

A place of belonging: Research at the intersection of faith and disability

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Abstract

What does it really mean for people with disabilities and their families to truly belong within their faith community? This review article addresses ten dimensions of belonging and their salience to the inclusion of people with intellectual disability, autism, and other developmental disabilities. In each area, I review available research and highlight implications for churches, ministry leaders, and congregation members. This framework is intended to spur new thinking about the ways in which churches might welcome and weave people with disabilities more fully into the relationships and activities that comprise life together in a community of faith.

Keywords

autism, hospitality, inclusion, intellectual disability, spirituality

Disability is a *natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society*. This simple statement—which brings both empirical and theological support—is prominent within myriad legislation focusing on people with intellectual and developmental disabilities (e.g., Americans with Disabilities Act, Developmental Disabilities Act, Individuals with Disabilities Education Improvement Act, Vocational Rehabilitation Act). It affirms that being part of a community is vital to the thriving of any person. Moreover, it prefaces a clear call on service systems to provide the assistance, supports, and opportunities people with disabilities need to participate in valued ways in all aspects of community life. When designed and delivered well, effective service systems strive to put people with disabilities in the best position to flourish in community with others.

Churches are called to be *places of welcome, belonging, and contribution for people with disabilities and their families*. This simple statement—which brings both theological and empirical support—is reflected across more than one hundred position statements and resolutions issued by

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denominational and faith groups over the last few decades.¹ It affirms that the presence and participation of people with intellectual and developmental disabilities is vital to the thriving of any faith community. Moreover, it conveys that the Church is incomplete without the gifts and faith of people with disabilities. When purposeful and person-centered, healthy congregations strive to enable people with and without disabilities to flourish in community together.

From these two distinct directions, a strong call converges to support people with disabilities and their families in all aspects of life, including a life of faith. The experiences and relationships that comprise ordinary community life still remain elusive, however, for far too many people with intellectual and developmental disabilities. Regardless of the metric one chooses—whether educational, vocational, residential, or recreational—the outcomes valued most by people with disabilities inconsistently or infrequently materialize.² This is also true in the area of spiritual and religious involvement. Numerous studies affirm the significance of faith and congregational connections in the lives of people with disabilities and their families.³ Indeed, the same percentage of Americans with and without disabilities considered their faith to be an important aspect of their lives.⁴ Yet the inclusion of people with intellectual and developmental disabilities in faith communities across the United States remains uneven, and many congregations still struggle to envision what it might look like to welcome this segment of their community well.

The purpose of this article is to review recent research focused on the intersection of faith and disability. I organize this scoping review around a multidimensional framework of belonging within congregational contexts.⁵ I will discuss these ten dimensions of belonging and highlight their salience to the inclusion of people with intellectual and developmental disabilities and their families, synthesize available research related to each dimension, and suggest implications for faith communities. Other articles in this special issue speak to *why* faith communities should be inclusive of people with disabilities. The present article offers an empirical perspective on this topic intended to address how well congregations are responding to this call, as well as to spur new thinking about the ways in which churches might welcome and weave people with disabilities more fully into the relationships and activities that make up faith community life.

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1. E. W. Carter, *Including People with Disabilities in Faith Communities: A Guide for Service Providers, Families, and Congregations* (Baltimore, MD: Paul H. Brookes, 2007), 203–207; see www.faithanddisability.org for a searchable database.
 2. A. Hewitt, T. Heller, and J. Butterworth, “Introduction to the Special Issue: National Goals 2015,” *Inclusion* 3 (2015): 201–204; L. Newman et al., *The Post-High School Outcomes of Young Adults with Disabilities up to 8 Years after High School* (Menlo Park, CA: SRI International, 2011), xiii–xxvii.
 3. E.g., M. Ault, “Inclusion of Religion and Spirituality in the Special Education Literature,” *The Journal of Special Education* 44 (2010): 176–89; T. L. Boehm, E. W. Carter, and J. L. Taylor, “Family Quality of Life During the Transition to Adulthood for Individuals with Intellectual Disability and/or Autism Spectrum Disorders,” *American Journal on Intellectual and Developmental Disabilities* 120 (2015): 395–411; E. X. Liu, E. W. Carter, T. L. Boehm, N. H. Annandale and C. E. Taylor, “In Their Own Words: The Place of Faith in the Lives of Young People with Intellectual Disability and Autism,” *Intellectual and Developmental Disabilities* 52 (2014): 388–404; D. J. Poston and A. P. Turnbull, “Role of Spirituality and Religion in Family Quality of Life for Families of Children with Disabilities,” *Education and Training in Developmental Disabilities* 39 (2004): 95–108; and L. L. Treloar, “Disability, Spiritual Beliefs and the Church: The Experiences of Adults with Disabilities and Family Members,” *Journal of Advanced Nursing* 40 (2002): 594–603.
 4. National Organization on Disability, *2004 NOD/Harris Survey of Americans with Disabilities* (Washington, DC: Author, 2004), 21.
 5. E. W. Carter, E. E. Biggs, and T. L. Boehm, “Being Present versus Having a Presence: Dimensions of Belonging for Young People with Disabilities and their Families,” *Christian Education Journal* (in press).

Dimensions of belonging

My colleagues and I recently completed a large-scale, mixed-method research project focused on the intersection of faith, flourishing, and disability. Through a series of in-depth interviews, surveys, assessments, and literature reviews focused on the experiences of youth and young adults with intellectual and developmental disabilities and their families, we sought to understand the place and prominence of faith and its contributions to thriving. Of particular interest to us was the question of how young people and their families think about what it means to be truly part of their faith community; to experience belonging within their church. Contemporary conversations about inclusion in churches tend to be limited in two ways. First, they frame inclusion as a construct primarily concerned with physical location. Such a narrow lens neglects the primacy of relationships, which can still be limited or altogether absent even when people with and without disabilities navigate the same spaces.⁶ Second, they do not place the personal perspectives of people with disabilities and their families at the forefront of these discussions. Such an omission can inadvertently lead congregations to adopt practices that ultimately do not lead people to feel welcomed and valued. In our study, we sought to learn from people with disabilities and their families about the multiple markers of inclusion and to solicit their input on the ways in which congregations might put them into practice.

Across nearly fifty interviews, we heard young people with disabilities and their parents speak to multiple dimensions of belonging.⁷ Collectively, the emerging themes provide markers that reflect a trajectory of deepening relationships within a congregation. To be present, invited, welcomed, known, accepted, supported, cared for, befriended, needed, and loved—all were identified by participants as aspects of what it means to be truly included in a community of faith. Although these ten dimensions of belonging are likely neither exhaustive nor universal, they can serve as helpful points of reflection for congregations and denominations committed to becoming more inclusive of people with disabilities and their families. For the present article, I include an adaption of this framework as a way of organizing available research and highlighting key areas that warrant further consideration.

Although this framework of belonging likely has relevance to people without disabilities or other types of disabilities (e.g., physical disabilities, sensory impairments), the accent of this article is on the experiences of individuals with intellectual and developmental disabilities. These children and adults are often known by labels such as Down syndrome, autism, multiple disabilities, or intellectual disability. Across the country, nearly one million students receive special education services for these disabilities.⁸ Moreover, between 1% and 3% of the residents of any city, county, or state—as many as seven million Americans—have some type of intellectual or developmental disability.⁹ Disability is a natural part of the human experience. The present article calls upon congregations to avoid defining their community too narrowly.

To be present

Belonging begins with presence. When people with disabilities and their families are not involved in worship, educational experiences, service activities, fellowship opportunities, and other aspects

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6. A. A. Webster and M. Carter, "Social Relationships and Friendships of Children with Developmental Disabilities: Implications for Inclusive Settings: A Systematic Review," *Journal of Intellectual and Developmental Disability* 32 (2007): 200–13.
 7. See Carter, Biggs, and Boehm, "Being Present"; Liu et al., "In Their Own Words".
 8. US Department of Education, *IDEA Data* (Washington, DC: Author, 2014), <http://www.ideadata.org> (accessed February 14, 2016).
 9. B. Zablotzky, L. I. Black et al., "Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey," *National Health Statistics Reports* 87 (2015): 1–10.

of faith community life, opportunities for relationships and a strong sense of connection remain restricted or unavailable. Indeed it is difficult for anyone to feel part of a community from outside its margins. Thus, it is not surprising that most recent discussions about congregational inclusion have focused on increasing the presence of people with disabilities and their families within churches across the country.

Recent research paints a portrait of uneven congregational involvement. For example, Carter, Kleinert, and colleagues examined the community experiences of more than 12,000 adults with intellectual disability who were receiving public service and supports.¹⁰ They found that less than half (48%) of these adults reported having attended any type of religious service in the prior month. Moreover, their involvement in congregational activities was much less common than participation in other community activities such as shopping, eating out, and exercising. According to Gillum and Trulear's analysis of the National Health and Nutrition Examination Survey-III, less than one-third of adults (ages 20–59) who identified as having a mobility impairment reported attending religious services at least weekly.¹¹ Somewhat older and smaller-scale studies reflect similar findings.¹² People with intellectual and developmental disabilities are involved in faith communities, but not often in widespread ways.

Among the few studies directly comparing the religious involvement of individuals with and without disabilities, a clear participation gap emerges. For example, the nationally representative Kessler Foundation/National Organization on Disability (2010) survey of people with and without disabilities found that 45% of respondents who identified as having a severe disability reported attending a place of worship at least monthly; 57% of respondents without disabilities had this same level of involvement.¹³ In her analysis of the Civic Engagement Supplement to the Current Population Survey, Brucker found that 11.8% of adults who identified as having a “cognitive impairment” had participated in congregational activities in the prior year outside of attendance at worship services; 17.3% of adults without disabilities had a similar level of involvement.¹⁴ Implicit—but not explicitly addressed—in this collection of studies is the question of what exactly contributes to the absence of people who desire to be active in their faith community. Barriers of architecture, awareness, attitudes, and access have all been cited as salient factors; each warrants additional exploration.

To be invited

An invitation, rather than an announcement, usually precedes presence. It is not uncommon to hear church leaders express some degree of confusion about the absence of people with disabilities from

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10. E. W. Carter, H. L. Kleinert, T. F. LoBianco, K. Sheppard-Jones, L. N. Butler and M. S. Tyree, “Congregational Participation of a National Sample of Adults with Intellectual and Developmental Disabilities,” *Intellectual and Developmental Disabilities* 53 (2015): 381–93.
 11. R. F. Gillum and H. D. Trulear, “Mobility Limitation and Frequency of Attendance at Religious Services in American Women and Men,” *Journal of Religion, Disability & Health* 11 (2008): 51–60.
 12. For example, J. McNair and H. K. Smith, “Church Attendance of Adults with Developmental Disabilities,” *Education and Training in Mental Retardation and Developmental Disabilities* 35 (2000): 222–25; C. A. Minton and R. A. Dodder, “Participation in Religious Services by People with Developmental Disabilities,” *Mental Retardation* 41 (2003): 430–39; and G. I. Orsmond, M. W. Krauss and M. M. Seltzer, “Peer Relationships and Social and Recreational Activities among Adolescents and Adults with Autism,” *Journal of Autism and Developmental Disorders* 34 (2004): 245–56.
 13. Kessler Foundation, *Kessler Foundation/NOD Survey of Americans with Disabilities* (West Orange, NJ: Author, 2010), 130.
 14. D. L. Brucker, “Social Capital, Employment, and Labor Force Participation among Persons with Disabilities,” *Journal of Vocational Rehabilitation* 43 (2015): 17–31.

their congregation. They may inadvertently (and incorrectly) conclude that people with disabilities do not reside in their community; if people with disabilities do, they must have limited interest in religious life. Broad announcements about a congregation's activities or its inclusivity—through websites, social media, signage, and other advertisements—may not necessarily reach people with more severe disabilities. For example, more than 630,000 adults with intellectual and developmental disabilities in the United States live away from their parents in supported living, group home, and other residential settings.¹⁵ This segment of their community, which often relies on service providers as its source of community information, may not encounter the ordinary outreach efforts congregations make. Instead, most people—whether or not they have a disability—come to a particular congregation for the first time, not through an announcement, but because they received a personal invitation.¹⁶ Yet when the lives of current congregation members never intersect with those of people with disabilities at work, at school, or in their neighborhoods—or when those members hold unfavorable attitudes about disability—such personal invitations rarely get extended.

Likewise, broad announcements about a congregation's hospitality may not resonate with families who have been excluded in the past. Examples of parents being asked to leave their congregation because of their son or daughter with disabilities abound in both the professional literature and on social media.¹⁷ For example, Gaventa recounted a panel of mothers who shared the number of congregations that had asked their family to leave—one counted thirteen, and another tallied seventeen.¹⁸ Such families may need additional assurance that this congregation will be different, that proclamations of "everyone is welcome" really do penetrate its practice and are much more than aspirational. Personal invitations provide the pathway through which such personal assurances can be made. The road to belonging may require extending new invitations in new ways.

To be welcomed

Welcome is felt through personal encounters. People move from merely being present to being actively engaged by others in the congregation. When people with disabilities and their families arrive at a congregation for the first time, however, a warm welcome cannot automatically be presumed (nor is it for anyone else). Although societal attitudes toward disability have improved in recent decades,¹⁹ the uncertainty and reluctance many people still feel toward getting involved in the lives of individuals with disabilities also exists within churches. Furthermore, uncertainty almost always leads to avoidance. When people remain unacknowledged, overlooked, or ignored within a congregation, they soon stop coming. A number of qualitative studies and other published accounts have highlighted the ways people with disabilities and their families have walked away

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15. D. Braddock, R. Hemp, M. C. Rizzolo, L. Haffer, E. S. Tanis and J. Wu, *The State of the States in Intellectual and Developmental Disabilities* (Washington, DC: American Association on Intellectual and Developmental Disabilities, 2015).
 16. T. S. Rainer, *The Unchurched Next Door* (Grand Rapids, MI: Zondervan, 2003).
 17. For example, A. E. Jacober, "Youth Ministry, Religious Education, and Adolescents with Disabilities: Insights from Parents and Guardians," *Journal of Religion, Disability, and Health* 14 (2010): 167–81; S. Speraw, "Spiritual Experiences of Parents and Caregivers who have Children with Disabilities or Special Needs," *Issues in Mental Health Nursing* 27 (2006): 213–20.
 18. W. Gaventa, "The Challenge and Power of Location and Role: Pastoral Counseling in the Lives of Children with Disabilities and their Families," *Sacred Spaces* 6 (2014): 53–86.
 19. K. Scior, "Public Awareness, Attitudes and Beliefs Regarding Intellectual Disability: A Systematic Review," *Research in Developmental Disabilities* 32 (2011): 2164–82; G. N. Siperstein, J. Norins and A. Mohler, "Social Acceptance and Attitude Change: Fifty Years of Research," in *Handbook of Intellectual and Developmental Disabilities*, ed. J. W. Jacobson, J. A. Mulick and J. Rojahn (New York, NY: Springer, 2007), 133–54.

from church feeling much more wounded than welcomed.²⁰ The attitudes and actions that contribute to this offense may be either unintended or overt. Nevertheless, the inevitable consequence is that people usually opt not to return when they feel unwelcome. Ault, Collins, and Carter found that nearly one third of parents (32%) reported having changed their place of worship because their son or daughter with an intellectual and developmental disability was not welcomed or included.²¹

Both intentionality and authenticity mark a meaningful welcome; it communicates that someone is gladly received. Welcoming people with disabilities and their families is not an entirely different endeavor than extending hospitality to anyone else. The principal requirement is not disability-related expertise or experience, but rather ordinary friendliness and common courtesies. In some cases, congregational staff and members may feel more confident extending a warm reception when given some guidance on disability etiquette, people-first language, and available congregational resources.²² More specific information also may be needed on how to approach individuals who have complex communication challenges, who behave in unfamiliar ways, or who have extensive support needs. Nevertheless, generous hospitality to people with disabilities is already within the capacity of any congregation member.

To be known

Although Christians are called to welcome the stranger,²³ the stranger should not remain one for very long. When sporadic interactions evolve into prolonged patterns, deeper connections among people can form. Moreover, when brief social amenities give way to sustained conversations and shared lives, people with disabilities and their families can become truly known. Being known marks the difference between “being present” and “having a presence.”²⁴ It is quite possible to navigate the same space as dozens or hundreds of other congregants week after week and never feel known. Within faith communities, people with intellectual and developmental disabilities are particularly at risk of being known about, but not known personally. Congregation members who invest time getting to know individuals with such labels often discover that many of their preconceived notions soon get overturned as enough of life is shared together.

Whether others know people well is an important aspect of belonging. Furthermore, *how* people with disabilities are known also matters. Many people with intellectual and developmental disabilities are known first and foremost by their labels, rather than by their names—by their deficits, rather than by their strengths and gifts. For example, people may all know of that young man with Down syndrome in their congregation, but few know him as John, the young man with a servant’s heart, a

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20. For example, Jacober, 167–181; E. S. Marshall, S. F. Olsen, B. Mandleco, T. T. Dyches, K. Allred and N. Sansom, “This is a Spiritual Experience: Perspectives of Latter-day Saint Families Living with a Child with Disabilities,” *Qualitative Health Research* 13 (2003): 57–76; E. E. O’Hanlon, “Religion and Disability: The Experiences of Families of Children with Special Needs,” *Journal of Religion, Disability, & Health* 17 (2013): 42–61; E. W. Richardson and Z. Stoneman, “The Road to Membership: The Role of Resilience in Seeking and Maintaining Membership in a Faith Community for Families of Children with Disabilities,” *Journal of Disability & Religion* 19 (2015): 312–39; Speraw, “Spiritual Experiences”, 213–20.
 21. M. J. Ault, B. C. Collins and E. W. Carter, “Congregational Participation and Supports for Children and Adults with Disabilities: Parent Perceptions,” *Intellectual and Developmental Disabilities* 51 (2013): 48–61.
 22. B. C. Collins and M. J. Ault, “Including Persons with Disabilities in Religious Community: Program Models Implemented by Two Churches,” *Journal of Religion, Disability, and Health* 14 (2010): 113–31.
 23. C. D. Pohl, “Responding to Strangers: Insights from the Christian Tradition,” *Studies in Christian Ethics* 19 (2005): 81–101.
 24. D. Granzen, “Inclusion and reciprocity,” Keynote Presentation at the Faith Inclusion Network Conference, Madison, WI, 2005.

love for God, and passion for the Lakers. Although disability service systems tend to view people in diagnostic terms, congregations should avoid this vantage and instead strive to know people with disabilities in personal ways. Carter, Boehm, and colleagues highlighted such an alternative perspective in their study addressing the character strengths of young people with intellectual and developmental disabilities.²⁵ They found that parents readily described their sons and daughters as possessing qualities such as kindness, empathy, humor, gratitude, optimism, forgiveness, and courage. Such findings offer a powerful counterpoint to prevailing deficit-based views of people. Moreover, they remind congregations of the importance of also seeing people with disabilities in terms of their gifts and contributions. People should be known for much more than their challenges.

To be accepted

Acceptance often comes through being known. The stigma associated with intellectual and developmental disabilities has been longstanding and widespread.²⁶ Although considerable efforts are being made to diminish stereotypes, prejudice, and discrimination worldwide, people with intellectual and developmental disabilities still struggle to find acceptance. This struggle takes place both within and beyond the Church. Among the parents we interviewed,²⁷ acceptance was evident when their son or daughter was known and embraced for all of who he or she is—as someone with a disability, but more importantly as an individual. They spoke of their child being welcomed without condition, treated like family, and included in all aspects of congregational life.

Although attitudinal research focused on educational and employment settings is extensive, few studies have focused directly on the views of congregation members toward people with disabilities. Carter, Boehm, Annandale, and Taylor asked parents to share their perspectives on the extent to which their current congregation was accepting of their child with intellectual disability or autism. More than half (55%) of parents strongly agreed that congregational leaders accepted their child; slightly less than half (48%) strongly agreed that other congregation members accepted their child.²⁸ Although multiple factors can shape attitudes, spending time with and learning about someone may exert the most powerful influence on acceptance.²⁹ Congregations often undertake formal awareness activities (e.g., a disability awareness Sunday, curricular units) as the formal avenue for fostering greater acceptance. Nevertheless, personal involvement in someone's life is a much more promising way of changing perspectives. The power of personal contact highlights the importance of minimizing separate programming for people with intellectual and developmental disabilities, which can inadvertently reinforce perceptions of difference and limit the extent to which people ever encounter one another in personal ways.

To be supported

Personalized supports make participation possible. Congregational leaders desire that all of their members be supported in the full life of the faith community. Most congregations take steps to

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25. E. W. Carter, T. L. Boehm, E. Biggs et al., "Known for My Strengths: Positive Traits of Transition-age Youth with Intellectual Disability or Autism," *Research and Practice for Persons with Severe Disabilities* 40 (2015): 101–19.
 26. S. Werner, "Stigma in the Area of Intellectual Disabilities: Examining a Conceptual Model of Public Stigma," *American Journal of Intellectual and Developmental Disabilities* 120 (2015): 460–75.
 27. Carter, Biggs, and Boehm, "Being Present."
 28. E. W. Carter, T. L. Boehm, N. H. Annandale and C. Taylor, "Supporting Congregational Inclusion for Children and Youth with Disabilities and their Families," *Exceptional Children* (in press).
 29. K. Scior and S. Werner, *Changing Attitudes to Learning Disability: A Review of the Evidence* (London, UK: Mencap, 2015), 4.

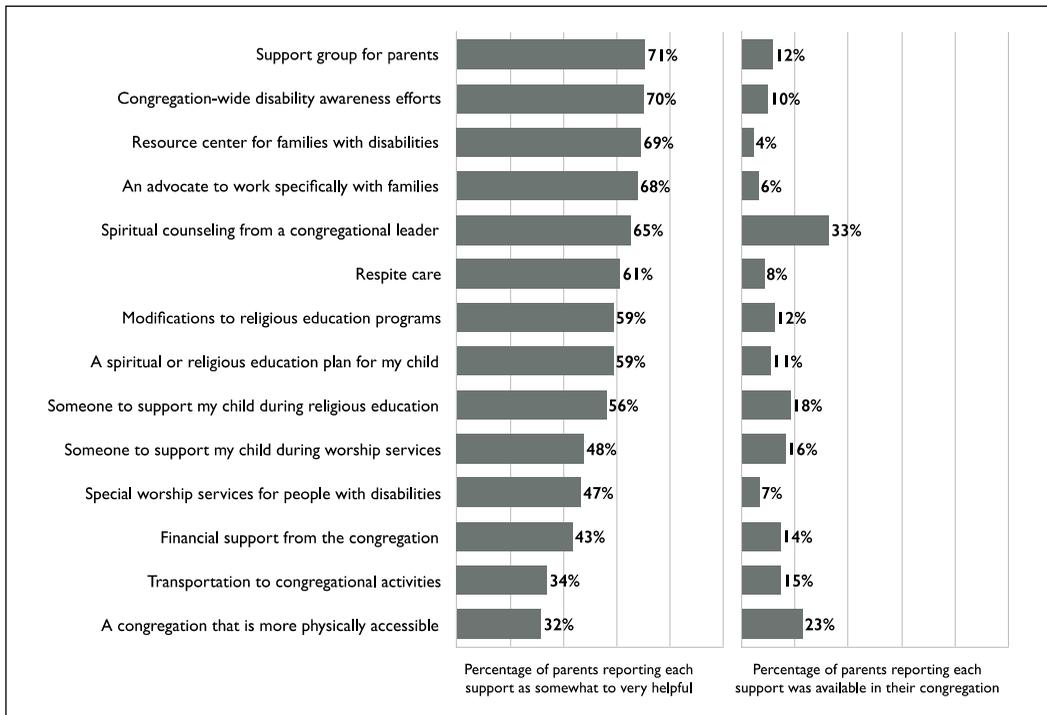


Figure 1. Parent views regarding the helpfulness and availability of congregational supports.

ensure that anyone who wants to be involved in their church is able to do so, whether through providing childcare, offering transportation, connecting families to small groups, or assisting financially. The ordinary supports congregations provide to any member should also be extended to families impacted by disability. At the same time, individuals with intellectual and developmental disabilities and their families often benefit from additional supports that may differ in their intentionality, intensity, or individualization. For example, some children and adults with disabilities have complex communication challenges that require thinking creatively about how they might participate in worship, learning, and social activities. Others exhibit behavioral challenges that necessitate thoughtful and proactive support plans. Most have cognitive impairments that will prompt exploration of needed adaptations and accommodations to enable active and meaningful participation. For many families, offering something beyond the ordinary is important to their being—and feeling—part of a faith community.

What supports might be especially helpful for these families? Carter, Boehm, Annandale, and Taylor reported on the extent to which each of fourteen disability-specific supports was viewed as helpful to parents of youth and young adults with intellectual disability or autism.³⁰ As shown in the first column of Figure 1, more than half of parents indicated that the following supports would be somewhat to very helpful: a support group for parents, congregation-wide disability awareness efforts, resources for families, a congregational advocate to work specifically with families, respite care, spiritual counseling from clergy, modifications to religious education programs, a spiritual or religious education plan for their child, or someone to support their child during worship services. Other supports—such as offering special worship services, offering financial support, or increasing

30. Carter, Boehm, Annandale, and Taylor, "Supporting Congregational Inclusion."

the physical accessibility of the congregation—received diminished endorsement. Although architectural actions (e.g., building ramps, widening doors, adding elevators) and specialized programming (e.g., separate classes or worship services) are often emphasized in conversations about disability ministry,³¹ it is intriguing that parents more heavily prioritized efforts to promote broader awareness and to strengthen supports in existing congregational activities.³²

It is important to emphasize that their list of potential supports is neither exhaustive nor prescriptive. In other words, it does not include the ordinary supports that any family in a congregation might draw upon and find helpful. A key reflection point for any conversation might be to determine supports that contribute to a sense of belonging for *any* member of the congregation, and then to ensure such supports are also available to families impacted by disability. Likewise, the supports prioritized in this study may not be the same supports a particular family in another congregation would necessarily want or need. Nearly every family in the study provided a unique combination of ratings, suggesting that a one-size-fits-all approach to providing support should give way to a more individualized approach for discerning which supports matter most to which families. Yet, the extent to which congregations avoid making presumptions and instead invite input appears to be limited. For example, Ault et al. found that almost half (46%) of parents indicated they had *never* been asked by a person in their congregation about the best way to include their child in religious activities.³³

As displayed in the second column of Figure 1, a sizable gap exists between the extent to which congregations offer the very supports that parents would consider most helpful. For all fourteen supports addressed in the Carter, Boehm, Annandale, and Taylor study,³⁴ the vast majority of parents (i.e., between 67% and 96%) indicated that each support was not currently available within their congregation. Moreover, nearly half of congregations were reported to offer none of these supports. An important opportunity exists in the gap between the two columns in Figure 1. To be places of belonging, congregations must also commit to providing the breadth of supports people might need to be actively involved in all corners of their community.

To be cared for

Healthy communities are marked by care for one another. They recognize and strive to support the spiritual, emotional, instrumental, and other needs of their members. For people with intellectual and developmental disabilities and their families, such care has been shown to contribute to their well-being and enhance their quality of life.³⁵ Families in our project highlighted the importance both of supports specifically related to the impact of disability, as well as more generic supports that might be drawn upon by any family in a congregation. The provision of care represents an important avenue of ministry *to* people with disabilities.

Consider the area of spiritual supports. In their survey of 223 parents of children with developmental disabilities more than two decades ago, Herman and Thompson found that almost half (44%) of parents reported that support from their congregational leaders was not available to

31. A. N. Amado, M. Degrande, C. Boice and S. Hutcheson, "Accessible Congregations Campaign: Follow-up Survey of Impact on Individuals with Intellectual/Developmental Disabilities (ID/DD)," *Journal of Religion, Disability, and Health* 16 (2012): 394–419; A. A. Herzog, ed., *Disability Advocacy among Religious Organizations: Histories and Reflections* (Binghamton, NY: Haworth, 2006).

32. Cf. Ault et al., "Congregational Participation," 53.

33. Ault et al., "Congregational Participation," 55.

34. Carter, Boehm, Annandale, and Taylor, "Supporting Congregational Inclusion."

35. E. E. Biggs and E. W. Carter, "Quality of Life for Transition-age Youth with Autism or Intellectual Disability," *Journal of Autism and Developmental Disorders* 46 (2016): 190–204; Boehm et al., "Family Quality of Life"; Poston and Turnbull, "Role of Spirituality and Religion in Family Quality of Life."

them.³⁶ More recently, we found that 67% of parents said spiritual counseling from a congregational leader was not available in their congregation (see Figure 1). In response, seminaries are being called upon to equip future clergy with the commitment and capacity to serve people who live with disabilities.³⁷ In terms of personal supports, fewer than 10% of congregations offer any form of respite care for families.³⁸ In response, new ministries are emerging to provide parents rare opportunities to spend time with their spouse or address personal needs while their son or daughter spends time with church members.

Such care might also extend beyond the walls of the congregation.³⁹ For example, unemployment rates for people with intellectual and developmental disabilities have stagnated at 85–90% for decades.⁴⁰ In response, congregations in four states are investing time learning about the strengths and passions of their members with disabilities and then tapping into the extensive social networks within their church to find a job where those gifts are most needed.⁴¹ More than one million people with intellectual and developmental disabilities live with aging parents, and more than 300,000 people live in group homes or larger residential facilities.⁴² In response, some seminaries are developing shared housing options that are inclusive of people with intellectual disability (see www.friendshiphousepartners.com), and some churches are supporting faith-based residential options. Also, nearly one-third of children with disabilities live in poverty.⁴³ In response, some churches are taking steps to assist with the material and financial needs of families whose children have extensive support and service needs.⁴⁴

A word of caution is warranted here. The history of disability is replete with examples of well-intentioned care being used in wounding ways. What feels like care to one person can be perceived as paternalism by another person. As in all areas of this framework, it is important to avoid making assumptions about what any individual or families might want or need. Instead, a preferred posture is to find out first hand what people want for their lives.

To be befriended

We were made for relationship. Although the theological support for this statement will be familiar to readers of this journal, the force of friendship also has been well documented by social scientists over many decades.⁴⁵ The companionship, intimacy, reciprocity, and support shared among friends

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36. S. E. Herman and L. Thompson, "Families' Perceptions of their Resources for Caring for Children with Developmental Disabilities," *Mental Retardation* 33 (1995): 73–83.
 37. N. H. Annandale and E. W. Carter, "Disability and Theological Education: A North American Study," *Theological Education* 48 (2014): 83–102; Association of Theological Schools, *Disability and Theological Education: Toward a Fully Inclusive Community* (Pittsburgh, PA: Author, 2008).
 38. Carter, Boehm, Annandale, and Taylor, "Supporting Congregational Inclusion"; C. Woolever and D. Bruce, *A Field Guide to U.S. congregations: Who's Going Where and Why* (Louisville, KY: Westminster John Knox, 2002).
 39. E. W. Carter, "After the Benediction: Walking Alongside People with Significant Disabilities and Their Families in Faith and Life," *Journal of Religion, Disability & Health* 15 (2011): 395–413.
 40. J. Butterworth, J. Winsor et al., *State Data: The National Report on Employment Services and Outcomes* (Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion, 2014).
 41. D. Nord, J. Timmons, E. W. Carter and W. E. Gaventa, "Building Community Capacity to Advance Employment: Putting Faith to Work," *Journal of Vocational Rehabilitation* 40 (2014): 161–64; see www.puttingfaithtowork.org.
 42. Hewitt et al., "Introduction to the Special Issue."
 43. S. L. Parish, R. A. Rose and M. E. Andrews, "TANF's Impact on Low-income Mothers Raising Children with Disabilities," *Exceptional Children* 76 (2010): 234–53.
 44. Carter, Boehm, Annandale, and Taylor, "Supporting Congregational Inclusion."
 45. J. E. Grusec and P. D. Hastings, *Handbook of Socialization: Theory and Research* (New York, NY: Guilford, 2007).

can be vital to one's thriving. As Sue Mosteller, a long-time member with L'Arche Daybreak in Toronto, suggests, "... alone we are poor, together we are rich."⁴⁶ Individuals in our project pointed to such relationships as contributing substantively to their sense of belonging within their faith community. All of the other dimensions mentioned so far in this article can be addressed in the absence of a close and ongoing relationship. Friendships take belonging deeper.⁴⁷

However, the friendships so fundamental to human flourishing remain elusive for far too many children and adults with intellectual and developmental disabilities. For example, one nationally representative study of adolescents with autism found that 44% of these youth never saw friends outside of school; 84% never or rarely received phone calls from friends, and 51% had not been invited to a peer's social activities during the past year.⁴⁸ Moreover, 24% of adults with intellectual disability receiving public services and supports report having no friendships and caring relationships with people other than support staff or family members.⁴⁹ It is important to emphasize that the absence of friendships is not inherent to having an intellectual or developmental disability. Instead, it is more often an artifact of the limited opportunities and supports people with and without disabilities have to meet and spend time with one another in sustained and satisfying ways.⁵⁰

These research findings emphasize the importance of what takes place *between* Sundays. Relationships are most likely to be forged when people participate together in shared activities over a sustained period of time. Life lived together beyond the walls of the congregation is what pushes people beyond mere acquaintances to close friends, whether by sharing a cup of coffee, participating in a favorite hobby, visiting the local mall, taking a stroll through the park, watching the big game, or joining the same small group. For youth and adults with intellectual and developmental disabilities, such ordinary gestures rarely take place with individuals outside the service system. As with extending a welcome, being someone's friend requires no specialized degree or extensive training.

To be needed

As relationships deepen, people come to see their need for one another. For many people in our project, authentic belonging was characterized by a real reciprocity, whereby each person both brings to and receives from the relationship. Although more and more churches are recognizing the importance of "ministry to" people with disabilities, many still struggle to move toward the place of "ministry by" people with disabilities. People with intellectual and developmental disabilities are still viewed as the "designated recipients" of service and outreach; the roles of giver and receiver remain strikingly static. Certainly people with disabilities might have much to gain from being part of a faith community (see the sections of this article on support and care), but it is also true that a faith community might have much to gain by encountering the gifts individuals with disabilities and their families have to bring. When this mutuality is expressed, belonging is nurtured. People with disabilities and their families are assured they belong when their faith

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46. S. Mosteller, *A Place to Hold My Shaky Heart: Reflections from Life in Community* (New York, NY: Crossroad, 1998), 9.
 47. B. T. Conner, *Amplifying Our Witness: Giving Voice to Adolescents with Developmental Disabilities* (Grand Rapids, MI: Eerdmans, 2012); H. S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: Eerdmans, 2008).
 48. M. Wagner, T. W. Cadwallader, N. Garza and R. Cameto, "Social Activities of Youth with Disabilities," *NLTS2 Data Brief* 3 (2004), 1–4.
 49. National Core Indicators, *Adult Consumer Survey: 2013–2014 Final Report* (Cambridge, MA: Author, 2015).
 50. E. W. Carter, K. Bottema-Beutel and M. E. Brock, "Social Interactions and Friendships," in *Equity and Full Participation for Individuals with Severe Disabilities: A Vision for the Future*, ed. M. Agran, F. Brown, C. Hughes, C. Quirk and D. Ryndak (Baltimore, MD: Paul H. Brookes, 2014), 197–216.

community sees itself as incomplete without their presence and participation. They are viewed not merely as an asset, but as truly indispensable.

Seeing individuals with disabilities in light of the gifts and strengths they bring to the faith community is one way of communicating that a person is needed.⁵¹ Supporting people with disabilities to assume valued roles throughout the congregation is another. When people with intellectual and developmental disabilities are involved in serving others—rather than the perpetual focus of service—they come to be seen in quite different ways within the congregation. Whether serving as an usher, helping in the nursery, visiting the people who are homebound, helping on an outreach project, volunteering on the prayer team, going on a mission trip, setting up the sanctuary, or joining the choir—opportunities and supports for service should be extended. People who are needed are usually missed when they are absent. And when a person finds they are missed, they know they belong.⁵²

To be loved

Love accompanied belonging for many of the individuals with disabilities and parents with whom we spoke. The language of love was used to describe both how families felt in their congregation, as well as the manner in which they were treated by others. In his article on spiritual valorization, Coulter affirmed Wolf Wolfensberger's message that, "healing for wounded persons with disabilities begins with three messages: (a) you are valuable, (b) you are as valuable as any other person, and (c) you are loved by those around you."⁵³ That there is almost no research literature to summarize on this aspect of belonging likely comes as no surprise to readers familiar with the professional literature. Social scientists working in this area have been largely silent on love. Indeed, "inclusion" is nearly always addressed in the literature without reference to this dimension. Real belonging cannot be considered apart from love.

Implications for research and practice

Research at the intersection of faith and disability is still in its infancy. Nevertheless, the portfolio of early findings presented in this article suggests several areas for future movement in this area of ministry. First, disability must become a deeper part of the dialogue within seminary and continuing education. More than 21 million families in the United States have at least one relative with a disability,⁵⁴ and most people will personally experience a disability at some point in their lives. Yet future clergy and ministry leaders receive limited preparation related to serving and supporting this segment of their community well. In their study of North American theological schools, Annandale and Carter reported that the topic of disability made limited appearance in the seminary curriculum, opportunities for direct involvement in the lives of people with disabilities and their families were infrequent, and the extent to which students with disabilities were well supported on campus varied.⁵⁵ Perhaps most concerning was that nearly three quarters of seminary leaders felt that their graduates received little or no preparation to either include people with

51. Carter, Boehm, and Biggs, "Known for My Strengths."

52. J. Swinton, "From Inclusion to Belonging: A Practical Theology of Community, Disability, and Humanness," *Journal of Religion, Disability, & Health* 16 (2012): 172–90.

53. D. L. Coulter, "Presidential Address 2005: Peace-making is the Answer: Spiritual Valorization and the Future of our Field," *Mental Retardation* 44 (2006): 65.

54. Q. Wang, *Disability and American Families: 2000* (Washington, DC: US Census Bureau, 2005).

55. Annandale and Carter, *Disability and Theological Education*.

disabilities into multiple dimensions of congregational life or to address the spiritual questions related to disability. Congregational leaders are influential factors in the degree to which the dimensions of belonging outlined in this article will be pursued and supported. Strengthening their commitment and confidence in this area is an important investment.

Second, conversations about the inclusion of people with disabilities in their faith communities should shift from *why* toward *how*. There is no shortage of position statements, resolutions, and articles addressing why congregations—and service systems—should be about the business of helping people flourish spiritually. The more pressing question is how this commitment might come to penetrate practice in communities across the country. What specifically does it look like to ensure people with (and without) intellectual and developmental disabilities are invited, present, welcomed, known, accepted, supported, cared for, befriended, needed, and loved within their church communities? What postures and practices make this possible and probable? Although much can be learned from the fields of education, rehabilitation, and community living about promising approaches, the congregational context is still quite unique and warrants much more attention.

Third, new models of inclusive ministry may be needed to foster these various dimensions of belonging. A longstanding disposition of churches has been to establish distinct programs or specialized ministries specifically for people with intellectual and developmental disabilities (e.g., special needs programs, distinct worship services, separate social events). Congregations see these mirror movements elsewhere in their community, such as special education classrooms, sheltered workshops, group homes, or special recreation programs. Missing from these specialized models, however, are opportunities for others in a congregation to meet, get to know, and receive the gifts of people with disabilities who are part of their community. When people with and without disabilities rarely encounter one another on Sunday morning or throughout the week, opportunities to be known, welcomed, befriended, needed, and loved become limited.

Fourth, efforts to foster belonging will benefit from both intentionality and regular reflection. The “church stories” of people with disabilities and their families offer a strong reminder that the dimensions of belonging addressed in this article are not automatically presumed;⁵⁶ they must be intentionally pursued. Congregation members committed to becoming places of welcome and belonging could use these ten dimensions as possible points of reflection (see Figure 2). Using questions adapted from Forest and Pearpoint,⁵⁷ a team comprised of members with and without disabilities might ask: “What are we doing well right now in this area? What could we be doing better, more of, or entirely different?” From the answers to these questions, teams can identify areas of priority and immediate movement.

Summary

From distinct directions, both congregations and service systems are called to support people with intellectual and developmental disabilities to thrive in community with others. This article has highlighted a collection of markers that might contribute to belonging within communities of faith. For people with disabilities and their families, this sense of connection and membership that might emerge from these indicators can contribute to their own flourishing in faith and life. For congregations committed to promoting belonging in this area, the relationships and faith they encounter may just contribute to their own flourishing as a community.

56. W. Gaventa, “Communities of Celebration that Reawaken Desire,” *Journal of Disability & Religion* 19 (2015): 97–105.

57. M. Forest and J. Pearpoint, *Four Easy Questions* (Toronto, ON: Inclusion Press, 1997).

Are people with disabilities and their families...	What are we doing really well right now?	What could be doing better, more of, or entirely different?
Invited		
Present		
Welcomed		
Known		
Accepted		
Supported		
Cared for		
Befriended		
Needed		
Loved		

Figure 2. Approach for reflecting on dimensions of belonging. Adapted from E. W. Carter, “Dimensions of Belonging: Listening to and Learning from Families.” Presentation at the 40th annual TASH Conference, Portland, Oregon, 2015.

Author biography

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