

## **GATHERING TOGETHER: TOWARD A CULTURE OF MUTUALITY AND FULL PARTICIPATION FOR PERSONS WITH DISABILITIES AND THEIR ALLIES**

**ORIGIN: PERMANENT COMMITTEE ON PROGRAMS FOR MISSION AND  
MINISTRY**

### **BACKGROUND AND CONTEXT:**

In July 2013, about 55 self-identified people with disabilities, and their allies, gathered for a two-day consultation to share stories, ideas, dreams, and hopes about what would enable The United Church of Canada to better live into its recent commitment to becoming an “open, accessible, and barrier-free church, where there is full participation of persons with disabilities in the church’s ministry and mission.”<sup>1</sup>

The consultation was one of the responses to recommendations offered in the report “Open and Accessible: Ministries with Persons with Disabilities”;<sup>2</sup> the report was approved by the Executive of General Council in March 2012. The theological background for this work was also detailed in that report. One report recommendation called for

a consultation with a diversity of persons living with disabilities—and their allies—in the United Church, and that the insights from this consultation be gleaned to develop a report with concrete policy recommendations for the Executive of General Council by the spring of 2014.<sup>3</sup>

Entitled *Gathering Together: Toward a Culture of Mutuality and Full Participation for Persons with Disabilities and Their Allies*, the consultation evolved from the recommendations in the March 2012 report, and it involved people with a wide range of disabilities—both visible and invisible disabilities—as well as allies, caregivers, and interested individuals. Those who gathered have personal lived experiences with a range of disabilities—including disabilities that are physical, cognitive, mental, sensory, emotional, developmental, medical, health-related, or some combination of these.

Participants shared their thoughts, ideas, stories, experiences, and practical suggestions from within The United Church of Canada as it relates to disability. These reflections formed the basis to further shape the United Church as a whole, including both programmatic direction and related proposals to the Executive of General Council. The proposals included in this report evolved from the consultation.

### **HISTORICAL OVERVIEW:**

The United Church of Canada has a long and rich history of ministries with people with disabilities. During the 1970s and 1980s, resources and programs were prepared to assist Christian education leaders working with children with various types of developmental

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<sup>1</sup> PCPMM 19 *Open and Accessible: Ministries with Persons with Disabilities*, Report to the Executive of General Council, March 24–26, 2012; p. 172.

<sup>2</sup> *Ibid*; pp. 172–181.

<sup>3</sup> *Ibid*; p. 172.

challenges. Materials were distributed to help congregations explore building changes to reduce physical barriers to people with mobility and hearing limitations. Infant stimulation and parent support resources were made available for families at the time of the birth of a child with developmental challenges. A 2008 publication entitled *Welcoming Differences: Including Children Who Experience Challenges* was geared toward church school leaders who had children with disabilities in their classes<sup>4</sup>.

In 1977, the 27th General Council of The United Church of Canada approved a report called “The Handicapped and the Wholeness of the Family of God,” This report said that the Church’s unity includes both the disabled and the abled and a Church which seeks to be truly united within itself and move toward unity with others must be open to all; yet able-bodied Church members, both by their attitudes and their emphasis on activism, marginalize and often exclude those with mental or physical disabilities<sup>5</sup>.

In 1981, during the United Nations’ International Year of Disabled Persons, The United Church of Canada held a national consultation with representatives from each Conference. This was an important gathering, which raised key questions and theological reflections on disability.

At this first consultation, five important themes emerged:

- raising questions about how to make church buildings more physically accessible
- creating space to make contributions to a quarterly church school curriculum—through the National Council of Churches in the USA—focused on children with developmental disabilities
- offering theological reflections on the concepts of healing, wholeness, and the image of God
- networking and connecting with other people living with disabilities in the United Church
- inspiring some people who were at the consultation to take local initiatives in their home presbyteries and Conferences.

This first consultation, while notable, did not offer recommendations on policy changes in the church, or about systemic changes to enable the church to become more accessible. Three decades after the first consultation, new questions and new issues were emerging about disabilities in the church. Gathering Together, the United Church’s second consultation focused on disabilities, sought to be a contemporary and contextual response to the reality of persons living with disabilities in the church today.

## **PROCESS:**

Gathering Together was designed by a planning team and staff. The planning team was chosen by General Council Office staff person Adele Halliday, and the team was carefully composed of self-identified people with differing disabilities, caregivers, and allies who were all actively involved in The United Church of Canada. The team worked together over the course of several

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<sup>4</sup> PCPMM 19 Open and Accessible: Ministries with Persons with Disabilities, Report to the Executive of General Council, March 24–26, 2012; pp. 172–181.

<sup>5</sup> 27th General Council of The United Church of Canada. “The Handicapped and the Wholeness of the Family of God. 1977.

months—solely by conference call—to design the consultation. The following were the members of the planning team:

- Sharon Aylsworth (member of Kingston Road United; Toronto, ON)
- Sharon Ballantyne (ministry personnel at Fairview United; Peterborough, ON)
- Adele Halliday (General Council Office staff; Toronto, ON)
- Tom Reynolds (professor of theology at Emmanuel College; Toronto, ON)
- Darla Sloan (ministry personnel; Quebec City, QC)
- Miriam Spies (candidate for ministry at Emmanuel College; Hamilton, ON)
- Tracy Odell (member of Knob Hill United; Toronto, ON)

The planning team shared goals and hopes for what would happen as a result of this consultation:

- people will feel empowered and energized
- stories of both successes and challenges will be shared
- there will be networking and gathering together with other people with disabilities in the church and their allies
- people will leave with a sense of what is possible in their faith communities
- the group will weave together a new way of being of the church, with hope
- people present would be coming to reconsider what “disability” means from a faith perspective
- ideas, thoughts, and recommendations will be offered for the church as a whole

The planning team and staff thought that storytelling would be a helpful format. Three panel presentations from panels offered “sparks” for conversations and storytelling in small groups. The format of the consultation was designed to be safe for people to tell their stories—however joyful or painful—and to be a non-judgmental and open community of faith where all stories and experiences are honoured. Each story was deemed to have value, and each story was received as important. No story was to be more privileged than another; each person was invited to speak their truth, with love.

As a result, people shared very personal stories about their experience in the United Church as it relates to disabilities.

In addition to sharing stories, the consultation was a broad exploration of how The United Church of Canada could become more open, accessible, and barrier-free. In thinking about the United Church, as it relates to disability, the group considered these questions:

- What should we, as church, start doing that we haven’t been doing?
- What should we continue doing that we are doing now?
- What should we stop doing?

The stories shared, responses to these questions, action ideas, recommendations, and forward-thinking strategies form the basis for the rest of this report and the resultant recommendations.

### **CONSULTATION FINDINGS:**

The storytelling format created space for people to share their own personal experiences. Stories were told with grace and power, honesty and vulnerability. Many participants shared about their

painful experiences in the church; for some, church has not been a positive experience. Several are living with grief and pain because of exclusionary attitudes experienced within their faith communities. The local congregation was named as one important space where transformative change could take place.

*Congregational life:*

One person, for example, living with disabilities reflected on the lack of welcome she received when she entered a new United Church congregation: “I felt that I wasn’t what she was looking for in a new member.”

Some shared their concern that whenever churches think about creating a more accessible space, they tend to only think about physical spaces, such as building a wheelchair ramp. When people think about creating access, they think it will require them to change their buildings and be a costly endeavour. Several stated, however, that it is really about attitude, and not about money. One person reflected that “how you treat people is more important than whether you have a ramp or stairs.”

Overall, churches are encouraged to reflect more about the gifts that people with disabilities are already bringing to the church. One way of enabling this to happen is through focusing on welcoming and belonging instead of inclusion.

One person reflected that “inclusion is when people make room for you. Belonging is when people go looking for you.” A notable critique of “inclusion” was offered in the report “Intercultural Ministries: Living into Transformation.”<sup>6</sup>

When one is “included,” it means that someone else has the power to include—and exclude. There are power imbalances implied in the word and process of “inclusion.” To say that someone can be included names a particular place of privilege. It might involve a person saying that another is welcome into their space—it implies a host and a guest. But “inclusion” is not necessarily mutual, and it is not always transformative. Someone can offer to include another, without making any other changes in their way of being. Inclusion does not necessarily mean mutuality, or that a hospitable or equitable space has been created. Often, instead, a minority person (or community) is invited into a culturally dominant space, without any other changes to help them feel at home.

Instead of being in churches that are intentionally creating spaces for welcoming and belonging, however, some people with disabilities find only minimal inclusion or worse. Others also find that their “ability” to participate in congregational life wanes as their disabilities increase. What people yearn for is empowering change, and the reflection of God at work in all.

Some, for example, described difficulty in taking communion. The movement to the front of the church was difficult for communion by intinction; when this was raised with the church

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<sup>6</sup> Executive of the General Council, March 24-26, 2012, PC-PMM 17 Intercultural Ministries: Living into Transformation, p. 149.

leadership, however, the leaders responded that “this is the way that the United Church does communion.” Others reflected that the nature of their disability made it difficult to swallow the bread without gagging; having flexible ministry personnel who were willing to perform communion in their home made it possible for them to participate in this important sacrament.

Another long-term and very active member of one congregation lamented that as they developed a disability later in life, the congregation was not able to cope with the impact of their progressive degenerative condition, and did not make any changes to enable them to continue to participate in congregational life. The person reflected, “If the church is not willing to change for me, then who will they change for?”

Others said that physically inaccessible spaces limited their participation:

- “When I could no longer reach the pulpit, my voice was no longer heard reading scripture.”
- “My participation in congregational life was restricted by the limited accessibility of the building, and by the attitude of those who scheduled ‘all inclusive’ meetings in places I could not reach. It didn’t have to be this way.”

Congregational life, however, was not a negative experience for all. Some shared that they experienced their call to ministry within their local community; others reflected that when they experienced barriers in society and in other parts of the church, their local congregation was a refuge for them.

The storytelling aspect was also noted as an important one; it may be helpful for people to share their stories as part of a worship service in which speakers share the message. This may be a small series or something that would invite people in the congregation to get to know the person a bit more.

Others noted that perhaps Mission and Service (M&S) could be asked to add stories of hope and encouragement sharing about a person with disability, or better still, actions and outreach with churches that practise full belonging and who have created accessible spaces, for all.

*Education, candidacy, and paid accountable leadership:*

Beyond the local congregation, there were two particular areas where people experienced barriers and had recommendations for church policy:

- candidacy processes for students
- ministry personnel living with disabilities

One person with a disability reflected, “My journey with The United Church of Canada has not been an easy one. At the time I was ordained, it did not seem like the rest of the United Church wanted me with my disability, but my little local church knew me and welcomed me.”

Some reflected that this area could be better understood if more people realized that a disability is not an individual “problem” that one person “has”; instead, it is a community concern. In reality, though, it usually falls to the individual with disabilities to ask for their own needs. For example, some students struggled in theological schools and had to become their own

advocates—desiring to do the academic work, but needing some accommodations to enable them to do that work effectively. When advocating for their own needs, however, some shared that their presbytery committees then viewed them as an individual nuisance who was always demanding things, rather than considering the ableist system that causes exclusion.

In some cases, people found that some schools, and teachers, were not open to making accommodations for them and their disabilities. For others, their student committees questioned if they could really become an ordered minister when they had a disability. Some committees did not seem to understand how people with disabilities could be in ministry.

As a result, some people dropped out of the process; it became too difficult to bear. Some people struggled through their discernment process, and therefore have few role models of people with disabilities actively engaged in ministry. Creating a matching process between students with disabilities and ministry personnel with disabilities was one idea that was shared.

Some experienced deep hurt in their educational process, and yet because of their deep sense of call continued to persevere: “We as people of faith living with disabilities have experienced problematic situations; we need to navigate this tough world of language and this world of hurt.”

*Theology of disability:*

Many participants recalled associating “disability” with “sin” or hearing the association between disability and sin. Some parents believed that they had done something wrong to have a child with a disability, who was considered “abnormal.” Many, therefore, struggled with a sense of what is “normal,” and with how “abnormal” is often equated with “faulted.” One person challenged this idea: “The normal construct doesn’t exist; we need to get rid of the concept that there is a normal.”

Because ideas of normalcy and imperfection remain and get reinforced in the church, some felt inadequate because of their disability: “It is as if we struggle with being good enough for God.” The difficulty of theology, and challenging the cult of “normalcy,” is something that could be explored further in theological education and with people in church leadership.

Some theologies also promote the idea that a “disability” can be healed through a miracle, and that if a person was not healed, they did not have enough faith. One person shared: “How often have we heard, ‘If you believe in Jesus, you will be healed?’”

As a result, several shared that it would be helpful for the United Church to develop its own theology of disability. It is noted that there is theological background in the report “Open and Accessible: Ministries with Persons with Disabilities,”<sup>7</sup> and that there is further work being done through the World Council of Churches’ Ecumenical Disabilities Advocates Network (EDAN). Both of these will be a helpful basis for developing and publicizing a theology on disability.

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<sup>7</sup> PCPMM 19 Open and Accessible: Ministries with Persons with Disabilities, Report to the Executive of General Council, March 24–26, 2012.

One offered an example: “What if God were a quadriplegic? What if God cannot speak and cannot move? What if we, therefore, are God’s able-bodied personal assistants in the world? How might that change our image of God? How might that change our image of ourselves?”

*Visible and invisible:*

Several participants shared that it can be easier for both church and society to respond to visible disabilities, particularly physical disabilities. It is much more difficult for people to understand invisible disabilities—particularly around mental health. Many reflected that there is still considerable stigma in relation to mental health; it is rarely spoken about in churches. As a result, it would be helpful to encourage people to talk more about mental health.

Breaking the silence, and the stigma, around mental health is one important step for churches: “When a pastor talked about mental health in a sermon, his phone kept ringing afterwards—he had opened the door to talk about the topic.”

Intellectual disabilities are also an underdeveloped area of attention for the church.

*Language and naming:*

Some also struggled overall with the matter of naming. “Disabled” means that something is no longer working or not functioning, such as a disabled car. People with disabilities, however, have much to contribute and offer.

Even if one names oneself as a person with disabilities, there is still a great deal of ableist language that communities struggle with and that disempower people with disabilities. Churches often use language like, for example, “vision statements,” “seeing more clearly,” or “taking the next step.” One person who uses a wheelchair shared, “If there is a stairway to heaven, how will I get there?”

Similarly, ableist language is embedded in many hymns that are in common use in both *Voices United* and *More Voices*. Offering suggestions for alternative language in worship was named as something that would be helpful for worship leaders.

It is important to emphasize that people with disabilities self-identify very differently. Further background is offered on this, and on the concept of identity, in the report “Open and Accessible.”<sup>8</sup> It arose at the consultation, perhaps not surprisingly, that people who develop disabilities later in life often have difficulty with the concept of disabilities, and are reluctant to think of themselves among the group of people living with disabilities. They may think of themselves differently from the stereotypes that they have known all their lives and that are often a part of our cultures. Still, a significant number of such people could use accommodations in our congregations. This could include people with diabetes, hearing loss, loss of sight, arthritis, stroke, depression, and so on, who could all use accommodations to help them continue to contribute and participate fully in the work and life of the church.

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<sup>8</sup> PCPMM 19 Open and Accessible: Ministries with Persons with Disabilities, Report to the Executive of General Council, March 24–26, 2012.

*Advocacy:*

The United Church of Canada might continue to work from a social justice perspective on initiatives regarding inclusion, belonging, and accessibility.

Because of differing work situations and different access to government assistance, some people with disabilities live with different levels of poverty. Some wondered, “What might be said to the government about this?” Mental health is also an area where further advocacy is needed. Broadly, the area of disability was noted as one where more advocacy could be done; the nature and focus of that advocacy work still needs to be nuanced.

*Networking:*

The consultation shied away from the idea of creating another standing committee, but did name the need to continue to network with one another, and the desire to create forward-thinking accountability processes. As one person reflected, “Don’t pray for a United Church committee; instead, create a network where anyone can belong.”

An active Facebook group has been the gathering space so far. In addition, the planning team from this consultation has offered to continue to help debrief and to be a think-tank for a three-year action plan. This group—not a formal committee—may find it helpful to continue to meet and talk further. In addition, resources will be added to the United Church’s website: [www.united-church.ca/intercultural/disability](http://www.united-church.ca/intercultural/disability).

*Overall – A Call to Action:*

As much as people engaged in conversation, people want more than just a policy or a report—it is important to also enable action and change. This is a call to action.

Additional areas for further exploration include the following:

- The importance of intersection, between other features of social life that call for justice, such as poverty, racism, immigration status.
- Further conversations with people from the Deaf community. While the Deaf community see themselves as a cultural linguistic group that uses sign language to communicate, there are differences between people who are culturally Deaf from birth, and people who are deafened over time and experience hearing loss later in life
- Exploration of advocacy, and what advocacy is needed in relation to disability.

Finally, while it has been noted before, it is important to continue to acknowledge that the community of people living with disabilities is diverse, and “disability” is only one identity that people hold, one aspect of being human that otherwise resists being reduced to “disability.”

Further, the lens through which one views one’s own disabilities depends on when one acquires that disability. The community of people who are deafened, named above, is one example of this. Another example is someone who acquires a physical disability because of an illness later in life.

**PROGRAM IDEAS FOR STAFF:**

Several ideas were shared that do not need policy proposals, but are program ideas that could be implemented by staff and/or program committees. Those ideas include the following:

- Creating a mental health awareness kit that would be available for congregations; the kit would address concepts such as stigma around mental health.
- Identifying churches based on their level of accessibility, so that people know how accessible a local congregation is. This could include whether a congregation has an accessible ramp, materials available in braille, large print materials, assisted hearing devices, and related items related to accessibility; it could be connected with the Church Locator available on the website and be searchable.
- Writing a resource for congregations and local ministries with very practical ideas of what people can do in relation to people with disabilities. This could be a handbook adapted from other already existing resources from other denominations and made available for United Church congregations, and it could include tips on how to make churches more accessible.
- Offering workshops and/or train-the-trainer programs on what is happening in churches.
- Facilitating a network of officers focused on disability concerns so that there are representatives from each region (perhaps done through Conferences or congregations); the people involved in this network could share knowledge, challenges, and resources about what they can better do in relation to disabilities. One suggestion would be to start with people who were involved with the Ontarians with Disabilities Act reps at each congregation as point people for Ontario churches, and then consider how to extend this model across Canada. This network could also help to identify advocacy-related needs. A related suggestion would be to work with Conferences and/or presbyteries to designate representatives as “accessibility” people, who could be trained to offer leadership in their regions.
- Create a related network of people who are interested in continuing to engage this work on disabilities, perhaps in an online consultation, or another place where people could continue to share stories.
- Research government grants available on accessibility, and/or look for a pool of funding that people could apply to for lifts and elevators; this may include bulk-buying.
- Write a three-year action plan on disabilities, and involve a group of elected members in animating the plan.

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