

SPIRITUALITY AND SUPPORTS FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

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Supporting people in flourishing is a core commitment of both disability service systems and faith communities. For individuals with intellectual and developmental disabilities (IDD) and their families, whose lives often straddle both of these worlds, the gulf that can exist between these seemingly separate realms is sometimes wide (Gaventa, 2018). The constellation of professionals investing in the lives of people with disabilities—including special educators, therapists, health care providers, support staff, and many other service providers—does not always give serious attention to the spiritual lives of individuals with IDD. Likewise, the constellation of congregations found all across the United States sometimes struggles to fully include individuals with IDD in faith communities. Renewed efforts to address the intersection of spirituality and disability can further the shared goal of helping people experience lives marked by meaning, satisfying relationships, full participation in society, and quality supports.

The purpose of this chapter is to highlight the spiritual lives of individuals with IDD and their families, and to suggest ways in which the secular and sacred spheres might work in concert to support these individuals, thriving in all areas of their lives. This chapter addresses four main objectives: (a) to review recent research addressing the place of spirituality and religion in the lives of

individuals with IDD and their families, (b) to highlight how faith communities might support their presence and participation, (c) to address professional practices that are attentive to this dimension of their lives, and (d) to identify pathways for research and practice that support people well in these areas.

A BROAD VIEW OF SPIRITUALITY

The spiritual lives of Americans have received considerable attention in both research and popular culture, yet conversations about this dimension of people's lives can be complicated by the myriad and evolving ways in which spirituality can be defined and described (Pearce et al., 2017). In this chapter, I adopt a broad perspective that views spirituality as a "search for the sacred" (Pargament et al., 2013, p. 14) and involves concepts of God, a higher power, or other transcendent experiences. In this way, spirituality can be experienced, expressed, and explored in a wide range of contexts and for a variety of purposes. In the United States, more than three quarters of Americans affiliate with an established religious tradition, and most attend religious services at least monthly (Pew Research Center, 2015). One primary purpose of religious institutions is to facilitate spirituality, and most local congregations offer an array of formal and informal activities aimed toward this goal (e.g., worship services, religious education,

<https://doi.org/10.1037/0000195-016>

APA Handbook of Intellectual and Developmental Disabilities: Vol. 2. Clinical and Educational Implications: Prevention, Intervention, and Treatment,
L. M. Glidden (Editor-in-Chief)

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service opportunities, social events). However, spiritual pathways can also be highly personalized and involve nontraditional approaches outside of an established religious tradition. In other words, people might consider themselves to be both spiritual and religious, but the two need not always go together.

SPIRITUAL PRACTICES, PARTICIPATION, AND PRIORITIES OF INDIVIDUALS WITH IDD AND THEIR FAMILIES

Research addressing the spirituality of individuals with disabilities and their families has made a regular, but still rare, appearance in the professional literature (see reviews by Ault, 2010; Hills et al., 2016; Sango & Forrester-Jones, 2017; Zhang & Rusch, 2005). Overall, these studies have been eclectic in their focus, methodologies, and conceptual frameworks. In this section, I highlight research addressing the practices that mark the spiritual lives of individuals with IDD and their families, their participation in congregational and faith community contexts, and the priorities they hold in this area of their lives.

Individuals With IDD

Practices. In many respects, the spiritual expressions of individuals with IDD appear more ordinary than exceptional. Qualitative studies illustrate the ways in which practices such as prayer, meditation, scripture reading, personal devotions, rituals, and adherence to particular religious tenets can be embedded within the lives of youth and adults with disabilities (e.g., Liu et al., 2014; Shogren & Rye, 2005; Turner et al., 2004). The practices displayed in Table 16.1 are quite noticeable in the lives of some individuals, while remaining in the background of the lives of others. Larger scale studies have also addressed the prominence of these practices. For example, Carter and Boehm (2019) queried 440 parents about the spiritual expressions of their daughters and sons (ages 13–21) with intellectual disability and autism. More than half of these young people regularly (i.e., daily/weekly or monthly) took part in 11 of the practices displayed in Table 16.1, including praying before or after mealtime (70%), reading or listening to scripture (66%), praying together with other family members at home (60%),

listening to religious music or radio (60%), singing or humming religious songs (58%), having conversations with family members about spiritual issues (56%), praying at bedtime or upon waking up (55%), and referencing religious or spiritual ideas in conversations (52%). On average, youth with IDD engaged in 10 of the practices displayed in Table 16.1, six of which occurred daily or weekly and four of which occurred monthly or yearly. However, there remains an absence of information about the spiritual formation and practices of younger children, as well as the experiences of individuals with significant communication, behavioral, and cognitive challenges.

Participation. Much more attention has been focused on whether and how individuals with IDD are involved in a local church, synagogue, mosque, temple, or other place of worship (e.g., Abells et al., 2008; Brucker, 2015; McNair & Smith, 2000; National Organization on Disability, 2010; Orsmond et al., 2004; Shogren & Rye, 2005). Although available studies each operationalize congregational participation in different ways, attendance at religious services is usually quite prevalent. For example, in his analyses of multiple waves of the National Survey of Children's Health, Whitehead (2018) found that 68% of children with autism spectrum disorder and 74% of children with intellectual disability attended religious services at least annually. Likewise, Carter et al. (2015) analyzed data from the National Core Indicators project that addressed the religious participation of more than 12,000 adults with IDD who were receiving services from state agencies. Almost half (48%) of these adults had attended a religious service at least once in the past month and 35% attended three or more times per month. However, whenever congregational participation rates among individuals with and without disabilities are compared, a sizable participation gap has been documented (Brucker, 2015; National Organization on Disability, 2010; Whitehead, 2018). In every comparative study, individuals with IDD are substantially less involved. None of these studies addressed the specific religious traditions (e.g., Christianity, Judaism, Islam, Hinduism) with which individuals with IDD affiliated.

TABLE 16.1

Examples of Spiritual Practices and Congregational Participation

Type	Practice
Personal practices	Praying before or after mealtime
	Reading (or listening) to scripture
	Praying at bedtime or upon waking up
	Listening to religious music or radio
	Praying together with other family members at home
	Singing or humming religious songs
	Practicing a weekly day of rest for religious or spiritual reasons
	Referencing religious or spiritual ideas in conversations
	Having casual conversations with family members about spiritual issues
	Contributing money to a religious group or congregation
	Participating in personal devotions
	Participating in family devotions
	Watching religious television programs or movies
	Sharing one's faith or witnessing with people outside the family
	Choosing jewelry or clothing that expresses spiritual or religious meaning
	Making connections to the divine through nature
	Celebrating religious holiday traditions at home
	Creating art, music, dance, or writing as a spiritual practice
	Accessing religious websites
	Praying using items such as rosary beads, icons, mezuzahs, crosses, etc.
	Attending a religious music concert
	Practicing other physical meditation techniques as a spiritual practice
	Following dietary laws as a religious practice
	Burning candles or incense as a spiritual practice
	Fasting or denying oneself something as a spiritual discipline
	Practicing yoga for spiritual reasons
	Congregational participation
Attending a Sunday school or religious education class	
Participating in a youth group	
Participating in a prayer, study, or small group	
Participating in prayer meetings	
Participating in sacraments (e.g., communion, confession, penance)	
Attending congregational fellowships, potlucks, and other social gatherings	
Serving in the choir or on a music team	
Serving as an usher or greeter	
Performing other forms of service for the congregation	
Participating in local outreach or service activities	
Leading prayers publicly during religious services	
Leading scripture readings during religious services	
Attending a religious youth retreat, conference, rally, or congress	
Serving as an acolyte or altar server	
Participating in rites of passage (e.g., communion, bar mitzvah, confirmation)	
Participating in a national or international mission activities	

Note. From "Religious and Spiritual Expressions of Youth With Intellectual and Developmental Disabilities," by E. W. Carter and T. L. Boehm, 2019, *Research and Practice for Persons With Severe Disabilities*, 44(1), pp. 42–43 (<https://doi.org/10.1177/1540796919828082>). Copyright 2019 by Sage. Adapted with permission.

In addition to regular worship services, most congregations have an array of educational offerings (e.g., Sunday/Sabbath school, adult religious education), service opportunities (e.g., serving within the congregation, community outreach), social gatherings (e.g., meals, small groups), or other activities for their members (see Table 16.1). In their study addressing the congregational experiences of 416 parents of children and adults with IDD, Ault, Collins, and Carter (2013) found that 61% of the parents' daughters and sons had participated in religious education programs in the past year, 25% had been involved in recreational activities, 16% had volunteered, and 14% participated in small group meetings. In their study of youth and young adults with IDD, Carter and Boehm (2019) found that 63% of individuals (ages 13–21) attended a Sunday school or religious education class; 59% attended congregational fellowships, potlucks, and other social gatherings; 47% attended a youth group; 35% participated in community outreach; and 33% were involved in some type of small group. On average, youth with IDD participated in five of the congregational activities displayed in Table 16.1 (bottom section), two of which occurred daily or weekly and three of which occurred monthly or yearly. Although both samples reflected predominantly Christian denominations, other traditions were represented in smaller numbers.

Although these studies indicate that many individuals with IDD are connected to congregational life, multiple factors can limit this participation (Carter & Boehm, 2019; Carter et al., 2015; Whitehead, 2018). For example, attendance at religious services tends to be less common for individuals who have externalizing behaviors, mobility difficulties, complex communication needs, more intensive support needs, health problems, and/or social-related skill deficits. Moreover, adults with IDD who live with someone other than their immediate family (e.g., group homes, institutions) have lower levels of participation. It is not clear whether the ways in which the individuals highlighted in this paragraph are participating in congregational life in similar ways (i.e., ordinary vs. adapted or alternative) and settings (i.e., ordinary vs. specialized or segregated programs) as individuals without disabilities.

Priorities. The prevalence of spiritual practices and congregational participation might imply that faith holds an important place in the lives of children and adults with IDD. However, this interpretation is more often assumed than asked. Few studies have directly addressed the priority that individuals with IDD place on religion and spirituality (e.g., Baldwin et al., 2015; Lifshitz et al., 2009; Liu et al., 2014) or asked about the beliefs they hold (e.g., Shogren & Rye, 2005). When asked about the faith of their daughters and sons with IDD (ages 13–21), 72% of parents indicated that their child enjoyed being around others of the same faith and 57% said their child looked to faith as providing meaning and purpose (Carter & Boehm, 2019). Moreover, these youths often initiated a variety of spiritual practices at home and personally chose to attend congregation activities. Many of the youths interviewed in Liu et al. (2014) affirmed the importance of their faith (all were associated with Christian denominations), spoke of the impact it had on their lives, and expressed a desire to go deeper in this area of their lives. In the only national study addressing this topic, the National Organization on Disability (2004) found that 84% of individuals who identified as having a significant disability considered their religious faith to be “somewhat” to “very important.” As is true among any segment of the population, there are also individuals with IDD for whom spirituality and religion are peripheral or immaterial to their lives (Caldwell-Harris et al., 2011). For example, Carter and Boehm (2019) found that 6% of young people with IDD did not engage in any spiritual practices, and 13% had not participated in any congregational activities. Nearly every published study includes a subset of individuals for whom an interest in spirituality is not evident. Such a finding is consistent with national surveys showing that individuals who do not have disabilities also reflect a mix of people who are and are not interested in spirituality or religion.

A heinous event on October 27, 2018 highlighted the inclusion and belonging of two brothers, both with Fragile X syndrome (see Volume 1, Chapter 7, this handbook), in their congregation at the Tree of Life synagogue in Pittsburgh, Pennsylvania. Cecil Rosenthal (age 59) and David Rosenthal (age 54) were among the 11 victims who were killed by a

lone gunman during the Sabbath service that day. Descriptions in various news outlets highlighted the brothers' dedication to their religion and their synagogue, their interest in Judaism, their roles in the synagogue, and the admiration and fondness that other congregants had for them. Comments such as "They were just part of the fabric that every group wants to have" and "They were kind, good people with a strong faith and respect for everyone around" indicate the value that their religious life had for Cecil and David, and the significance of what they gave to others (see <http://www.post-gazette.com/news/crime-courts/2018/10/28/Brothers-Cecil-David-Rosenthal-victims-synagogue-Tree-of-Life-attack-Pittsburgh/stories/201810280185> for more information).

Parents and Other Family Members

The spiritual lives and religious involvement of parents can shape—and are shaped by—their children with IDD (Carter & Boehm, 2019). This influential role highlights the importance of understanding the practices, participation, and priorities of these families. Most of the research in this area to date has focused on parents of younger children with disabilities (e.g., Haworth et al., 1996; Rogers-Dulan, 1998; Skinner et al., 1999; Weisner et al., 1991), highlighting the need for more of a lifespan approach within research.

Practices. The ubiquity of prayer is reflected in the high percentage of all American adults who report praying daily (55%), weekly (16%), or monthly (6%; Pew Research Center, 2015). Prayer is also quite common among parents of children with IDD (Marshall et al., 2003; Poston & Turnbull, 2004). For example, Tarakeshwar and Pargament (2001) found that 52% of parents of children (ages 4–24) with autism reported that they prayed at least daily, while Boehm and Carter (2019a) found that 73% of parents of children (ages 1–74) with an intellectual disability reported that they prayed daily. Other practices reported by parents include scripture study, meditating, contemplation, following dietary practices, and practicing acts of kindness. Most studies in this area have reflected predominantly Christian samples (with a wide range of denominations), highlighting the importance of also examining

practices among parents affiliated with other religious traditions.

Participation. Many parents also report having at least some involvement in the worship, learning, fellowship, and service activities that take place through a local congregation (e.g., Luther et al., 2005; Tarakeshwar & Pargament, 2001; Tway et al., 2007). Boehm and Carter (2019a) examined the congregational activities of 530 parents and caregivers of family members who have an intellectual disability. They found that 49% of these parents and caregivers attended congregational fellowships, potlucks, and other social gatherings; 43% participated in prayer, study, or other small groups; 38% attended a Sunday school or religious education class; and 38% participated in local outreach activities. Carter, Boehm, Annandale, and Taylor (2016) reported that 58% of participants attended religious services at least weekly, 14% attended at least monthly, 16% attended at least yearly, and 12% attended less frequently or never.

Priorities. For many families, spirituality and congregational participation are considered important aspects of their lives (e.g., Ault et al., 2013). In their study of 250 parents who were of Mexican or Puerto Rican origin and had children under age 6 with intellectual disability or developmental delay, Skinner et al. (2001) found that 92% of parents indicated they were somewhat or very religious and associated with a local church, synagogue, or other place of worship. In their study involving 41 mothers of children with Fragile X syndrome who were under age 12 and who came from various religious backgrounds, Michie and Skinner (2010) found that religious faith was described as "important" or "extremely important" by 68% of participants. Carter and Boehm (2019) reported that 90% of parents of children with IDD said they look to their faith to provide meaning and purpose in their lives, and 87% said that their faith impacts many of their decisions. At the same time, spirituality and religion are not prominent for all parents. Across most studies, as many as 5% to 15% of parents of children with IDD do not identify with a particular religion or consider spirituality to be an important aspect their lives (e.g., Boehm & Carter, 2019a; Tarakeshwar &

Pargament, 2001). As mentioned previously, the priorities of families should not be presumed, but rather inquired about.

Spirituality and Flourishing

The potential shaping influence of spirituality among Americans has been researched extensively. Hundreds of studies document positive associations between various indicators of spirituality and religiosity and various measures of well-being and quality of life in the general public (Koenig et al., 2012; Park et al., 2017). Moreover, spirituality is often included as a component of quality of life in many conceptualizations within disability fields (Albers et al., 2010; Gaventa, 2018). Among the few studies examining the relation between spirituality and flourishing among individuals with IDD or their families, a similar portrait has emerged.

Among individuals. Only a few studies have examined the associations between spirituality and well-being for individuals with IDD. In her religiously diverse sample, Rambow (2016) found a significant positive relationship between self-reported measures of spiritual well-being and quality of life satisfaction among 50 adults with IDD. Follow-up interviews indicated that spirituality provided a framework for life, a sense of connectedness, an inner well-being, an opportunity to contribute, and a source of identity. Biggs and Carter (2016) examined correlates of quality of life among transition-age youth with intellectual disability or autism. Strength of religious faith was predictive of two quality of life domains—social support and peers, and autonomy and parent relations. Congregational involvement may have provided youth with opportunities to participate in activities with peers that led to new relationships and social supports. In addition, some other studies have included references to the contributions spirituality has made to individuals' quality of life (e.g., Büssing et al., 2017; Liu et al., 2014; Turner et al., 2004).

For families. Many studies describe the positive impact that spirituality can have on the lives of parents and caregivers (e.g., Brown et al., 2006; Carter, Boehm, et al., 2016; Lim & Lee, 2007; Marshall et al., 2003; Minnes, 1988; Poston &

Turnbull, 2004; Rogers-Dulan, 1998; Speraw, 2006; Tarakeshwar & Pargament, 2001). Spiritual beliefs and practices can help families cope with stressors, provide a framework for understanding disability, bring a sense of purpose and direction, represent a source of strength to meet everyday challenges, influence decision making about services and supports, and sustain them in the midst of advocating for their child's needs. Involvement within religious communities can also bring access to a wide variety of practical (e.g., respite, financial assistance), emotional (e.g., pastoral counseling, encouragement), spiritual, and relationship supports. For example, Poston and Turnbull (2004) identified a strong spiritual component to family quality of life and highlighted the sense of well-being gained through the religious beliefs and social support among parents and other caregivers. Boehm and Carter (2019b) examined family quality of life (FQOL) among 529 parents who had daughters or sons (ages 1–74) with intellectual disability. Greater overall spirituality was independently associated with higher FQOL ratings. Similarly, Boehm et al. (2015) found that greater strength of religious faith was significantly associated with higher FQOL ratings among parents of youth and young adults with IDD (ages 13–21), even after accounting for a variety of child and family factors. Finally, Boehm and Carter (2019a) found that 83% of parents said they experienced a sense of hope as a result of their beliefs, 73% reported that prayer or meditation helped them cope in times of stress, and 84% indicated that the same practices brought them peace of mind. Consistent with religious patterns in the United States, all four studies had predominantly Christian samples, with a small number of other religious traditions also represented.

Although most literature highlights spirituality's positive impact, it is important to emphasize that it can also be experienced in worrisome or wounding ways. For example, some beliefs can contribute to unrealistic expectations, negative coping practices, or the avoidance of needed care (Koenig, 2013). Some families have spoken quite vividly of the negative attitudes, inadequate supports, or injurious beliefs related to disability that they have encountered within religious communities (Carter, Boehm, et al., 2016; Gaventa, 2018). For example, Ault et al. (2013)

reported that nearly one third of parents had changed their place of worship because their child with IDD was neither included nor welcomed within their religious community.

Key Themes

Several important themes emerge from this small, but insightful, collection of studies. Each has implications for the ways in which service systems and faith communities might support the flourishing of people with disabilities and their families.

Theme 1: Spirituality has relevance to the lives of individuals with IDD and their families. Service systems have sometimes overlooked or ignored the spiritual dimensions of the lives of people with disabilities, just as religious communities have sometimes overlooked or ignored people with disabilities. However, a priori assumptions about the inappropriateness or inapplicability of spirituality for individuals with IDD should be avoided. Indeed, there is nothing inherent in the definitional or diagnostic criteria of disability to suggest a diminished capacity for spirituality and religious participation. In other words, spirituality represents a potential area of consideration in planning, supports, and quality of life.

Theme 2: Spirituality can have considerable importance. Individuals with IDD and their families are just as likely as anyone else to affirm the salience of spirituality in their lives. In a country in which most people believe in God, identify with a religion, and engage in spiritual practices (Putnam & Campbell, 2010), it is also likely that Americans with disabilities will hold a similar range of spiritual priorities. For many individuals and families, spirituality will be of principal importance; for others, it will assume a more peripheral place. To the extent that service systems strive to address the priorities of the individuals with IDD whom they support, spirituality is likely to be among the areas that will warrant some consideration. Likewise, participation in the life of a faith community is likely to be pursued by many individuals and their families.

Theme 3: Spirituality is experienced and expressed in very diverse ways. The spiritual practices, participation, and priorities of individuals with IDD and their families are highly varied and cannot be

predicted in advance based on a disability label. The portrait emerging across studies indicates that people vary widely in their spiritual expressions, in the regularity of their religious service attendance, in the combination and number of congregational activities they access, in the beliefs they espouse, in the traditions with which they affiliate, and in the spiritual supports upon which they draw. This diversity also includes a small proportion of individuals who do not consider spirituality or religion to be a salient aspect of their lives. Such findings underscore both the importance of asking good questions and the challenge of providing supports that are truly responsive to individualized preferences and contexts.

Theme 4: Spirituality is rarely static. Although longitudinal studies have been absent from the literature, both cross-sectional and qualitative studies suggest that spirituality reflects more of a journey than a destination. The practices, participation, and priorities of individuals with IDD and their families are dynamic and can change over time. This suggests that efforts to understand and address needs in this area of people's lives may need to be revisited periodically as circumstances change.

Theme 5: Spirituality can be highly influential. Spirituality is rarely inconsequential or immaterial. It can influence how people with disabilities and their families determine their goals and priorities, define their quality of life, relate to others, organize their daily experiences, choose the persons with whom they affiliate, make everyday decisions, find comfort, interpret their circumstances, and much more. Moreover, spirituality can often enhance well-being and improve life satisfaction. Knowing something about whether and how individuals with IDD and their families draw upon spiritual practices, beliefs, and relationships can inform the ways in which some services and supports are designed or delivered.

Theme 6: Spirituality can require planning and support. Although the previous five themes reflect what people with and without disabilities share in common, this final theme highlights one area of potential difference, albeit a difference of degree. Most individuals with IDD will require some amount

of support in order to participate fully in the spiritual practices and religious activities they value most. This is especially true for individuals with significant cognitive impairments, behavioral challenges, mobility difficulties, or complex communication needs. Although this support might come from a variety of sources—including family, friends, faith communities, and/or service systems—intentional and individualized supports can be critical to ensuring full participation in this dimension of life.

THE INVOLVEMENT OF FAITH COMMUNITIES

Involvement in a faith community is a primary context within which spirituality can be explored and expressed in community with others. More than half of adults in the United States are members of a religious congregation and more than three quarters are affiliated with a particular religious tradition (Ellison & McFarland, 2013). In addition to providing spaces for shared spiritual practices with others who hold similar beliefs, churches, synagogues, temples, mosques, and other congregations also serve other social and practical functions. Participating in worship services, attending religious education programs, serving in or through congregations, and connecting socially with others each represent common aspects of religious life.

As is true of many schools, businesses, and other community settings, faith communities sometimes struggle to be places of inclusion and belonging for individuals with IDD. Across the many anecdotes shared by families, experiences of extravagant welcome intermingle with stories of deep wounding (Carter, Biggs, & Boehm, 2016; Walsh et al., 2008). Barriers of accessibility, awareness, and attitude can be encountered as often as postures of hospitality, acceptance, and creativity. To date, research addressing the motivations and movements of congregations related to the inclusion of people with disabilities has been quite sparse (e.g., Amado et al., 2012; Carter, Boehm, et al., 2016; Griffin et al., 2012; Larocque & Eigenbrood, 2005; Patka & McDonald, 2015). Supporting the spiritual lives of individuals with IDD and their families may require progress across seven key areas: responding, reflecting,

inviting, preparing, supporting, befriending, and influencing.

Responding

The impetus for inclusion of individuals with IDD in faith communities can differ from the primary catalysts in other contexts. The language of laws, policy mandates, and research-based practices so often used to spur movements in schools, workplaces, and neighborhoods may not resonate within local congregations. Instead, the call to be inviting and inclusive of people with disabilities usually emerges from sacred scriptures, theological reflection, and specific religious tenets and traditions. For example, scores of formal resolutions and statements issued by different religious denominations articulate why and how faith communities should be inclusive of individuals with disabilities (Carter, 2007). New scholarship in the fields of biblical studies, pastoral care, and theology is revisiting longstanding interpretations of and responses to disability (e.g., Melchner et al., 2017; Schumm & Stoltzfus, 2016). Additionally, an array of conferences and other gatherings are challenging clergy, religious educators, and other ministry leaders to “widen their welcome” for individuals with IDD and their families. With growing intensity, faith communities are being called upon to respond in new and noticeable ways (e.g., Carter, 2013; Golden, 1962).

Reflecting

More than 335,000 congregations—reflecting an incredible diversity of religious traditions—exist in communities all across the United States. Each represents a unique combination of beliefs, priorities, cultures, histories, assets, and memberships. As a result, the ways in which each moves forward in this area will vary from one congregation to the next.

Rather than adopting a prescribed set of actions, congregations should undertake a process of collaborative reflection through which they consider existing barriers, pressing needs, available resources, and desired destinations that are specific to their faith community. Carter (2017) reviewed multiple tools and processes (sometimes referred to as “inclusion audits” or “congregational assessments”) that can provide different lenses through which

congregations can reflect on the ways and places they gather. As shown in Table 16.2, these reflection approaches focus on (a) architecture and accessibility, (b) personal attitudes, (c) indicators of welcome, (d) congregational commitment, (e) dimensions of belonging, and (f) collective actions. Although this diversity of options may reflect a lack of consensus regarding exactly what constitutes an “inclusive” faith community, the variety of reflection approaches also enables congregations to identify what they already are doing well and determine what they should begin to do more of, do better, or do differently moving forward. Soliciting input from a cross section of stakeholders from within and beyond the congregation can ensure that the vantage point

of both “members” and “strangers” are considered. The perspectives of individuals with IDD and their families are essential to incorporate, as they are in the best position to describe what makes them experience welcome, support, and belonging.

Inviting

For those congregations in which individuals with IDD and their families are not yet present, inclusion will require new invitations. This entails shifting from a passive posture of waiting for people to arrive toward an active approach of pursuing people who are not already there. Individuals with IDD and their families who have been excluded in the past may be skeptical that proclamations of “all are

TABLE 16.2

Example of Congregational Reflection Tools and Approaches Related to Disability

Tool	Description	Examples
Accessibility checklists	Addresses the <i>physical, programmatic, and communication</i> accessibility of the areas (e.g., sanctuaries, classrooms, bathrooms, offices) and activities in which congregation members gather	Holland, Gilger, and Gaunt, 2016; Leichty, 2013; Patterson and Vogel, 2003; Vierkant, Hollingsworth, and Stark, 2006
The Five Stages	Addresses behaviors and perspectives that suggest a progressing posture of <i>ignorance about, pity toward, care for, friendship with, and co-laboring alongside</i> individuals with disabilities	Vander Plaats, 2016
Indicators of Welcome	Addresses specific ways in which congregations can demonstrate hospitality and inclusion in the areas of <i>worship services, religious education, service, outreach, fellowship, family supports, general awareness, community partnerships, and accessibility</i>	Carter, 2007
Journey of a Congregation	Addresses 14 aspects of a congregation’s response related to: <i>awareness, internal advocacy, discussions, plans, accommodations, welcoming environment, hurdles, inclusion, local outreach, leadership, new consciousness, transformation, external advocacy, and outreach</i>	Larocque and Eigenbrood, 2005
Dimensions of belonging	Addresses the extent to which individuals with disabilities and their families are <i>invited, present, welcomed, known, accepted, supported, cared for, befriended, needed, and loved</i> within their faith community in ways that lead to belonging	Carter, 2016
Community conversations on faith and disability	Reflection events involving a cross-section of congregational and community members to collaboratively respond to key questions: <i>What could we do to include people with disabilities and their families well in the life of their faith community? What could we do to come alongside them in other areas of their lives? How might we support one another—and new congregations—in these areas?</i>	Carter, Bumble, Griffin, and Curcio, 2017

Note. Italics indicate domains within each tool.

welcome” are made with them in mind (Ault et al., 2013). Announcing the accessibility of activities and the availability of supports in print and electronic communications can convey a congregation’s commitment to inclusion. Moreover, congregations can partner with local residential providers, supported employment agencies, disability organizations (e.g., local chapters of The Arc, autism societies, Down syndrome associations), independent living centers, parent networks, and county programs as avenues for sharing their invitations to individuals and families.

Preparing

Although inclusion has become more widespread in recent decades, many congregational leaders and members still express uncertainty about how best to support the participation of individuals with IDD and their families. Seminaries and theological schools in North America are inconsistent in providing future clergy with substantive experiences and training related to serving people with disabilities and their families (Annandale & Carter, 2014). Moreover, prevailing attitudes and expectations related to people with disabilities can vary widely within and across congregations (Carter, Boehm, et al., 2016; Carter, Bumble, Griffin, & Curcio, 2017; Griffin et al., 2012; McNair & Sanchez, 2008). Congregations may need to actively build commitment to and capacity for supporting the inclusion of individuals with IDD in all aspects of religious life. Congregation-wide efforts—such as disability or inclusion awareness events, curricular units embedded within religious education, or incorporation of information materials into communication venues—constitute formal avenues for fostering greater acceptance. Periodic training for program leaders and volunteers can ensure that members have the knowledge and skills needed to support students (Baggerman et al., 2015; Christensen, 2018). Finally, ministry models addressing how individuals with IDD will be supported within the full range of existing activities and programs should be developed (Goldstein & Ault, 2015; Muskat & Putterman, 2016). Although most congregations already include members with expertise or experience related to disability, professionals from outside of the faith community can also be sought out as sources of guidance and resources across these areas.

Supporting

The absence of supports can further limit the involvement of individuals with IDD in worship, learning, service, and social activities. Parents have described the availability of supports for their children with disabilities in multiple ways—from inconsistent to reliable, from insufficient to unstinting (e.g., Howell & Pierson, 2010; O’Hanlon, 2013; Richardson & Stoneman, 2015). Although some individuals with IDD will benefit from the ordinary supports available to anyone in the congregation (e.g., transportation, mentorship, accessible materials), others will require support that is more individualized, intensive, or intentional. A person-centered support plan can be developed to address the different aspects of faith community life that are important to the individual, as well as the accommodations, modifications, and supports they need to participate meaningfully. Because the priorities and preferred involvement of people can change over time, such plans should be regularly revisited. Congregations might also consider incorporating those supports or programmatic offerings identified as helpful by families within recent studies (Ault et al., 2013; Carter, Boehm, et al., 2016). These include support groups for parents, disability awareness initiatives, resources for families impacted by disabilities, congregational advocates, spiritual counseling from a congregation leader, respite care, a spiritual or religious education plan that details necessary modifications and adaptations, additional support from someone during religious education, additional support from someone during worship services, adapted worship services for people with disabilities, financial support from the congregation, transportation to congregational activities, and additional investments toward physical accessibility. Across each of these areas, a sizable gap can exist between the desire for and the provision of these supports (Carter, Boehm, et al., 2016).

Befriending

Relationships are among the defining features of what makes a faith community truly inclusive. Too often, individuals with IDD are present within a congregation without having much of a presence; they are seemingly integrated but often remain apart from

ongoing interactions. Being known, needed, and loved are core elements of belonging that are only experienced within the context of personal relationships (Carter, Biggs, & Boehm, 2016). Designing worship, learning, service, and social activities so that individuals with and without IDD have regular opportunities to participate in shared activities with sufficient supports can create the contexts needed for friendship to form. Some congregations have also established formal social programming aimed at connecting adults within inclusive small groups or throughout the week (Amado et al., 2013; Preheim-Bartel et al., 2015). Among children and youth, these efforts take the form of buddy systems or peer partner programs. For parents as well, relationships with others who share their faith can be instrumental (Lim & Lee, 2007). However, access to social support through a local congregation is not always available. Boehm and Carter (2019a) reported that only 64% of parents knew someone in their religious or spiritual community to whom they could turn, and only 35% sought out others from this community when they needed help.

Influencing

As faith communities become invested in inclusive practices, they often discover the ways in which they are strengthened by the presence and contributions of individuals with IDD and their families. Moreover, they come to recognize the host of societal and structural barriers that can keep people with disabilities from flourishing in other areas of their lives. Such congregations sometimes extend their efforts outward, toward influencing other congregations and broader systems. For example, congregations have launched local faith inclusion networks to support other congregations in launching new ministry efforts (Jackson, 2012). Other congregations have begun supporting the work of local disability agencies, working for greater community access, and advocating for legislative and policy changes (Carter, 2013; Herzog, 2006).

THE INVOLVEMENT OF PROFESSIONALS AND SERVICE SYSTEMS

As addressed previously in this chapter, spirituality can have considerable significance in the lives of individuals with IDD and their families as well

as comprise a source of substantial support. Yet its introduction into conversations about formal service and supports can evoke a wide range of responses (Carter, 2007):

- We never really considered it.
- It is irrelevant to the people we serve.
- It is not our responsibility to address it.
- We do not have time to address it.
- We feel uncomfortable addressing it.
- We are uncertain how to address it.
- We are concerned about imposing it.
- We are not allowed to address it.
- We think someone else is addressing it.
- We are already addressing it well.
- We want to address it better.

The concerns and questions that lie behind these statements are not unique to spirituality. They also emerge when the “it” refers to sexuality, intimate relationships, political participation, or any of the personal choices that might matter most to someone. Service systems have always struggled to support the full range of preferences and priorities that individuals with IDD hold. As a result, the rights of individuals with IDD in each of these areas are sometimes overlooked, disregarded, or abridged.

Additionally, professionals working in disability fields rarely receive formal preparation on navigating this dimension of people’s lives. Most participate in training regarding person-centered planning and individualized supports, and many are steeped in the importance of self-determination, community inclusion, natural supports, and quality of life. However, they may lack confidence or guidance about how to apply this knowledge to the areas of spirituality and congregational participation, especially when an individual’s preferences, backgrounds, and traditions differ substantially from their own. As with faith community leaders, this domain can be an area of hesitation and uncertainty for many professionals.

Understanding and honoring the spiritual beliefs, commitments, and resources of people with disabilities and their families is now advocated as best practice (Carter, 2013; Gaventa, 2005, 2016). Indeed, several national organizations have issued

strong statements related to spirituality and religious participation. A joint position paper written by the American Association on Intellectual and Developmental Disabilities and The Arc (2015) emphasized that “spirituality, spiritual growth, and religious expression that respect a person’s history, tradition, and current preferences are rights that must be honored by service systems and faith-based communities, as should the choice not to participate” (p. 1). A similar statement by TASH—an international organization advocating alongside individuals with severe disabilities and their families—affirms that “all people with disabilities have the right to spiritual expression including the reflection upon and sharing of spiritual purposes for their lives” and “further supports the right of individuals with disabilities to participate in spiritual expression or organized religion as they so choose and promotes the provision of any and all supports needed by people with disabilities to so participate” (TASH, 2010, p. 1).

For many individuals with IDD and their families, interactions with professionals related to education, health care, therapies, residential, employment, and other services can be frequent and substantial. Because the roles different professionals assume in the lives of individuals with IDD and their families can vary widely, interactions related to spirituality will look different. For some professionals, understanding the spiritual beliefs, strengths, and resources held by families will inform or enhance the delivery of services in ways that make them more relevant, valued, or effective. In other cases, professionals may be directly involved in supporting individuals in expressing, exploring, or enhancing their spirituality. In other words, professionals’ engagement will depend on many factors—their professional roles, the contexts in which they work (e.g., public vs. faith-based organizations), their relationships with individuals and families, the type of services and supports they provide, and the desires of individuals and families. Recognizing this wide range of possibilities, in the following sections I highlight six areas in which attention might be given to spirituality—assessing, planning, connecting, supporting, partnering, and reflecting.

Assessing

As emphasized earlier in this chapter, the diversity of convictions and commitments that are evident in any community can also exist among individuals with IDD and their families. Replacing advance assumptions with thoughtful assessment can provide needed insight into the salience of spirituality and its relevance to service delivery. Informally, this can involve listening as people share their stories and circumstances, discerning what is important to them, noticing references to spirituality or religious involvement, and following up with appropriate questions. Formally, it could involve introducing structured questions that address the beliefs, practices, and support systems of individuals with IDD and their families, as well as asking about whether and how each might inform the services professionals provide. Table 16.3 includes examples of questions that can be adapted to explore these topics. As with all good assessments, they should be individualized and adapted when used with people who have significant cognitive or communication challenges.

Scores of assessment approaches drawn from diverse fields can be incorporated into these conversations and adapted for individuals with IDD (e.g., Fitchett, 2002; Maugans, 1996). For example, Puchalski and Romer (2000) suggested a series of questions aligned with the mnemonic FICA:

- F (Faith and Belief): What brings you meaning? Do you consider yourself to be spiritual or religious?
- I (Importance and Influence): How important are these beliefs in your life? What influence do they have on the decisions you make?
- C (Community): Do you belong to a congregation or other spiritual community? How important is this community to you?
- A (Address or Application): How (if at all) would you like us to address these issues through our supports and services?

Likewise, Anandarajah and Hight (2001) recommended the mnemonic HOPE to guide these conversations:

- H (Sources of Hope): What are your basic spiritual resources? What gives you support? What sustains you in difficult times?

TABLE 16.3

Example Questions Addressing the Spirituality and Support Needs of Individuals With IDD

Area	Example questions
Spiritual practices	What are some things that give you joy or happiness? What brings meaning to your life? Do you have religious or spiritual beliefs that are important to you? What are those beliefs? What are some of the ways that you express your faith or spirituality? What traditions, rituals, or practices are especially important to you? Are there holy days, festivals, or other special events that you observe? What gives you strength? How do you cope when going through difficult times? To whom do you turn? What would you say are your gifts? What do people compliment you on? Have you experienced a sense of calling in your life? What else is important for us know about your religious and spiritual beliefs?
Congregational participation	Do you currently attend a congregation (e.g., church, mosque, synagogue, temple)? Tell me about it. Who do you go with? What do you do there? How do you participate in services and activities? How often do you go? What do you like most about it? What do you wish was different? How is being part of this congregation important in your life? In what ways would you like to be more involved? Less involved? If you could try out any new class, program, or activity, what would it be? Is your congregation supportive for you? How so? Are there particular people who are especially friendly or helpful? What keeps you from being involved in the ways that you would like? Were you involved in a congregation when you were younger? Was this an important part of family life?
Support needs	What supports will you need to be involved in your congregation in the ways you would like? Which of these supports can we provide? Which would you prefer to come from someone else? Would you like help finding a congregational home? Do you have the spiritual supports, relationships, and connections that you would like? Are there religious practices or restrictions we should keep in mind as we support you? Would you like us to help you address your spiritual needs? If so, how? Would you like help learning more about your faith? How well are we doing at helping you meet your spiritual needs? Do you have any needs that are not being addressed?

Note. IDD = intellectual and developmental disabilities. From *Including People With Disabilities in Faith Communities: A Guide for Service Providers, Families, and Congregations* (p. 159), by E. W. Carter, 2007, Paul H. Brookes. Copyright 2007 by Paul H. Brookes Publishing Co., Inc. Adapted with permission.

- O (Organized Religion): What role does organized religion play in your life? What aspects are most and least important to you?
- P (Personal Spirituality and Practices): What spiritual practices are important to you? How would you describe your relationship with God?
- E (Effects on Care): How should your spiritual needs, strengths, and resources impact the supports and opportunities we provide?

Any assessment approach should recognize spirituality as multifaceted, complex, and highly

personalized. The primary goal is to learn more about the role spirituality plays in the lives of individuals with IDD and their families rather than to categorize them as either spiritual or not. This may require creative or alternative approaches when supporting individuals who have limited expressive communication or significant cognitive impairments. For example, adapting questions, encouraging multiple modes of communication, noticing body language, using pictures and other visuals, and incorporating hands-on experiences can be helpful. Whenever

personal preferences and priorities are difficult to discern, the input of family members, friends, and others who are known and trusted by the person will be especially critical.

Planning

Careful planning can ensure that the spiritual practices, participation, and priorities identified as important to an individual with IDD are honored. Addressing spirituality within existing person-centered planning approaches can help identify the opportunities, connections, relationships, and supports people will need in this area of their lives. For example, individuals may need guidance, assistance, or resources related to (a) exploring aspects of spirituality anew or for the first time, (b) connecting to a congregation or other spiritual activities in their community, (c) maintaining their current practices or congregational participation, (d) deepening their involvement in existing activities and communities, or (e) changing their practices or affiliations. Written plans often address the goals or valued outcomes that individuals with IDD have in these areas, the instruction they will need to participate in preferred practices and activities, the information they will need about available options, the steps staff will take to provide or find assistance, the ways in which natural supports will be developed, the avenues through which collateral needs (e.g., transportation, finances) will be met, and the approaches used for evaluating success. A growing number of state-funded and faith-based agencies incorporate this topic into existing planning processes or develop a stand-alone plan (e.g., Gaventa, 2016; Merrill, 2012; New York State Office for People with Developmental Disabilities, 2011).

The spirituality of families also has implications for professionals who work closely with them. Boehm and Carter (2019a) found that 77% of parents of individuals with IDD indicated that their faith impacts their decisions, and many said they found emotional or social support through their spiritual practices or congregational community. Determining whether and how parents' values, beliefs, sources of strength, and connections will be addressed within service delivery can contribute to culturally competent and family-centered supports (Gaventa, 2018; Whitley, 2012)

Connecting

Whereas most people independently act on their spiritual preferences and arrange their own involvement in faith communities, individuals with IDD may need help forging these connections. For children with disabilities, families are typically the avenue through which congregational participation is facilitated. Providing interested families with information about welcoming and supportive congregations in the area, religious ministries that serve the disability community, or spiritual programs that are inclusive and accessible could point them toward opportunities they might not otherwise encounter. For example, some faith communities host parent support groups, offer respite care, host social events, or provide other supports that could be beneficial to families (Carter, Boehm, et al., 2016).

For the more than 700,000 adults with IDD who reside in supported living or other residential settings, direct support staff can be a bridge between interested individuals and local congregations. This might include helping these individuals learn about available programs and opportunities in their area, introducing them to clergy or religious program members, or joining them on visits to different congregations. In one innovative partnership, residential agencies identified "spiritual inclusion partners" from the local community who supported individuals with IDD in meeting their personal goals related to inclusion in a church, synagogue, mosque, or other place of worship (New York State Office for People with Developmental Disabilities, 2011). Each volunteer partner linked individuals with IDD to people and places in the community that aligned with their spiritual goals, identified ways in which individuals could be more involved in preferred activities and relationships, and helped circumvent any barriers to meaningful participation.

Supporting

Many individuals with IDD will benefit from additional support in participating in those spiritual practices and congregational activities that matter most to them. In some cases, professionals will be directly involved in providing this support. This might include providing transportation, accompanying someone to religious services or other

congregational events, developing a behavior or community support plan for a religious setting, making modifications or adaptations to spiritual practices, or teaching skills that will enable or enhance someone's participation in the life of their faith community. In other cases, this support might be more indirect and might take the form of sharing information, making referrals, or coordinating services. For example, a professional who is familiar with the supports and accommodations that work well for an individual with IDD in school, work, or other community settings might share this information so that congregations can apply them within religious education programs, worship services, or other congregational activities.

Partnering

Faith communities can be strong allies in broader efforts to foster self-determination, community inclusion, and quality of life among individuals with IDD and their families. Disability agencies and organizations can invite local congregations to participate in efforts to address pressing needs related to employment, affordable housing, social integration, and health disparities. Promising approaches have been developed for involving faith communities in elevating employment outcomes for young people with IDD (Nord et al., 2014), creating inclusive and affordable housing options (Becker, 2018), and forging friendships that extend beyond the walls of a congregation (Amado et al., 2013). However, most congregations would need invitations and guidance to stretch into new spaces like these. Professionals can also help build the commitment and capacity of local congregations to welcome and include individuals with IDD and their families, just as they might do for any other community programs. Offering occasional workshops or individual trainings on topics related to accessibility, universal design, positive behavior supports, person-centered approaches, and disability etiquette can prepare congregations to better serve their entire community. Finally, many professionals are themselves members of religious groups. In their own faith communities, their expertise and experience related to disability could be drawn upon to spur new or deeper movements toward the inclusion of people with IDD.

Reflecting

Disability organizations and agencies should periodically reflect on their principles, policies, and practices related to spirituality, services, and supports. How well are the roles and responsibilities of professionals in this area clearly defined and communicated? To what extent do staff know whether, when, and how to ask about the spirituality and support needs of the individuals and families whom they serve? How confident are they in providing direct support or making connections to others in the community? Do staff know where to go when they have questions or need guidance? How familiar are individuals and families with the organization's commitments and practices related to the area of spirituality? Figure 16.1 displays a tool that can be used to guide reflection related to each of these topics. Involving leadership, staff, individuals with disabilities, families, and other community partners in the reflection process can ensure that multiple perspectives are obtained. Indeed, this is an additional area in which a partnership with representatives of local congregations could be beneficial.

ADDRESSING SPIRITUALITY ACROSS THE LIFESPAN

Spirituality can be a source of strength, support, and connection in almost any dimension of life, as well as throughout the lifespan. However, its importance and influence can be particularly prominent during several periods.

Initial Identification

The point at which a child's diagnosis is first discovered can be a defining moment for families. A whirlwind of emotions—including confusion, doubt, relief, blame, gratitude, and guilt—can mark this experience. Moreover, the ways in which spirituality intersects with how families navigate this period can vary widely. For some parents, their beliefs shape how they interpret a diagnosis of intellectual disability, autism, or another developmental disability. Spirituality can impact parents' answers to an array of questions surrounding the causes and implications of their child's disability (e.g., Rogers-Adkinson, Ochoa, & Delgado,

Indicators	How well does this describe our agency at the present time?			What steps should we take to improve in this area?
	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
Our mission statement reflects a commitment to support the choices of individuals with IDD, including those related to spiritual exploration and religious expression.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
Our written policies explain the importance of supporting the religious preferences of individuals with IDD, as well as point to practical strategies for doing this well.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
Our staff and the individuals with IDD whom we serve are aware of and familiar with these policies.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We can identify someone (e.g., staff person, board member, advocate) who is responsible for ensuring that spiritual supports are addressed and that our policies permeate practice.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We understand the different ways that we should be addressing the spiritual and religious needs of the people whom we serve.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We discuss with new staff the importance of listening for, seeking out, and supporting the choices and preferences of individuals with IDD, including their religious preferences.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We provide staff with the training they need to do this effectively and with confidence.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We thoughtfully ask about the spiritual needs, strengths, and connections of individuals with IDD when they first begin receiving our services and supports.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We revisit these conversations periodically to make sure we are continuing to meet their needs.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We orient individuals with IDD and their families/advocates to the types of supports we make available for individuals interested in being involved in a faith community.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We provide the opportunities, space, and support people need to explore and express their spirituality at home, within a congregation, or elsewhere, if they so choose.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We periodically assess and seek to remove potential barriers that hinder us from addressing the spiritual and religious needs of individuals with IDD.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
It is clear that the individuals with IDD whom we serve are involved in the faith community of their choice.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
Participation in community activities, including attending congregational activities, is not used to reinforce good behavior or punish inappropriate behavior.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We have established relationships with local congregations and faith-based organizations as partners in this work.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We recognize and affirm the sense of calling and vocation held by our staff providing direct support to people with disabilities.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
We recognize the spirituality of our staff and strive to define support roles and responsibilities that align with those values.	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
Additional indicator:	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	
Additional indicator:	<input type="checkbox"/> Not at all	<input type="checkbox"/> Somewhat well	<input type="checkbox"/> Very well	

FIGURE 16.1. Tool for reflecting on the principles, policies, and practices of agencies related to spirituality and supports. IDD = intellectual and developmental disabilities. From *Including People With Disabilities in Faith Communities: A Guide for Service Providers, Families, and Congregations* (p. 165), by E. W. Carter, 2007, Paul H. Brookes. Copyright 2007 by Paul H. Brookes Publishing Co., Inc. Adapted with permission.

2003; Tarakeshwar & Pargament, 2001; Treloar, 2002; Salkas et al., 2016; see also Chapter 9, this volume). Some parents blame God for the diagnosis, assume that God has abandoned them, perceive that they are being punished by God, question God's goodness, or rethink God's very existence. Other parents describe their child's disability as a gift from God, a special blessing, a part of God's plan, or an affirmation of God's presence. Some parents may even hold a combination of these views over time. The spirituality of families can also impact how they adapt to and cope with the diagnosis. Some parents draw on their beliefs and spiritual practices as a source of comfort, direction, assistance, and healing. By learning how families interpret and respond to disability, professionals and clergy can better align their own responses and supports in ways that recognize each unique starting point and point families toward meaning and thriving.

Early Childhood

An initial diagnosis can be the catalyst for entry into new educational and disability service systems. This transition ushers in a collection of new routines, therapies, professionals, and settings. Parents must also learn about different service options, understand eligibility requirements, and master specialized language. These multiple changes can be overwhelming and anxiety producing for children and families alike. The emotional, practical, social, and spiritual support from a faith community can be especially encouraging as families navigate these transitions (e.g., Meadan et al., 2010; Skinner et al., 2001). Whether by providing occasional respite care, pastoral counseling, camaraderie from fellow congregants, financial support, or other forms of individualized assistance, congregations can be instrumental in helping families throughout this period (Carter, 2019). Families may also desire guidance on how best to support the spiritual formation and religious involvement of their children with IDD.

Transition to Adulthood

As children with IDD graduate from high school, they leave the predictability of school services and enter an adult service system that can be

fragmented, restricted, and inconsistent (see Chapter 11, this volume). For many parents, this transition to adulthood is a period marked by uncertainty, stress, worry, and struggle (Boehm et al., 2015). When access to formal services diminishes, families may rely more heavily on relational and spiritual supports to address many of the needs and challenges they face (Boehm & Carter, 2016). They may also turn to other members of their faith communities for guidance and practical assistance during this transition. For example, some faith communities offer programs focused on the employment, financial, and social needs of their members. This might take the form of vocational discernment, job clubs/career ministries, financial literacy classes, mentoring, and organized activities and classes geared toward young adults with IDD.

Social Relationships

Service systems often struggle to connect individuals with IDD to friendships and other supportive relationships that are central to both community and belonging (Bigby et al., 2017). By offering opportunities and supports for individuals with IDD to participate in the full range of worship, learning, service, and social activities that comprise congregational life, faith communities can create rich contexts for new friendships to develop (Amado, 2013; Carter, 2011). Many congregations also establish formal programs to create regular and intentional opportunities for people with and without IDD to participate in shared activities over time. For example, Amado et al. (2013) described a congregational program called BeFriender Ministry that focuses on establishing supportive, individual relationships; the reach of some congregations included individuals with IDD. Preheim-Bartel et al. (2015) developed a supportive care model that establishes a consistent and durable network of people who are very intentional about spending time with an individual with IDD. Finally, several faith-based ministries establish inclusive small group studies or group-based gatherings aimed at supporting both faith and friendship formation among people with and without IDD (e.g., Friendship Ministries, Young Life Capernaum).

Vocation and Employment

A good job provides much more than a paycheck. It also offers opportunities to share one's gifts and talents, to contribute to the needs of others, to be productive, and to live in a manner consistent with one's sense of calling. However, unemployment and underemployment are widespread for individuals with IDD (see Chapter 13, this volume). A growing number of congregations are becoming involved in expanding employment opportunities for their members with disabilities (Carter, 2011; Gaventa et al., 2014). For example, the Putting Faith to Work model draws upon the social capital, creativity, and commitment within a faith community to connect the gifts and talents of people with disabilities to meaningful work (Carter, Endress, et al., 2016). A small group of friends, family, and fellow members participate in a person-centered meeting focused on identifying the individual's work-related interests, goals, experiences, strengths, and calling. The group then taps into the personal and professional networks of congregation members to identify strong job matches, invites members to contribute to the individual's job search and preparation, and offers prayer and other support as individuals find and maintain employment.

Community Living

Although many individuals with IDD want to live apart from their immediate families, safe and inclusive housing options are limited in most communities (see Chapter 14, this volume). More than 1,000,000 adults with IDD now live with aging parents and more than 600,000 live in group-based settings with other individuals with disabilities (Hewitt et al., 2015). Some faith communities support the growing community living movement by providing faith-based residential programs, advocating for local affordable housing, addressing the material needs of community members with disabilities, providing financial assistance, and helping individuals find roommates and host families (Carter, 2011). For example, the Friendship House Partners model has established integrated housing options in which seminarians and graduate students live in community with their peers with IDD (Floding, 2012). Future clergy develop personal and lasting

relationships with a segment of their community that they may not have otherwise met, as young people with IDD receive help in living independently within a caring and supportive community.

Grief and Loss

Times of grief and loss can punctuate any person's life. As individuals with IDD are living longer than they did in the past, they may be more likely to experience the death of relatives, friends, and close caregiving staff (see Chapter 19, this volume). Families, professionals, and faith communities can often hold inaccurate assumptions about how individuals with IDD understand and deal with death, illness, or loss (Gaventa, 2018). Individuals with IDD may be shielded from learning about the death of loved ones, prevented from participating in funerals and other ceremonies, or not provided spaces to share and process emotions. Indeed, their grief may go unrecognized, unaddressed, and unsupported. For professionals, this may require anticipating and planning for eventual illness or loss; building relationships with local counselors and clergy; considering the spiritual values, resources, and connections an individual might possess; and providing guidance and training to staff (Read, 2014). For faith communities, this means supporting individuals with IDD in the communal rituals, rites, and mourning processes that comprise their tradition, as well as providing comfort and companionship through individual relationships. Such intentionality and thoughtful planning also are important as individuals with IDD approach the ends of their own lives.

MOVING FORWARD IN RESEARCH

Strong scholarship at the intersection of spirituality and disability is still needed (Carter, 2013). Several areas of research hold particular promise for moving this area of the field forward. First, people rarely experience and explore spirituality in isolation of and apart from the influence from others (Pargament et al., 2013). Individuals with disabilities are members of families, they may be served by multiple agencies, they participate in local congregations, they affiliate with broader religious traditions, they

reside within particular communities and cultures, and they encounter societal influences—all at a specific point in time. Although the practices, participation, and priorities of individuals with IDD have received modest empirical attention, this work has been carried out with little consideration of the multiple contexts and forces that may shape their spiritual journeys. Future research should incorporate multiple levels of description and analyses to provide a richer understanding of the ways in which the spiritual lives of individuals with IDD shape and are shaped by others.

Second, this area of research is replete with measurement complexities. The multidimensional nature of spirituality means numerous constructs could be considered, including personal and institutional beliefs, private and corporate practices, affiliations, attendance, commitment, meanings, motivations, coping, supports, resources, relationships, and much more (Fetzer Institute, 2003; Park et al., 2017). Although a wide range of measures exist across these areas, their reliability and validity for individuals with IDD have yet to be explored. As reflected throughout this handbook, individuals with IDD are quite heterogeneous in their strengths and needs. Given the heavy reliance on self-report in research on spirituality, additional work is needed to identify measures and methodological approaches for capturing the experiences of individuals who experience significant cognitive impairments, possess sensory impairments, have reading difficulties, or lack a reliable means of communication.

Third, many of the studies reviewed in this chapter were small in scale and focused on localized samples. Recruiting larger and more representative samples of individuals with IDD and their families is especially difficult in light of privacy provisions, disclosure concerns, and the low incidence of certain disabilities. However, future projects should develop nationally representative samples to strengthen the overall portrait of IDD and to enable comparison across demographic and geographic factors. Expanding the scope of studies and surveys already addressing spirituality for Americans (see the Association of Religion Data Archives) to include variables related to disability could provide one promising pathway for extending current research. Such an approach

would also provide comparative data to determine whether the practices, participation, and priorities of individuals with IDD are typical, elevated, or diminished in relation to individuals without disabilities.

Fourth, the United States is a religiously diverse country composed of numerous denominations and faith traditions. Although most studies addressing spirituality and disability involve participants with a variety of affiliations, the majority come from Christian traditions. Future studies should also explore the practices, participation, and priorities of individuals and families with other religious backgrounds. Likewise, great attention should be directed toward understanding how different religious belief systems contribute to or impede the inclusion and acceptance of individuals with IDD.

Fifth, the dearth of intervention studies in this area is quite striking. Although many promising practices have been suggested in the literature and implemented by agencies and congregations, their effects have yet to be the focus of rigorous evaluation. Future research is needed to examine the implementation and impact of individualized approaches for assessment and planning, practices designed to support spirituality, policies intended to guide service delivery, and training aimed at equipping professionals and congregations.

CONCLUSION

For many individuals with IDD and their families, spirituality can be an important factor in their own flourishing. Too often, this particular dimension of life is overlooked, ignored, or insufficiently supported. As the priorities of people with IDD are more fully honored and community inclusion becomes more widespread, the importance of attending to the spiritual and religious needs of people with disabilities will continue to grow. The contributions of faith communities and service systems—both individually and collectively—can help ensure that individuals and their families have the opportunities, encouragement, and supports they need to experience their spirituality in personally valued ways. An expanded research agenda that is implemented effectively can help to guide us in how best to achieve these goals.

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