

**Beyond Welcome: What People with Intellectual Disabilities
have to Teach the Church.**

By Shannon L. MacLean

**A Graduate Project Submitted to
Atlantic School of Theology, Halifax, Nova Scotia;
in Partial Fulfillment of the
Requirements for the Degree of
Master of Divinity.**

March 25, 2019

© Shannon L MacLean, 2019

**Approved: The Rev. Canon Dr. Jody Clarke
Associate Professor of Pastoral Theology
Date: April 3, 2019**

Table of Contents

Certificate of Ethical Acceptability for Research Involving Humans	ii
Abstract	iii
Introduction.....	1
Literature Review.....	4
The Church and Disability	4
Re-defining Disability	7
Transformation from Walls that Isolate to Barrier Free Environments	9
L’Arche as an Example to the Church	14
Theological Framework	16
The Christian Church’s Role in the Exclusion of People with Disabilities	17
Theologies of Disability	18
The Body of Christ in the World Requires the Gifts of All Members	23
Research Question	26
Methodology	26
Data Analysis	30
Theme 1: Deep Rooted Spirituality.....	31
Theme 2: Call to Authentic Belonging	34
Theme 3: Worship For and By Everyone.....	37
Theme 4: Breaking Open Worship to All Ministries	40
Conclusions.....	43
Appendix.....	46
Appendix A: Letter of Invitation.....	46
Appendix B: Letter of Informed Consent	48
Appendix C: Research question: What People with Intellectual Disabilities Have to Teach the Church.....	49
Appendix D: Letter of Appreciation	51

Certificate of Ethical Acceptability for Research Involving Humans

This is to certify that the Research Ethics Board has examined the research proposal:

AST REB File number:	00082018
Title of Research Project:	What do Churches have to learn about helping people have a close relationship with God from people with intellectual disabilities
Faculty Supervisor:	Dr. Jody Clarke
Student Investigator	Shannon MacLean

and concludes that in all respects the proposed project meets appropriate standards of ethical acceptability and is in accordance with the Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans (TCPS 2) and Atlantic School of Theology's relevant policies.

Approval Period: 31 December 2018 to 30 April 2019
--

Dated this 2nd day of January, 2019 at Halifax, Nova Scotia.

Dr. Alyda Faber
Chair, Research Ethics Board
Atlantic School of Theology
660 Francklyn Street
Halifax, Nova Scotia
B3H 3B5

Abstract

“Beyond Welcome: What Do People with Intellectual Disabilities have to Teach the Church?”

Author: Shannon L. MacLean

“Beyond Welcome” is a Grounded Theory study that examines what people with intellectual disabilities have to teach the church. People with intellectual disabilities and those who have respectful and trusting relationships with them were interviewed. These research partners have all lived in L’Arche communities as core members or assistants and were involved in the leadership of L’Arche community prayer. They have also been involved in their own church congregation. Through the wisdom of these eleven research partners, four main themes emerged. The first is that people with intellectual disabilities are particularly able to model a deeply rooted spirituality. The second is that they call us to authentic belonging. This includes the wisdom that the church must let go of formality and the striving for perfection and instead focus on helping people experience that they belong and are the beloved of God. The third theme was that worship must be for and by everyone. Worship needs to include all voices in leadership roles. It also needs to engage all the senses by moving beyond just words. Finally, their wisdom revealed how the church can be transformed by creating time and space for the richness of the gifts of all people. Instead of trying to fit people into pre-cut holes, worship can be broken open to the Spirit by embracing the diverse; and sometimes non-traditional; ministries of all people. The Church is the body of Christ and we are all part of this body that is called to do the work of Christ in the world. This can only be accomplished if people with intellectual disabilities are fully included in the Church.

Introduction

At the very heart of Jesus's ministry were the most vulnerable of God's children. In the gospel of Matthew, Jesus says "Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me" (Mt 25:40).

Jesus was "constantly challenging the status quo and overturning assumptions about what normal is – refocusing community away from the centre towards the margin, welcoming the uninvited outcast as the honoured guest."¹ He turned the world upside down and he tore down walls. He valued those shunned by society.²

Jesus sought out people with disabilities, those who lived on the margins.³ However, people with disabilities have experienced being cast out, oppressed and excluded from the church because of their differences. Certain theological perspectives have led to the continued oppression of people with disabilities. Throughout Christian history, disability has often been interpreted negatively. It has been understood as punishment for sins, as a sign of lack of faith, or as a result of demonic possession. These views have created oppressive structures which were reinforced by societies - as well as churches.⁴

In 1 Corinthians 12, the apostle Paul shares the vision of the Church as the Body of Christ. And we, the diverse parts of the body, are all important and have our distinctive roles to play.

¹ The United Church of Canada, Theology and Inter-Church Inter-Faith Committee, "Report: Theologies of Disabilities." *United Church of Canada 42nd General Council (August 8-14, 2015, Corner Brook, Newfoundland)*, 604-613. under <https://commons.united-church.ca/Documents/What%20We%20Believe%20and%20Why/Disabilities/Theologies%20of%20Disabilities%20Report.pdf>, (accessed Oct 19, 2018), 612.

² *Ibid.*, 612.

³ *Ibid.*, 605.

⁴ World Council of Churches, "A Church of All and For All". Ecumenical Disabilities Advocates Network. Nairobi, Kenya (2003), under <https://www.oikoumene.org/en/resources/documents/commissions/faith-and-order/ix-other-study-processes/a-church-of-all-and-for-all-an-interim-statement>, (accessed October 19, 2018), 4.

When the voices and ministries of people with disabilities are missing from the church, the Church, as the Body of Christ in the world, is incomplete. The church is called to move beyond *welcoming* people with disabilities. We are called to move beyond constructing ramps and changing the physical accessibility of our buildings.⁵

A woman named Laura Dorwart made a poignant comment on Twitter. She said, “I notice so many places where (some) disabled people could participate passively, but not be leaders. Churches with accessible pews, but stairs to the pulpit; places for students to sit, but an inaccessible podium. Accessibility means leadership, not just spectatorship!”

Within the disability community, those with intellectual disabilities have traditionally been doubly marginalized. Although names such as “[i]diot, imbecile, moron, retard, the feeble-minded”⁶ have been replaced, the stigmatization has never been repaired. Even within the disability rights movement, the intentional exclusion of people with intellectual disabilities is still palpable.⁷

People with intellectual disabilities are particularly vulnerable in our society today. In my experience, they are also almost completely absent from any leadership roles within the church. Yet, some of the people who have taught me the most about God are people with intellectual disabilities. I was an assistant in a L’Arche community for most of a year in the 1990s. During that time I was transformed by the wisdom and spirituality of people with intellectual disabilities

⁵ The United Church of Canada, Executive of General Council, March 2013. “PCPMM 19 Open and Accessible: Ministries with Persons with Disabilities”, under [https://commons.united-church.ca/Documents/Governance/General%20Council%20Executive/GC40%20Executive%20\(2009-2012\)/Minutes/2012-03-24-26%20GCE%20\(pages%20449-490\).pdf](https://commons.united-church.ca/Documents/Governance/General%20Council%20Executive/GC40%20Executive%20(2009-2012)/Minutes/2012-03-24-26%20GCE%20(pages%20449-490).pdf), (accessed on October 19, 2018), 166.

⁶ Amos Yong. *The Bible, Disability, and the Church: A New Vision of the People of God* (Grand Rapids: Wm. B. Eerdmans Publishing Co., 2011), 96.

⁷ *Ibid.*, 96-100

with whom I built relationships. Thérèse Vanier, a longtime member of L'Arche, writes about the gift of vulnerability found in relationships with people with intellectual disabilities: "it is the particular powerlessness of people with mental handicaps which has the power either to touch and liberate hearts, or else disturb and destroy and thus oblige others to defend themselves, building barriers around their own hearts."⁸

In the community of L'Arche where I lived, we were intentional in discovering the gifts of everyone and how those gifts called each of us into our own distinctive ministries. It is for these reasons that people with intellectual disabilities are the focus of my project. This project is an exploration of what the church can do to live into what we are called to do: to hear the voices and the wisdom of people with intellectual disabilities.

There are many people with intellectual disabilities who are able to advocate for themselves, so why have I, a person who does not have an intellectual disability, chosen to research this topic? As I previously mentioned, I would not be who I am today had it not been for the mutually transformative relationships I have with people with intellectual disabilities. I became a mother when Julia and I became a family through adoption. Julia was three at the time she came to live with me and was diagnosed with a "significant global developmental disability".⁹ She is now an adult and one of the most successful people I know. Julia will likely never earn great wealth or hold much power in our society, but she has helped me to push back against the way our culture defines "success". Julia is the happiest, most helpful and content

⁸ Thérèse Vanier. *One Bread One Body: The Ecumenical Experience of L'Arche* (Leominster: Gracewing and Novalis Publishing, 1997), 4.

⁹ According to psychological and medical testing done at the time.

person I know. She has so much to teach people. And without her gifts, her ministry, the Church is poorer.

I have been called to a life of ordained ministry and as such, I want to help the church hear the voices and wisdom of people with intellectual disabilities. This project is one small way I can facilitate their voices being heard. It is not my story, it is theirs that I will share through this research.

Literature Review

There was little to no literature found on what people with intellectual disabilities have to teach the church. The church has focused on ministering *to* people with intellectual disabilities instead of *with* them. However, there are many areas of literature that are necessary for laying the foundation of why this is an overlooked but vitally important area of study. This literature review will start with the broad topics of church and disability. It will then look at various ways disability is defined. Next it will explore the transformation that is necessary to tear down the walls that isolate so that barrier-free environments may be created. Finally, the ground work will be laid to suggest L'Arche communities can be an example to the church in how people with intellectual disabilities are empowered to live into their ministries. This will give us the necessary foundation for beginning to ask the question: What do people with intellectual disabilities have to teach the church?

The Church and Disability

The World Council of Churches (WCO), 2003 report on the church and disabilities, "A Church of All and For All" says:

The church is by definition a place and a process of communion, open to and inviting all people without discrimination. It is a place of hospitality and a place of welcome. It is a

community of people with different yet complementary gifts. It is a vision of wholeness as well as of healing, of caring and of sharing at once.¹⁰

Yet this same report states that churches have not lived into what they are called to be. People with disabilities and their allies lament:

It is painful that the churches throughout the world have not addressed more vigorously the sufferings of the marginalized, poor, blind, and physically and mentally limited people. We do not need pity, or mercy, but compassionate understanding and opportunities to develop their vocations, possibilities and abilities.¹¹

At the 42nd General Council (2015) of the United Church of Canada (UCC), the Theology and Inter-Church Inter-Faith Committee spoke to many people with disabilities and created a report called “Theologies of Disabilities”. The problem was clear. As a person with a disability shared, “I have been bemused, saddened, and perplexed by the way our church has treated those like me, and has largely refused to hear that there is even a problem.”¹²

If there was a report card to grade how well the church supports people with disabilities, I am afraid that many, including the UCC, would fail. In 2011, the UCC conducted a National Identity Survey. It revealed that the 5.3% of the respondents who identified as a person with a disability, are less comfortable than their non-disabled peers in participating in events outside of regular worship. They also expressed discomfort in sharing their opinions with others in the church.¹³

The Ecumenical Disabilities Advocates Network acknowledges that we are on a journey: “from Jesus’ day until now, churches around the world “have often wrestled with how best to

¹⁰ World Council of Churches, “A Church of All and For All,” 16

¹¹ World Council of Churches, “A Church of All and For All,” 13.

¹² The United Church of Canada, “Theologies of Disabilities,” 604.

¹³ The United Church of Canada, “Open and Accessible,” 173.

exercise an appropriate ministry for, to and with persons with disabilities.”¹⁴ Being on this journey and welcoming people with disabilities into a place of worship, means we need to move beyond just welcoming them into our building by changing our structure to be physically accessible. It means creating a barrier-free environment where all are able to participate.¹⁵ Perhaps a scripture that can inspire churches is Isaiah 54:2 “Enlarge the site of your tent, and let the curtains of your habitations be stretched out; do not hold back; lengthen your cords and strengthen your stakes.”

In order to make this happen, churches may need to consider their rules, particularly the unwritten ones about what behaviours are and are not acceptable. These codes of behaviour need to be prayerfully discerned. For example, some people with intellectual disabilities love to sing out with joy and praise, but not necessarily following the same musical rules as others. Working with a congregation to view this as, at worse, a mild distraction (instead of unacceptable annoyance) is a step in the right direction.¹⁶ However, there are many other steps that must be taken.

The UCC historically has made attempts at being more intentionally welcoming to people with intellectual disabilities. The 27th General Council (1977) passed a resolution called, “The Handicapped and the Wholeness of the Family of God” that had previously been passed by the WCOC in 1975. This report stated that the church needed to include both “the disabled and the abled”.¹⁷ In 2008, *Welcoming Differences: Including Children Who Experience Challenges* was

¹⁴ *Ibid.*, 178.

¹⁵ The United Church of Canada, “Open and Accessible,” 166.

¹⁶ World Council of Churches, “A Church of All and For All,” 15.

¹⁷ The United Church of Canada, “Open and Accessible,” 174.

published for Sunday School teachers who had children with intellectual disabilities in their class.¹⁸ However, this type of literature is only helpful if it is accessible for use, and I was unable to find it on the UCC website or through a google search.

Still, strides are being made to be intentional in welcoming and involving people with disabilities as part of the church. In 2013, the Executive of the General Council approved the proposal put forward by the Permanent Committee on Programs for Mission and Ministry Communities in Ministry which affirmed that: “The United Church of Canada is committed to being an open, accessible, and barrier-free church, where there is full participation of persons with disabilities in the church’s ministry and mission.”¹⁹

Re-defining Disability

What becomes very unclear when talking about disabilities is defining what it actually means to have a “disability.” The category of disability is a broad one, one which encompasses a vast range of visible and invisible disabilities. People with disabilities are so much more than their disability. By labeling someone as disabled, we often fail to acknowledge that there are other aspects of their lives that “resist the ‘disability’ label.”²⁰

Throughout much of history, disability has been equated with loss.²¹ One common way disability is interpreted is as a “limit”. The UCC report, “Open and Accessible”, challenges the definition of limitations, because limits are social constructs. It states “the social model of disability brings us to the understanding that it is not the impairment that creates disabling

¹⁸ *Ibid.*, 173.

¹⁹ The United Church of Canada, “Open and Accessible,” 173.

²⁰ Yong, *The Bible, Disability, and the Church*, 9.

²¹ World Council of Churches, “A Church of All and For All,” 1.

condition, but rather the barriers encountered within our society that prevent full and equal participation for all.”²² For example, the inability to climb stairs could be seen as a disability. However, another interpretation is that it is society, not the person, who has created a limit. In a society without stairs this “limitation” does not exist.

The WCOC says the understanding of disability as a limit needs to be challenged because, after all, all people live with different limitations. People with disabilities also live with abilities that others do not have. God created a rich, diverse world, where each person is gifted in different ways.²³

An alternative understanding is to see disabilities as difference such as in the UCC “Open and Accessible” report: “Persons with disabilities are people who may move, see, hear, speak, and think differently from one another.”²⁴

Welcoming people with disabilities and their allies as full participants in churches have their roots in a theological imagination that understands disability neither as flaw nor defining characteristic, but instead as part of the variation that makes up our communities across the range of human experience.²⁵

The United Nations Convention of the Rights of Persons with Disabilities also says we must have respect for difference, since disability is one way diversity occurs in humanity.²⁶

We need to strive to see disability in this way, so we can become what the UCC report “Theologies of Disabilities” calls an inter-cultural church where relations that exclude are

²² The United Church of Canada, “Open and Accessible,” 175.

²³ World Council of Churches, “A Church of All and For All,” 5.

²⁴ The United Church of Canada, “Open and Accessible,” 174-175.

²⁵ The United Church of Canada, “Theologies of Disabilities,” 610.

²⁶ *Ibid.*, 606.

transformed and “differences become sources of energy, alternative visions of reality, and ways of moving beyond binary thinking into models of multiplicity, mutuality, and dialogue.”²⁷

Transformation from Walls that Isolate to Barrier Free Environments

In “A Church of All and for All”, the WCOC states that mainstream society has created “walls” to isolate people with disabilities. This is done through shame, prejudice, hatred, competition, fear, ignorance and theological prejudice and cultural misunderstanding.²⁸ And because of this, people with disabilities often suffer from both economic poverty as well as poverty of relationships and opportunities.²⁹ But we are reminded that Ephesians 2:14 emphasizes that Jesus came to tear down the walls that divide.

The church preaches that we are all born with gifts and inadequacies “in order so that God’s works might be revealed in us.”³⁰ Yet churches have not been prophetic voices against the oppression of people with disabilities. Often when societal advancements have been made, the churches were the ones following society, not the other way around.³¹ Leviticus 19:14 speaks of our role in supporting people with disabilities: “You shall not revile the deaf or put a stumbling block before the blind.” Yet a person with a disability shares their impression of the UCC by saying, “The church is behind, playing catch up and not leading. This saddens me, because of your history of fighting for social justice... This is a justice issue in our midst.”³²

²⁷ Ibid., 606.

²⁸ World Council of Churches, “A Church of All and For All,” 1.

²⁹ Ibid., 3.

³⁰ Ibid., 12.

³¹ Ibid., 4

³² The United Church of Canada, “Theologies of Disabilities,” 605.

The barriers created for people with disabilities are significant and have done incredible damage. This is particularly the case for people with intellectual disabilities as they can challenge and disrupt the accepted order in society.³³ Society's disregard for the value of people with intellectual disabilities is made shockingly clear when looking at the rates of abortion of fetuses with Down syndrome. In 2017, CBC News reported that Iceland had almost eradicated Down syndrome. In Iceland, abortions are permitted past the 16th week if the fetus has a deformity. Down syndrome falls into this category of "deformity".³⁴ In the United States, pregnancies are terminated at a rate of 19% but the rate of termination when prenatal testing suggests Down syndrome increases to an estimated 85%.³⁵ Jeanne Mancini, writing for the Toronto Sun, wrote, "A number of years ago, a medical student shared with me that his professor told students that they had a "responsibility" to encourage parents to terminate babies who receive a Down syndrome prenatal diagnosis. Likewise, many parents have written about the pressure to abort their children once diagnosed."³⁶ This suggests a failure of the medical community to consider all available scientific research as research has shown that people with Down syndrome have "very high levels of satisfaction in their lives" as do those who love them.³⁷

³³ Statistics Canada, "A profile of persons with disabilities among Canadian aged 15 years or older, 2012" under <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2015001-eng.htm> (2012): (accessed October 23, 2018).

³⁴ Julian Quinones, Arijeta Lajka, "What kind of society do you want to live in?": Inside the country where Down syndrome is disappearing." *CBN News Website* (2017), <https://www.cbsnews.com/news/down-syndrome-iceland/> (accessed October 20, 2018).

³⁵ Quinones & Lajka. 2017. "What kind of society do you want to live in?" *CBSN News Website* (2017) under <https://www.cbsnews.com/news/down-syndrome-iceland/> (accessed March 17, 2019).

³⁶ Jeanne Mancini, "Why are we trying to eliminate people with Down syndrome?" *Toronto Sun Website* (August 27, 2017), under <https://torontosun.com/2017/08/27/why-are-we-trying-to-eliminate-people-with-down-syndrome/wcm/61fc906b-9003-4f00-9a70-00b0989bd0b6> (accessed, March 16, 2019).

³⁷ Jeanne Mancini, "People with Down syndrome are happy. Why are we trying to eliminate them?", *The Washington Post Website* (August 24, 2017), under

In reality, many people with disabilities do not seek to be fixed, instead they seek the same opportunities as everyone else in sharing their gifts, skills and ideas.³⁸ What seems to stand in the way of people with intellectual disabilities participating in the church and worship is not their own impairments but the attitudes and assumptions others hold about them. It is often believed that they are to be ministered to, but not that they have gifts to offer others.³⁹ People with disabilities often require extra care and because of this they are interpreted as weak and objects in need of charity instead of contributing members of the community.⁴⁰

In the last few decades, there is evidence that the prevalence of positive attitudes in churches towards people with disabilities has increased.⁴¹ This new way of understanding church means honouring and engaging in difference and this involves risk and struggle.⁴² This risk includes re-imagining worship so people with intellectual disabilities are able to participate. For example, church leaders need to consider how words further divide those with and without disabilities. For example, how are the words in “Amazing Grace”, “I was blind but now I see”, heard by a blind person?⁴³ It means reimagining the use of words in worship; perhaps replacing the common response in prayer, “Lord, *hear* our prayers” to something that does not elevate the

https://www.washingtonpost.com/news/posteverything/wp/2017/08/24/people-with-down-syndrome-are-happy-why-are-we-trying-to-eliminate-them/?noredirect=on&utm_term=.1bfa4a9034a4 (accessed on October 20, 2018).

³⁸ The United Church of Canada, “Open and Accessible,” 180.

³⁹ Amy Julia Becker. 2018. “The Ministry of the Disabled: How Christians with Intellectual Disabilities Are Serving Churches (Not Just Being Served by Them).” *Christianity Today* 62, no. 4 (May 2018): 34–43. under <http://search.ebscohost.com/login.aspx?direct=true&AuthType=cookie,ip,shib&db=rft&AN=ATLAI58180507000402&site=ehost-live&scope=site&custid=s5315951> (accessed October, 2018), 42.

⁴⁰ World Council of Churches, “A Church of All and For All,” 4.

⁴¹ *Ibid.*, 13.

⁴² The United Church of Canada, “Theologies of Disabilities,” 607.

⁴³ World Council of Churches, “A Church of All and For All,” 14.

ability to hear like “Lord, *receive* our prayers”.⁴⁴ The church also needs to engage the other senses through worship since for some people words can be tiresome or confusing. Therefore, intentional development of the sensory experience in worship is vital.⁴⁵ It is only through changes in how disabilities are understood, that churches have been able to recognize the riches brought to the Church by people with disabilities.⁴⁶

In *Amazing Gifts: Stories of Faith, Disability, and Inclusion*, Mark I. Pinsky advocates that embracing people with disabilities needs to focus on transforming the beliefs of congregation members before the building.⁴⁷ The most important thing that a congregation can offer a person with a disability is the sacred gift of friendship.⁴⁸

Creating worship that can be experienced by all is important, but for people with disabilities to really feel welcome in a church, they need to see people like them in leadership roles.⁴⁹ Because without the presence of people with disabilities in our churches we are not complete: “Without the insight of those who have experience of disability, some of the most profound and distinctive elements of Christian theology are easily corrupted or lost.”⁵⁰

God’s word being heard through disabilities isn’t new. Moses was called by God to lead the Israelites, not in spite of his speech impairment, but *with* this disability.⁵¹ Bill Gaventa

⁴⁴ The United Church of Canada, “Webinar Series: Disabilities and the Church: Let’s Talk Disability and Diversity”, <https://united-in-learning.com/index.php/disabilities-and-the-church> (Webinar accessed live on March 12, 2019).

⁴⁵ World Council of Churches, “A Church of All and For All,” 14.

⁴⁶ World Council of Churches, “A Church of All and For All,” 5.

⁴⁷ Mark I. Pinsky, *Amazing Gifts: Stories of Faith, Disability, and Inclusion* (Hendon: The Alban Institute, 2012). xxiv.

⁴⁸ Pinsky, *Amazing Gifts*, 3.

⁴⁹ World Council of Churches, “A Church of All and For All,” 14.

⁵⁰ *Ibid.*, 7.

⁵¹ *Ibid.*, 11.

director of the Summer Institute on Theology and Disability, says, “We make a far too automatic assumption that disability means inability to contribute.”⁵² Gaventa points to a human desire to be givers, not just receivers, in the body of Christ. People with intellectual disabilities “have been equipped by the Spirit to contribute to the loving work of the church in the world.”⁵³ All people have been called to share their God-given gifts, and when people with intellectual disabilities are empowered to live into their individual ministries, the body of Christ is enhanced and strengthened.⁵⁴

In the Executive of General Council 2013 report “Open and Accessible: Ministries with Persons with Disabilities” it is admitted that the idea of focusing on ministries *with* people with disabilities is new: “What is new for the United Church is to create policy in this area, and to enable access, voice, and agency for persons with disabilities that facilitates the full participation of all in this church of ours.”⁵⁵ Julia Becker, author of “The Ministry of the Disabled” raises a question at the heart of this issue about the challenge and opportunities this presents for churches, “How to enable individuals with intellectual disabilities to participate fully in the life of their local churches so they can grow as disciples and ministers alongside their typical peers.”⁵⁶

We have waited too long to discover what people with intellectual disabilities have to teach the church about helping all people have close relationships with God. So now where can

⁵² Becker, “The Ministry of the Disabled,” 37.

⁵³ Becker, “The Ministry of the Disabled,” 38.

⁵⁴ *Ibid.*, 38.

⁵⁵ The United Church of Canada, “Open and Accessible,” 173.

⁵⁶ Becker, “The Ministry of the Disabled,” 41.

we start? The obvious place is with people with intellectual disabilities who are already living into their ministries within the L'Arche communities.

L'Arche as an Example to the Church

L'Arche began in France in 1964 when Jean Vanier chose to live out his calling from God.⁵⁷ Kathryn Spink writes in *The Miracle, The Message, The Story: Jean Vanier and L'Arche*, that Vanier had

the desire simply to live together, not as 'educators' and people with disabilities, but as sharers in a life of communion, highlighted by contrast the great gulf more often fixed in our divided world between the strong and the weak, the powerful and the vulnerable, the clever and the disabled, between those with a voice in human affairs and those with none.⁵⁸

Vanier's small community became an inspiration to others and a sign of a radically different way to live. It quickly grew into an International Federation, and today there are 149 L'Arche communities in 37 countries around the world.⁵⁹ Part of the Mission of L'Arche is to: "Make known the gifts of people with intellectual disabilities, revealed through mutually transforming relationships," "L'Arche demonstrates that when all people, including the most marginalized, take their place, society becomes more human – more colourful, welcoming, creative, compassionate, and joyful."⁶⁰

French theologian Christian Salenson says it would be logical to assume L'Arche is like other institution for people with intellectual disabilities that "define[s] itself primarily as an

⁵⁷ L'Arche Canada Website, "A Brief History of l'Arche" accessed October 29, 2018 , <http://www.larche.ca/about-larche/our-history>

⁵⁸ Kathryn Spink. 2006. *The Miracle, The Message, The Story: Jean Vanier and l'Arche* (Toronto: Novalis), 2.

⁵⁹ L'Arche Canada Website, "A Brief History of l'Arche" accessed October 29, 2018 , <http://www.larche.ca/about-larche/our-history>

⁶⁰ L'Arche Canada Website, "Mission and Vision", accessed October 29, 2018 , <http://www.larche.ca/mission-and-vision>

institution, equipped with an educational project and the necessary human resources that must be managed with authority.”⁶¹ But L’Arche is more than that, it is a community of faith where people are invited to come as they are.⁶² The L’Arche Halifax website states the following:

Unlike many agencies, which operate according to certain medical or social service models of care for persons with disabilities, L’Arche has pioneered a “community model” based on the belief that human beings develop their abilities and talents most fully when given the opportunity to form mutual relationships of friendship with others.

Within this community model:

- persons with disabilities are called “core members”, rather than “clients”, “patients”, or “consumers”
- those who assist them are called “assistants”, rather than “staff” or “counsellors”
- relationships based on friendship are considered to be as important as professional relationships in promoting the personal growth of persons with disabilities
- assistants generally live in the homes with core members just as they would live with any family
- everyone in the home—core members and assistants alike—is considered to be equally responsible for the life of the community⁶³

Christian Salenson says one of the things that makes L’Arche unique is that it expects core members and assistants to come to the communities as their whole selves, which includes bringing their past, their stories, religion and philosophical beliefs. Unlike other organizations where *professionalism* creates boundaries between the “staff” and the “clients”, foundational to L’Arche is that “[they] are open to and living in mutual friendships giving and receiving” as “we discover that mutual relationships change us.”⁶⁴

⁶¹ Christian Salenson, “Session: Faith Community” (lecture, L’Arche en France, France, November 29, 30, 2007).

⁶² Christian Salenson, “Session: Faith Community” (lecture, L’Arche en France, France, November 29, 30, 2007).

⁶³ L’Arche Halifax Website. “Being a Core Member”. Accessed on October 29, 2018 at <https://www.larchehalifax.org/get-involved/being-a-core-member/>

⁶⁴ Part of the “Servant Leadership Model” created by l’Arche Canada, 2014.

Theological Framework

The understanding that people with disabilities are part of the Church is well supported biblically. This theology of disability, inherent in the Scripture, means that following Jesus involves showing radical hospitality to everyone, regardless of their ability.⁶⁵

It is really only since the civil rights movement that people with disabilities have begun to name and challenge the normate⁶⁶ attitudes that have continued to oppress them.⁶⁷ The phrase “normate biases” refers to how people who are non-disabled define what is normal and therefore decide that everything unlike them is inferior.⁶⁸ This is so prevalent, that in biblical times, and still in the world today, people with disabilities have been considered to be “subhumans, menaces to society, or objects of pity, dread or ridicule”.⁶⁹ Unfortunately, this ableism is not just alive and well in the world, but also in the church.

Amos Yong wrote, *The Bible, Disability and the Church: A New Vision of the People of God* with the objective of transforming the way the church understands disability. He attempts to interpret what the Bible actually says about disabilities when read through a disability, as opposed to a normate, lens.⁷⁰ In the Bible, there is no biblical notion that is equivalent to how we use the term *disability* in the present day. Therefore, when he writes about the Bible he tries not

⁶⁵ The United Church of Canada, “Theologies of Disabilities,” 605.

⁶⁶ According to Yong, Rosemary Garland Thomson coined the term “normate” to mean the assumption that what is normal, and therefore superior, is non-disability. These normate attitudes evolve into prejudices, or normate bias, which results in people with disabilities being labeled as inferior. Found in Yong, *The Bible, Disability, and the Church*, 10.

⁶⁷ Yong, *The Bible, Disability, and the Church*, 11.

⁶⁸ Garland Thomas in Amos Yong. 2011. *The Bible, Disability, and the Church: A New Vision of the People of God*. (Grand Rapids, Cambridge: Wm. B. Eerdmans Publishing Co.), 10.

⁶⁹ Yong, *The Bible, Disability, and the Church*, 11.

⁷⁰ *Ibid.*, 8.

to use our present day understanding or normative assumptions when interpreting what the biblical authors actually intended to communicate with us.⁷¹

Even though there are many scriptures like Matthew 25:40, highlighting Jesus's preferential treatment of the marginalized and vulnerable, the Christian church has not always followed Jesus in this respect. In fact, there is a significant history of the church using theology to further oppress people with disabilities. For example, Christian people with disabilities reported to the WCOC that although they do feel united through God's love and the compassion Jesus showed to people who were sick and disabled, they report that the teachings they found in the church were too limited, and they have needed to find this understanding *outside of the church*.⁷²

The Christian Church's Role in the Exclusion of People with Disabilities

The WCOC report, "A Church of All and For All", addresses how the Church is called to include people with disabilities as valued and important members. The report laments that the history of the Christian church's treatment of people with disabilities has been, in many respects, devastating. Instead of the Christian church being the place of radical inclusion and acceptance that it has been called to be, the church has had many theological perspectives that actually led to the continued oppression of people with disabilities.⁷³ Yong agrees with this and states that normative biases have resulted in misinterpretation of what the Bible says about disabilities. This

⁷¹ Ibid., 12.

⁷² World Council of Churches, "A Church of All and For All."

⁷³ Ibid., 4.

has strengthened the ableist worldview that continues to marginalize, stigmatize, and exclude people with disabilities from our churches even today.⁷⁴

The UCC report “Theologies of Disabilities” was written in consultation with people with disabilities and speaks to the many theological messages perpetuated by the church which alienate some people with disabilities. For example, a mother of a child with a disability reflects:⁷⁵

I was told that God would not give me more than I can handle. I heard these opinions often, and for a young mother (of a child with disabilities) struggling with constant feelings of exhaustion, fear, and uncertainty these suggestions not only did it not “cheer me up,” but they engendered feelings of inadequacy and shame.⁷⁶

Many insensitive statements are made to people with disabilities and those who love them with the intention of making them feel better. However, they exclude people with disabilities from our communities and our churches, often without even realizing it. While this type of understanding about God might make the people who identify as non-disabled feel better, at the same time it has caused people with disabilities to feel unsupported.⁷⁷ These understandings of God, which cause people with disabilities to feel/be excluded from the church have the grave consequence of preventing the church from living out its call to be the body of Christ in the world.

Theologies of Disability

We know that all people face challenges in their lives. Yet somehow the challenges of those with disabilities are considered ones that need to be fixed. Although people with disabilities tend to live normal, satisfying lives, society often wants to “fix” them so they can be

⁷⁴ Yong, *The Bible, Disability, and the Church*, 17.

⁷⁵ The United Church of Canada, “Theologies of Disabilities,” 610.

⁷⁶ *Ibid.*, 610.

⁷⁷ *Ibid.*, 610.

*like us.*⁷⁸ But what about people for whom *curing* their *disability* would mean that they were no longer the same person at all? This would be the case for many people with Down syndrome or other intellectual disabilities. The healing stories of Jesus have sometimes been used to promote the idea that all disabilities need to be cured, as opposed to disability being understood as part of the diversity of God's creation.

In the Gospels, Jesus does not treat disability as a sign of spiritual need or punishment, however, this theological understanding has been clearly present throughout history in the church.⁷⁹ Many theologians would refute the idea that Jesus was healing people to "perfection". Instead they interpret Jesus's healings as wholeness and holiness, not necessarily cure.⁸⁰ Jesus's healings can be understood as an illustration of how people can be liberated; freed to live a richer life.⁸¹ This may or may not have necessitated the need to be cured of their illness or disability. The emphasis is placed on personal and social transformation!⁸²

When disability is defined as a social construct, healing can be interpreted as the removal of social barriers and the restoration of community instead of a cure. For example, when people had leprosy, they were banished from their community and all of the support that comes from being part of these interdependent relationships. In Mark 1: 40-45, the man with leprosy wants to be clean so that he can be restored to his community. In Mark 2: 1-12, the paralytic man was healed when his sins were forgiven, which removed the stigma associated with the cultural

⁷⁸ Yong, *The Bible, Disability, and the Church*, 13.

⁷⁹ The United Church of Canada, "Theologies of Disabilities," 612.

⁸⁰ The United Church of Canada, "Open and Accessible," 180.

⁸¹ World Council of Churches, "A Church of All and For All," 4.

⁸² The United Church of Canada, "Theologies of Disabilities," 612.

understanding that linked disability and sin.⁸³ This does not mean that these men were not also looking for a cure from leprosy or paralysis, but it demonstrates that they needed to be liberated from the social barriers erected because of their conditions.⁸⁴

Yong reminds us that there are stories in the Bible of people with disabilities who were not cured. Zacchaeus (Luke 19:3) was very short in stature and at this time, Parsons in *Body and Character in Luke and Acts* (p 99), says this would have been “generally seen in physiognomic terms as reflecting ‘smallness in spirit’.”⁸⁵ Yet, Jesus did not “cure” Zacchaeus of this disability but treated him like everyone else who needed to repent. Another example is the Ethiopian eunuch’s baptism by Phillip in the gospel of Luke. Although the eunuch has defects according to the Holiness Code (Lev. 21:17-23), he was not cured of these blemishes, but accepted just as he was in the coming reign of God.⁸⁶ These are powerfully subversive stories in Luke which support Yong’s statement that “people with intellectual disabilities are redeemed not by being cured of Down syndrome or other congenital conditions but by being just as they are, like Zacchaeus and the Ethiopian eunuch”.⁸⁷

If we are to follow Jesus, then we must recognize that Jesus sought out people living with disabilities and those who were marginalized. There is a theology of disability within Scripture. “It affirms that all are created in the image of God, and that all of God’s people are welcomed into the radical hospitality of Jesus, wherever they are on the spectrum of ability.”⁸⁸ Christians

⁸³ Ibid., 8.

⁸⁴ World Council of Churches, “A Church of All and For All,” 8.

⁸⁵ Yong, *The Bible, Disability, and the Church*, 67.

⁸⁶ Ibid., 67-68.

⁸⁷ Ibid., 103.

⁸⁸ The United Church of Canada, “Theologies of Disabilities,” 605.

are called to live in community. In order for this to happen, we must live counter culturally and rebel against the value society places on independence. We are called to something different. We are called to inter-dependence, so that we depend on each other and on God.⁸⁹ We are called to “Bear one another’s burdens, and in this way you will fulfill the law of Christ” (Gal 6:2).

“A Church of All and For All” it states, “Disabled people disturb notions of perfection, purpose, reward, success and status; they also disturb notions of a God who rewards virtue with health and prosperity.”⁹⁰ This is threatening to those who are striving for a perfection that does not include disabilities. It is threatening for churches that limit their understanding of inclusion to providing ministries *for* people with disabilities, instead of *with* them. Accepting a theology of disability may require letting go of previously clung to “theologies,” and struggling with a different understanding of God. This is not an easy transition, as theologies of disability may actually challenge people’s core beliefs about God and maybe even themselves. However, it is a vital transition if the church is to live into its part in working for God’s mission in the world.

In the first creation story in Genesis, God created the world and said it was “good”. God did not say that it was *perfect*. Much harm has been done to people who do not meet society’s definition of “perfect” or “normal”. God’s creation is both good *and* diverse. Churches need to work to remove social barriers as we restore our communities to diverse wholeness because “by welcoming one another as Christ welcomed us, we welcome the Divine.”⁹¹

I have never believed that my disability was a “gift from God” or God’s way of “testing” me. I find such ideas abhorrent and nauseating. [A]ll of my physical and psychological imperfections, visible and invisible in no way detracts from the light that shines in within

⁸⁹ World Council of Churches, “A Church of All and For All,” 17.

⁹⁰ World Council of Churches, “A Church of All and For All,” 11.

⁹¹ The United Church of Canada, “Open and Accessible,” 181.

me. I know I am made in the image of God. I have God's thumb-print on my soul. At my core I know I have been "fearsomely, wondrously made."⁹²

What would happen if churches really did started seeing disabilities as neither flaws nor blessings, but instead as just one of the ways diversity is present in humanity? What if we honoured the unique and different ways that God's image is revealed in each of us? After all, God called people with disabilities to lead in the Bible! Moses had a stutter and Jacob had a limp. They were not chosen because of their disability, but they do stand as examples of how God works through people with different gifts and abilities.⁹³

The Gospel of John (1:14) speaks of the Word becoming flesh in Jesus of Nazareth. Jesus was fully human, including the brokenness that accompanies our humanity. The resurrected Christ still displayed the human wounds he suffered during his execution (Luke 24: 36-39).⁹⁴ Christians look to Jesus to attempt to understand God, who is Holy Mystery. "A Church of All and For All" states, that because Jesus of Nazareth became the true image of God, Christian theology is called to be critical of success, power and perfection and instead uplift and honour weakness, brokenness and vulnerability:⁹⁵

As Christians, we worship a God who became flesh and hung motionless and utterly incapacitated on the Cross. Ours is a God of vulnerability and woundedness. Yet often, we choose to forego or forget the crucifixion, preferring to turn directly to the resurrection. Christ rose from the dead with His wounds. We too discover Him in our wounds, and we discern His presence in our vulnerability and in our courage to live the lives we have been given.⁹⁶

⁹² The United Church of Canada, "Theologies of Disabilities," 611.

⁹³ The United Church of Canada, "Theologies of Disabilities," 611.

⁹⁴ World Council of Churches, "A Church of All and For All," 11.

⁹⁵ *Ibid.*, 6.

⁹⁶ *Ibid.*, 11.

After Jesus's resurrection, he bore the scars that were signs of his vulnerability and suffering. This revealed that God suffered with humanity and this was displayed as a disability. Nancy Eiesland calls this the disabled God. "Disability is central to the life of God's own presence in Christ, revealing a new wholeness."⁹⁷ Each time we celebrate communion, we are reminded of Christ's damaged and disabled body when we remember his words from the Last Supper by saying: Take, eat; this is my body, which is broken for you. This theology of a disabled God, invites solidarity with people with disabilities.⁹⁸

The Body of Christ in the World Requires the Gifts of All Members

Yong shows how Paul's image of the Church being the body of Christ in 1 Corinthians 12 is deeply rooted in an inclusive theology of disability. He makes the case for the possibility that the apostle Paul had a disability himself, and so is speaking from a place of intimate understanding. This very interesting revelation can be explored further in Amos Yong's book *The Bible, Disability, and the Church: A New Vision of the People of God*. Yong links the theology of weakness with people with disabilities. Although he cautions us against interpreting weakness through an ableist lens. Yong says it is people with disabilities, especially those with intellectual disabilities, the most vulnerable among us, who are the weak and less honourable in this passage. However, the scripture actually says these members are not weaker, but "seem to be weaker" and are those that we "think are less honourable". This Pauline passage emphatically states that the "weaker" members of the body are not inferior but are equal to the other parts, and are also specifically named as conduits for the Spirit's gifts:⁹⁹ "God freely distributes the Spirit's

⁹⁷ The United Church of Canada, "Theologies of Disabilities," 612.

⁹⁸ The United Church of Canada, "Theologies of Disabilities," 612.

⁹⁹ Yong, *The Bible, Disability, and the Church*, 89 – 94.

charisms to *all* members of the body so that each one can contribute to the common good of the body.”¹⁰⁰ Because these gifts are distributed to all members, it means that people with disabilities are just as capable, if not more, of contributing to the ministry of their communities of faith. This is emphasized in the Scripture as the marginalized members are said to be given “greater honour” and are to be “treated with greater respect” (12:23).¹⁰¹

In “A Church of All and For All” Norma Mengel has this to say: “When any one of us, or a group of us, is excluded because of some lack of ability, we are prevented from using our God-given gifts to make Christ’s body complete.”¹⁰² The report continues:

Being in Christ is being the Body of Christ. This is essentially a corporate image; a body is made up of many members, all of whom bring different contributions to the whole (1 Cor 12, Romans 12). Indeed, the weak limbs (members), and even those body parts we are ashamed of and cover up (see the Greek of 1 Cor 12:23), are indispensable and are to be especially honoured, their essential contribution recognized. Christ was abused, disabled, and put to death. Some aspects of God’s image in Christ can only be reflected in the Church as the Body of Christ by the full inclusion and honouring of those who have bodies that are likewise impaired.¹⁰³

The Church “is called to embrace and affirm people of all levels of ability.”¹⁰⁴ Isaiah 56:7 says “for my house shall be called a house of prayer for all peoples”.

Without the full incorporation of persons who can contribute from the experience of disability, the church falls short of the glory of God, and cannot claim to be in the image of God. Without the insight of those who have experience of disability, some of the most profound and distinctive elements of Christian theology are easily corrupted or lost.¹⁰⁵

¹⁰⁰ Ibid., 94.

¹⁰¹ Ibid., 93-96.

¹⁰² World Council of Churches, “A Church of All and For All,” 7.

¹⁰³ Ibid., 6-7.

¹⁰⁴ The United Church of Canada, “Open and Accessible,” 179-180.

¹⁰⁵ World Council of Churches. 2003. “A Church of All and For All, 7.

We are called to celebrate the goodness and diversity of God's created world. We are called live into the theology presented by Apostle Paul and to be the Church through our inter-dependence and connectedness. It is only through the incorporation of people with disabilities into the life, work and ministry of the Church that we can fulfill our call to be the hands and feet of Christ in the world.

[T]he church is constituted first and foremost of the weak, not the strong: people with disabilities are thus at the centre rather than at the margins of what it means to be the people of God each person with disability, no matter how serious, severe or even profound, contributes something essential to and for the body, through the presence and activity of the Spirit; people with disabilities are therefore ministers empowered by the Spirit of God, each in his or her own specific way, rather than merely recipients of the ministries of non-disabled people. [P]eople with disabilities become the paradigm for embodying the power of God and manifesting the divine glory.¹⁰⁶

We must not only invite people with disabilities into our community but also empower them to share their contributions. The church is obligated to include people with disabilities in its work. The Pauline insistence that "the members of the body that are indispensable" (1 Cor 12:22) reminds us that people with disabilities must not be relegated to being passive recipients of the church's charity but empowered to use their God-given gifts to contribute to the body of Christ.¹⁰⁷

This is the foundational theological understanding of this grad project. The Church cannot be the body the Christ in the world without the gifts of people with intellectual disabilities. People with intellectual disabilities have not traditionally received the great honour and respect that we, the Church, are called to give them.

¹⁰⁶ Yong, *The Bible, Disability, and the Church*, 95.

¹⁰⁷ *Ibid.*, 109.

Research Question

A goal of this grad project, is to give voice to people with intellectual disabilities and explore what they have to teach the church. The voices and ministries of people with disabilities have been disregarded for long enough. From their voices and the voices of those who have built mutually transformative relationships with them, there are signs of hope as we all reconsider what it means to truly be the Church, the body of Christ in the world. My hope is that this will begin to shed light on the question: what do people with intellectual disabilities have to teach the church?

Methodology

The literature review revealed that there are no existing theories or answers to my research question. I did not want to begin with a hypothesis, or prediction of what answers I would receive. Instead, I was interested in seeing what themes would emerge solely from the data collected. The methodology called Grounded Theory asks a question and then looks for what the answer to that question is grounded, or rooted, in. Therefore, I used Grounded Theory as the qualitative research method for this study.¹⁰⁸

The participants, whom I shall call research partners, were not randomly selected but were a theoretical sampling of people. This means they all met the criteria I deemed necessary for this study. This criteria included people who live, or who have lived, in a L'Arche community in Canada. As well, half were people with intellectual disabilities, or core members, and half were assistants. Finally, all the people I interviewed have been involved in the

¹⁰⁸ John W. Creswell & Cheryl N. Poth, *Qualitative Inquiry Research Design: Choosing Among Five Approaches* 4th ed (Thousand Oaks: SAGE Publications, Inc, 2018), 82-90.

leadership of weekly community prayer at L'Arche and they have also attended church in the wider community. But that is where the similarities end. My research partners were both male and female, ranged in age, abilities, religious affiliation, and number of years they have lived in a L'Arche community. For reasons of confidentiality, I asked each research partner to choose a pseudonym which I will use throughout this paper.

Each research partner received a letter of invitation explaining the research project (Appendix A) and signed a Letter of Consent (Appendix B).

For this study, data was collected through five interviews, each of which included one core member and either one or two assistants, depending on the support that was required. I interviewed a total of 11 research partners: five core members and six assistants. Each interview lasted one to one and a half hours. Six questions were asked. Each question was broken down into smaller, more concrete questions to facilitate understanding. During the interviews, each broad question was asked, followed by the sub questions and then the broad question again to gain any information that had not been covered. The questions are attached in Appendix C. During these interviews, stories were shared by both people with intellectual disabilities (core members) and the assistants who have built respectful and trusting friendships with them.

Interview one: November 27, 2018 with "Hillary" and "Beth". Hillary is a core member who attended the UCC growing up and was confirmed as an adult. She stopped attending a number of years ago. She has been involved in planning community prayer, being part of a choir and doing mimes. Beth is an assistant whose work is focused on the spiritual life of her L'Arche community. She is very involved in community prayer at L'Arche, including supporting others in their leadership. She attended a very small UCC until four years ago. She left because it was

not meeting her spiritual needs. However, she did learn a great deal about leadership in the church.

Interview two: December 15, 2018 with “Drogon”, “Samwell” and “Tyrion”. Drogon, a core member, speaks in a language that is uniquely his. He grew up attending the Roman Catholic Church and still attends church occasionally, although it is no longer part of his regular routine. At community prayer he is an altar server when the priest officiates at Mass. He also has a pastoral ministry of welcoming and intentionally spending time with people during prayer. He participates in spoken prayer and sometimes in leading with sign language. Tyrion, an assistant, translated Drogon’s language for the interview. Tyrion is a long-time assistant at L’Arche. When he came to the community he had no religious background but now is a confirmed Roman Catholic who attends Mass and community prayer each week with his family. He often shares in the ministry of music at the L’Arche chapel and participates in a variety of leadership roles. Tyrion and Drogon were with me for the interview and Samwell joined us through Skype as he lives in a different province. Samwell was an assistant at L’Arche and lived and worked with Drogon a number of years ago. He was very involved in the spiritual life and leadership of community prayer at that time. Samwell grew up a Fundamental Evangelical Protestant but is now an active member of the Anglican Church. He also regularly attends worship in a Mennonite community.

Interview three: January 3, 2019 “Maria” and “Liesl”. Maria is a core member who is very involved in community prayer leadership and as a mentor in the community. She is part of a liturgical dance group and has been involved in most aspects of spiritual leadership in the community. She grew up attending a Missionary Alliance Church, which she still attends when she visits her parents, and although she seems happy to attend any worship experience, she most

regularly attends a Protestant Evangelical church in her community. Liesl is an ordained Anglican priest and a L'Arche assistant whose work is focused on the spiritual life of the community. She is very involved in community prayer and empowering others to fill leadership roles.

Interview four: January 4, 2019 “Ashley”, “Fred” and “Tyrion”. Ashley is a core member who strongly identifies as Roman Catholic. He attends Mass and community prayer religiously. At community prayer he is an altar server when the priest visits. He also is often called upon to share prayers with the community and to lead in a variety of ways. Tyrion was present as a local support for Ashley and Fred joined us through Skype. Fred was a member of this L'Arche community in the past and worked closely with Ashley in leadership of prayer. Fred is Roman Catholic but employed in the Anglican Church. He lives in another province with his family and continues his involvement with l'Arche there.

Interview five: January 8, 2019 “Marshall” and “Nana Mac”. Marshall is a core member who is involved in a vast array of aspects of the leadership of community prayer at L'Arche. She is a member of the Anglican Church and also sometimes attends meetings of the Quakers in her community. Nana Mac is officially retired from L'Arche as the spiritual life coordinator, but she is still involved in community life. She is trained as a lay minister in the Anglican Church and is active in her local parish.

Each interview was transcribed. The scripts were then coded using open coding, which begins to categorize the data into different categories, for example, the parts of script that spoke about worship needing to engage all the senses were categorized, as were parts of the script that spoke about where God is felt in community, and areas where core members could have helped lead in the church but didn't have the opportunity. It was imperative that any biases I had

remained bracketed, so that I was able to really hear what the participants were saying through the data. During this process, memos were made about how the categories were beginning to answer the question. The next step was axial coding to find connections between the categories and memos. This was the first attempt in finding the themes that emerged from all of the interviews in answering my research question. Finally, through selective coding, the essential themes that emerged from the data were determined.¹⁰⁹

My data analysis was shared with my research partners for additional feedback. At the conclusion of all research, a letter of appreciation (Appendix D) was sent to each participant.

Data Analysis

During these interviews, I heard stories of joy and triumph. I heard wisdom for the church and hope about the future, but I also heard stories of pain. Marshall, a core member, shared about feeling invisible in church: “If I walked into a room, people would pretend that they did not see me because I am different.”

The core members also spoke about the pain associated with lost opportunity. For example, Maria is extremely involved in the leadership of community prayer in her L’Arche community. She talked about her sadness at not being able to share her gifts by reading scripture in the church she grew up attending. She was turned down and told that they already had people doing all of the jobs and that she had enough to do at the L’Arche chapel.

Hillary identified that she thought she would be good at pastoral care and helping with the ministry of music. But she was never asked to be part of those ministries in her church. Marshall reflected on this further: “I think the churches are sort of set in a certain kind of way of

¹⁰⁹ Methodology based on John W. Creswell & Cheryl N. Poth, *Qualitative Inquiry Research Design: Choosing Among Five Approaches* 4th ed (Thousand Oaks: SAGE Publications, Inc, 2018), 82-90.

doing things. And I think a lot of work has to be done to make the church more accessible to people with exceptionalities.”

Ashley is active as an altar assistant and in various leadership roles at community prayer, but at church he isn't involved in any leadership. Although he said he would not feel comfortable asking the priest if he could be involved, he does desire it: “Well, I would like to someday. Probably some year”.

However, from their voices and the voices of those who have built mutually transformative friendships with them, there are signs of hope as we all reconsider what it means to truly be the Church, the body of Christ in the world. My interviews revealed four main themes.

Theme 1: Deep Rooted Spirituality

People with Intellectual disabilities have a spirituality that is deeply rooted within their identity. The assistants spoke of having to cultivate an awareness of God's presence in ordinary moments. However, the people with intellectual disabilities spoke of a different experience of faith. For them, it is not something that can be strengthened or weakened at different times, but it is deeply part of who they are and all they do.

When Ashley, a core member, was asked what his gifts are, he said he has a gift of “loving God”. Because of this, some of my questions were completely unfathomable to Ashley and left him confused. He seemed offended when I asked why prayer was important! And when I asked him, “when is a time you didn't feel close to God?” his response spoke volumes: “Oh no! God! I would never say that. No, no, no.”

An assistant, Fred, said that he is greatly affected by the faithfulness of the core members he has relationships with. He said, “Ashley's fidelity was a sign of a deep spiritual life and a life

of faithfulness.” He shared that any prayer spoken by Ashley “would start with gratitude. Every time.” For Fred, this acted as a reminder of “the simplicity of a life of faith that it needn’t be terribly complicated that closeness to God.”

Liesl, who is ordained and works at L’Arche, spoke about how a youth group she once brought to community prayer at L’Arche reflected in amazement at how the core members offered prayers from their hearts so freely: “They didn’t hold back and they didn’t worry about it.” They just offered what they had with their whole hearts.

Liesl and Maria were interviewed together. And Liesl shared that Maria brings an “awareness” of God into conversations and normal everyday activities. Maria is somebody who is often called upon to pray at community gatherings and she freely shares her deep prayers. Liesl spoke about how much she has learned from Maria’s deeply rooted spirituality. She said, “every time I listen to you Maria, I go WOW! You teach me something about prayer.” To which Maria nonchalantly responds, “My heart’s open I guess.”

Maria talked about God’s constant involvement in her life. Whenever she would quote a Scripture, she said things like, “That is the Spirit reminding me of the verses.” She spoke about living her life to make God happy and the constant presence of the Holy Spirit whispering in her life:

Maria: “It’s like a whispering like that,” (*she whispered*)

Shannon: “So what does the whispering say?”

Maria: “Come to me. Like, come to me. God is like this, whispering like this, so quiet.”

In L’Arche communities, the “come to me” is answered by all people. This can serve as an example to the church of what happens when people with intellectual disabilities share their diverse gifts and wisdom; when they are invited to lead. My research partners shared some of the things that are possible when the spirituality of people with disabilities is taken seriously.

The assistants that I interviewed spoke about their relationship with God and how their relationships with people with intellectual disabilities helped to nurture it. Beth said:

Someone asked me many years ago where did I see God? And certainly, it may sound a little sweet, but certainly in the faces of people. And usually in the faces of people who have suffered the most is where I see the face of God: in the bitten hands, in the scarred skin, in the torment of cry, that is where I have seen God. Because as saddened as it has been to watch that, I have also felt it in myself.

Tyrion shared:

When I came to this community and we would gather in the chapel... and particularly the moments of the prayer that were in silence - which is never silent with our group - but that sort of burbling silence that happens with a lot of people; you know people who can't be silent but are trying to create a sense of peace together and sitting quietly. And I would just sit and not necessarily think about what the prayer was supposed to be about but just think about all these people around me and their untold stories. And how different we all were from each other but how there was this moment, this moment of an attempt at unity and peace.

Samwell, who was interviewed with both Tyrion and Drogon, said that at L'Arche people are free in a way they aren't in other places. He said, "They are given the freedom to have a spiritual life. I think it is just revolutionary." He expanded to say that church isn't something that just happens on a Sunday morning, but faith was integrated into Drogon's daily life. Tyrion shared about Drogon's spirituality:

I remember Drogon's parents talking about how when he was a little boy, he would set up a table and do the whole Mass. You know, even as a little kid, he knew all the steps of the Mass and he cast himself in the role of the priest and he had sort of an imaginary congregation out in front of him and he would say Mass for them.

Liesl spoke about the unashamed way Maria shares her love with the people she lives with. She writes little reminders on cereal boxes so they find it unexpectedly, messages like "I miss you," "I love you," or "I care for you." This deeply rooted sense of God was sometimes expressed as a physical feeling by several of the core members, including Marshall, who said, "Often after I pray, I get a really warm feeling afterward."

Each interview ended with me asking the core member if they would like to say a prayer. The prayer shared by Maria was so touching and such a powerful example of this deeply rooted spirituality, that I will include the entire script:

Maria: OK. Let us pray.

Our loving heavenly father. I pray, Lord Jesus to be with – what’s her name?

Liesl: Shannon

Maria: Shannon. Just help Shannon in a very special way Lord. This is in a new venture for her Lord, a pastor, coming into pastor leadership, we pray Lord Jesus. You be with her. May you just guide you. I mean, may you with the Holy Spirit just guide her into this new role Lord Jesus at this time. Don’t make it too hard, just help her, dear Lord, to take one day at a time. Time to figure out how to do this. But you can lead her to things you never thought you could do but make it all easy for her Lord, dear Lord, just help her to understand what this is all about, dear Lord. This is very important in the church. Please help her Lord, she is new at this. Give her time dear Lord. It takes time, but you can help her, dear Lord. In your name I pray, Amen.

My partners gave powerful examples of how embodied, deeply rooted the spirituality of people with intellectual disabilities is. Although this gift is not exclusive to core members, within this study, what became obvious was how people with intellectual disabilities seem to be particularly able to share this gift with the church. And to remind the church of the importance of our call in helping people integrate their spirituality with all aspects of their lives.

Theme 2: Call to Authentic Belonging

The openness that was named as a gift of people with intellectual disabilities brings us to the second theme. Tyrion says “[there is] just a level of openness, you know, a level of sensitivity that I have learned from my relationship with people with disabilities and I think the church can learn that too.” One thing that emerged from these interviews, directly and indirectly, is that there is a gift that accompanies spending time with core members. That gift is the call to authenticity and the importance of belonging.

Tyrion, an assistant, talks about how people bring their whole selves to prayer at the L’Arche chapel. He says, “everything has to be a bit down to earth if people are going to

interrupt and talk and they are going to fart and somebody else is going to laugh at the fart, and you can't get too fancy. I appreciate that.”

What became evident in the words of my research partners is that to build a strong relationship with God we must be willing to be vulnerable enough to expose our authentic selves.

Samwell, who was an assistant at L'Arche for a number of years says:

I think there is Godliness in vulnerability. And often the way we connect to each other and we connect to God is through our own vulnerability and the way that God knows to be vulnerable. And people with intellectual disabilities are a living witness of that.

My partners spoke of the beauty in being around someone who freely acts out their joy - by dancing or someone who cries out when they are sad or expresses their agitation in church, seeking out someone else's presence and a gentle touch. When this happens, we all are reminded of our own authentic humanness. And it is within this vulnerable humanity where we build deep, extraordinary relationships with God and with each other. And that is the work of the church, right?

Samwell speaks about his relationship with a core member who I will call “Paul”,

Samwell says:

[Paul] comes to my mind a lot, [as] someone who just really shaped me. And I just think that being in relationship with him helped me to realize how vulnerable, I myself was. And that opened me to God in a significant way. And I think that is actually one of his gifts.

Beth shares that L'Arche has something to teach churches. She says she believes

churches are:

yearning for perfection in the presentation and we don't look for that here in community. We look for what you can give. We look for you to say yes. Somebody once told me there is no room for God in perfection. And ever since then it's sort of my mantra. Because my history has been one of wanting to do things in a way that there wasn't room for God. And so I have to constantly be alert to that.

Beth spoke about the connection between the freedom to be your true self and deep relationship with God. She talked about:

those unexpected moments of ministry [in church], when [someone] keeps putting her hand up because it is somebody's birthday in her house and she wants everybody to acknowledge that this individual is being celebrated that day. You know those unexpected [moments], which can often be interpreted as disruptive. But when people feel they belong, they are not interruptions, they are news announcements. They are sharings.

It is an extraordinary thing to feel like you belong, like you are LOVED for who you really are. The church is called to mirror this unconditional love of God, and my research partners spoke again and again of the importance for the Church to help people experience this feeling.

Throughout the interviews people spoke about how the experience of being loved, with all their gifts and challenges, has helped them on their faith journey. This feeling of acceptance and belonging was spoken about by core members and assistants. Nana Mac expanded on this important lesson for the church. She says "there were times when my church community hasn't really supported me in different ways, [however] I have been able to be who I am within the L'Arche community."

Beth spent her entire life going to church but she stopped a few years ago. She reflected further on this theme of authentic belonging and said, "I think for me, what I liked and what I needed from the church was a sense of community."

I don't know if the church has lost its sense of welcome, if it ever had a sense of welcome, but the church has to come up with ways of helping people know that they belong. That they are the beloved of God! [I]t is more than getting dressed up to go someplace on Sunday morning. That it's, it's about realizing that we are all special in God's eyes. And that I am no better than you.

People with intellectual disabilities call us into authenticity. My partners shared the wisdom that the church needs to let go of formality and the striving for perfection and instead

create space for God moments to break through in unexpected ways. Relationships with God are deepened when people feel that they belong and the church is called to help people experience being loved as their whole selves.

Theme 3: Worship For and By Everyone

Another theme that emerged from my research partners was about the importance of creating a worship experience that is for and by everyone. Hillary, a core member shared that church didn't meet her at her level:

I don't go to church [anymore] cause I find it, I don't know, I find it boring sometimes."... "maybe [church needs to] get more people involved. Maybe hav[e] sermons that are more exciting. And don't use big huge words that some people can't understand.

Beth, a spiritual life coordinator in her community, spoke about the richness of coming up with ways of engaging everyone. She says:

we attempt to be inclusive. So whether you have someone who might be hearing impaired, or someone who doesn't use words to communicate, whatever [it is], we are constantly challenged in looking at how we are able to include everyone who comes.

Samwell said that some core members, including Drogon, do not "live at the level of verbal language most of the time. But being able to mimic, and being swept up into the drama helps him to belong and helps him to be included and helps him to lead actually."

These changes to worship, to make it more experiential and engaging for all the senses, is not just important at L'Arche but in the church was well. It can be a rich experience for all people. Samwell said:

It's a bit like how curb cuts aren't just good for people who use wheelchairs but they are good for people who use strollers and use grocery carts and you know when you make something more accessible for a person, or a particular type of person, it works for lots of other people too.

Tyrion shared, “I don’t have much of an attention span for church services. So all the things we do to try and make things more understanding and appealing to people with disabilities, also work for me.”

Nana Mac expanded on the importance of worship being about more than words:

It is a lot of words, and not just for people with disabilities but I think for a lot of people. I am not a good word person, I tend to learn more from visual things. So I think the church has a lot to learn around doing that allows people to enter into worship that isn’t all books and words, but it is more visual or more tactile.

Through my interviews some very practical suggestions were made of ways to move beyond words in worship. Some of the ideas raised were:

- the use of songs that have actions or are short and repetitive – and therefore easy for everyone to learn and join in
- Beth, reflecting on the place of story in worship said, “Really good story engages people in ways that a very formulated sermon doesn’t quite hit, you know?”
- the intentional use of movement
- Nana Mac remembered a how meaningful the use of mime is. She recalled that Marshall had led a Good Friday mime that was “was absolutely beautiful and brought [everyone] to tears.”
- sign language can add a whole new dimension (even if just a few simple signs)
- PowerPoint or videos can be used as a visual reference or to illustrate the theme
- the incorporation of dance. For example, Maria is part of a group who helps to lead worship through dance. For example, at Liesl’s ordination service, her group danced to the song “How Can I Keep From Singing” as they processed the Gospel to the front

- creating space to be silent together: Samwell shared, “There is just something, especially when living with people who are non-verbal; sharing the silence together is really meaningful.”
- inviting everyone to light a candle, or giving everyone an object to hold, or participation in collaborative art

For some people, these non-verbal elements create an experience with God more than words ever could. Many of these are not new ideas, just an invitation to focus on the non-verbal elements in worship. There are already non-verbal parts of all worship services including the use of banners and liturgical colours. We stand and sit at different times. We light candles and shake hands or hug. We bow our heads or kneel in prayer. For some people, these non-verbal elements create an experience with God more than words ever could.

Communion was named as one of the experiences that can truly be shared in worship. Tyrion said, “I like the moments of quiet and contemplation that happen at church. The central thing for me is communion. And I interpret that word very broadly, but the bread and the wine specifically, as kind of the focus of that. I deeply appreciate that it is so tactile.” Tyrion has children with and without intellectual disabilities and he expressed that communion is deeply meaningful for him because it is a part of worship where all of his children “have exactly the same experience of communion as [he does].”

My research partners stressed how essential it is for all voices to be included in our churches. Unfortunately too often, there are some voices that are not heard! Nana Mac told a story of a young man with autism who does not communicate with spoken words who attends worship at her church regularly. She has a desire to include him in worship. She says, “I think there are ways of including him in the prayers because he has a board that speaks,” but she

laments “when he comes to church he doesn’t bring it with him.” This is an extreme example of a person’s voice being silenced in church.

Nana Mac spoke of the importance of, “involving [everyone] in planning [by rotating leadership].” She said, “And we try to have something [that] reflects on the theme that people can be part of it, whether it is sharing around a question, or whether it is a physical activity where you bring things forward and they becomes part of prayer.”

What became clear is that when worship is created by all voices it becomes a collaborative experience that is deeply meaningful for all involved. Tyrion says, “There is something about the prayer life that we share at L’Arche that when I go to a church service it just seems like it is black and white and the stuff we do at the chapel is in colour somehow.”³⁴⁵

Theme 4: Breaking Open Worship to All Ministries

Often churches try to find people to fill positions that already exist and need to be filled. So perhaps they are looking for a lay reader and ask people who might be good readers. I heard lots of stories about how people with disabilities were able to fill these important roles in churches, although not always in the traditional ways.

Samwell told a story about a time he and Drogon (who speaks in a language that is uniquely his) were attending church. Samwell was tapped on the shoulder and asked if he would be the lay reader. He and Drogon went forward together. Samwell said:

I would point to the book at the pulpit and Drogon would read. He would read it in his language. And then I would read it in my language. [He] was really involved and that was really meaningful for me. I think it was really meaningful for him, and also the people, it sort of breaks through. It just makes the service come alive in a new way when they see something out of the ordinary.

Tyrion spoke about how his son used to get in trouble each week for trying to pull the rope that rang the church bell. Eventually, the church appointed the role of bell-ringer to him! So

the very thing he once got in trouble for became his special job. Tyrion said, “People appreciate those things so much. They feel good about finding ways to incorporate people like that. Even if it is not done quite right.”

Nana Mac and Marshall shared about how it took a lot of time and convincing, but eventually Marshall was welcomed as a member of their Church Council. During her time on Council, Marshall was able to give a perspective that has often not been heard in their church.

There were lots of examples of how people with disabilities were able to share their gifts and fill these important roles within the church. But there was also the suggestion that we are actually doing this all backwards! Samwell says, “there is a more radical way, I think. That is allowing the service itself to change in response to the people that are involved, as opposed to slotting people into pre-cut holes.”

It is about looking beyond the ordinary and providing the time and space for the ministries of people with disabilities to change the church. Tyrion, a long term L’Arche assistant, said:

the things that most of the people who we know can do in church are pretty paltry. You know, to carry a plate up to the front or to pass out pamphlets at the back. To shake hands and say peace or to sing along. They are pretty small actions. And so the biggest ministry that people with intellectual disabilities can have in the church is the ministry of presence. And I think if they are present, if the church listens and searches for ways that they can become leaders and their gifts can be revealed, that the church will naturally kind of form around these people in a way that makes it a better church.

The richness that comes from inviting people to discern and share their God-given gifts with the church has the potential to break open worship services to allow people to truly experience the Holy Spirit.

Maria has a deep faith and never tires of learning ways she can be part of the body of Christ. She shared about being invited to participate in courses that had been specifically adapted

to suit to her learning style. This enabled her to learn about Alzheimer's, how to be an altar server, and pastoral care.

Beth spoke about joy in revealing a person's gift. The core members often spoke of the joy they felt when their gifts were revealed, gifts they did not know they had. Beth expressed that the same thing happens with assistants. Beth shared about the beauty in having a band who plays out of tune and off kilter but with so much joy. She says:

I think of [one core member], who now is such an important member of the band. He has his small drum and he knows exactly when he is supposed to play and he plays with great vigor and zest. There is no actual rhythm or tune to what he is playing but it is the look on his face. You know, "I'm doing it! I'm giving it my all!" We have other members who love to sing, who can't. But it just adds so much to what we do together. It is the intention that is put into revealing the gift, that's what it is all about.

Tyrion and Marshall spoke about the moment of connection that is created when people get up and dance during the last song in church, or when one of the core members starts conducting the whole congregation. Samwell expands further when he says:

That is breaking the service open a bit... and I think when a church can do that, allow it to break the formality a bit, or even allowing people with disabilities to have a radical voice. [It is a] deeper sort of inclusiveness. It isn't just that we are going to put a wheelchair ramp on but we are actually going to change the service so that you can thrive in it.

I was reminded of the importance of continuing to ask: inviting a person over and over until they believe that their gifts are truly welcomed and valued by the Church. Liesl shared a story about a group of people with disabilities who regularly attended and contributed to her church but had never been asked to attend the congregational retreat. After some conversation about why they had never been invited, one person said, "I mean, what do you think they are going to get out of it?" Liesl said, "I think I was a little surprised by her question. And then I said, well, what does anybody get out of a weekend like that? We get to be together, we get to pray together, we get to have meals and have fun. I think the same thing as everybody else does."

Tyrion shared a story about a core member, “Paul”, who often found it difficult to settle during worship. On one particular day, he was pacing at the back of the chapel during mass. He was repeating everything the priest said - something he often did when he was agitated. Tyrion shared that the priest:

finally burst out laughing and - he stopped the Mass, invited [Paul] to come up to the front, and they conducted the rest of the service together. [They] pretty much have done that since then. That is many, many years, whatever is going on, [Paul] is always at the priest’s side when he comes to say Mass. So it’s a deep story about inclusion there. Not just in the church but many realms of life, if people are not included and well supported, they disrupt the people around them. But when we find a way to have an active role, and for their gifts to be incorporated into the thing that we are sharing together, they add something instead of taking something away.

Conclusions

This project attempted to look beyond welcoming people with disabilities into our buildings to allow them to share their wisdom with the Church so that we may be the body of Christ in the world. In the Scriptures it says that in the body of Christ, those who seem to be weaker are indispensable: “But God has so arranged the body, giving the greater honor to the inferior member, that there may be no dissension within the body, but the members may have the same care for one another” (1 Corinthians 12: 24-25). The church still has a long way to go to turn this belief into reality, that people with intellectual disabilities have specific gifts to share with the Church.

We need to start by naming the systematic prejudices which build walls and create boundaries. We are called to challenge our “isms” and welcome the diversity of gifts that all, especially those on the margins of society, have to share. Although the church has taken steps in including people with disabilities, we still have far to go. One place to begin is by naming our prejudices; including the ones that we do not even know we have. Ableism is an insidious prejudice. It is possible to be judgmental without even being aware of it. Some of our prejudices

are invisible until we can see them in a new light. For example, in March 2018, Stephen Hawking died. He was called a visionary physicist and his children summed it up well when they said, “He was a great scientist and an extraordinary man whose work and legacy will live on for many years.”¹¹⁰ Soon after his death there were many cartoons drawn depicting him leaving his wheelchair behind; being *freed* from his disability. It was only after much advocacy that people with disabilities and their allies were able to demonstrate how *ableist views* lead to these cartoons. In an opinion piece, editorial cartoonist Daryl Cagle writes that Hawking spoke of not being able to make his contributions in spite of his disability, but perhaps because of it:

Hawking was an advocate for the rights of the disabled. He was quoted in Science Digest saying, “My disabilities have not been a significant handicap in my field, which is theoretical physics. Indeed, they have helped me in a way by shielding me from lecturing and administrative work that I would otherwise have been involved in.”¹¹¹

What was evident through these interviews was that people with intellectual disabilities are particularly able to share their deeply rooted spirituality with the church. They call us to expose our true authentic selves and remind us of the importance of the church helping people experience that they belong and are the beloved of God. Their wisdom revealed how the church can be transformed by creating time and space for the richness of gifts brought by all people. And that instead of trying to fit people into pre-cut holes... worship can be broken open to the Spirit by embracing the diverse, and sometimes non-traditional, ministries of all people.

This study demonstrates that there is much we can learn from people with intellectual disabilities. We all have unique stories and different gifts. The Church is the body of Christ and

¹¹⁰ BBC Website, (March 4, 2018), “Stephen Hawkins: Visionary physicist dies aged 76” accessed Feb 12, 2019.

¹¹¹ Noozhawk: The Freshest New in Santa Barbara, (March 19, 2018) Opinions: Daryl Cagle: Cartoonist Send Stephen Hawking Into the Universe. accessed Feb 12, 2019
https://www.noozhawk.com/article/daryl_cagle_cartoonists_send_stephen_hawking_into_the_universe_20180319

we are all part of this body that is called to do the work of Christ in the world. And that means that if we are to follow Jesus, we too must turn the world upside down, tear down walls and welcome the uninvited outcast as the honoured guest. We are called to value those who seem to be weaker or who we think are less respectable. We are called to include everyone, particularly those on the margins. Maria says it well: “We don’t want to leave them out because they are part of the family, aren’t they?”

This is an exciting time for the Church. Let’s embrace this wisdom and strive to transform our worships from black and white to technicolour. This is well summed up by the words of Tyrion, “There is something sacred about all of us imperfect, broken people coming together to try and do this holy thing together. Together we are better than any one of us on our own.”

Appendix

Appendix A: Letter of Invitation

Dear _____,

You were both suggested to me as people who might be interesting in participating in a research project I am doing. I am looking for feedback on the question, “What do churches have to learn about helping people have a close relationship with God from people with intellectual disabilities?”

I am interested in this topic for a few reasons. First, there is a great deal of information available that supports the fact that L’Arche is a place where people’s spirituality is nurtured. I experienced that myself when I lived at L’Arche as an assistant more than 20 years ago. One need only read some of the books written about L’Arche to know it is a place of transformation and that includes a close relationship with God for many people.

Second, as a future ordained minister in the United Church of Canada I am deeply passionate about helping people build relationships with God. I do not think we are doing as good a job in mainline churches as L’Arche communities do.

Many churches are putting much time and energy into trying to be more inclusive and accessible. However, it is still clear that people with disabilities are underrepresented in our churches. Perhaps part of the reason for this is that the church continues to focus on ministries *for* people with disabilities instead of looking to them for leadership.

This project has the mission of finding out about the wisdom people with intellectual disabilities have to share with the church.

As part of this project, I will interview people who are involved in prayer at L’Arche and also attend (or used to attend) worship at a protestant church outside of L’Arche. I will interview two people together, one core member and another person who is also involved in the spiritual life of their L’Arche community. The interviews will last about 45 minutes and if possible will happen in person, and in other situations through Skype. During this time a series of open ended questions will be asked. There will be a number of broad questions asked, but they will be broken down into smaller parts in order to help with understanding. The interviews will be video and audio recorded and later I will type out all that was said.

Every effort will be made to protect the participant’s confidentiality. This will include using pseudonyms instead of real names, keep all data in password protected files on password protected computers and cloud drives.

From this data I will try to find some common themes that came up in discussion and create a theory that is grounded in this data.

Talking about our personal faith and relationship with God is counter cultural as there is a common held belief that faith is a personal (and therefore private) issue. Speaking about it therefore has the potential to cause stress for some people. Another possible risk for participants is that the speaking about the church could raise some negative feelings if the church, or worship experiences, ever caused trauma in your life. There will be no point in the interview where anyone will be forced to talk about anything they are uncomfortable with. Your decision to not answer any of the questions will be respected. However, it is important for any participant to consider these potential risks before agreeing to participate.

There are also possible benefits from participating in this study. Like I said, the church has done a substantial amount of work on how to welcome and minister to people with disabilities. Much has been done about physical disabilities and the need for churches to become barrier free. Some work has also been done about how we can be inclusive of people with intellectual disabilities as well. People with intellectual disabilities have gifts to share with the church. I am hopeful that this study will begin to open the conversation more about what the church has to learn from people with intellectual disabilities. Hopefully you will feel the empowerment that accompanies the knowledge that your story, and what you have to say, is important. The knowledge that you share could be part of positive change in helping churches learn ways to minister to all people and help them feel closer to God.

Once you have had time to understand and discuss this information together, please do not hesitate to contact me with any further questions. I can be contacted at the contact information listed after my name. If you decide to participate, you will both be asked to fill out a consent form acknowledging your decision to be part of the study. At any time during the process, for any reason, you can withdraw from this study.

Should you have any enquiries or questions about the project in the meantime, please contact me at XXX-XXX-XXXX or XXX. In addition, if you ever require pastoral care, have any concerns and would like to speak to my supervisor, you can reach the Rev. Canon Dr. Jody Clarke at XXX-XXX-XXXX or XXX.

I appreciate your consideration of this request and look forward to hearing if you would like to be participants in my study.

Shannon MacLean, Candidate for Ordained Ministry

Atlantic School of Theology Grad Student

Appendix B: Letter of Informed Consent

Informed Consent: I acknowledge that I have read the description of the research project, “What do churches have to learn about helping people have a close relationship with God from people with intellectual disabilities?” contained in the Letter of Invitation.

- I acknowledge that the research objectives, methods and procedures have been outlined to me.
- Any questions I may have had regarding the procedures have been answered to my satisfaction.
- I know that I can contact the researcher at any time, should I have further questions. Shannon MacLean XXX-XXX-XXXX or XXX.
- Should you ever have need for pastoral care or any concerns and would like to speak to Shannon MacLean’s supervisor, you can reach the Rev. Canon Dr. Jody Clarke at XXX-XXX-XXXX or XXX.
- I am aware that my participation is strictly voluntary.
- I am aware that an audio recording of the interview will be made, and field notes may be taken. This recording along with the transcript of the interview and field notes will be destroyed following the completion of the research project.
- I am aware that my participation is confidential. My name and any other personal identifiers will be changed in order to maintain confidentiality.
- This consent form will be stored separately from the research data in order to maintain confidentiality.
- I recognize that my participation in this research is voluntary and I can end my participation in the project at any point in the process.

This project has been approved by the Research Ethics Board of the Atlantic School of Theology. Any ethical concerns about this project may be taken to this Research Ethics Board.

By signing this consent form, you are indicating that you fully understand the above information and agree to participate in this study.

Signature of Participants:

Name _____ Date _____

Name _____ Date _____

Appendix C: Research question: What People with Intellectual Disabilities Have to Teach the Church

“Prayer” is the word used at L’Arche in this region for community worship moments.
“Church” is understood to mean worship outside of L’Arche in denominational churches.

In consultation with Jenn Power, the regional director of L’Arche, and Silas Donham, who has lived at L’Arche Cape Breton for more than 20 years, I was advised that each large, complex, question would need to be broken down into smaller questions beginning with who, when and where questions, which are the easiest to understand because of the concreteness of them then proceeding through “what” and “why”..

Research Questions

What is your experience of worship and God at L’Arche?

- Do you go to prayer?
- What do you do at prayer?
- Who is at prayer when you go?
- What do you like about prayer?
- What do you dislike about prayer?
- Why is prayer important to you?

Are there times outside of prayer when you feel close to God?

- What are the other times when you pray in community? (*can prompt with examples: like bedtime, meals, while walking etc...*)
- Why do you pray?
- Can you tell me about a time you felt close to God?

Jean Vanier said, ““A growing community must integrate three elements: a life of silent prayer, a life of service and above all of listening to the poor, and a community life through which all its members can grow in their own gift.” How have you experienced this at L’Arche?

What is your experience of worship and God at church?

- Do/did you go to church?
- What do/did you do at church?
- What do you like about church?
- What do you dislike about church?

- Why is church important to you?

What advice or wisdom do you have for the church about how it can better help all people to feel closer to God?

- What would make you like church more?
- What would help you feel closer to God in church?

What gifts have you witnessed people with intellectual disabilities have to share with the church?

- Are there ways you help lead prayer at L'Arche?
- Are there ways you help lead worship at church?
- What are you really good at doing to help out at church?
- Are there any ways that you would like to help out at church if you were given the chance?

Ask the Core member if they would be comfortable closing our session with a prayer.

Appendix D: Letter of Appreciation

Dear,

Thank you for taking the time to talk with me about your experiences of God at prayer and in church. Your candidness in answering the personal questions about your faith was greatly appreciated as was your honesty and willingness to assist in this important research.

The information and wisdom you shared will make a valuable contribution to answering my research question “What do people with intellectual disabilities have to teach the church?”

Please be assured that your real names will not be used in any of the work I produce.

On March 11 & 12, 2019, I will be presenting my findings at the Atlantic School of Theology. You are more than welcome to attend the public presentation. This presentation will be videotaped and made available on Youtube at a later date. Also, I will be writing a final paper on this piece of qualitative research for the end of April. Once available, I will forward you the necessary links to these items, should you be interested in the final product.

Should you have any enquiries or questions about the project in the meantime, please contact me at XXX-XXX-XXXX or XXX. In addition, if you ever require pastoral care, have any concerns and would like to speak to my supervisor, you can reach the Rev. Canon Dr. Jody Clarke at XXX-XXX-XXXX or XXX.

Once again, please accept my sincere thanks for so generously sharing a part of your experiences with me.

Blessings,

Shannon MacLean