

The Changing Landscape of Disability and Ministry in the Church

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The postures and practices of communities in relation to disability have changed dramatically over the last fifty years. Throughout much of the last century, individuals with intellectual disability¹ were intentionally excluded from everyday school, work, and community activities. Barriers of attitude, awareness, and architecture (among others) converged to limit who could (and was expected to) participate in everyday community life. As new policies and laws were instituted, many of the new opportunities that subsequently emerged still served to segregate individuals with intellectual disability from others. Special schools, sheltered workshops, specialized recreation programs, and large group homes in rarely traveled corners of the community still meant that the lives of people with and without disabilities rarely intersected. In the 1980s and 1990s, greater strides were made to integrate individuals with intellectual disability into the ordinary activities available within their communities. Yet a certain separation remained when they attended classes in a different area of the same school or worked in different settings within the same local business. The last twenty years, however, has emphasized the full inclusion of individuals with intellectual disability. Increasingly, children and adults with intellectual disability are expected to be active participants

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within their schools, workplaces, and neighborhoods—just like anyone else. As individuals with and without intellectual disability develop mutual relationships and see one another as indispensable members, communities soon become places of belonging. Each of these five different portraits of community are displayed visually in Figure 1. Overall, this progression of history reflects a movement from the margins toward the middle; from exclusion toward embrace.²

Taken together, these varied portraits also reflect the current landscape of disability and ministry within the contemporary church. In other words, they depict the prevailing models of

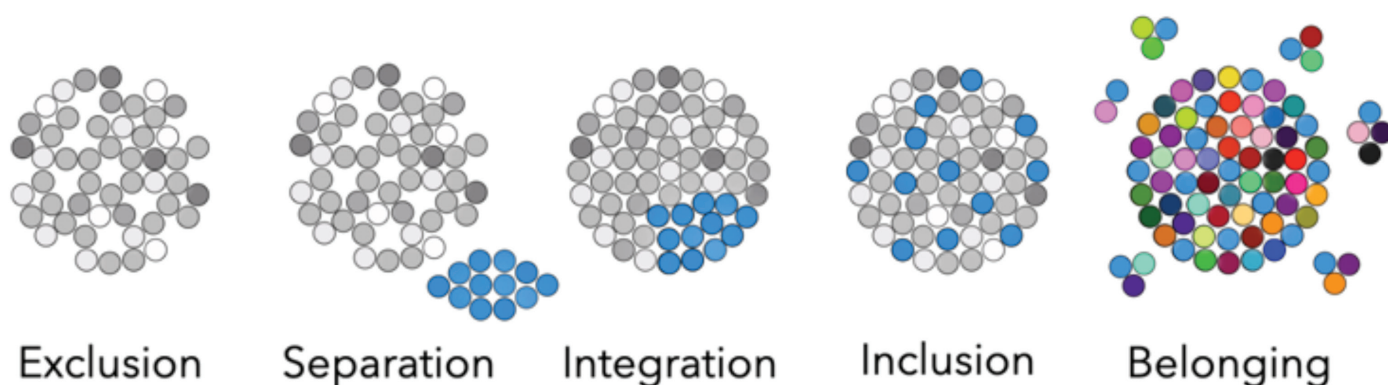


Figure 1. Five prevailing portraits of community.

1. The *American Association on Intellectual and Developmental Disabilities* defines intellectual disability as a disability that originates before the age of 22 and is “characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills.” See <https://www.aaidd.org/intellectual-disability/definition>

2. Erik W. Carter, “Dimensions of belonging for individuals with intellectual and developmental disabilities,” in *Belonging and resilience in individuals with intellectual and developmental disabilities: Community and family engagement*, eds. Jennifer L. Jones and Kami L. Gallus (New York: Springer, 2021), 13-34.

ministry across the United States and around the world. Examples abound of congregations marked by the *exclusion, separation, or integration* of individuals with intellectual disability (and other disabilities as well). A much smaller—but fortunately growing—number of congregations are being described as places of true *inclusion* and deep *belonging*. In this article, I will discuss each of these five approaches to ministry and their implications. Why do congregations adopt the postures and practices that they do? What does this mean for individuals with intellectual disability and their families? What might congregations be missing out on by staying stuck where they are? In characterizing these approaches, I draw from Bill Gaventa's³ discussion of critical prepositions as a way of describing how a faith community views their relationship to those impacted by disabilities: ministry apart, ministry to, ministry among, ministry with, or ministry by. I also incorporate findings from our ongoing *National Study of Disability and Ministry* and an array of empirical studies addressing disability and religion.⁴

Exclusion (Ministry Apart)

Ministry still takes place apart from people with disabilities in far too many congregations. Although disability is widely prevalent among children, youth, and adults residing in any city or state,⁵ these neighbors and their family members may not have a presence in the worship services, religious education programs, service opportunities, and fellowship activities that make up the life of a congregation. What would a glance into your gatherings and buildings say about who might be missing from your midst? National studies indicate that large proportions of adults with intellectual disability,⁶ children with autism,⁷ and adults with “significant disabilities”⁸ are not involved in a local faith community. Such absence is certainly not an indication of



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limited interest in doing so. Other barriers still stand in the way.

Few congregations would say they intentionally exclude people with intellectual disability. Yet, both long-ago and present-day choices about where and how we gather as a community can inadvertently lead in the very same direction. The ways our buildings and spaces are designed, the expectations we have for behavior and participation, our approaches to preaching and teaching, and the places we gather and go—each speaks volumes about who we truly expect to be part of our faith community. Each makes a theological statement about the boundaries of a body. Whenever we begin with a far-too-narrow vision for who might eventually show up, we end up limiting who might later come back. In other words, exclusion is often the natural outcome of unintentionality.

At the same time, the congregational stories of individuals with disabilities and their families do sometimes involve experiences of deliberate exclusion. Wounding remarks, penetrating stares, refused supports, revoked invitations, denied baptisms, and referrals elsewhere are all among the testimonies shared about how congregations have responded to the presence of people with disabilities.⁹ In one of our studies, for example, we found that one in three parents had left their congregation because their child with intellectual disability was not welcomed or included.¹⁰

Put simply, the exclusion of people with disabilities and their families is unfaithful to the gospel.¹¹ The scriptures are replete with calls to invite the uninvited, to be lavish with hospitality, to find a place for every gift, to jump the last to first, and to love beyond our usual circles. A congregation that does not include people with

3. William Gaventa, “Religious Ministries and Services with Adults with Developmental Disabilities,” in *The Right to Grow Up: An Introduction to Adults with Developmental Disabilities*, ed. Jean Summers (Baltimore: Brookes, 1986), 191–226.

4. Erik W. Carter, “Research on Disability and Congregational Inclusion: What We Know and Where We Might Go,” *Journal of Religion and Disability* (in press), <https://doi.org/10.1080/23312521.2022.2035297>.

5. More than seven million Americans have an intellectual disability. One in seven children receive special education in their local schools and nearly one in four Americans identifies as having a disability.

6. Erik W. Carter et al., “Congregational Participation of a National Sample of Adults with Intellectual and Developmental Disabilities,” *Intellectual and Developmental Disabilities* 53, no.6 (December 2015), 381–393, <https://doi.org/10.1352/1934-9556-53.6.381>

7. Li-Ching Lee, Rebecca A. Harrington, Brian B. Louie, & Craig J. Newschaffer, “Children with Autism: Quality of Life and Parental Concerns,” in *Journal of Autism and Developmental Disorders* 38, no. 6 (December 2007), 1147–1160, <https://doi.org/10.1007/s10803-007-0491-0>

8. National Organization on Disability, “Kessler Foundation/NOD survey of Americans with Disabilities” (Washington, D.C.: Author, 2010).

9. Erik W. Carter et al., “Addressing Accessibility Within the Church: Perspectives of People with Disabilities,” in *Journal of Religion and Health* (in press), <https://doi.org/10.1007/s10943-022-01508-6>

10. Melinda J. Ault, Belda C. Collins, and Erik W. Carter, “Congregational Participation and Supports for Children and Adults with Disabilities: Parent Perceptions,” in *Intellectual and Developmental Disabilities* 51, no. 3 (April 2016), 48–61, <https://doi.org/10.1177/0014402915598773>

11. Brian Brock, *Disability: Living into the Diversity of Christ's Body* (Ada, Michigan: Baker Publishing Group, 2021).

intellectual disability does not resemble the great banquet (Luke 14) or a beautiful body (1 Corinthians 12). For individuals and families who experience exclusion, the impact on their faith, their friendships, and their flourishing can be profound.

Separation (Ministry To)

For some congregations, the response to exclusion has been to establish new ministries designed specifically (and only) for individuals with intellectual disability. Most often, this takes the form of small groups for adults with cognitive impairment held outside of the usual times for religious education. For example, congregations have formed partnerships with local group homes and disability organizations to establish weekday Bible studies or social gatherings. Another approach has been to launch separate worship services that are designed to be more welcoming and accessible to individuals with intellectual disability than traditional services. For example, the service might be more interactive, the sermon simplified, the expectations relaxed, and modes of personal participation expanded. Others host once-a-year “special needs proms” or recreational gatherings in which everyone without an intellectual disability is a volunteer. When these options for involvement become all that is actually (or practically) available to individuals with intellectual disability within a particular congregation (e.g., invitations to or support within typical activities are not provided), a parallel ministry emerges in which the lives of members with and without disabilities rarely intersect.

This ministry approach might emerge for multiple reasons. Sometimes, congregations are simply adopting practices they see elsewhere in their community. Segregated approaches to schooling, employment, recreation, and residential living remain widespread around the country and the world, despite their incongruity with recommended practices and the rich blessings of life lived together. In other cases, ministry leaders may start with the assumption that the needs of those with intellectual disability are strikingly different from those of others in their congregation. In other words, different approaches are designed for what people consider to be special needs (i.e., different needs). However, separate programs are most often born because the rest of a congregation remains resistant to altering its current practices in ways that would widen its welcome.

Although many individuals with intellectual disability value these gatherings and grow in their faith, opportunities for reciprocity and relationships often remain limited. Like anyone else, individuals with intellectual disability have God-given gifts and compelling friendships that are needed by others within the congregation. Yet the lives of people with and without disabilities never intersect when gatherings and groups take place on different days and locations. A divided body is diminished, for every part needs every other part. Although separate ministries



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are sometimes intended as an initial entry point into other aspects of congregational life, there are too few occasions when it accomplishes this effect.

Integration (Ministry Among)

More and more congregations are taking steps to integrate individuals with intellectual disability into the ordinary experiences that comprise their faith community. This often involves establishing formal (and usually named) programs focused on promoting access to worship, learning, and service. Within religious education, for example, specialized classes for children, youth, and/or adults with intellectual disability might be offered as an alternative to the standard Sunday school classes available to members without disabilities. These classes frequently use different curricula, combine a wider range of ages, and have small ratios of leaders/volunteers to participants. Some congregations also designate seating areas for individuals with intellectual disability within the sanctuary, who then leave the worship services at the start of the sermon to attend an alternate experience. Although people with disabilities are present within their congregation at the same times as other members, a certain degree of distance remains. People with and without disabilities may be *among* one another without always being *near* one another. Such approaches to ministry are particularly prevalent in larger congregations when multiple people are seen as having the same labels, conditions, or experiences. However, integration also intermingles with inclusion in some congregations; individuals with intellectual disability remain a part of some congregational events, but apart for others.

Some of the factors that contribute to separate ministries also lead to integrated ministries. Congregations may experience uncertainty about how to adapt how they worship, teach, or gather to enable wider participation; others may be reluctant to make such changes. The creation of alternative arrangements also

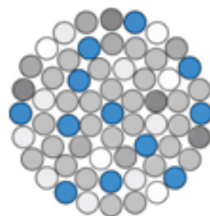


mirrors the format of most special education programs in local schools for students with intellectual disability (e.g., students are served primarily or exclusively in self-contained classrooms). Because many ministries are led by special educators or related service providers, the similarity in approaches is not altogether surprising. But it may also reflect an underlying belief that an intellectual disability is the most salient characteristic by which to group people or that faith formation is best supported within a specialized setting. Neither tends to be true. Finally, many ministry leaders describe this decision as a way to ensure that parents can worship, participate, and serve in Sunday morning activities. In other words, caring for their children in a safe space is a way of ministering to parents. At the same time, these congregations recognize that there must be no separate congregation for those with disabilities.¹²

When integrated ministry becomes the dominant approach, the likelihood that people with and without disabilities will encounter one another, develop new friendships, and discover their need for one another remains restricted—even though everyone attends the same church. It is quite common for people to know about their congregation's disability ministry, but still not know the names of anyone who is involved. Of course, relationships (and especially friendships) most often emerge through participation in shared activities around common interests across time. Steering children and adults to different classes also keeps congregations from experiencing the myriad benefits that come from reflecting on and addressing barriers to inclusion in typical church programming. As Bill Gaventa¹³ notes, activities that are more universally designed often end up enhancing the participation of a wider range of church members, whether or not they have a disability.

Inclusion (Ministry With)

Most congregations offer an array of opportunities for worship, learning, service, discipleship, outreach, and fellowship. Inclusion means ensuring individuals with intellectual disability are encouraged and supported to participate in the same breadth of valued experiences as anyone else. It reflects a noticeable shift in posture—from ministry *among* to ministry *with*. Inclusive ministry is advanced by casting a vision, equipping leaders and volunteers, promoting awareness, adopting person-centered approaches, individualizing supports, selecting the right curricula, encouraging flexibility, reflecting regularly, and remaining intentional. In one of our recent research projects, people with disabilities described multiple areas that warrant consideration when designing inclusive and accessible experi-



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ences in their congregations, including: architecture, attitudes, communication, contributions, expectations, interactions, level of understanding, liturgy, mindsets, sense of community, sensory factors, supports, and technology.¹⁴

For many congregations, the commitment to inclusion is grounded in core theological beliefs. The absence of asterisks or exceptions throughout the scriptures leads them to wonder why it would be any other way. Indeed, “all” and “everyone” are said more often than “some” or “few.” Moreover, scores of denominational statements and resolutions emphasize the importance of removing barriers to full participation and welcoming more widely.¹⁵ Inclusion also begets inclusion. As people with and without intellectual disability share their faith, friendship, care, and companionship, they tend to pull further away from practices that prevent these exchanges. Practical reasons also exist. In smaller congregations, inclusion is seen as the only alternative to exclusion. Rather than talking about “disability ministry,” the ministry is described as supporting Kendrick or Eliza or Aaron to be a part of all the congregation offers.

Inclusion is rightfully critiqued when it only entails the sharing of space, when it is defined merely by location. In other words, people with and without intellectual disability are often present in the same places without having much of a presence in each other's lives. Likewise, it must mean more than welcoming a person's presence without changing how everyone gathers. Finally, inclusion can sometimes be seen through an “us” (those who include) and “them” (those who are included) dichotomy. Yet, it is God who so graciously includes us all and does so without distinction.

Belonging (Ministry With and By)

14. Erik W. Carter et al., “Toward Accessible Worship: The Experiences and Insights of Christians with Disabilities” (Manuscript submitted for publication).

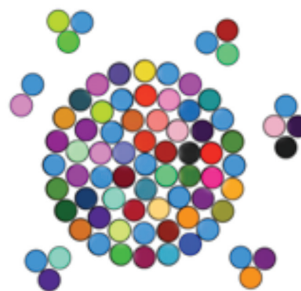
15. Erik W. Carter, *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families, and Congregations* (Baltimore: Brookes, 2007).

12. United States Catholic Conference, “Pastoral Statement of U.S. Catholic Bishops on Persons with Disabilities” (Washington, D.C.: Author, 1978).

13. William Gaventa, “A Rising Tide Floats All the Boats,” *Currents in Theology and Mission* (this issue).

Congregations marked by belonging adopt postures and practices that aim toward each of these key areas: to be present, invited, welcomed, known, accepted, supported, cared for, befriended, needed, and loved. We do this in response to God’s incredible generosity to us, because we belong to God. We love because we have been loved. We befriend because we are befriended. We care for others because we are cared for. We accept because we have been accepted.

Most congregations aspire to be communities in which believing and belonging abound together—where every person knows for certain that they belong to God and to one another. Most of us have experienced firsthand the joy of belonging to a people or place. Likewise, we have also felt the hurt that comes when we know we do not belong. We all long to belong. Although the same is true for individuals with intellectual disability and their families, belonging can be much more elusive. But this should never be so within our congregations. In one of our studies exploring their experiences within a faith community, we asked young people with intellectual disability and their parents about the things that assure them that they truly belong.¹⁶ Ten aspects of belonging emerged across these conversations: to be present, invited, welcomed, known, accepted, supported, cared for, befriended, needed, and loved. Congregations marked by belonging adopt postures and practices that aim toward each of these key areas. We do this in response to God’s incredible generosity to us, because we belong to God. We love because we have been loved. We befriend because we are befriended. We care for others because



we are cared for. We accept because we have been accepted. And on and on and on.

I suspect that belonging may be more likely in congregations that are all-in-on-inclusion. As people with and without intellectual disability worship together, learn together, serve together, and fellowship together over time, they come to see each other and their community differently. Preconceived ideas about “the other” melt away as lives are shared and friendships formed. Those all-too-common distinctions between who is the giver and who is the receiver, between “us” and “them,” or between the members and the strangers gradually give way to mutuality and reciprocity. Every person is seen as having equal and inestimable worth; every person feels valued. Such congregations are much more willing to move in new ways. Rather than expecting newcomers to fit into the way things have always been done, they are eager to explore new ways of gathering that widen the welcome for all.

Moving Forward

How might congregations move toward inclusion and belonging? What changes in attitude and action are needed to change the prevailing landscape? We recently asked more than three dozen adults with different disabilities (some of whom had an intellectual disability) to share their recommendations as part of a study exploring the meaning and markers of accessible worship.¹⁷ Among their many recommendations, they emphasized nine primary actions:

1. *Advocating*: Speaking up regarding accessibility needs and calling upon the congregation to respond
2. *Reflecting*: Regularly examining all aspects of congregational life to identify areas of existing accessibility and pressing need
3. *Asking*: Inviting the perspectives and preferences of people with disabilities regarding accessibility and inclusion
4. *Researching*: Seeking out the expertise and experiences of others from outside of the congregation (e.g., disability organizations, self-advocates)
5. *Equipping*: Increasing the capacity and commitment of church members to support inclusion
6. *Embracing*: Adopting a posture or culture that values people with disabilities and recognizes their gifts
7. *Proacting*: Taking active and advanced steps to welcome and include people with disabilities
8. *Including*: Weaving and welcoming people with disabilities within all aspects of congregational life
9. *Praying*: Seeking guidance and support from God in all these endeavors

16. Erik W. Carter, Elizabeth E. Biggs, and Thomas L. Boehm, “Being Present Versus Having a Presence: Dimensions of Belonging for Young People with Disabilities and Their Families,” in *Christian Education Journal* 13, no. 1 (January 2016), 127-146, <https://doi.org/10.1177/073989131601300109>

17. Erik W. Carter et al, “Addressing Accessibility,” Figure 1.

Let me conclude by returning to the series of images I shared at the outset of this article (see Figure 1). Which of these five portraits describes the communities you worship in, serve in, work in, learn in, or live in? Is your congregation invested in ministry apart, ministry to, ministry among, ministry with, or ministry by people with disabilities? There is an invitation here for every one of us—perhaps even a plea. Be catalysts for change in the ministries and communities you are part of. Spur them toward practices and postures that deepen their commitment, widen their welcome, and strengthen their embrace of those impacted by disability. So that all really do belong.

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