In broader sense, Yong argues that "disability is engaged not only from a posture of charity but from one of mutuality."¹⁹³ Yong's understanding is that both 'disabled' and 'nondisabled' enter into a communal mutual friendship and commitment to living lives together and moving forward together. Unfortunately, this type of inclusive community

¹⁹⁰ 1 John 4:10-11, New International Version.

¹⁹¹ Reinders., 178.

¹⁹² Amos Yong, *Theology and Down Syndrome: Reimagining Disability in Late Modernity* (Waco, TX: Baylor University Press, 2007), 225.

¹⁹³ Ibid., 294.

is elusive for AWDs. A victim of a wrong interpretation of the body, as disability curatives, narrates her ordeal. She states:

This woman does not know me. She doesn't have the intimacy that prayer or accountability or sarcasm require. She simply interprets my cane as something that requires "fixing" and ropes God into her ableism, the belief that disabled people are less valuable or less human than our nondisabled counterparts....I don't need prayer for healing. My body has already been satisfied and redeemed...my dignity is not up for debate, particularly here, in God's house...this woman is an echo of every prayerful perpetrator before her. They have many faces, but they always approach me with the same paternalistic confidence, eager to rid me of my wheelchair or cane."¹⁹⁴

So, how can AWDs experience meaningful relationship and trust within the Christian community? It is (1) **By making visible the invisible** - there is the need to reconstruct a theology for the full inclusion of AWDs in the worship life of the church. AWDs must be seen as part of the Body of Christ for whom Christ died. One of this study's participants said, *"the church I earlier attended concluded I was possessed with evil spirit because the miracle service they conducted on me failed. I was stigmatized against and embarrassed."*

As noted above, Amy Kenny, in her work *My Body Is Not A Prayer Request* shares her story of when a stranger patronized her, and laments that it is dehumanizing to know that the ableist society could interpret her cane as a mark of being less human, and her already redeemed body in need of prayer for healing.¹⁹⁵ For the church, then, accommodating people with disabilities requires more than just seeing them as

¹⁹⁴ Kenny, 1&2.

¹⁹⁵ Ibid., 2.

anomalous objects of pity and defective individuals that need compassion but as fellow brothers and sisters who all have a place and right to belong.

AWDs in the church should be accorded due respect and considered fellow believers in Christ who all have a place. Paul in 1 Cor 6:15 bringing up the notion of the church as the body of Christ, raises a fundamental theological question with Christians. He asks, “Do you not know that your bodies are members of Christ himself?”¹⁹⁶ Paul needs Christians to understand that they are members of a larger body. In the earlier text, Paul presents the church as an organism that comprises “the complex structure of the Body of Christ which carries on living activities by meanings of the individual believers, who are distinct in function but mutually dependent on and governed by their relation to Christ, the Head.”¹⁹⁷ In 1 Cor 12:12-27, Paul makes the point that we do not all have to be the same, that the body needs both ears and eyes. We are meant to be and need to be each unique and valued for our unique contribution to the whole. This is a scriptural celebration of diversity as part of the one Body of Christ.

(2) Through authentic friendship and fellowship— In John’s account of the ministry of Jesus in John 15:15, Jesus tells believers, “I no longer call you servants, because a servant does not know his master’s business. Instead, I have called you friends, for everything that I learned from my Father I have made known to you.”¹⁹⁸ The diverse expressions of friendship (theological, scriptural, and philosophical) in the

¹⁹⁶ 1 Cor 6: 15, New International Version (NIV)

¹⁹⁷ Charles C. Ryrie, *Biblical Theology of the New Testament* (Chicago: Moody, 1959), 191.

¹⁹⁸ John 15:15, New International Version.

church is clearly explained by Greig. He argues that for true meaningful relationship, inclusion, and flourishing of AWDs to happen, four things must be accomplished. One, the church must be able to reconstruct her theology on friendship. What Greig means here is that the Christian tradition must move past ‘I do this for you; then you do this for me,’ which reduces true friendship to “mere equal exchange and relations of “sameness”¹⁹⁹ and embrace rather Christian ethos of friendship that starts with God and is extended to others. In other words, our experience of friendship with God should reflect in our relationships with others. Two, the church must search through the scriptures and find out what Jesus means in the text of John 15:15 in which Jesus mentions that he no longer calls his disciples slaves but friends. The argument of Greig here is that Jesus’s model of friendship is an invitation of everyone into an intimate relationship with God that is characterized by love and care for “those cast aside and forgotten.”²⁰⁰ Three, the church must explore how AWDs can participate in authentic friendship and relationship. According to Greig, for genuine friendship to happen for AWDs, there will be a need for the church to “strongly recognize the fundamental uniqueness and goodness of their whole persons, one that demands the utmost respect and reverence,”²⁰¹ four, taking into consideration the moral implication of relating with AWDs as friends rather than as mere objects.²⁰² In Greig’s view, the moral implication

¹⁹⁹ Greig, 116.

²⁰⁰ Ibid., 129.

²⁰¹ Ibid., 146.

²⁰² Ibid., 5.

of an authentic friendship with AWDs lies at the root of what kinds of values, practices, and narratives a community must have to fully support AWDs.

(3) **Through Communion** – Most of the research participants expressed that they participated in the church prayer meetings, monthly Lord’s supper, and various church fellowships. They however responded that they need more of such Christian gatherings and forums for communion with God and interconnection with others. One respondent said, “*when the church makes one feel relevant, it gives a great sense of belonging.*” Another one said, “*we partake in the church picnics and love feast. More of love feasts where we interact and share ideas.*”

Through a closer look at John Swinton’s work, in *Dementia: Living in the Memories of God*, it becomes clear that AWDs are not just persons, but also beings in relation. Swinton argues that “standard neurobiological explanations of dementia are deeply inadequate for a full understanding of the nature and the experience of dementia.”²⁰³ The question Swinton is trying to address here is, how may the relationship between individual and God be understood in the light of dementia? For Swinton, to fully grasp what it means to experience dementia, it is expedient to first seek to know what it means to be human. With the relational perspective of being human, Swinton holds that “All of us are deeply interconnected and dependent on one another for our very being.”²⁰⁴ He writes that genuine human relationship is a gift from

²⁰³ John Swinton, *Dementia: Living in the Memories of God* (Grand Rapids: Eerdmans, 2012), 9.

²⁰⁴ Ibid., 143.

God, it is rooted in Him and it is to be shared with and experienced by others.²⁰⁵ In essence, what Swinton is saying is that as human beings we are interdependent creatures nourished into being among and by others such that ‘selfhood’ is joined to others, hence the church ought to be a place where true friendship and relationship are practiced, and where everyone grows into his or her purpose as a truly human person. For Swinton, if someone is deficient in relationship, they are deficient in true personhood. Although, Swinton’s argument here is simple but difficult to articulate for AWDs with profound disabilities who have limited mobility, institutionalized, isolated or who are only dependent on others for basic care. However, Swinton’s final submission in his book is key: that memories are held in God, even when a person loses them in dementia – and the implications are powerful for AWD, in that, their identity is rooted in God’s loving care and not in their profound disabilities. How might this experience shape our thinking as we practice true welcoming and hospitality for AWDs?

What does spirituality as being connected mean for AWDs, and when can they feel the sense of being connected?

First, spirituality as used and described by the participants includes engagement, conversation, and connection. All the participants shared that they had some spiritual connection, social conversation, and meaningful engagement. But they also said the spiritual connection is lacking to some extent, the social conversation is limited because of human and inbuilt barriers, and the meaningful engagement can be improved upon by the church. Just like Swinton describes in his work *From Inclusion to Belonging*, most

²⁰⁵ Ibid., 161.

churches and church pastors are not seeing the bigger picture when it comes to inclusion and belonging for disabled people. Swinton uses the thick and thin analogy to describe how the church view the experience of spirituality in the lives of AWDs. According to Swinton, thick description is wholistic in nature, but thin is peripheral (mere surface). Swinton argues that a thick description of a phenomenon centres not necessarily on the physical activity, but much more the “context and the deep and meaningful activities that participants engage in.”²⁰⁶

Reynolds notes that there are a lot of misconceptions among clergy and the church congregations on the subject of inclusion and active participation of AWDs in the church worship life. He points out that “ a deepening is needed in the way access is considered and practiced by congregations.”²⁰⁷ I think this perception is what is missing in the church and pastors’ ministries which needs to be urgently addressed to birth a new and inclusive Christian community.

The experience of spirituality as connection to the divine, significant others, and community by AWDs was evident in the experiences shared by the research participants about the level of their involvement in church activities and community programs. Participants believed the experience of connection can be linked to their experience of spirituality. They described connection in terms of the enrichment of their (body, soul, and spirit), meaningful relationship with significant others (God, family, and friends), and community (a place of worship or faith community). Most participants described being connected to one’s spiritual self as a significant connection. They identified the

²⁰⁶ Swinton, “From Inclusion to Belonging,” 180.

²⁰⁷ Reynolds., 213.

use of prayer, reading of the Bible and participating in Bible study, and caring for self and others as strategies they use to achieve spiritual connection to themselves, to God, and to others. One participant explained, *“My car broke down and I had just retired from active service. Pension was not forthcoming. I am a polio victim. I move around with walking sticks. It was a time of great challenge. There was no one I could go to. I had to rely on God in prayers every hour for provision. That drew me very close to God than ever in my life. I became more dependent on God. And as God would have it, it ended in praise.”* Another said, *“I love singing and listening to sermon.”* Another participant claimed, *“singing Christian music and reading Christian literature.”*

Although the participants acknowledged that they experienced connection in one aspect, they also feel disconnected in another aspect. For example, most of the participants experienced significant connection with God, family, and friends, but felt disconnected from their community (church and social institutions). This disconnection was associated with their perceptions of being marginalised and feelings of how the church treat them by establishing various conscious and unconscious barriers that are hindrances to their genuine inclusion and belonging. For instance, a few of the participants shared the feeling of hostility, helplessness, hopelessness, and alienation from the church. One of the participants said, *“I am not mobile. I was attending a church along Ashi road and it involves trekking a long distance because the church is quite far from the main road. Many church members with cars do not offer or accept to assist.”*

Some of the AWDs are disconnected from the church because there is still no authentic conversation with them, and no action with respect to their belonging. Others

have been ostracised and left the church because they are being traumatized and stigmatised by the name-calling and disability rhetoric that the church members and leaders use against them. Eric Carter's paper refers to a study describing the experience of 12,000 adults with intellectual disability. The report states "that less than half (48%) of these adults reported having attended any type of religious service in the prior month."²⁰⁸

Following the current discussion on various dimensions of spiritual expressions and experiences of AWDs, the next section offers a conclusion and implications for the improvement of the church and pastors' ministries in meeting AWDs spiritual needs.

²⁰⁸ Erik W. Carter, "A place of belonging: Research at the intersection of faith and disability," *Review and Expositor* 113 no. 2 (May 2016): 170, [https://DOI:10.1177/0034637316637861](https://doi.org/10.1177/0034637316637861)

CONCLUSION, THE IMPLICATIONS, AND RECOMMENDATIONS

Given this project's aims , which are (1) to explore the importance of spirituality as expressed and experienced by AWDs, (2) to engage the research participants in the entire research project for people to hear their voices, and what the church and pastors can learn from this research to improve their ministries to meet these spiritual needs, (3) to use the findings of this project to better comprehend how AWDs relate to their spirituality within the church, and how the church understands and nurtures the expression of that spirituality, (4) to use the result(s) of the data collected to help pastoral caregivers and faith communities understand the implied and inherent attitudes and practices that have caused AWDs and their families to feel unwelcomed within their congregations, and (5) to provide an exciting opportunity to advance researchers' knowledge on disability studies, there are a few take aways which are highlighted in this concluding part of my dissertation. This includes the CBPR approach, using the criteria for the conduct of high-quality participatory action research - participation, power sharing, knowledge generation, and praxis. Also, about myself, and about the three dimensions of spirituality that informed how the participants view, understand, and experience spirituality.

Therefore, this section of my dissertation will examine the significance of the use CBPR, including highlights of my personal reflection, discuss the implications of the three dimensions of spirituality in the lives of AWDs for the improvement of the church and pastors' ministries in meeting their spiritual needs, mention the impact of

this research on my pastoral care ministry and my spiritual journey, discuss the reconstruction of theology informing attitudes and behaviour towards disabled persons, and then give the conclusion.

The Significance of the Use of Community Based Participatory Research (CBPR)

The CBPR approach to finding out about the importance of spirituality to AWDs has proven to be a very useful research framework. The research approach was understandable to the co-researchers and reflected their participation, their voices, and lived experiences on the importance of spirituality. The method also addressed communication and other barriers to their active involvement and participation such as the ability to understand what is being said and to communicate back in English. Here are a few highlights of the benefits of using the CBPR approach and my learnings (personal reflections).

Community Participation

The CBPR approach enables the voice of the research participants to be heard and tangible information to be produced by them. Because of their direct involvement and active participation in the entire research process, the research participants were able to express their needs, discussed issues of concerns, and proposed strategies for change. For instance, the seven participants indicated in their responses to the interview questions, to what extent they have been involved in and supported by the church and the changes they would like to see happen within the Baptist congregation in the immediate or distant future. Most of the participants said the church can help them by

organising more of the programs they would like to participate in and people can help them with what they like to do by doing those activities with them i.e., organise disability awareness programs, retreats where they can socialise more, position someone close to them to read the bible with them, and put material and physical structures in place to aid their access to worship. Through the CBPR approach, it can be observed that the research participants were eager to participate and share their experiences and how they feel when they are included and not marginalised by the Pastor and the congregation.

The research study provides an opportunity for me to **connect** with the research participants over what spirituality means for them and how they feel connected to the church, and to learn from one another. During the first two team meetings, I was able to pay close attention to how the research participants were participating. As an insider researcher, I was able to seek possible ways to connect and build a trusting relationship with the via Zoom. For instance, during the pre-interview meetings via Zoom, I shared my own personal experience caring for and supporting a cousin with cerebral palsy whose family I lived with for several years when I was younger. In addition, having worked with persons with intellectual and developmental disabilities in diverse settings - school, religious communities, and group care homes in Nigeria - provided a grounding for me to be able to relate with some of my participants' experiences. Khaliza Saidin and Aizan Yaacob in their work, *Insider Researchers; Challenges and Opportunities*, mention the incredible roles that insider researchers can play in guaranteeing the success of a community-based participatory or indigenous research.

These include the researchers' understanding of the participants' culture and contexts and bringing their previous experiences to bear in the entire research process.²⁰⁹

During the study, with the participants' consent, I asked them to share their personal and family stories. More knowledge (data) about the participants were generated through story telling. Wallerstein and Duran refer to this type of knowledge as "culturally bound knowledge" from which participants may share their own experiences of traumas, tragedies, and triumphs as relate to their disability, culture and backgrounds.²¹⁰ However, Wallerstein and Duran argue that such culturally bound knowledge can sometimes be undermined by research experts with scientific knowledge who focus more on empirical evidence rather than knowledge that comes from the indigenous narratives.²¹¹ Shawn Wilson adds to this line of thoughts on Western ontology and epistemology regarding indigenous narratives. He emphasizes the importance of understanding the indigenous paradigm and building relationships with research participants within their localised setting.²¹² In addition, Wilson suggests to the Western researchers the need to balance their worldview with other worldviews including indigenous worldview by questioning their assumptions and identifying their personal biases that may impact the research process within the indigenous community.

²⁰⁹ Khaliza Saidin and Aizan Yaacob, "Insider Researchers Challenges and Opportunities," In *Proceeding of ICECRS, 1 (2016) 849-854*, DOI: <http://ojs.umsida.ac.id/index.php/icecrs>

²¹⁰ Nina B. Wallerstein and Bonnie Duran, "Using Community-Based Participatory Research to Address Health Disparities," *Health Promotion Practice*, Vol. 7, No. 3, 312-323, July 2006. 315. <https://journals.sagepub.com/doi/10.1177/1524839906289376>

²¹¹ Wallerstein and Duran, 315.

²¹² Shawn, Wilson, *Research Is Ceremony: Indigenous Research Methods*, (Winnipeg: Fernwood Publishing, 2008), 7.

I believe the centrality of Wallerstein, Duran, and Wilson's approach to indigenous and /or community based participatory research is relational. This is the approach I used during my main research. The data that I was able to gather from the story telling provided more information of how-to better support AWDs and affirm their capabilities with which they express their potentials and skills within the church congregations.

Nina Wallerstein and Bonnie Duran, in their paper, "The theoretical, historical, and practice roots of CBPR," capture many of the principles of high-quality Community Based Participatory research. They begin with *participation* being one of the core principles in doing CBPR, with some critical questions on what, who, for whom, and to what extent the people are participating.²¹³ Wallerstein and Duran are quick to point out that the issue of participation in participatory action research has an antecedent and has been a transformative journey between the academic researchers and the research participants (community members). However, they argue that despite the CBPR's tradition that requires genuine and active participation between researchers and the community members, the practicality of this relationship remains a complex one.²¹⁴

Blumenthal reflects more deeply on community participation as one of the core principles of CBPR. He writes that a CBPR model should not just be about research location, or the people being researched, but rather signifies the equitable roles the community members (research participants) are to play in every aspect of the research:

²¹³ Nina Wallerstein and Bonnie Duran, "The Theoretical, Historical, and Practice Roots of CBPR," In *Community-Based Participatory Research for Health*, (January 2008), 29-30. <https://researchgate.net/publication/306452424>

²¹⁴ Wallerstein and Duran, 30.

“identifying the research topic and the research question, planning and executing the project, collecting and analyzing the data, and disseminating the results.”

Wallerstein, Duran, and Blumenthal’s perspectives on community participation which, taken together, help us to understand that participation of those that are marginalised is possible in a research process, and if well planned and discussed among the research partners, may constitute one of the significant CBPR principles to pursue to have a dependable and reliable community-based research outcome.

Power Sharing

The participatory approach utilized in this project provides life-changing opportunity for me in giving the research participants an authentic voice in the research to advocate for a change they would like to see in the church ministry of the Baptist congregation in Nigeria. I was able to collaborate with the research participants , share from their knowledge and experiences, and engage in their responses within the group. The project expressed their opinion on what spirituality and belonging meant to them and what it feels like to be part of the church. During the project, the researcher observed that the participants brought with them some church experiences and spirituality that have been nurtured over the years. Their responses during the meetings and to the interview questions best showed that their sense of inclusion and connection is based on their family background of church accessibility and participation. Isabel C. Scarinci et al note that CBPR is exploratory in nature and often provides a common

ground for the research partners (researcher and the research participants) to learn from one another and allow for continuous open dialogue.²¹⁵

The participants made the choice of the research location. The meetings between the participants and I took place in an educational setting of the participants' choice. They focused on the research activities for each day and arrived at the venue of the meeting promptly. Because of the research location, participants needed to travel a few kilometres to get to the venue of the research. Transportation was arranged through the Research Assistant. Laura Robinson et al, while exploring changes that can happen for AIDDs when they are included, explain that rather than focusing on their stigma, adults with disabilities are likely to pay more attention to their individual and specific needs: to be heard, supported, and empowered.²¹⁶

For me, because I needed to connect with the participants via Zoom, due to time zone difference between Canada and Nigeria where my participants are, I had to wake up in the middle of the night and stayed awake for several hours during the research process. But because I felt it was important **to commit** myself fully to the success of the research work since it was the first time the voice of the persons impacted with disabilities in the church will be heard, I decided to give it all it took to be available whenever it was required.

²¹⁵ Isabel C. Scarinci, "Planning and Implementation of a participatory evaluation strategy: A viable approach in the evaluation of community-based participatory programs addressing cancer disparities," *Eval Program Plann.* August; 32(3): 221–228. Doi: 10.1016/j.evalprogplan.2009.01.001, 1-3.

²¹⁶ Laura Robinson, "The subjective experience of adults with intellectual disabilities who have mental health problems within community settings," In *Advances in mental health and intellectual disabilities* 10 (2): 106-115, Abstract. <http://dx.doi.org/10.1108/AMHID-04-2015-0017>

I observed via Zoom that the venue of the meeting also provided a platform for more interactions of the participants. During the break time, they chatted and talked with each other. They all felt that they are part of a group dealing with similar issues that are important to them. I learned that involving AWDs required more than just communication. It included providing them with autonomy and rational choice as to how they would like to be represented and where they would like the venue of the research to be for their safety, confidentiality, and easy accessibility.

However, during the first two team meetings, I observed via Zoom that two of the research participants felt slightly anxious about the research process probably because it was their first experience. Despite my explanation to them via Zoom about the reason for the meetings and the study, they were still uncertain where the discussions at the meeting was ultimately heading. Because it was their first-time experiencing participation in a research activity, they showed some negative emotions at the initial stage of the research process asking some few questions for clarifications. I repeatedly assured them via Zoom that I would be present with them on Zoom to provide support. I asked them to let me know if there was any support they would need to participate before, during, and after the meetings.

Before the interview via Zoom, I observed that participants were eager to share their personal stories. A few stories that were shared during the pre-team meetings created in me a feeling of **concern and care** to provide more time and attention for them to tell their stories and voice their concern. Dena Hassouneh, Amana Alcala-Moss, and Elizabeth McNeff note that productivity issues are most likely to pose a problem

because of the physical disabilities and related symptoms of research participants.²¹⁷

They suggest that issues related to delayed response during the research process can be very sensitive, and open and honest approach to discussing and addressing this reality is essential.²¹⁸ To this end, I asked the research participants at the beginning of the research process via Zoom how I can support them. I ensured the provision of a flexible timeline for the discussion and reflections for the research participants . During the meetings and after the breaks I observed that they were more relaxed and willing to continue with the research process. The research participants went over the sample research questions with each other while I listened and facilitated via Zoom.

During the meeting, through the research assistant, I provided some bottles of water, drinks, and snacks for each day of the meeting, with two to three breaks during the meeting. However, after the second meeting, I observed that they got to the project location much earlier than the previous days. They were eager to know what we were going to do next. All the participants and I were excited in the process by the extent to which conversations became both a learning and self awareness, and the connection between us.

In Scheneider et al.'s research, during the data collection task, the group members faced some anxieties because of their lack of experience, knowledge and skills needed to conduct the interview. But eventually, the research group learned and felt comfortable to engage the research process as the interview advanced. According to

²¹⁷ Dena Hassouneh, Amana Alcala-Moss, and E. McNeff, "Practical Strategies for Promoting Full Inclusion of Individuals with Disabilities in Community-Based Participatory Intervention Research," *Res Nurs Health*. 2011 June; 34 (3); 253-265.

²¹⁸ Ibid., 253

Schneider et al., the level of research members' participation in the research process changed because of an enabling and conducive environment that they (academic researchers) created among the research group as the research progressed. They state, "through the interviewing, we became a caring and supportive community of friends."²¹⁹ I learned that through the participatory research approach, mutual relationship with research members is possible.

Knowledge Generation

The data collection procedure provided one of the participants with training on how to interview and learn some research skills. At first the trained research interviewer was nervous about her role as an interviewer, but as time went by, she started to have confidence in the research process. I validated her feelings of nervousness and anxiety via the Zoom. I deployed my **creative** teaching skills, reminding the trained interviewer that the research interview is not required to be perfect and that she should be free to ask for break during the training process. Apart from having a copy of the final interview questions, I printed the sample questions with bold letters for the trained interviewer to read and say repeatedly. This allowed the trained research interviewer to take her time to go over the training with less stress and worries.

The research study provided an opportunity for me not only to involve the research participants in the research, but also to discover their gifts and to understand their new experiences both to conduct interview and to be interviewed. During the

²¹⁹ Barbara Schneider et al. "Communication Between People with Schizophrenia and Their Medical Professionals: A Participatory Research Project" *Qualitative Health Research*, Vol. 14; 2004. 567.

study, participants worked in a team of two to identify sample research questions about feeling connected, about spirituality being meaning making, and about meaningful relationship and trust, and developed them into final interview questions. It was a moment for them to connect with each other and with me via Zoom. I observed during the group meetings via Zoom that they asked some questions from me for clarifications, corrected each other's mistakes, laughed over it, and learn from each other. Through their participation they were able to learn some new skills and activities about doing research. Also, through their contributions, I believe other researchers may know more about people with disabilities, and how researchers can improve their research.

Knowledge generation, as one of the CBPR principles, Wallerstein and Duran say, is emancipatory. They make the point in connection with the ability of the research to demonstrate that both the academic researcher and the community members are learning from each other, reflecting on their biases and values, contributing their expertise, and building trusting relationships as they “engage in dialogue with each other about their communities and the larger social context.”²²⁰ Wallerstein and Duran argue that emancipatory practices of CBPR provide a platform for the community members to freely express themselves and make informed choices about their own lives.²²¹

I learned that the semi-structured interview format that I used allowed the research participants to learn and engaged in the research. None of the research participants had been interviewed before, and none had conducted interviews. The team

²²⁰ Wallerstein and Duran, 33.

²²¹ Wallerstein and Duran, 33.

meetings provided me with the opportunity to have an open, meaningful, and honest discussions and conversation with them about the idea of what questions would be asked during the interview. This relationship building between myself, and the research participants developed over a significant period.

As the research progressed, they felt more confident and expressed themselves freely during the entire research process. Qualitative methods, such as unstructured interviews, are considered suitable for areas where “little research has been done.”²²² The unstructured nature of the interviews allows “all participants to be asked the same questions within a flexible framework”²²³ allowing (the interviewees) to narrate their experiences and explore areas of particular concern. It also allows the researcher to identify “patterns and relationships of meanings, as experienced and described by the participants of the study”²²⁴

The mode of knowledge generation is often quite complicated. Donna McCloskey et al. note that generating ideas from the community members is one of the ethical considerations for doing quality community research because it involves community engagement. They write that community engagement is difficult but achievable by recognising the set of skills and diverse experiences that individual bring

²²² J. W. Creswell, *Research Design, Qualitative, Quantitative and Mixed Methods Approaches*, 3rd ed., (London: Sage publications, 2009), 18.

²²³ C. Dearnley, “A Reflection on the use of Semi-Structured Interviews,” *Nurse Researcher*, Vol. 13, No.1, 2005,19-28.

²²⁴ Sally Diane Hartley and Mohammed Muhit, “Using Qualitative Methods for Disability Research in Majority World Countries,” *Asia Pacific Disability Rehabilitation Journal*, Vol.14 No.2, 2003,105.

to research project.²²⁵ They suggest that the academic researchers must have foreknowledge about the research group to be investigated: their values, history, experiences, and capacity building.²²⁶ Dona McCloskey points out that knowing and understanding the participants beforehand can “help identify strengths they can build upon and barriers they need to overcome.”²²⁷

In Hassouneh et al.’s projects, data collections were conducted by research subjects, women with physical disabilities within the disability community organisations, who were also research .²²⁸ Although the two research projects give an account of who participated in the data collection, the study reveals that the turnaround time for submitting data was too slow. Hassouneh et al. acknowledges, “these approaches, however, do not enable flexibility of data collection time points”.²²⁹ Having considered this blind spot, I took time during the research team meeting via Zoom to get to know each one of them, kept my sentences very short and brief, and provided them with enough time to respond. This type of flexibility in research design to accommodate changes where necessary, especially in a complex situation such as research dealings with the disability population, may not be negotiable.

²²⁵ Donna Jo McCloskey et al., *Principles of Community Engagement*, NIH Publication No.11-7782, June 2011, 51.

²²⁶ Donna Jo McCloskey et al., 47.

²²⁷ Donna Jo McCloskey et al., 48.

²²⁸ Hassouneh et al., *Res Nurs Health*, 2011. 256.

²²⁹ Hassouneh et al., *Res Nurs Health*, 2011. 257.

Praxis

The post interview sessions via Zoom provided opportunity for the participants to open to more conversation about their learnings and take aways. Marit Borg et al refer to this type of conversation as ‘informal talk’ which can enable to feel at ease and speak freely about their everyday life and experiences.²³⁰ According to Borg et al, such “informal chats are never tape-recorded.”²³¹ I think Borg et al recognise the intrinsic motivation factor for the participants when the principal researcher is from the same culture, has the same background, and share similar values. Jarg Bergold and Stefan Thomas describe this type of informal setting as a ‘safe place’ where individual participants can “disclose their personal views of the situation, their own opinions and experiences.”²³² Bergold and Thomas further point out that such “openness is [only] displayed towards good and trusted friends, but hardly in institutional settings or towards strangers.”²³³

I believe what Berg et al, Bergold, and Thomas arguments centre on is that indigenous research may require more than just knowledge about area or topic being studied, it may require being aware of indigenous worldview that can address the nuances in the research and enable the participants make their voices heard. Times like this remind me of how AWDs who are agitated about their abilities to participate in the

²³⁰ Marit Borg, Bengt Karlsson, Hesook Suzie Kim & Brendan McCormack, Opening Up for Many Voices in Knowledge Construction, FQS 13(1), Art.1, January 2012. 7.
<http://nbn-resolving.de/urn:nbn:de:0114-fqs120117>.

²³¹ Borg et al., 7.

²³² Bergold and Thomas, 5.

²³³ Ibid., 5.

preliminary meetings and interview can be affirmed and supported when an enabling environment is provided for them.

After the interview, the developed more interest in the research process. They were willing to participate further in the study. By incorporating the seven participants in the research process and allowing them to share their stories and experiences of spirituality, they were able to provide information that can help to advance changes desired in the church. For instance, Harriet Radermacher and Christopher Sonn, in their research survey on people with special needs, provide us with changes that are possible in the community settings when participatory approach is utilised in carrying out an investigation regarding a phenomenon. In Radermacher and Sonn's study, participants actively participated and shared their experiences throughout the research process.²³⁴ Through the collaborative research effort of the researchers and the participants, they were able to come up with new intervention strategy for people with special needs in advocacy organisation. Also, through this initiative, they were able to make contribution to community psychology research and provide information for decision making that may impact the way people with high needs are being supported.²³⁵

In summary, I believe the choice and use of CBPR can (1) provide researchers with opportunity to learn from their participants and the community. (2) contribute to the empowerment of AWDs. Iseke-Barnes points out that “through traditional storytelling, Indigenous peoples are empowered, and research becomes “our” rather

²³⁴ Harriet Radermacher and Christopher Sonn, “Towards getting it right: participatory action research (PAR) with an advocacy organisation”, *The Australian Community Psychologist*, Vol. 19 No 1, May 2007. 61-73.

²³⁵ Radermacher and Sonn, 61-73.

than “theirs”²³⁶ (3) contribute to researcher’s knowledge and insight, as well as to the improvement of research processes and products.²³⁷

This concludes my discussion of the use of CBPR in my research and the highlights on some things I have learned and would advise other researchers to include when working in the CBPR approach with adult disabled people.

The next section of this concluding part of my dissertation looks at the implications of three dimensions of spirituality in the lives of AWDs and for the reconstruction of theology informing attitudes and behaviour towards disabled persons.

The Implications of Three Dimensions Of Spirituality In The Lives of AWDs

The findings of this study have implications and recommendations. The implications include the three dimensions of spirituality as expressed and experienced by the AWDs in the study, and how the church and pastors can improve ministry to AWDs in their various congregations. Through my study, I learned that the expression and experience of spirituality by AWDs is very significant to the participants, and it is their need for life meaning and purpose, meaningful relationship and trust, and being able to connect with self, others, and the Divine. In *Whose Story Am I*, Swinton et al. echo how important it is for the church to explore the spiritual experiences of persons with disabilities: how they own these experiences, share these spiritual feelings and

²³⁶ Judy Iseke-Barnes, “Indigenous storytelling as research,” *International Review of Qualitative Research*, 6 559-577. Doi:10.1525/irqr.2013.6.4.559

²³⁷ Ferreira and Gendron, *International Journal of Critical Pedagogy*, Vol 3 (3) 2011, 161.

emotions with others within the context of their religious communities.²³⁸ When asked about the activities that make him (express and experience spirituality) feel close to God and how does the church help him to do this, James emphasizes the significance of personal prayers, being present in the church, church activities, and church fellowship. “I rely on God in prayers...special church programs..., and revivals.” Carter notes that a great number of studies have asserted that faith and congregational connections are important aspects (meaning making and significant relationships) in the lives of people with disabilities and their families.²³⁹

It is also worthy of note to mention that friendship and fellowship matters in the lives of AWDs. Most AWDs are dependent on God and others not only for greater social participation and basic daily needs (needs for friendship and fellowship) but also for meaning making, mutual relationship, and facilitated communication and connection. Greig affirms this area of needs in AWDs lives, but emphasizes also that “friendship with God cannot occur without the inclusion of the friendship of others, both those in the church and those left stranded by late modernity.”²⁴⁰ The question then remains as to how the Baptist church leaders and congregations are responding to this area of spiritual and existential needs in the lives of persons with disabilities in the church. Across seven interviews that were conducted during the study, research

²³⁸ John Swinton, Harriet Mowat, and Susanna Baines, “*Whose Story Am I? Redescribing Profound Intellectual Disability In the Kingdom of God*,” *In Journal of Religion, Disability , and Health* 15:5-19, 2011. 5. <https://www.researchgate.net/publication/254374143>

²³⁹ Erik Carter, *A Place of Belonging: Research at the Intersection of Faith and Disability*, Review and Expositor, Vol 1, 13 (2) 167-180. https://www.researchgate.net/publication/301940021_A_place_ofbelonging_Research_at_the_intersection_of_faith_and_disability/

²⁴⁰ Greig., 159.

participants note that there has been some commitment to mutual relationship and friendship .

“I got a letter inviting me to address the men’s fellowship, an arm of the church...The President of the men’s fellowship also wrote me a very touching message on my birthday – (James)

When there is a discussion in church and I raise up my hands to talk, the Pastor grants me audience first...When I lost my dad, they all came to me, sat with me and encouraged me. They took turns to visit me. I was not alone. (Steven)

The church see me as part of the congregation...They show concern in my academics, well being, and social life. (Howfred)

They check on me whenever I am not around in the church...The Pastor even once visited me in my school and workplace. (Abednego)

Through this study, I have come to realize that the church can lead these individuals to celebrate fullness of life as they experience acceptance in a caring and loving community. On the other hand, the church can sometimes be a lonely place for them. Being able to have fellowship, interact, and celebrate the church lives together with others is part of the rights and privileges that people with disabilities have and need to continue to celebrate within the Christian community.

This research has identified eight implications, if reflected on and attended to, can enhance the practice of church and Pastors’ ministry to meet the spiritual needs of

AIDDs in their congregations:

The need for the church to understand, reflect, and redefine its mission in the world and live out its vocation as an inclusive community.

The church's history of meeting the physical and existential need of the underprivileged – the poor, the sick, and the marginalised – has also included those with developmental disabilities. The book of Acts, in 2:42-47 and 4:32-35, reveals the true nature and purpose of the church in the early times, with no discrimination, nor segregation or marginalisation of any member within the Christian community. The early church was inclusive in their teachings and practices. Acts 4: 32 states, "All the believers were one in heart and mind. No one claimed that any of his possessions was his own, but they shared everything they had."²⁴¹ In verse 34, it says, "There were no needy persons among them."²⁴²

Up until now, the church has yet to understand how AWDs express and experience their spirituality. For instance, when asked the research participants on how well are people with disabilities supported in the church. Emmnauel says: *"It is not really encouraging. The church should be different from what is obtained outside but the cases are similar. Some people even struggle with seats with a physically challenged person in church."* This means church must faithfully support everyone to fulfil their dreams and accomplish their goals as truly human persons. The church is called to

²⁴¹ New International Version, *Life Application Study Bible*, (Eastbourne: Kingsway Publications, 1991), 1939 & 1943.

²⁴² New International Version, 1943.

invite AWDs not as one of “them,” not other or alien, but part of the Body of Christ and affirm their identity as “fearfully and wonderfully made.”²⁴³ The church should not only include AWDs but also welcome them as bonafide members of Christian communities and made to feel so. This will involve freedom to interact fully with their fellow church members and actively participate in the worship life of the community. Creig notes that “like many physically disabled persons, removing barriers (both physical and attitudinal) and opening up access lie at the heart of their agenda.”²⁴⁴ For example, the church might need to modify the inbuilt environment or make some structural planning in architecture that can help facilitate the AWDs full functioning in the church.

The need for fellowship, friendship and belonging.

The role of fellowship, friendship, and belonging seems to be critical in the lives of the research participants. AWDs desire to have fellowship, to choose who they want to be friends with, and to belong. Emily, for example, exemplifies the role that friendship can play in the lives of AWDs through daily life sharing experiences. She says:

“I share my workplace and neighbourhood experiences with them [Sunday school members]. We laugh together . They encourage me when I am sad and remind me that everyone has their bad times. After the encouragement , we share the Word of God and I feel light.”(Emily).

²⁴³ Psalm 139:14 (New International Version)

²⁴⁴ Greig, 104.

The question then is when is the true friendship and belonging going to be fully embodied by the church? I believe for real friendship and belonging to happen for people with disabilities, (1) the faith communities must first be awakened to their spiritual responsibility, promote a more embodied vision of friendship and fellowship that is founded on true communion and solidarity, (2) the church must correct the faulty notion of personhood which is rooted in our ecclesiology and theological anthropology, the imagery of who we are as human beings and who we are as a church, hence the need for church theology to change, (3) access to place(s) of worship must be given an utmost priority by the church. Where there is no accessibility to worship space, it is a sign that people with disabilities are not wanted. Kabue points this out more clearly, “the evidence of this situation is the fact that up to the present time, very few churches are accessible to people with disabilities.”²⁴⁵ (4) Also, through an awareness of the treatment of people with disabilities in the church and the wider society, the Christian community can better address and resolve these differences focusing on both the theological and ecclesiological solutions.

I found out that the ability of AWDs for friendship and fellowship is their most valuable gift. This is important because both friendship and belonging are fundamental elements of human flourishing. Therefore, the church must stand ready to provide a place and space for AWDs to receive and share their gifts of friendship. This is very important because meaningful relationships, authentic friendships, and belonging to AWDs, are very significant, if not more important than access to church facilities.

²⁴⁵ Samuel Kabue, “Disabled people in Church and Society: A Historical and Sociological Perspective,” In *Disability, Society and Theology: Voices from Africa*, eds Samuel Kabue, Esther MoJoseph Galgalo, and C.B. Peter, (Limuru: Zapf Chancery, 2011), 15.

Reynolds explains that these reconstructions by the church “entails an ongoing process of deep welcome and hospitality that not only removes barriers to participation but cultivates participation and cocreation of life together among differences.”²⁴⁶

The need to meet the physical and emotional needs of AIDDs.

The need to meet the physical and emotional needs of AWDs is very significant. My research highlights how these needs affect the way the research participants were connected and experienced a true sense of belonging. Emily, for example, talked about her experience with her Christian friends.

She says: “when I was in a boarding secondary school, the church was not within the school premises. My friends hold my hands as a visually impaired person to guide my way to church. They also come to my room to encourage me on Sundays to go to church.” (Emily)

The research participants’ expression and experiences of physical and emotional supports they receive in their church resonate with the conclusion that Carter makes in that “congregations committed to promoting belonging in this area, the relationships and faith they encounter may just contribute to their own flourishing as a community.”²⁴⁷

The need for the church and Pastors to be intentional in meeting not only the spiritual needs of AWDs, but also their physical and emotional needs cannot be overemphasized. The church will need to define these needs practically and dialogue with AWDs about what changes they would like to see. This also means that the church

²⁴⁶ Reynolds, “Prophetic Belonging..,” 54.

²⁴⁷ Carter, “A Place of Belonging...,” 179.

will need to identify the resources that they need to effect these changes. For example, the church can provide some counselling support, regular visitation, and assistive technology tools and devices to make life easier to support AWDs quality of life.

The need for the Pastors to continue to affirm the spirituality of AWDs in their church.

There is the need for the Pastors to continue to affirm the spirituality of AWDs in their church, how they experience and express their spirituality, and how they can be supported in the most meaningful way. Spirituality may be the part of an individual that seeks meaning and purpose for human pain and suffering. Steven, for example, shared how the church responded to his moment of loss and grief. He says: “when I lost my dad, they all came to me, sat with me and encouraged me. They took turns to visit me. I was not alone.” Lancaster and Palframan in their work *Coping With Major Life Event* point out that finding meaning in an extreme life situations can be spiritually transforming.²⁴⁸

The Pastors must continually remind themselves of their obligation to provide compassionate care for all their brothers and sisters. They must through their teaching and preaching encourage individual members of their church to develop a culture of hospitality towards AWDs. Hospitality in Henri Nouwen’s view, is a paradigm shift from a place of hostility to a place of hospitality; it is a place of love, community, and

²⁴⁸ Brian Les Lancaster and Jason Timothy Palframan, “Coping With Major Life Event The Role of Spirituality and Self-Transformation,” In *Mental Health, Religion, and Culture*, June 2008. 4. <http://www.informaworld.com/smpp/title~content=t713437783>.

true friendship.²⁴⁹ Reynolds also add to the thoughts on the influence of hospitality in the lives of AWDs. He argues that true hospitality is when members of faith communities share God's hospitable love with one another in the most difficult circumstances, and being present with one another, and it is then that "hospitality can become a spirituality of relations that fuels practices of genuine belonging."²⁵⁰ These thoughts have value for encouraging behaviour that respect the dignity, recognizes, and celebrates the humanity of the disabled members.

The need to be intentional about how AWDs are participating in the church.

In my experience with the participants and other disabled people in the church, AWDs practice their spirituality through prayers, singing, Bible reading, retreats, and participation in the church liturgy (holy communion). Sadly, AWDs in various churches are still experiencing complete denial of access to the worship life of the church, to human connection, to social justice, and perhaps to economic resources. Some have been in this state for decades and centuries. AWDs are part of the same Body of Christ, yet perpetually tormented by persecution. In many churches today, adults with disabilities do not feel that they are "one in heart and mind" with their spiritual community, and regrettably, there are many "needy persons" among us. Today, the situation of AWDs in the church and Christian communities is of utmost concern.

²⁴⁹ Henri J. M. Nouwen, *Reaching Out: The Three Movements of the Spiritual life* (:Crown publishing Group, 1986), 1-7, <https://sichaconversation.files.wordpress.com/2014/03/reaching-out-with-footer.pdf>

²⁵⁰ Reynolds, "Prophetic Belonging," , 6.

Church and church pastors must be cognizant of the presence and active participation of AWDs in the church.

We must intentionally invite them through love and acceptance, instead of seeing their presence as unending prayers for their healing and deliverance. Organising services and socials that isolate disabled people is not acceptable. Kenny states that the common practice in many modern churches is “removing disabled people from their services through whispers and side-glances...pretending that befriending disabled people is a unique calling.”²⁵¹ AWDs should be treated as humans. The gorgeous rope of the choir, the fine set of musical instruments, and the beautiful array of public address system in our churches are all ceremonial and mere aesthetics. It may look as if the church is flourishing, but the reality is “no sermon or liturgy or song is more important than disabled people belonging.”²⁵²

The need for the church to connect with the stories, experiences, and challenges of AWDs.

In this study, I have had the privilege of listening to the stories of AWDs, the stories of care, love, acceptance, and at the same time the uncomfortable stories of hatred, resentment, and stigmatisation. Some AWDs who are in the church may be welcomed but do not feel accepted and included because nobody seems to understand and respect them for who they are. In this connection, I think of a youth diagnosed with

²⁵¹ Kenny, *My Body Is Not A Prayer Request*, 34.

²⁵² Kenny, 34.

ADHD who was raised in one of our local Baptist churches in Ibadan. I also think of my cousin who had cerebral palsy, with whom I lived for about 6 years, who had Christian worship with his parents on Sundays. How do we relate to such persons? Having worked closely with some Nigerian Christian families with disabilities, I observed that there are so many heated emotions which reflect intense bitterness and anger over their denial of full participation and involvement in their church life.

The need to understand and respect the spirituality of AWDs.

The spirituality of AWDs in this study, as expressed in their comments and stories sounds very much like the stories other people tell. As members of the One body of Christ our spirituality and spiritual needs are the same.

Every human being has a spiritual need to celebrate, mark significant moments, bear witness to truths learned about life, play, tell their story, grieve, mourn, lament, connect with the past, pray, make significant journeys, express themselves symbolically, seek purpose and meaning, ask ultimate questions, have a satisfactory way to think and speak about the beginning and the end of life, survive, flourish, experience longing and enjoy its satisfaction, relax, cope with life circumstances, be seen, be heard, have a name that's remembered, be part of a larger community, organize experience meaningfully so as to make sense of it, maintain human dignity, see the future as hopeful, and experience transcendence.²⁵³

All members with or without disabilities bring unique talents and gifts to the church. Validating and identifying the gifts they have and supporting them to use these gifts in the church is one of the ways to respect the rights and freedom of their choice to worship. The right to choose their own spiritual expression, practice their beliefs, and to participate in the religious community of their choice is one of the components of

²⁵³ Bellous & Clark, 2022, p. 1-12, citing Bellous, 2006, 2012.

human rights. To validate their spirituality is to expand the opportunity for them to express and make their choices, support them to actively being involved and participate in the life and activities of the church. This might require making a conscious effort to assess information about each member with regards to their strengths and possible areas of challenges. In addition, the church might need to identify the types of knowledge and skills the members need to participate in the worship life of the church.

The Implications for Reconstruction of Theology Informing Attitudes and Behaviour Towards Disabled Persons

In this section of my dissertation, I will be highlighting what has surfaced for me in my literature review of the experiences of disabled person in Nigeria; my reflection on the disability theologians that I have covered; and the recommendation from my study that sheds light on the actual experiences of disabled persons who were my participants.

Reflection from the experiences of AWDs and reconstruction of the church theology

In view of reflection from diverse experiences of AWDs from the Nigerian disability advocates, as a trained Nigerian Baptist Pastor, I have two concerns about the way Nigerian Christians deal with theological issues and the way scripture is being interpreted by some church leaders in Nigeria. I too struggle with some theological issues and biblical interpretations however the focus here is what influences the way one interprets the scripture and practices pastoral care ministry. First, is the concern for

Nigerians' religious worldview. Some church congregations most likely have some theological interpretations for their various experiences. For example, some Nigerians believe that disability is a consequence of sin or punishment from God. According to Ekebuisi, most church leaders have the opinion that the presence and membership of disabled persons in the church is a sign of spiritual weakness and prayerlessness on the part of the church in its inability to appropriate scriptures to deal with demons that are perceived to be the cause of such disabilities.²⁵⁴ To shift from this bad theology about disability to one in which disabled persons are seen, respected, and supported, the church would need to reexamine Paul's admonition to believers in Romans 12: 4-5 in which he uses 'body' as a metaphor to illustrate the unity of Christian believers: that we are one body already sanctified and not needing to change, and God's unconditional friendship is reflected in our friendship with one another.

My second concern is the training of pastors and some religious leaders. Most religious workers do not have adequate theological training and are deficient in their interpretation of the scripture. They teach bad theology to members of their congregations. For instance, there have been some misguided efforts by some church leaders to associate disability with 'abnormality' or sin. I suggest a more wholistic training for pastors. This wholistic approach can start from the pastors viewing theology from disability perspective which includes theological reflection, learning, and inclusive practices. For example, there is the need to introduce disability studies into the Baptist theological institutions' curriculum, and in addition bring disability discourses into Baptist conferences, associations, and pastoral meetings where pastors can relate the

²⁵⁴ Ekebuisi, *Perspectives on Disability*, 2016. 42.

theological stories, languages, and symbols in the scriptures to the experiences of disabled people in their congregations.

Reflection on the work of disability theologians

In view of the reflection on disability and spirituality from the works of Eiesland, Reinders, Swinton, I believe there a few suggestions to offer to a reconstruction of Christian theology and religious practices towards AWDs in the church and society. First, disability has nothing to do with sin or human rebellion against God, but rather it is part of the unique and various ways people with disabilities experience God's presence. Disability can also be part of the limits and vulnerabilities of God's good creation. For instance, I take my theology of disability and sin from what Jesus himself said when his disciples asked him about a man who was born blind: "Rabbi, who sinned, this man or his parents, that he was born blind?"²⁵⁵ Jesus's answer is "Neither this man nor his parents sinned... but this happened so that the work of God might be displayed in his life."²⁵⁶ The fact that someone has a disability does not make them a less human being or perhaps in Christian context, a distorted image of God. In my view of Christian theology, sin cannot be associated with disability because the link between both concepts is incompatible. I like how Thomas E. Reynolds, in his work, *Vulnerable Communion: A Theology of Disability and Hospitality*, reflects on his experience raising one of his children with a disability. He argues against the attempt of the church to justify its theology of God's goodness (theodicy) in the face of human

²⁵⁵ John 9:2 (New International Version)

²⁵⁶ John 9:3 (New International Version)

suffering particularly in their treatment of those with disabilities. He articulates the theology of welcome for people with disabilities in the church and urges theologians caution in their interpretation of the scriptures about God, disability, humanity, and other biblical concepts. Reynolds condemns the inhumane treatment of people with disabilities that characterizes the Christian community and reinforces hope for AWDs that are despairing about their place in the church and in the world. In his knowledge and personal experience with disabilities, Reynolds invites AWDs as well as non-disabled in the church to see God's imminence in their vulnerability as they continue in their search for meaning.²⁵⁷

Second, people with disabilities desire a need for connection and belonging. It is not just because it is a need in their lives, but more importantly because it is their right. I have learned from Swinton's work *Inclusion and Belonging* that a desire to belong "for freedom, choice, justice, and equality"²⁵⁸ can empower people with disabilities to achieve their full potential. I also adopt the four aspects of belonging (seen, connected, supported, and proud) advanced by COQUAL, a research organisation based in New York, to demonstrate the feelings that people with disabilities might have when they belong.²⁵⁹

Third, I believe that spiritual nurturing and deepening can happen for AWDs in the faith community when the church actively encourages and welcomes them to be involved and fully participate in both its spiritual and social

²⁵⁷ Thomas E. Reynolds, *Vulnerable Communion: A Theology of Disability and Hospitality*, (Grand Rapids: Brazos Press, 2008), 32.

²⁵⁸ Swinton, 5.

²⁵⁹ COQUAL, The Power of Belonging, Part 1.

life. For instance, promoting AWDs' gifts and inviting them to share and participate in music, singing, and perhaps in paintings and art works with collaboration of volunteer church members and leadership support, may well be an avenue for them to learn and understand what it means to be loved by God and to share this love with others. There is no doubt that spirituality is crucial in the lives of AWDs.

In summary, having considered spirituality and disability from the lens of contemporary theologians like Eiesland, Reinders, and Swinton, coupled with the works of Reynolds, *Prophetic Belonging* and Swinton, *Inclusion and Belonging*, their various accounts, experiences, and expressions hold possibilities for people who are impacted with intellectual and developmental disabilities in the faith communities.

However, Eiesland and Reinders' concepts are not, in my view, sufficient to promote the authentic inclusion and belonging of people with disabilities in the Christian community because one can be liberated and included and not feel welcomed or as one who belonged.

But when inclusion is fostered with friendship and fellowship, when one is seen to be a contributor and not a burden or liability, and when one is connected and not excluded, supported, and not marginalised by their community, the result can provide people with disability with a sense of belonging. This is what I have found with Swinton's work, *Inclusion and Belonging*, and this is what I have explored in my research work with AWDs in selected Baptist churches in Nigeria.

Human relationships, friendship, and connections are extremely important. They make us thrive and flourish. Spiritual experiences of AWDs matter.

Recommendations Provided By The Research Participants In This Study

Despite some positive experiences of AWDs in the church, there are still rising concerns and doubts as to whether the church actually represents the voices of persons with intellectual and developmental disabilities in their congregations. This was exactly the focus of my research, investigating the importance of spirituality in the lives of AWDs and how the church and pastors have supported or fail to validate these spiritual needs in their lives.

Four out of the seven participants drew attention to the role that the church plays in affirming and supporting their spiritual as well as their social needs and their recommendations for additional support. This is very significant because this role highlights their voices and echoes their unmet spiritual and other needs. The four participants James, Steven, Emmanuel, and Abednego asked the church to continue to provide a more robust and generous spiritual and social support network for them and other disabled people within the congregations.

“It will be a very good thing if the church organizes more of such programs {Revivals} to draw one from the distractions of life” (James)

We might need to do some aggressive disability awareness campaign because there are some things church leaders do not know.(James)

*Very few churches have sign language interpreters. There are only two of such in this city. Provisions should be made to make the church more accessible and participatory for everyone with disabilities.***(James)**

“The church can make the Bible readable for blind persons like me” **(Steven)**

“The church can create more time for me during the Bible study” **(Emmanuel)**

“The church can help me by making Christian music available on our phones so we can listen from time to time and feel encouraged whenever we are down.” **(Abednego)**

“Opportunity to hold the microphone to lead the praise songs, to read the Bible and to play some of the musical instruments. The church can create more opportunities and platforms to do these things.” **(Emmanuel)**

Limitations of the Study and Areas for Future Research

At the start of my study, the task of involving AWDs in my research seemed very daunting. The reason being that it was the first time hearing from AWDs how they express and experience spirituality in their lives, and the implications of these experiences in the way Baptist churches and the pastors practice their ministry to meet these spiritual needs. For both myself and the research participants, the research process was an uncharted territory. But eventually, the process became learning experiences for each one of us. However, there are a few limitations to this study. One, the research was limited to two Baptist churches of the Nigerian Baptist Convention in the south western Nigeria. I believe this is an issue with my research sample and selection. In the future,

AWDs participation in the research of this nature could be extended to other locations within Nigeria to provide a random sampling and to draw valid conclusions. This is because the unmet spiritual needs that AWDs experience within the Baptist congregations vary significantly and can be met when they are given the opportunity or platform to share their stories. Each AWDs have their unique story and the solution to their respective needs may not be “one size fit all.” Two, is the inability of the study to have equal gender representation among the research participants. In this study, it was only seven participants that participated in the research, and six of the seven participants were male. I believe from the sharing of the findings of this research within a larger Baptist forum, more opportunities can be opened for more female AWDs in other Baptist churches to participate in future research. Three, the results of (lessons learned from) this study will be shared at Baptist ministers’ gatherings such as Baptist convention, conferences, and associations to improve the way pastoral care ministry towards AWDs is being practiced within the Baptist congregations. And, the responses of the church and the pastors to participants’ voices could determine the practicality of implementing the recommendations put forward by the researcher and the research participants in this study. Four, there are very few prior research on the importance of spirituality in the lives of AWDs and this lack of previous studies on the topic of my research constituted the basis for limited literature review for my study. I believe these identifiable literature gaps could present the need for researchers in the area of church ministry and disability studies to further develop research in this area of study.

The Implications of this Study on my Practice of Ministry and Spiritual Journey

My experience in Pastoral ministries with AIDDs in the Baptist denomination in Nigeria is my motivation for doing this research. As a Pastor who has been in the Pastoral care ministry for more than two decades, I have come across ministry challenges with AWDs which have invited me to examine myself for insight, understanding, and knowledge on how to deal with those situations in my Pastoral ministry. For example, in 2004 I had an encounter with a new member of my church. He asked me about what I think about people with disabilities. I was shocked, speechless, and at the same time very helpless. Because I did not know the honest answer to his question at that time. This and several other encounters with AWDs had motivated me to search for knowledge, engage with their perspectives about who they are, their needs, and how to deepen my understanding on how best to provide pastoral care ministry support to them, hence the rationale for this study.

The findings in this study have implications in the areas of my pastoral care ministry practice and my spiritual journey.

Implications for my Pastoral Care Ministry Practice

This research study has identified a few implications for Pastoral care ministry practice. One, I having listened to and heard the participants talk about various spiritual needs in their lives during the research process, I have learned that paying attention to these needs are crucial and central to my Pastoral care ministry. Pastors need to start by listening to the stories of expression and experiences of faith and spirituality from people with disabilities and their families. Also, I have come to realize through this

study that issues and matters of concerns by the AWDs should be considered from their perspectives, not from my view or any other.

Two, in my ministry practices with AWDs, I have adopted a medicalized view of their disability, specifically that disabilities arise out of physical, not spiritual pathology. Disabilities represent complex health conditions that require medical treatments and rehabilitation always. My understanding was that the disability situation of AWDs will only need to be managed if there are no medical treatments to change the situation or in a worst-case scenario rehabilitated to fit into the society built-in environment. In this study, I have learned that constricting AWDs lives to just medical intervention is a violation of their inherent dignity, deep perversion of their human right, and their deprivation of their recognition as being part of human society.

Three, I will need to review my theology about God, sin, and disability. In my various spiritual experiences and encounters in the Baptist churches and a wider society, I view God as the creator of all things including human beings, and His love and kindness are seen demonstrated through all His creatures in their perfect and beautiful nature and variations. However, during my spiritual journey I have struggled with how to understand God's creation as perfect because some people have disabilities and others do not. Could disabilities possibly be an anomaly in God's creation or human consequence of sin? But through this study, I have been able to clarify through the works of disability scholars and through the shared stories of the that disability is not resulting from sin, rather it is the label or stereotype that people have about disability and people with disabilities.

Four, across my entire two decades of pastoral care ministry, I have viewed AWDs as having enormous potential and abilities but as being limited in how they use these gifts, probably because of their dependence on others, not only for care and support but also for meaningful quality of life. For instance, I have observed that often they struggle with how to have healthy relationships, maintain their physical health and wellbeing, choose their religious beliefs, and how to find and engage in employment. Through this study, I have been able to understand from the experiences and expressions of the during the interview that they are embodiment of gifts, talents, and great potentials with which they can contribute to the church and other human society.

Implications for my spiritual journey

As I am learning through this study, there are a few implications for my spiritual journey. One, I need to continue to believe that spirituality in the lives of AWDs is real and it matters. I believe exploring how individuals with disabilities understand and express their spirituality can help provide church ministers, including myself, with a new knowledge of human experience and change the way pastoral care ministry is being practiced with this population.

Two, I need to put their voices at the fore front in the practice of my Pastoral ministry. For instance, I will be asking and involving my research participants if they will be interested in participating in my future presentation about my research work on any platform in Nigeria. It is not just enough to hear about AWDs, their relationships and experiences of connection and meaning making, but also create forums where they can share their stories and consistently working with them and learning from them.

Three, I need to reflect on the values essential for me to uphold in my relationships with people in my daily encounters.

Four, through my interaction with some AWDs and their families in Nigeria, I understand that they are still unsure about their self identity and personhood (who they really are and their place in the church and the world). That I need to continue to work with and support AWDs and other disabled people in the church and a wider society.

Five, that I need to improve in my commitment to friendship with AWDs and also encourage pastors to become friends with all disabled people in our practice of pastoral ministry. I borrow significantly from my understanding of Reinder's theology of friendship 1) that God's friendship is consistent regardless of our human condition, 2) that our action or inaction does not alter the divine nature of God's love for humanity, 3) that our friendship with all people in the world is what makes us stronger and better, and it is in the expression of this friendship that we demonstrate our true spirituality to God and to others. Reinder's theology of friendship is indeed a wake-up call for me and other pastoral caregivers, and to all theologians in disability studies to consider the theology of friendship by focusing on our shared humanity rather than on human differences, and to invite people with disabilities for friendship or accept their friendship as they choose us to be friends with them.

In summary, the importance of spirituality, how AWDs express and experienced spirituality, within and/or outside the church, and how their spiritual needs can be met, has not been fully understood by the church and the pastors in their practice of the church and pastoral ministry. The findings of this study have suggested that:

One, the resistance (the conscious and unconscious barriers) from our Christian community towards AWDs is widespread, and the failure of the church to fully address it is longstanding. William Gaventa points out that being an accepted and a functional member of an inclusive community is what AWDs have envisioned.²⁶⁰ So, what theology and practices should the church and Pastor embody that are inclusive of AWDs? I suggest I John 4:7-8 as a liberational tool to rebuild a theology of friendship, love, and welcome by the church. Here is what 1 John says, “Dear friends, let us love one another, for love comes from God. Everyone who loves has been born of God and knows God. Whoever does not love does not know God, because God is love.”²⁶¹ As a model pastoral caregiver who advocates for the need for justice, acceptance, love, and respect for every member of the congregation, 1 John presents a new understanding and calls for a theological reform that addresses the needs of AWDs in the church. 1 John is telling believers to fully welcome, accept, and include other members of the body of Christ with themselves including those who vehemently oppose to what is not permitted. The role of the church therefore is to accommodate everyone and treat everyone as members of God’s family. Further, in 1 Cor 12:12, Paul states, “Just as a body, though one, has many parts, but all its many parts form one body, so it is with Christ.”²⁶²

Two, participants responses and suggestions that are provided in the study, if reflected and acted upon by the church and pastors, could open AWDs to opportunities

²⁶⁰ Gaventa, *Recovering Wholeness*, 247.

²⁶¹ 1John 4:7-8, New International Version.

²⁶² 1 Cor 12:12, New International Version.

for better access to the congregational life and make AWDs feel more connected to the Divine and others in the church. Reynolds, a theologian, and a father of a son with autism, in his work, *Invoking Deep Access: Disability Beyond Inclusion in The Church*, shares an incredible story of an AWDs who was rejected by the church priest to partake in the church communion because of his bodily impairment.²⁶³ Reynolds in his work pushes for greater access of disabled people to church life. He challenges the church community to welcome and accept those with differing bodies in a spirit of care, not as anomalous objects of pity to be manipulated, but as equal participating members in the Body of Christ. Reynolds advocates sharing of daily life together with AWDs, whereby the rejected receive their worth, respected, and “cultivating a barrier-free communion of vulnerable and caring mutuality that is created by all and for all in which people with disabilities are valued among others as contributing members.”²⁶⁴

Three, that through authentic welcoming and active participation of AWDs in the church, the church care ministry practices can be improved, and church leaders and workers can provide more spiritual support to people with disabilities and their families in the Baptist church ministries and a wider church ministry.

Four, that providing AWDs with the opportunity to share their personal reflections related to spirituality and belonging within the church congregations can inspire in them a future of hope and possibilities. It is also possible that by inviting and including AWDs, the church can provide space for them to explore what it means to

²⁶³ Reynolds, “Invoking Deep Access,” 212.

²⁶⁴ Ibid., 213.

express their unique gifts and passions, find friends in each other, and possibly be a specific support group beyond the church, and may attract new members.

Five, that there is an authentic and transformative experience when the church and the Pastors reflect more deeply on the importance AWDs place on their spirituality, how their gifts might be explored, and their needs responded to in the most positive way within and outside their church congregations.

Six, the church and congregations need to provide as many opportunities as possible within worship and the everyday life of the congregation so that people with disabilities can increase trust in God and enhance their receptivity to God, as facilitated by the people in the congregation, i.e., to trust God through the trustworthy and welcoming receptive behaviours of people in the congregation.

Seven, as the body of Christ we have to learn to see ourselves in one another. No matter who we are, what we look like, and how we worship, we are connected. The church holds within it a lot of differences and diversity, yet with more hopes and possibilities the church can be transformed and grow to be a better place for everyone. I like how Erik Carter describes the churches, “places of welcome, belonging, and contribution for people with disabilities and their families.”²⁶⁵

²⁶⁵ Carter, “A Place of Belonging,” 167.

Bibliography

- Akanle, Olayinka, and Adetayo Olorunlana. "Christianity, and Disability in Post-Colonial South-Western Nigeria." *Journal of Environment and Culture*, 11 Number 2, (March 2014): 30-44. <https://www.researchgate.net/publication/315715577>.
- Ai, Amy, L., and Crystal L. Park. "Possibilities of the Positive following violence, and trauma: Informing the coming decade of research." *Journal of Interpersonal Violence*, 20 (2), 2005: 242-249. <https://www.academia.edu/2432938>.
- Arskey, Hilary, and Peter T. Knight. *Interviewing for Social Scientists: An Introductory Resources with Examples*. London: SAGE, 1999.
- Aydogdu, B. Nuran. "Disability and Spirituality." *Spiritual Psychology and Counseling* 4, No.2 (June 2019). <https://doi10.12738/spc.2019.4.2.0072>
- Ayanrinola, Comfort. *Impactive Parenting: God Given Responsibility*. Ibadan: Baptist Press (Nig.) Ltd, 2013.
- Barry, Carolyn McNamara, Larry J. Nelson, Sahar Davarya, and Shirene Urry, "Religiosity and Spirituality during the transition to Adulthood," In *International Journal of Behavioural Deveelopment*, 34 (4): 11-324, April 1, 2010. https://www.researchgate.net/publication/240285664_Religiosity_and_spirituality_during_the_transition_to_adulthood
- Bellous, Joyce E. and Margaret B. Clark. *Thick Listening at Thin Moments Theoretical Groundwork in Spiritual Care*. TallPine Press: Edmonton, 2022.
- Bergold, Jarg and Stefan Thomas. "Participatory Research Methods: A Methodological Approach in Motion." *Historical Social Research*, (37) 4, 2012: 191- 222. <http://dx.doi.org/10.2307/41756482>.
- Borg, Marit, Bengt Karlsson, Hesook Suzie Kim, and Brendan McCormack, "Opening Up for Many Voices in Knowledge Construction." *FQS* 13(1), Art.1, January 2012. <http://nbn-resolving.de/urn:nbn:de:0114-fqs120117>.
- Boswell, Boni, Michael Hamer, Sharon Maureen Knight, Mary Glacoff, and Jon McCherney. "Dance of Disability and Spirituality." *Journal of Rehabilitation*, Vol. 73, No. 4, October 2007: 33-40. <https://www.researchgate.net/publication/287003272>
- Carter, Erik W. "A place of belonging: Research at the intersection of faith and Disability." *Review and Expositor* 113 no. 2, (May 2016): 167-180. <https://DOI:10.1177/0034637316637861>.

- Carter, Erik W., and Thomas L. Boehm. "Religious and Spiritual Expressions of Young People with Intellectual and Developmental Disabilities." *Research and Practice for Persons with Severe Disabilities*, Vol. 44(1), 2019:37-52.
<https://www.researchgate.net/publications/331227567>
- Carter, Erik. *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families and Congregations*. Baltimore, MD: Paul H. Brookes, 2007.
- Carter, Erik W., Elizabeth E. Biggs, and Thomas L. Boehm. "Being Present Versus Having Presence: Dimensions of Belonging for Young People with Disabilities and Their Families." *Christian Education Journal (CEJ)*, Series 3, Vol. 13, No 1, 2016: 127-146. <https://doi.org/10.1177/073989131601300109>.
- Centers for Disease Control and Prevention (CDC). *Developmental Disabilities*. Accessed, March 28, 2022.
<https://www.cdc.gov/ncbddd/developmentaldisabilities/index.html>
- Christian Blind Mission. *Disability, and the Women's Agenda: We Work to See Change Happen*, United Kingdom. Accessed March 29, 2021.
<https://www.cbm.org/news/news/news-2016/disability-and-the-womens-agenda-we-work-to-see-change-happen/>.
- Clinebell, Howard. *Basic Types of Pastoral Care and Counselling: Resources for the Ministry of Healing and Growth*, ed. Bridget Clare McKeever. 3rd ed. Nashville: Abingdon Press, 2011.
- COQUAL, "The Power of Belonging: What it is and why it matters in today's Workplace." *Centre for Talent Innovation*. Belonging series, Part 1, <https://coqual.org/wpcontent/uploads/2020/09/CoqualPowerofBelongingKeyfindings090720.pdf>
- Creamer, Deborah Beth. *Disability and Christian Theology: Embodied Limits and Constructive Possibilities*, An American Academy of Religion Book. New York, 2008; online edn, Oxford Academic, (1 Jan, 2009).
<https://doi.org/10.1093/acprof:oso/9780195369151.001.0001>, accessed 16 Nov. 2023.
- Creamer, Deborah. "Including All Bodies in the Body of God: Disability and the Theology of SallieMcFague," In *Journal of Religion, Disability, and Health*, Vol. 9 (4), 2005. <http://www.haworthpress.com/web/JRDH>
- Creswell, John W. *Educational Research Planning, Conducting and Evaluating Quantitative and Qualitative Research*. 4th ed. Upper Saddle River, New Jersey: Pearson Education, Inc, 2012.

- Creswell, John W. *Research Design, Qualitative, Quantitative and Mixed Methods Approaches*. 3rd ed. London: Sage publications, 2009.
- Crystal, Park, and Folkman, S. "Meaning in The Context of Stress and Coping." *Review of General Psychology*, 1 (2), 1997:115-144.
<http://dx.doi.org/10.1037/1089-2680.1.2.115>
- Danley, Karen sue and Marsha Langer Ellison. *A Handbook for Participatory Action Researchers*. Boston: Boston University Center for Psychiatric Rehabilitation, 1999.
- Darroch, Francine and Audrey Giles. "Decolonizing health research: Community-based participatory research and postcolonial feminist theory." *Canadian Journal of Action Research* 15, no 3, 2014: 22-36.<http://dx.doi.org/10.33524/cjar.v15i3.155>.
- Dearnley, C. "A Reflection on the use of Semi-Structured Interviews." *Nurse Researcher*. Vol. 13, No.1, (Feb. 2005):19-28.
<http://dx.doi.org/10.7748/nr2005.07.13.1.19.c5997>.
- Eiesland, Nancy. *The Disabled God: Towards a Liberatory Theology of Disability*. Nashville: Abingdon Press, 1994.
- Ekebuisi, Chinonyerem. "Persons with Disability and the Worship Life of the Church." In *Perspectives on Disability: A Resource for Theological and Religious Studies in Africa*. Edited by Samuel Kabue, Helen Ishola-Esan, and Isaac Deji Ayegboyin, Ibadan: Baptist Press Nig. Ltd, 2016.
- European Evangelical Alliance. *Disability, and the Church: Looking for a Theology of Inclusion*, June 2019. Accessed March 7, 2021. <https://www.europeanea.org/church/resources/disability-and-the-church/>.
- Ferreira, Maria Pontes and Fidji Gendron. "Community-based participatory research with traditional and indigenous communities of the Americans: Historical context and future directions." *International Journal of Critical Pedagogy* 3, no.3 (November 2011):153-168. <https://www.researchgate.net/publication/265404812>.
- Ferguson, Philip M. and Emily Nusbaum, "Disability Studies: What Is It and What Difference Does It Make?" In *Research and Practice for Persons with Severe Disabilities*, Vol 37, No 2, 2012, 70-80.
- Fisher, John. "The Four Domains Model: Spirituality, Health and Well-Being." *Religions*, 2, 2011:17-28. <https://sci-hub.sc/10.3390/rel2010017>.
- Finkelstein, Victor Berel, *Attitudes and Disabled People: Issues of Discussion*. *World Rehabilitation Fund*. International Exchange of Information in Rehabilitation, 1980: 6-8.

<http://disabilitystudies.leeds.ac.uk/wpcontent/uploads/sites/40/library/finkelstein-attitudes.pdf>

Folkins, Tali. “Church may create “envy” for People with Disabilities:Hiltz.” *African Journals*. February 5, 2018.

Galgalo, Joseph D. ‘Perfect God and Imperfect Creation: In the Image of God and Disabled,” In *Disability, Society and Theology: Voices from Africa*. Edited by Samuel Kabue, Esther Mombo, Zapf chancery: Limuru, Kenya, 2011.

Gardner, Leslie. *Towards a Spirituality of Research*, A paper presentation at St. Stephen’s College, Edmonton on July 13, 2022.

Gaventa, William C. *Disability and Spirituality: Recovering Wholeness, Studies in Religion, Theology, and Disability*. Texas: Baylor University Press, 2018.

Gaventa, C William, and David Coulter, *Spirituality and Intellectual Disability: International Perspectives on the Effect of Culture and Religion on Healing Body, Mind, and Soul*. New York: The Harworth Press, Inc, 2001.

Gomez, Wilfredo. “When Strangers Read My Body: Blurred Boundaries and the Search for Something Spiritual.” *Tikkun* 29, no.4 (2014): 41-42.
<https://doi.org/10.1215/08879982-2810134>

Gove, Walter R. “Book Review: The Cloak of Competence: Stigma in The Lives of the Mentally Retarded.” *American Journal of Sociology*. Vol. 78, No.3 (Nov., 1972): 723-724. <https://www.academia.edu/30452856>.

Greenwood, M. et al. Hear my voice: old age and disability are not a curse. A community-based participatory study gathering the lived experiences of disabled people and older people in Tanzania, 2016. Accessed July 9, 2020.
<http://www.sightsavers.org/voices-of-the-marginalised/>

Green, Laurie et al. “HELP for behaviours that challenge in adults with intellectual and developmental disabilities.” *Clinical Review*. Vol 64 (Suppl 2) April 2018:23-31
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5906788/pdf/0640s23.pdf>

Greig, Reimer Jason *Reconsidering Intellectual Disability – L’Arche, Medical Ethics, and Christian Friendship*. Washington: Georgetown University Press, 2015.

Hartley, Sally Diane and Mohammed Muhit, “Using Qualitative Methods for Disability Research in Majority World Countries.” *Asia Pacific Disability Rehabilitation Journal*, Vol.14 No.2, 2003.

Hassounch, Dena and Amana Alcala-Moss, and E. McNeff, “Practical Strategies for Promoting Full Inclusion of Individuals with Disabilities in Community-Based

- Participatory Intervention Research.” *Res Nurs Health*. 34 (3) (June 2011):253-265.
<https://doi.org/10.1002/nur.20434>.
- Hauerwas, Stanley *Suffering Presence*. Notre Dame, Indiana: University of Notre Dame, 1986.
- Heumann, Judith, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*. Boston: Beacon Press, 2020.
- Higgins, Micheal W. *Jean Vanier, Logician of the Heart*. Minnesota, Liturgical Press, 2016.
- Hosking, David L. “Critical Disability Theory” Paper presented at the 4th Biennial Disability Studies Conference at Lancaster University, Lancaster, UK, September, 2-4, 2008.
- Ikuomola, Adediran Daniel. “Socio-Cultural Conception of Albinism and Sexuality Challenges among Persons with Albinism (PWA) in South-West, Nigeria.” *IJAH*. 4(2), S/No. 14, (April 2015):189-208.
<https://www.ajol.info/index.php/ijah/article/viewFile/118908/108384>.
- Ishola-Esan, Helen Olomu. “Impact of the Remnants of African Worldviews on Perception of Pastors Towards Ministering to Disabled people in Nigeria.” *Journal of Disability & Religion*. 20:1-2, (2016): 103-118, DOI:[10.1080/23312521.2016.1152940](https://doi.org/10.1080/23312521.2016.1152940).
- James, William. *Varieties of Religious Experience: A Study in Human Nature*, Centenary Edition. Routledge Taylor & Francis Group, London, 2002.
- Kabue, Samuel. “Disabled people in Church and Society: A Historical and Sociological Perspective,” In *Disability, Society and Theology: Voices from Africa*, eds Samuel Kabue, Esther MoJoseph Galgalo, and C.B. Peter, Limuru: Zapf Chancery, 2011.
- Kenny, Amy. *My Body Is Not A Prayer Request: Disability Justice In The Church*, Michigan: Brazos Press, 2022.
- Koenig, Harold G. “Religion, Spirituality, and Health: The Research and Clinical Implications (Review Article).” *International Scholarly Research Network ISRN Psychiatry*, Volume 2012.
- Kovach, Margaret. “Conversational method in Indigenous research.” *First People, Family and Child Review*. 5 (1), 2010:40-48. <http://dx.doi.org/10.7202/1071291ar>.
- Krafft, Jane. *The Ministry to Disabled people*. Minnesota: The Liturgical Press, 1988.

- Cuddeback, Lorraine. "Becoming Friends : Ethics In Friendship and In Doing Theology," in *Journal of Moral Theology*, Vol.6, Special Issue 2, 158-179, 2017.
- Lancaster, Brian Les, and Jason Timothy Palframan. "Coping With Major Life Event The Role of Spirituality and Self-Transformation," In *Mental Health, Religion, and Culture*, June 2008. <http://www.informaworld.com/smpp/title~content=t713437783>.
- Liu, Eleanor X., Erik Carter, Thomas L. Boehm, Naomi Annandale, and Courtney E. Taylor. "In Their Own Words: The Place of Faith in the Lives of Young People with Autism and Intellectual Disability." *Intellectual and Developmental Disabilities* Vol. 52. No 5. (October 2014): 388-404.
<http://dx.doi.org/10.1352/1934-9556-52.5.388>.
- Lloyd, Vicki, Amanda Gatherer, and Sunny Kalsy. "Conducting qualitative interview research with people with expressive language difficulties." *Qualitative Health Research*, (December 1, 2006):1386-1404.<https://doi.org/10.1177/1049732306293846>.
- McCloskey, Donna Jo, Mina Silberberg, Jennifer Cook, Cheryl Drescher, Sarah Weaver, Linda Ziegahn. "Principles of Community Engagement." (2nd ed.) NIH, Publication No.11-7782, Last reviewed (June 2015): 1-19.
<https://www.atsdr.cdc.gov/communityengagement/pdf>.
- Marini, Irmo. "The History of Treatment Toward People with Disabilities." In *Psychosocial Aspects of Disability- Insider Perspectives and Strategies for Counsellors* (2nd ed.) by Marini Irmo, Graf Noreen M., and Millington Michael. (Springer publishing company: New York, 2017). DOI:10.1891/9780826180636.
- Manantenasa, Ralphyne R. "Disabled people in Madagascar." In *Disability, Society, and Theology: Voices from Africa*. Edited by Samuel Kabue, Esther Mombo, Joseph Galgalo, and C.B. Peter. Limuru, Kenya: Zapf Chancery, 2011.
- Meekosha, Helen and Russell Shuttleworth. "What is so 'Critical' About Critical Disability Studies?" *Australian Journal of Human Rights*. 15, no.1, November, 2009: 7- 9. <https://www.researchgate.net/publication/258919369>.
- Metzler, Irina. "A Social History of Disability in the Middle Ages: Cultural Considerations of Physical Impairment," in *Routledge Studies in Cultural History Early Twentieth-Century Medical Historians*. New York: Routledge, 2013.
- Miller, Patricia T. "Some Perspectives on Disability and Possible Pastoral Responses." In *Perspectives on Disability: A Resource for Theological and Religious Studies in Africa*. Edited by Samuel Kabue, Helen Ishola-Esan, and Isaac Deji Ayegboyin. Ibadan: Baptist Press, 2016.
- Miller, Ted R. "Grace and Love as Models of Inclusivity for People with Disabilities." In *Perspectives on Disability: A Resource for Theological and Religious Studies in Africa*. Edited by Samuel Kabue, Helen Ishola-Esan, and Isaac Deji Ayegboyin.

Ibadan: Baptist Press, 2016.

- Minkler, Meredith, Victoria B. Vasquez, Joanne R. Warner, Helen Steussey, and Shelley N. Facente. "Sowing the seeds for sustainable change: a community-based participatory Research Partnership for health promotion in Indiana, USA and its aftermath." *Health Promotion International*. 21, no. 4. (January 2007):293–300. <http://dx.doi.org/10.1093/heapro/dal025>.
- Minkler, M. "Community-Based Research Partnerships: Challenges and Opportunities." *Journal of Urban Health*, Vol. 82 No 2, Supplement 2, 2005: 1-9. doi:10.1093/jurban/jti034
- Nihilola, Emiola "Between Prosperity and Spirituality: A Theological Examination of the Perspective of the Church in the 21st century African Society," *Ogbomoso Journal of Theology* XI, no. 1 (December 2006): 28-41.
- Nouwen, Henri J. M. *Reaching Out: The Three Movements of the Spiritual life*. New York :Crown publishing Group, 1986.
- Olaniyan, Gabriel. "Societal Responses to People with Disabilities in Africa," In *Perspectives on Disability: A Resource For Theological and Religious Studies In Africa*. Edited by Samuel Kabue, Helen Ishola-Esan, and Isaac Deji Ayegboyin. Ibadan: Baptist Press, 2016.
- Olajide, Grace O. "Disability and Image of God," In *Perspectives on Disability: A Resource for Theological and Religious Studies in Africa*. Edited by Samuel Kabue, Helen Ishola-Esan, and Isaac Deji Ayegboyin. Ibadan: Baptist Press, 2016.
- Oliver, Micheal and Colin Barnes. *Disabled People and Social Policy: From Exclusion to Inclusion*. New York: Longman, 1998.
- Pain, Rachel, Sara Kindon, and Mike Kesby. "Participatory Action Research: Making a Difference to Theory, Practice, and Action." In *Participatory Action Research Approaches and Methods Connecting People, Participation and Place*, (New York, NY: Routledge, 2007). <https://doi.org/10.4324/9780203933671>
- Park, C., & Folkman, S. "Meaning in The Context of Stress and Coping." *Review of General Psychology*, 1 (2), 1997.
- Plante, Thomas G. and Allen C. Sherman. Research on Faith and Health: New Approaches to Old Questions." In *Faith and Health: Psychological Perspectives*. Edited by Thomas G. Plante and Allen C. Sherman. New York: Guilford, 2001.
- Pretorius, Stephan P. "Understanding Spiritual Experience in Christian Spirituality," *Acta Theologica Supplementum* 1 (1), (July 2014):147. <http://dx.doi.org/10.4314/actat.v1i1.105667>.

- Radermacher, Harriet and Christopher Sonn. "Towards getting it right: participatory action research (PAR) with an advocacy organisation", *The Australian Community Psychologist*, Vol. 19 No 1, May 2007. 61-73.
- Reinders, Hans S. *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics*. Grand Rapids: William B. Eerdmans, 2008.
- Reynolds, Thomas E. *Vulnerable Communion: A Theology of Disability and Hospitality*. Grand Rapids: Brazos Press, 2008.
- _____. "Invoking Deep Access, Disability Beyond Inclusion in the Church." *Dialog: A Journal of Theology*, Vol. 51, No 3, September 2012.
- _____. "Prophetic Belonging: Disability, Hospitality, and Being Church Together." *Spiritus: A Journal of Christian Spirituality*. Volume 23, Number 1, Spring 2023.
- Roche, Brenda. *New Directions In Community-Based Research*, TWI New Directions CBR, Report, Wellesley Institute, 3.
<http://www.wellesleyinstitute.com/wp-content/uploads/2011/11/newdirectionsincbr.pdf>
- Robinson, Laura. "The subjective experience of adults with intellectual disabilities who have mental health problems within community settings," In *Advances in mental health and intellectual disabilities* 10 (2): 106-115, Abstract.
<http://dx.doi.org/10.1108/AMHID-04-2015-0017>
- Rodriguez, Jeremiah. "why many advocates prefer the term 'disabled people' over 'people with disabilities.'" In *CTV News.ca*, published Wednesday, February 10, 2021. accessed December 6, 2023. <https://www.ctvnews.ca/canada/why-many-advocates-prefer-the-term-disabled-people-over-people-with-disabilities-1.5303797?cache=>
- Ryrie, Charles C *Biblical Theology of the New Testament* Chicago: Moody, 1959.
- Saidin, Khaliza and Aizan Yaacob, "Insider Researchers Challenges and Opportunities." In *Proceeding of ICECRS, 1 (2016)*: 849-854.
<http://ojs.umsida.ac.id/index.php/icecrs>
- Scarinci, Isabel C. "Planning and Implementation of a participatory evaluation strategy: A viable approach in the evaluation of community-based participatory programs addressing cancer disparities." *Eval Program Plann.* August; 32(3): 221–228.
Doi: 10.1016/j.evalprogplan.2009.01.001.
- Schneider, Barbara et al. "Communication Between People with Schizophrenia and Their Medical Professionals: A Participatory Research Project." *Qualitative Health Research*. Vol. 14; 2004.

Stone, Howard W. and James O. Duke. *How to Think Theologically*, 3rd ed. Minneapolis: Fortress Press, 2013.

Sue, Karen Danley and Marsha Langer Ellison. *A Handbook for Participatory Action Researchers*. Boston: Boston University Center for Psychiatric Rehabilitation, 1999.

Swinton, John. "Reclaiming Soul: A Spiritual Perspective on Forensic Nursing." In *Forensic Nursing and the Multidisciplinary Care of The Mentally Disorders Offender*. Edited by Kettles A, Robinson D. London: Jessica Kingsley Publishers, 1999.

_____. *Dementia: Living in the Memories of God*. Grand Rapids: Eerdmans, 2012.

_____. "From Inclusion to Belonging: A Practical Theology of Community, Disability, and Humanness." *Journal of Religion, Disability, and Health* 16, no. 2 (April 2012): 172-190. <https://www.researchgate.net/publication/254374391>.

_____. "Who is the God We Worship? Theologies of Disability: Challenges and New Possibilities." *International Journal of Practical Theology* Issue 14, no. 2 (February 2011). <http://dx.doi.org/10.1515/ijpt.2011.020>.

Swinton, John, Harriet Mowat, and Susanna Baines, "Whose Story Am I? Redescribing Profound Intellectual Disability In the Kingdom of God," In *Journal of Religion, Disability, and Health* 15:5-19, 2011. 5. <https://www.researchgate.net/publication/254374143>

Swinton, John and Elaine Powrie. *Why are we here? Understanding the Spiritual Lives of People with learning Disabilities* (London, UK: T&T, 2004), referenced in John Swinton, "From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness," *Journal of Religion, Disability, and Health* 16, no. 2 (April 2012): 175-176. <https://www.researchgate.net/publication/254374391>

Shilling, Chris. "The Body as a Project." in *Sociology Themes and Perspectives*. (7th ed) by Micheal Haralambos, London: Harper Collins Publications Limited, 2008.

Schneiders, Sandra M. "Spirituality in The Academy." *Theological Studies* 50, (December, 1989): 676-697. <https://doi.org/10.1177/004056398905000403>.

Shiriko, Joseph. "Disability: Social Challenges and Family Responses," in *Disability, Society and Theology Voices from Africa*, eds., Samuel Kabue, Esther Mombo, Joseph Galgalo, and C.B. Peter Kijabe: Kijabe, Printing Press, 2011.

Tacey, David. *The Spirituality Revolution, The Emergence of Contemporary Spirituality*. Hove and New York: Brunner Routledge, 2000. <https://philosophiatopics.files.wordpress.com/2018/10/david-tacey-the-spirituality-revolution-the-emergence-of-contemporary-spirituality-2004.pdf>

- Timpe, Kevin. *Disability, and Inclusive Communities*. Grand Rapids: Calvin Press, 2018.
- Tzounis, Efthymios, “Constructing and Deconstructing the Terminology of Spirituality: A Journey Back to the Greek Roots,” *Journal of Traditional Medicine and Clinical Naturopathy*, Volume 248, Issue 6, 2017. Abstract.
- The Duke Center for Spirituality, *Summer Research Workshop on Spirituality and Health*, Theology and Health, Duke University medical Center, Durham, NC, 2022.
- The Minnesota Governor’s Council on Developmental Disabilities, *Parallel in time: A history of developmental disabilities*. 2021.
<https://mn.gov/mnddc/parallels/four/4a/2.html>
- Vanier, Jean. *Being Human, Introduction*. Toronto: House of Anansi press Inc., 2008.
- Vanier, Jean. *Becoming Human*. New York: Paulist Press, 1998.
- Vis, Jo-Ann & Heather Marie Boynton.” Spirituality and Transcendent Meaning Making: Possibilities for Enhancing Posttraumatic Growth”, *Journal of Religion and Spirituality in Social Work: Social 27 (1-2) (June 2008):69-86*.
<http://dx.doi.org/10.1080/15426430802113814>
- Vijayan, Geethu “Disability Studies: A Path Breaking Approach in Literature,” in *The Creative Launcher*, Vol. 5, no. 6, 2021, Perception Publishing, India, 16.
<https://doi.org/10.53032/TCL.2021.5.6.03>
- Wallerstein, Nina, and Bonnie Duran. “The Theoretical, Historical, and Practice Roots of CBPR.” *Community-Based Participatory Research for Health*, (January 2008): 24-46. <https://researchgate.net/publication/306452424>
- Weathers, Elizabeth, Geraldine McCarthy, and Alice Coffey. “Concept Analysis of Spirituality: An Evolutionary Approach.” *Nursing Forum*, Volume 51, Issue 2, 2015, 1-18. <https://doi.org/10.1111/nuf.12128>.
- Wilson, Shawn. *Research Is Ceremony: Indigenous Research Methods*, Winnipeg: Fernwood Publishing, 2008.
- World Bank Group. “Disability Inclusion in Nigeria, A Rapid Assessment.” *Social Analysis*, June 2020, <https://elibrary.worldbank.org/doi/abs/10.1596/34073>.
- Wadell, Paul J. “Pondering the Anomaly of God’s Love: Ethical Reflections on Access to the Sacraments.” In *Developmental Disabilities and Sacrament Access: New Paradigms for Sacramental Encounters*, ed. Edward Foley Collegeville, Mn: Liturgical Press, 1994.

- Wallerstein, Nina B. and Bonnie Duran. "Using Community-Based Participatory Research to Address Health Disparities," *Health Promotion Practice*, Vol. 7, No. 3, 312-323, July 2006. <https://journals.sagepub.com/doi/10.1177/1524839906289376>.
- Wallerstein, Nina and Bonnie Duran, "The Theoretical, Historical, and Practice Roots of CBPR," In *Community-Based Participatory Research for Health*, (January 2008), 25-46. <https://researchgate.net/publication/306452424>
- Wansbrough, Ann and Nicki Cooper. "Recognising All Members: The Place of People with Disabilities in the Uniting Church in Australia." *Journal of Religion, Disability, and Health*. Vol. 8, No. 1-2, (September, 2004): 145-165. https://doi.org/10.1300/J095v08n01_12.
- Wilson, Richard F. "Contextual Theology and Global Baptists," in *Contemporary Gospel Accents: Doing Theology in Africa, Asia, and Latin America*. Edited by Daniel Carro and Richard F. Wilson, Georgia: Mercer University Press, 1997.
- Wilson, Shawn, *Research Is Ceremony: Indigenous Research Methods*, Winnipeg: Fernwood Publishing, 2008.
- Yong, Amos. *Theology and Down Syndrome: Reimagining Disability in Late Modernity*. Waco, TX: Baylor University Press, 2007.
- Zhang, DongDong and Frank R. Rusch. "The Role of Spirituality in Living with Disabilities." *Journal of Religion, Disability & Health* 9, No. 1 (October 2008): 83-98, https://doi.org/10.1300/J095v09n01_06

Appendix A

Possible Research Interview Questions (Sample)

Research Study

Ethics Number: Pro00124056

Biodata

1. What is your name: first name and last name?
2. What is your gender? Male, Female or (Other- Please specify)
3. What is your age? 20-29, 30-39, 40-49, 50-59.
4. If you have a support person with you during the team meetings, who is that? Circle the one that applies – Mother, Father, Grandfather, Grandmother, Sister, Brother, Aunt, Uncle, Wife, Husband, and Health Care Provider.

a. The Interview (Sample)

This format is unstructured and hopes to be modified in collaboration with my Research Team before use. During the completed Pilot Project, I learned that the unstructured interview format that I used allowed the to learn and engaged in the research. None of the had been interviewed before, and none had conducted interviews. The team meetings provided them with the opportunity to have an idea of what questions would be asked during the interview. As the research progressed, they felt more confident and expressed themselves freely during the entire research process. Qualitative methods, such as unstructured interviews, are considered suitable for areas where “little research has been done.”²⁶⁶ The unstructured of interviews allows “all participants to be asked the same questions within a flexible framework”²⁶⁷ allowing (the interviewees) to narrate their experiences and explore areas of particular concern. It also allows the researcher to identify “patterns and relationships of meanings, as experienced and described by the participants of the study”²⁶⁸.

As we listen to what the participants are saying in the Research Team discussions, the Research will be getting ideas and suggestions about the kinds of words to use in the interview questions. The interview topics: spirituality as being connected, spirituality as meaningful relationships and trust, and spirituality as life meaning, with the follow up questions will be developed into the actual interview questions. The six questions are open-ended and relate to each other, with follow-up probes to draw out more information from the interviewees and might be helpful to try to encourage a lengthier conversation. Some of the probes are going to be focusing

²⁶⁶ J. W. Creswell, *Research Design, Qualitative, Quantitative and Mixed Methods Approaches*, 3rd ed., (London: Sage publications, 2009), 18.

²⁶⁷ C. Dearnley, “A Reflection on the use of Semi-Structured Interviews,” *Nurse Researcher*, Vol. 13, No.1, 2005,19-28.

²⁶⁸ Sally Diane Hartley and Mohammed Muhit, “Using Qualitative Methods for Disability Research in Majority World Countries,” *Asia Pacific Disability Rehabilitation Journal*, Vol.14 No.2, 2003,105.

specifically on the ways spirituality and belonging are important in their lives.

Possible interview questions on the importance of spirituality and belonging in the lives of AIDDs.

1. Tell me a story about a time when you felt very close to God. (Where were you? What were you doing? Who was there?). How important are times like that to you?
2. What kinds of things or activities help you feel close to God? How does your church help you to do that? What could your church do to make that feeling even stronger?
3. Tell me a story about a time when you felt that people really cared about you, accepted you for who you are, and wanted to be friends with you. (Where were you? What happened? What were you doing? Who was there?) How important are times like that to you?
4. What kinds of things or activities help you feel cared about and accepted for who you are? How do people at your church help you to feel like that? What do people at church do to be your friend? What makes you feel that they are your friends? (What kinds of things do you do together? Can you share good times with them and laugh together? What kinds of things do they do for you if you are feeling sad? How do they show you they care about you?)
5. Tell me a story about a time when you felt that you really belonged to your church. (What was happening that helped you feel that way? What were you doing? Who was there and what were they doing?) How important are times like that to you?
6. What kinds of things or activities help you feel like you belong at your church? What could people at church do to make that belonging feeling happen even more?

Appendix B



St. Stephen's College



Ethics Submission Pro 00124056

PARTICIPANT CONSENT FORM

Title of Study: The importance of spirituality in the lives of Adults with Intellectual and Developmental Disabilities (AIDDs) and how church and pastors can improve their ministries to meet these spiritual needs.

Principal Investigator

Dr. Leslie Gardner
St. Stephen's College
University of Alberta,
8810 112 St. NW,
Edmonton, AB, T6G 2J6

Research/Study Coordinator

Olutayo Stephen Shodipo
St. Stephen's College
University of Alberta,
8810 112 St. NW,
Edmonton, AB, T6G 2J6

You are being invited to take part in a research study. Before you take part, I will explain the project to you. I am happy to answer any questions you ask me about anything you do not understand. I will give you a copy of this form to keep.

Why am I being asked to take part in this research study?

I am asking you to be in this study because you are interested in what spirituality and belonging mean to people who have disabilities, and what it feels like to be part of the church.

What is the reason for doing the study?

The goal of this study is to find out about spirituality in the lives of adults with disabilities, and how the church can improve its ministries to meet these spiritual needs.

I will ask questions about spirituality and feeling connected during a series of Zoom meetings with you. I am asking these questions so that I can tell the church what you have to say without naming you. This information might help the Baptist church to improve the ways it offers spiritual support to people with disabilities and their families.

The result(s) of this study may help people know how disabled people feel about their participation in the church and how people can support them. The result(s) will also be used to finish my higher degree at St. Stephen's College, University of Alberta.

What will I be asked to do?

You will meet with me via Zoom and several other participants who will be with you in-person for 30 to 45 minutes, three times in a week. We may need more time in a second week if necessary. You can have a support person available during the group meetings.

You will work with me via Zoom and other research to develop questions that we want to ask each other, and to answer those questions when one of the research asks you.

I will train one of you via Zoom to ask questions and to also get responses to the questions asked, which will be audio-recorded. Together with me via Zoom that person will interview each of the other participants individually in a separate room about his or her experiences of spirituality and worship and what it feels like to be part of the congregation.

You will work with me via Zoom and other research in-person to look closely together at what the members have all said in response to each of our questions and pick out common themes. We will talk about the themes together and come up with ideas for congregations to support you in meeting your spiritual needs.

I will give you the interview questions before the scheduled interview. I will also be available by Zoom for any necessary support as we interview people together. The interview will take place in a comfortable location within your church building.

At the next Zoom meeting after the interview, I will read to you a written copy of your interview. I will ask you to tell me if you want to make any changes to what you have said and what is written down.

Once research have approved their own written copies, we will continue to meet as a research team in group meetings using Zoom to draw out the main ideas from what everyone has said. To help this, I will group important parts of research ' answers to our questions under each question. Research can talk about the answers and shift the parts of the answers around as we wish together. As we talk, it is likely that we will come up with ideas for things we may want to see changed.

What are the risks and discomforts?

You may feel a bit anxious or stressed if this is the first time you have been involved in research. If you are talking about some negative times and feelings about being part of a church, you may feel sad or upset. I will be there by Zoom to support you. I will also have a research assistant from the congregation whom you know who can follow-up after each Zoom meeting and support you if you need it.

I will be doing other things to help you feel less stressed, anxious, or upset. Here they are:

First, I will send someone in a car to pick you up from your home and bring you to our research meeting place, and then home again afterwards. I am doing this to avoid the stress for you of taking public transport.

Second, I want to help you to feel as safe and comfortable as possible during our group meetings via Zoom. So, I will ask you what type of support you may need to take part before, during and after our

meetings.

Third, I will be flexible and give us the time we need to finish what we are working on during our Zoom meetings. This will include the time to explain our research and to get your agreement to take part in the study. I will make sure we get lots of breaks. You can leave the study at any time if you want. I will make sure that your real name is not used in the study, and I will store the information you give me in a safe, and secure spot.

Fourth, I will welcome you as an important and valued member of the research team. You will take part in the decisions and activities at every stage of the research with me. You will develop the interview question with the research team and get a copy ahead of time before your own interview.

Fifth, I will ask you to stay home if you feel unwell, use face mask, and keep physical distancing wherever and whenever possible. Face masks will be provided on the meeting/interview site.

Lastly, I will be present during the group meetings by Zoom with the research team and the individual interviews. I will give you my name, my telephone number, and my e-mail address so that you can easily contact me. I will give you the same information about my supervisor. This is so that you can tell us if you have any concerns before and after your interview.

It is not possible to know all the risks that may happen in a study, but I have taken all reasonable safeguards to minimize any known risks to you.

What are the benefits to me?

This study may help you to speak out and use your voice to improve your own and others' lives. You can say what you think about how the church treats you. You can tell leaders of your church about your ideas and can suggest changes you think they should make, and they will not know who said it, unless you want them to.

You will meet other people with disabilities who may feel the way you do and might support you during and after the study. You may feel that you are part of a group who know and understand you. They are all dealing with similar issues that are important to you. After the study, the people who take part in this study might decide to keep meeting as a group to support one another and might even invite new people to join.

You may learn some new skills and activities about doing research. You may help other researchers know more about people with disabilities, and how researchers can improve their research.

When the study is done, St. Stephen's College will keep a record of the study. People who use the findings from the study may be able to help churches serve those who have disabilities in their congregations better, especially Baptist congregations of the Nigerian Baptist Convention.

It is also possible that you may feel no benefits to you in being part of this study.

Do I have to take part in the study?

No. Being in this study is your choice. You can choose to be a part of this research, or not be a part of this research. You do not have to answer any question if you do not want to. If you want to leave, you can. You do not have to say why you want to leave.

If you choose to be a part of the research, you will be working with me and other members of our

research team throughout the whole study via a series of meetings using Zoom. But, if you want to quit, you can do so at any time. You can withdraw your information during the training session or after, during the interview process or after, or during the review of the written copy of what you said. I will read the written copy to you and ask you to approve what is written down. You will have two weeks after that to withdraw your information from the study. Then, after the two weeks, what you said that is written down will not be able to be withdrawn from the study.

You need not contact me if you wish to withdraw your consent to participate in the study. However, to withdraw from the study you can contact me (Olutayo Shodipo or Leslie Gardner)

Will I be paid to be in the research? No

Will my information be kept private?

During this study I will do everything I can to make sure that all information you provide is kept private. I will not release any information relating to this study, including your real name, outside of my research office. I will not publish any information from this study unless you give me your express permission. Sometimes, by law, I may have to release your information with your name so I cannot guarantee absolute privacy. However, I will make every legal effort to make sure that your information is kept private.

I will audio-record and take notes during the interviews that will be done using Zoom. The written version of the audio- recording and notes will not include your name or who you are, so any quotes we use to illustrate our themes will not identify you. Only I will have access to the audio-recordings that will be stored on my computer, and only I will have the password to my computer. I will hire someone to make a written copy of each recording. When your interview is written down, I will assign a pseudonym (fake name) to protect your identity. If you would like to choose your own fake-name, please say so in the interview. If you would like us to use your real name, please indicate this on the signed consent form on the last page of this document.

What will happen to the information or data that I provide?

The information that you will share will be kept safe and will be used solely for the purposes of my doctoral work. The types of information I will collect in this study are:

- 1.The audio recording of the group meetings via Zoom and the interview with you via Zoom;
- 2.My own notes from our research team meetings, notes on our flip chart;
- 3.My notes I make during the interview with you via Zoom;
- 4.The research ' names and contact information which I need in order to keep in touch with you throughout our work together.

The only people who will have access to the information are myself and the research supervisor. On occasion, this data will need to be checked for accuracy. For this reason, your data, including your name, may also be looked at by people from the Research Ethics Board or by the University of Alberta auditors.

While I will strive to protect the confidentiality of the data, I cannot guarantee that others from the research team group will do the same.

The information you provide will form part of my doctoral research at St. Stephen's College, University of Alberta. It may also be used as part of public or academic presentations, in news or

academic publications, as well as for examples during teaching. At no point will you be identified in this work.

After the study is done, I will store your data for a minimum of five years, following the University of Alberta policy. With your consent, those written copies and the electronic data on a flash drive, will stay in a locked filing cabinet in my home office which is also locked. After the study, I will store the original recordings at St. Stephen's College, who will destroy them after five years. I will keep the written copies of the recordings and notes at home for five years after the study. Then I will destroy them.

What if I have questions?

If you have any questions about the research now or later, please contact me (Olutayo Shodipo or Leslie Gardner).

If you have any questions regarding your rights as a research participant, you may contact the University of Alberta Research Ethics Office at reoffice@ualberta.ca and quote Ethics ID Pro00124056. This office is independent of both me and my supervisor.

How do I indicate my agreement to be in this study?

By signing below, you understand:

- That you have read the above information and have had anything that you do not understand explained to you to your satisfaction.
- That you will be taking part in a research study.
- That you may freely leave the research study at any time.
- That you do not waive your legal rights by being in the study
- That the legal and professional obligations of the investigators and involved institutions are not changed by your taking part in this study.

SIGNATURE OF STUDY PARTICIPANT

Name of Participant giving verbal consent

Pseudonym (if necessary)

Name of Participant giving written consent

Pseudonym (if necessary)

Signature of Participant

Date

NAME & SIGNATURE OF PERSON OBTAINING VERBAL AND WRITTEN CONSENT

Name of Person Obtaining verbal and written Consent

Contact Number

Signature of Person Obtaining verbal and written Consent

Contact Number

SIGNATURE OF THE WITNESS

Name of Witness

Signature of Witness

Date

A copy of this information and consent form has been given to you to keep for your records and reference.

Appendix C



St. Stephen's College



UNIVERSITY OF
ALBERTA

Letter of Invitation

Research Study

Ethics Number: Pro00124056

Date _____

Dear _____ (Research Partner's Name)

My name is Revd. Olutayo Shodipo, a Doctor of Ministry student at St. Stephen's College, University of Alberta, Canada. I am doing a study about the importance of spirituality in the lives of persons affected by disabilities, their spiritual experiences, and spiritual needs within their congregations.

I would like to ask for your help in selecting participants for my main study. I am asking for your help to select three participants with disability within your congregation who might be interested in being interviewed for this study.

The criteria for selection of the participants will be age range of between 20 and 55; with mild to moderate intellectual disability, possesses expressive language and the ability to understand what is being asked of them, and to communicate clearly in their responses in English. As needed or desired, the participants, who will become research working with me, can have a support person available at the group meetings but not for the individual interview, because of confidentiality. I would appreciate your making this selection by September 5, 2023, and passing on their name(s) to me, with their permission.

Once the research have been recruited and individual participants indicate their willingness to participate in the study, I will schedule a first meeting with the individual participants by Zoom to review the Information Letter and Consent Form with them, and ask them to sign the Consent Form, which will commence the research. The research will decide among themselves when and where the research meetings should take place.

My plan is to meet with you and other Research Partners via Zoom once at the beginning to describe the research to you and enlist your support and collaboration; and once at the end of the project to present the results and ask for your ideas and collaboration in communicating and disseminating the findings and recommendations for implementing any changes.

Thanks in advance for your kind cooperation.

Researcher:

Address _____

Telephone Number _____

Appendix D



St. Stephen's College



UNIVERSITY OF
ALBERTA

Confidentiality Agreement Form

Research Study: Ethics Number: Pro00124056

Project title - The importance of spirituality in the lives of Adults with Intellectual and Developmental Disabilities (AIDDs) and how church and pastors can improve their ministries to meet these spiritual needs.

I, _____, the transcriptionist for the above Project have been hired to transcribe from audio to written form the audio files provided to me by the Researcher, Rev. Shodipo, which will form the raw data transcripts for the Project.

I agree to -

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the *Researcher(s)*.

2. keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession.

3. return all research information in any form or format (e.g., disks, tapes, transcripts) to the *Researcher(s)* when I have completed the research tasks.

4. after consulting with the *Researcher(s)*, erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher(s)* (e.g., information stored on computer hard drive).

(Date)

(Print Name)

(Signature)

Researcher(s)

(Date)

(Print Name)

(Signature)

Appendix E - Demographics Table

Participants' Characteristics

Name (Pseudonym)	Disability	Age (20-59)	Gender	Educational Background/Status	Church Involvement
Abednego	Physical (Polio)	50-59	Male	Degree/ Current Vice Principal	Church Counselor
Emily	Visual Impairment	50-59	Female	Degree/Current School Principal	Deaconess/Sunday School Teacher
Emmanuel	Visual Impairment	30-39	Male	Certificate/Musician/ Sportsman	Church Musical Instrumentalist
Howfred	Visual Impairment	20-29	Male	Degree/Undergraduate Student	Children Teacher/ Interpreter
James	Physical (Polio)	50-59	Male	Degree/Retired School Principal	Deacon/Sunday School Teacher
Steven	Visual Impairment	40-49	Male	Certificate/Unemployed	Church Counselor
Ultima	Developmental	20-29	Male	Diploma/Undergraduate Student	Church Choir

Appendix F: Activity/Focus of each of the 10 meetings

Days	Persons Involved	Activity/Focus
Introduction	Researcher on Zoom, Research Partners, and seven research participants.	During the first (1hr – 1 hr 30 minute) meeting, the Researcher via Zoom welcomed each of the two participating congregations' pastors (Research Partners) and the seven research participants from the two congregational churches. I introduced the main project and what the steps will be each day of the meeting and answered some questions. One of the Research Partners decided to volunteer as a Research Assistant since the research participants will need someone to be physically present and to work with them throughout the whole research process. The research participants decided when and where they will be meeting. Some of the research participants suggested the meeting should be held at Cheshire School in Ibadan, and to start on September 13, 2023. All the research participants agreed! The meeting ended!
Day 1	Researcher on Zoom, Research Assistant, and seven participants.	During this second (1hr – 1 hr 30 minute) meeting, the Researcher via Zoom arranged introductions among the , familiarized them with the research steps, and described the possible roles they could be playing. Researcher read and reviewed the Information & Consent Form with the individually and copies of the consent form signed by the through the Research Assistant. The Research Assistant brought the consent form into the separate room and after the signed, he left the room. After everyone has signed the consent form, the Researcher via Zoom discussed with the in a group and shared possible roles the might be interested or prefer to play. The meeting ended.
Day 2	Researcher on Zoom, Research Assistant, and seven research participants.	During this Day 2 (1hr – 1 hr 30 minute) meeting with the research participants , additional clarification of the roles of interviewer and interviewee were provided as needed. The Researcher brought forward the points covered from last meeting and answer any questions. Researcher via Zoom shared his own personal story for connection and trusting relationship in a group meeting with all the seven participants . The topics for this meeting: spirituality as being connected, spirituality as meaningful relationships and trust, and spirituality as life meaning, and what those phrases feel like for them e.g. the difference between being just invited to some place vs. feeling welcome and that you belong. Researcher provided facilitation support: encouraged sharing information and assuring the research participants that they were in a safe place. I presented the six guided questions, that related to the topics already discussed, to the research participants for them to develop in a

		<p>group. They all reflected on the six guided questions together. The seven participants agreed to the list of guided questions, but Emily, Stephen, and James suggested additional two questions that capture the concerns and displeasure of persons with disabilities in the church. For example, Emily suggested the question, how well are people with disabilities accepted in the church? The two questions were added to the six guided questions. All the eight guided questions were approved as interview questions by the research participants . Researcher asked the during the group meeting for a volunteer to be trained as an interviewer. Four (Steven, Emmanuel, James, and Emily) indicated their interest in being trained by the Researcher as an interviewer but only one – Emily- was chosen among the others. Emily agreed and all the participants agreed! The meeting ended!</p>
Day 3	Researcher, Research Assistant, and seven participants.	<p>During this (1hr – 1 hr 30 minute), the meeting focused on the interviewer. These 30-45 minute session was audio recorded and transcribed. The meeting gave the interviewer the opportunity to learn how to interview another person for research purposes using the interview questions developed in the meeting Day 2. I modelled interviewing for the interviewer and facilitated the interviewer having the chance to ask the interview questions by herself. Training section and one-on-one interview with the trained interviewer (Emily) began in a separate room, while other research participants were in the group meeting area. Before the training started, Researcher asked Emily if she was okay to undergo the training, and if there was any question or concern, she has. She replied (No), that she was ready for the training! Then the training started with Emily via Zoom and audio recorded. The training was about the interview process and procedure: how, when, where, and what? For example, Emily was trained to conduct the interview in a separate room with each research participants , use the participants pseudonyms when addressing them during the interview, and to ask for their biodata.</p>
Day 4	Researcher via Zoom, Research Assistant, and seven research participants.	<p>This (1hr – 1 hr 30 minute) meeting focused on Emily (the trained interviewer) and the interviewees, two of the research participants– James and Steven. Both were interviewed by Emily one after the other in a separate room, used the eight interview questions for interview with James and Steven, while I facilitated via Zoom. Data were collected during the interview through audio recordings.</p>
Day 5	Researcher via Zoom, Research Assistant, and seven research participants.	<p>This (1hr – 1 hr 30 minute) meeting focused on Emily (the trained interviewer) and the interviewees – Howfred and Ultima, one after the other in a separate room, used the eight interview questions for interview with Howfred and Ultima, while I</p>

		facilitated via Zoom. Data were collected during the interview through audio recordings.
Day 6	Researcher via Zoom, Research Assistant, and seven research participants.	This (1hr – 1 hr 30 minute) meeting focused on Emily (the trained interviewer) and the interviewees – Emmanuel and Abednego, one after the other in a separate room, used the eight interview questions for interview with Emmanuel and Abednego, while I facilitated via Zoom. Data were collected during the interview through audio recordings. After all the interviews, the audio files were presented to the transcriptionist who transcribed from audio to written form. The meeting ended.
Day 7	Researcher on Zoom, Research Assistant, and seven research participants.	This (1hr – 1 hr 30 minute) meeting focused on raw data (transcript). Researcher on Zoom read the transcript and check with the audio to be sure what the research participants said is what is transcribed. Researcher read the written copy of what the research participants had said to them individually in a separate room and asked if they would like to make changes to what they have said. Each of them said they are okay with what was written down. The meeting ended.
Day 8	Researcher on Zoom, Research Assistant, and seven research participants.	This (1hr – 1 hr 30 minute) meeting focused on facilitating group analysis of the research data with the seven participants. I facilitated via Zoom the participants organising what was said grouped under each interview question from the data from the approved transcript and placing the responses from the seven interviewees under each of the respective interview questions. I asked them via Zoom to include relevant sections of the transcript that best illustrate the themes for them and to give the themes names. See Appendix C - Emerging themes and participant's responses. The meeting ended.
Day 9	Researcher on Zoom, Research Assistant, and seven participants.	This (1hr – 1 hr 30 minute) meeting focused on facilitating further participants' discussion. I put excerpts from the text for themes for each interview question for the participants to review them and discuss. For example, an excerpt of what Emmanuel says " <i>...sing praises to God. And whenever I have the opportunity to sit and meditate on the Word of God,</i> " from the data which falls under the theme " <i>expression of being close to God and its importance.</i> " During this process, the research participants flagged some recommendations that surfaced. (see page 145). The meeting ended.

Appendix G - Analysis Table

Table 3. Emerging Themes/Participant's responses

Common themes/ Participant's responses	Expression of being close to God	Importance of spirituality & belonging	Feeling welcomed	Feeling connected	Church supporting belonging
Emily (responses to)	Q1	Q1, Q2, & Q3	Q3, Q4, & Q5	Q4 & Q6	Q7 & Q8
Steven (responses to)	Q1	Q1, Q2, & Q3	Q3, Q4, & Q5	Q4 & Q6	Q7 & Q8
Emmanuel (responses to)	Q1	Q1, Q2, & Q3	Q3, Q4, & Q5	Q4 & Q6	Q7 & Q8
Ultima (responses to)	Q1	Q1, Q2, & Q3	Q3, Q4, & Q5	Q4 & Q6	Q7 & Q8
Abednego (responses to)	Q1	Q1, Q2, & Q3	Q3, Q4, & Q5	Q4 & Q6	Q7 & Q8
James (responses to)	Q1	Q1, Q2, & Q3	Q3, Q4, & Q5	Q4 & Q6	Q7 & Q8
Howfred (responses to)	Q1	Q1, Q2, & Q3	Q3, Q4, & Q5	Q4 & Q6	Q7 & Q8