# Religious and Spiritual Expressions of Young People with Intellectual and Developmental Disabilities

## Erik W. Carter[1] iD and Thomas L. Boehm[2]

## Abstract

Although the importance and influence of spirituality in the lives of youth and young adults have garnered much attention, few studies have focused on the religious and spiritual lives of young people with intellectual and developmental disabilities (IDD). We examined the congregational activities, spiritual practices, and strength of religious faith of 440 individuals with IDD (aged 13-21 years) as reported by their parents. Such activities and practices were described as having particular prominence, with most youth participating in multiple ways both in a local congregation and at home. However, participation patterns were individualized and strongly associated with the importance of faith in their lives. We offer recommendations for families, congregations, agencies, and researchers aimed at better understanding and supporting this often-overlooked dimension of the lives of youth with IDD.

The spiritual lives of youth have long captured the attention of families, religious leaders, and researchers. The window from adolescence through early adulthood represents both a distinctive and prominent period of spiritual development (Jacober, 2011; King & Roeser, 2009). The shaping influence of religion and spirituality on the relationships, values, vocation, identity, beliefs, and well-being of young people is well established. The majority of youth in the United States affiliate with a religious group, attend congregational activities, and identify spirituality as a salient aspect of their lives (Smith & Denton, 2005; Smith & Snell, 2009). For example, more than two thirds (68.7%) of youth aged 12 years to 17 years attend religious services at least once per month (National Survey of Children's Health, 2011/2012) and more than half (53.7%) of high school seniors report that religion plays a pretty or very important role in their lives (Bachman, Johnston, & O'Malley, 2014).

The place of faith in the lives of youth with intellectual and developmental disabilities (IDD), however, is much less clear. More than 750,000 adolescents and emerging adults with intellectual disability, autism, or multiple disabilities live in the United States. Amid the multitude of studies addressing the experiences and priorities of these youth across diverse educational and life domains, the dearth of attention to the spiritual dimensions of these young people's lives is striking (Carter, 2013). Among the few studies touching on this topic, most include a single or small set of questions addressing very broad indices of involvement or importance (e.g., Abells, Burbidge, & Minnes, 2008; Buttimer & Tierney, 2005; Orsmond, Krauss, &

[1]Vanderbilt University, Nashville, TN, USA
[2]Wheaton College, IL, USA

**Corresponding Author:**
Erik W. Carter, Professor, Department of Special Education, Peabody College, Vanderbilt University, PMB 228, Nashville, TN 37203, USA.
Email: erik.carter@vanderbilt.edu

Seltzer, 2004). Further research is needed to address several gaps in our understanding of this area of adolescent development.

First, involvement in congregational activities is a primary avenue for religious expression among many Americans. Attending worship services, participating in religious education and youth programs, serving in or through the congregation, and connecting socially with others reflect common avenues of corporate involvement in religious life (Pearce, Hayward, & Pearlman, 2017). Such activities provide contexts for shared practices with others who share similar beliefs, as well as access to an array of resources through formal institutions and fellow congregants (Smith, 2003). Among the few studies that included measures related to these practices, none have focused specifically on youth. For example, Carter et al. (2015) found that less than half (46%) of adults with IDD between the ages of 18 years and 30 years had attended a religious service in the prior month. Other avenues of congregational involvement were not addressed. In their multistate study involving 416 parents of children and adults with IDD (primarily between the ages of 3 years and 30 years), Ault, Collins, and Carter (2013) asked participants about whether their daughters and sons had participated in each of the 13 different congregational activities at any point in the past year. Although 85% attended religious services and 61% participated in religious education programs, involvement in recreational activities (25%), volunteering (16%), and small-group meetings (14%) were much less common. Participation in other activities that may have salience during this period of transition to adulthood—such as involvement in youth programming, social or fellowship events, congregational leadership roles, and rites of passage—have yet to be explored. A closer look into the frequency with which youth with IDD are involved in a wider variety of congregational activities could provide insights into how faith communities may be a place of participation and connection for these young people.

Second, spiritual practices (e.g., prayer, scripture reading, devotions, fasting, dietary practices, days of rest) are another avenue through which individuals experience and express their spirituality beyond the walls of one's congregation. Such practices—often undertaken or initiated on one's own—can incorporate religious behaviors as well as provide a means for personal connection to the sacred (Pearce et al., 2017). Prior surveys have not focused on spiritual practices taking place beyond the walls of the congregation. Evidence of such expressions among individuals with IDD has been referenced in just two qualitative studies involving older adults (Shogren & Rye, 2005; Turner, Hatton, Shah, Stansfield, & Rahim, 2004). One exception is a study by Liu, Carter, Boehm, Annandale, and Taylor (2014) involving interviews with 20 youth (aged 13-21 years) with IDD for whom faith was considered to be an important aspect of life. Almost all participants spoke of the primacy of personal prayer as an avenue of spiritual expression and many described other personal practices such as studying scripture, giving financially, doing devotions, and striving to live out religious commandments in their daily lives. Understanding the occurrence and variety of these spiritual practices would provide insights into their importance in the lives of youth with IDD.

Third, the salience of faith in the lives of Americans has been regularly surveyed and frequently studied. Faith can be considered in myriad ways, including its overall importance, its relevance to individual identity, or its influence on other aspects of a person's life (Pearce et al., 2017). As with the other dimensions previously discussed, limited attention has focused on the priority of faith in the lives of youth with IDD (e.g., Lifshitz, Weiss, Fridel, & Glaubman, 2009). In their qualitative inquiry, Liu et al. (2014) included vivid and varied portraits of the relevance and strength of faith among youth with IDD who also participated in local congregations. Still unexplored is the extent to which youth with IDD look to their faith as a source of meaning and an influence on their decision making.

The purpose of this study was to examine the religious and spiritual expressions of youth and young adults with IDD. We examined five research questions:

**Research Question 1:** How involved are youth with IDD in congregational activities?
**Research Question 2:** What spiritual practices do youth with IDD engage in at home and elsewhere?
**Research Question 3:** Who tends to initiate these congregational activities and spiritual practices?
**Research Question 4:** How do parents perceive the religious faith of their daughters and sons with IDD?
**Research Question 5:** To what extent do the spiritual and religious lives of youth with IDD vary based on child and parent factors?

This research is a companion to a qualitative study involving individual interviews with 20 youth and young adults with IDD from whom an interview format was well suited (Liu et al., 2014). In the present study, we drew upon parents as informants to address the religious and spiritual expressions of young people with IDD who experienced a wider range of communication, cognitive, and reading abilities. Therefore, we focused on those practices that would be directly observable to parents, recognizing that youth with IDD often experience less independence and spend most of their out-of-school time in the company of these adults.

## Method

### Participants

This study focused on the spiritual and religious expressions of 440 youth and young adults with IDD (referred to as "youth" in the remainder of this article). These youth ranged in age from 13.0 years to 21.0 years ($M = 16.4$ years, $SD = 2.5$). Consistent with prevalence estimates, the majority (69.3%) was male. Race/ethnicity was 81.1% White; 16.6% African American/Black; 2.5% Hispanic, Latino, or Spanish origin; 0.7% Asian; 0.2% Pacific Islander; 4% identified multiple race/ethnicities; 0.7% another race; and 0.5% did not report race/ethnicity. (More than one race/ethnicity could be selected.) When in school, 42.5% of youth received special education under the category of autism, 37.7% under intellectual disability, 12.7% under both autism and intellectual disability, and 7.1% under other categories or the category was not identified (e.g., home schooled, private school). Although the primary mode of communication for most youth (83.9%) was speech, 10.7% relied primarily on gestures, facial expressions, or body language; 2.0% on an electronic communication device or computer; 1.8% on vocalizations; 0.9% on manual signs or sign language; 0.5% on a nonelectronic communication board or book; and 0.2% on other methods. More than one third (35.3%) of children were reported to sometimes or often exhibit challenging behaviors (e.g., aggression, self-injury) outside the home; the remainder rarely (33.2%) or never (31.6%) engaged in such behaviors. Just over one third (35.5%) were eligible for free or reduced-priced meals at school; the remainder were either not eligible (57.3%) or information was not reported (7.3%). Among students who were in school the prior academic year, 21.7% spent most or all of their day in general education classrooms, 14.9% were in both general and special education classrooms equally, 50.2% spent most or all of their day in special education classrooms, and 13.2% were in other settings (e.g., community-based transition programs).

We assessed support needs by asking parents to indicate how much support their daughter or son typically needed across seven types of activities (i.e., advocacy, community and neighborhood, health and safety, home living, school learning, school participation, social). Response options were provided on a 5-point Likert-type scale: 1 = *no support needed*, 2 = *a little support needed*, 3 = *medium support needed*, 4 = *a lot of support needed*, and 5 = *total support needed* (Lee, Wehmeyer, Palmer, Soukup, & Little, 2008). We derived total scores by using the mean of all seven items; higher scores reflected higher support needs. The overall rating of parents was 3.43 ($SD = 0.99$). We evaluated functional abilities using a four-item measure asking parents how well their child does each of the following things on his or her own without help: reading and understanding common signs (e.g., stop, men, women, danger), telling time on a clock with hands, counting change, and looking up phone numbers, and using the telephone (1 = *very well*, 2 = *pretty well*, 3 = *not very well*, 4 = *not at all well*). The functional ability score was the average of the four items, with higher scores reflecting a greater deficit in functional abilities (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). The overall rating of parents was 2.56 ($SD = 0.90$).

Data were provided by 440 parents or caregivers of youth with IDD. To be included in the study, parents or caregivers (referred to as "parents" in the remainder of this article) must have, at the time of completing the study, the following: (a) lived in Tennessee and (b) had a child with an intellectual disability or autism between the ages of 13 years and 21 years. These participants ranged in age from 31.0 years to 72.0 years ($M = 48.1$ years, $SD = 7.7$). Most (85.4%) participants identified themselves as the mother of the individual with the disability, 9.6% as the father, 2.7% as a grandparent, 1.8% as other (e.g., aunt, legal guardian), and 0.5% did not identify their relationship. (Two sets of measures were jointly completed by a mother

and father.) Current marital status was married (67.5%), divorced (16.0%), separated (5.7%), never married (5.7%), widowed (2.7%), and living as married (2.3%). The highest level of education was 5.0% less than high school, 10.5% high school graduate, 23.7% some college, 7.5% trade/technical/vocational training, 30.8% college graduate, and 22.4% postgraduate work/degree. Parents reported affiliation with 35 different religious traditions. The largest affiliations were Baptist ($n = 152$), nondenominational Christian ($n = 45$), Catholic ($n = 37$), Church of Christ ($n = 31$), Methodist ($n = 31$), Presbyterian ($n = 23$), Pentecostal ($n = 12$), Church of God ($n = 8$), Unitarian Universalist ($n = 7$), Lutheran ($n = 6$), Episcopal ($n = 5$), Holiness ($n = 5$), and Latter-Day Saints ($n = 5$); all other traditions were identified by fewer than five respondents (e.g., Anabaptist, Adventist, Buddhist, Brethren, Jewish, Eastern Orthodox, Jehovah's Witnesses, Mennonite, Messianic Jewish, Muslim, New Thought Movement). When asked about their frequency of religious service attendance, 17.8% said several times a week, 39.3% said weekly or about weekly, 10.1% said 2 to 3 times a month, 3.7% said about once a month, 11.0% said several times a year, 5.0% said once or twice a year, 5.9% said less than once a year, and 7.1% said never.

## Recruitment

Because no publicly available list of youth with disabilities and their families exists, we adopted a multifaceted recruitment approach involving partnerships with an array of disability- and family focused organizations and networks to identify those who had relationships with individuals meeting our inclusion criteria. After receiving institutional review board approval, we partnered with more than 151 groups in Tennessee, including the following: local Special Olympics programs ($n = 22$), disability service providers ($n = 16$), autism support/advocacy groups ($n = 15$), sports and recreation programs (not Special Olympics; $n = 14$), Arc chapters ($n = 10$), family support programs ($n = 10$), parent support groups ($n = 10$), Down syndrome support/advocacy groups ($n = 7$), faith-based ministries ($n = 7$), congregations ($n = 6$), school-based programs ($n = 6$), various University Centers of Excellence in Developmental Disabilities programs ($n = 6$), health services providers ($n = 5$), individuals ($n = 5$), employment service providers ($n = 3$), social service providers ($n = 3$), civic organizations ($n = 2$), statewide advocacy organizations ($n = 2$), and other organizations ($n = 2$). We worked within and beyond disability networks to also involve families not affiliated with advocacy groups. Likewise, we recruited within and beyond religious networks to involve families with a broad range of religious affiliations (including no religious affiliation).

The invitations distributed to parents included a brief description of the study (i.e., a study focused on the ". . . strengths, supports, spiritual expressions, and well-being of young people with intellectual disabilities or autism. . . .") and its inclusion criteria, instructions on how to request participation, and information about the study incentive (i.e., a US$20 gift card). We emphasized in recruitment materials that we wanted to hear from individuals for whom religion/spirituality was and was not important. More than half of our recruitment partners distributed study invitations through either print mailings (51.7%) and/or email versions (68.9%). Other avenues of distributing invitations included handing out invitations at meetings, conferences, and other events (11%); posting fliers (32%); email newsletters (9%); website postings (7%); and/or announcements in print newsletters (3%). In all cases, parents were required to request participation by mailing in their contact information using a business-reply envelope, emailing/calling in their contact information, or enrolling online.

## Measures

We collected information from parents using a variety of research measures addressing the demographics, strengths, skills, support needs, spiritual and religious expressions, well-being, and community involvement of their daughters or sons with IDD. In the absence of existing measures for individuals with IDD, we drew from measures designed for youth and adults without disabilities by incorporating items that reflected observable expressions and collectively addressed multiple dimensions of the spiritual lives of youth. The present study focuses primarily on three measures addressing involvement in congregational activities, engagement in spiritual practices, and strength of religious faith. Prior to data collection, we received

feedback on the content, clarity, and length of all measures from a pilot sample of 12 parents from diverse backgrounds and faith traditions who had daughters or sons with IDD.

*Congregational activities.* We asked parents to report the extent to which youth were involved in each of the 17 activities taking place in or through a local congregation (e.g., attending worship services, participating in a youth group, attending a Sunday school or religious education class, participating in rites of passage; see Table 1 for a complete list). We also provided space to write in up to two other congregational activities not already listed. Parents indicated how often their daughter or son participated in each activity: *never, daily or weekly, monthly, yearly*, or *unsure.* We selected these items from prior studies and reviews addressing the religious involvement of individuals with and without disabilities (e.g., Ault et al., 2013; Baylor University, 2005; Carter, 2007; Denton, Pearce, & Smith, 2008; Fetzer Institute, 1999/2003). Items in this section had strong internal consistency ($\alpha = .826$). For each of the activities in which their daughter or son has been involved, we also asked parents to indicate which person(s) mostly initiates each activity: *their child, a family member*, or *both equally.* We incorporated this second question to provide insight into the importance youth might place on involvement.

*Spiritual practices.* We asked parents to report the extent to which youth participated in each of 26 spiritual practices that take place at home or outside of a congregation (e.g., praying before or after mealtime, reading or listening to scripture, participating in personal devotions, following dietary laws; see Table 2 for a complete list). We selected items from prior measures and reviews addressing spirituality among individuals with and without disabilities, prioritizing those that would be observable to parents (e.g., Ault, 2010; Hill & Hood, 1999; Swinton, 2002; Zhang & Rusch, 2005). Items in this section had strong internal consistency ($\alpha = .866$). Parents indicated how often their daughter or son participated in each activity: *never, daily or weekly, monthly, yearly*, or *unsure.* As with the prior section, we also asked parents to indicate which person mostly initiates each practice: *their child, a family member*, or *both equally.*

*Strength of religious faith.* Parents completed two versions of the Santa Clara Strength of Religious Faith Questionnaire—Short Form (Plante, Vallaeys, Sherman, & Wallston, 2002); one focused on themselves and the other focused on their daughter or son. It is important to emphasize that these latter ratings reflect only the perceptions of parents as they were not corroborated by youth. Respondents provided their level of agreement with five statements related to religious faith (Table 3) using a 4-point, Likert-type scale: 1 = *strongly disagree*, 2 = *disagree*, 3 = *agree*, 4 = *strongly agree*. We averaged ratings across items to generate an overall rating, with higher scores reflecting a stronger religious faith. Prior studies using this short form reported strong internal consistency and test–retest reliability (Storch, Roberti, Bagner, et al., 2004; Storch, Roberti, Bravata, & Storch, 2004). Because our study involved parents across faith traditions, we substituted the word "congregation" for "church" in one item. The parent and youth proxy versions differed only in their reference ("I/My" vs. "My child"). Both versions had strong internal consistency ($\alpha = .943$ and .933, respectively).

*Child factors.* We examined several factors that could be associated with the spiritual and religious expressions of youth with IDD: age, race/ethnicity, primary communication mode, extent of challenging behaviors, support needs, functional skills, and presence of an autism label. We determined whether children used speech by asking parents, "What is the *primary* way your child communicates with others?" Response options included speech (talking); nonelectronic communication board or book; electronic communication device or computer; gestures, facial expressions, or body language; vocalizations; manual signs or sign language; writing or drawing; and other. We determined the extent of challenging behaviors by asking parents, "How often does your child exhibit challenging behaviors (such as aggression, self-injury) outside of the home?" (1 = *never*, 2 = *rarely*, 3 = *sometimes*, 4 = *often*). We assessed support needs and functional abilities, as described in the "Participants" section. We determined whether children had a label of autism (alone or in combination with another label) based on parent response to the question, "What is your child's primary special education category?"

**Table 1.** Youth Participation in Congregational Activities and Person(s) Initiating Each Activity.

| Activity | Never | Daily/ weekly | Monthly | Yearly | Unsure | Child | Both equally | A family member |
|---|---|---|---|---|---|---|---|---|
| | Frequency of expression (% of responses) | | | | | Initiator (% of responses) | | |
| Attending worship services | 13.8 | 63.0 | 12.6 | 9.9 | 0.7 | 7.1 | 49.7 | 43.2 |
| Attending a Sunday school or religious education class | 35.9 | 48.4 | 8.3 | 6.3 | 1.2 | 18.3 | 46.4 | 35.4 |
| Participating in a youth group | 53.0 | 26.8 | 11.6 | 6.2 | 2.4 | 37.8 | 35.2 | 27.0 |
| Participating in a prayer, study, or small group | 67.0 | 23.2 | 5.4 | 1.9 | 2.6 | 28.8 | 38.1 | 33.1 |
| Participating in prayer meetings | 73.9 | 13.4 | 5.6 | 3.8 | 3.3 | 22.1 | 37.2 | 40.7 |
| Participating in sacraments (e.g., communion, confession, penance, anointing) | 59.3 | 10.2 | 19.1 | 9.3 | 2.1 | 25.4 | 42.9 | 31.6 |
| Attending congregational fellowships, potlucks, and other social gatherings | 37.2 | 8.4 | 27.8 | 22.5 | 4.1 | 7.9 | 44.0 | 48.0 |
| Serving in the choir or on a music team | 83.1 | 7.2 | 3.2 | 4.9 | 1.6 | 37.2 | 37.2 | 25.5 |
| Serving as an usher or greeter | 82.2 | 5.8 | 5.1 | 4.6 | 2.3 | 38.5 | 22.0 | 39.6 |
| Performing other forms of service for the congregation (write in) | 79.4 | 5.5 | 6.5 | 3.0 | 5.7 | 31.9 | 37.4 | 30.8 |
| Participating in local outreach activities (e.g., serving a community center, visiting shut-ins) | 64.3 | 5.1 | 10.0 | 16.8 | 3.7 | 13.8 | 39.5 | 46.7 |
| Leading prayers publicly during religious services | 86.9 | 4.7 | 3.7 | 2.6 | 2.1 | 29.3 | 32.0 | 38.7 |
| Leading scripture readings during religious services | 89.0 | 3.7 | 2.3 | 2.3 | 2.6 | 28.1 | 25.0 | 46.9 |
| Attending a religious youth retreat, conference, rally, or congress | 70.2 | 2.3 | 2.8 | 21.4 | 3.3 | 32.1 | 43.5 | 24.4 |
| Serving as an acolyte or alter server | 93.3 | 2.1 | 2.1 | 1.4 | 1.2 | 28.8 | 36.5 | 34.6 |
| Participating in rites of passage (e.g., first communion, bar mitzvah, confirmation) | 80.3 | 1.4 | 2.3 | 10.1 | 5.9 | 14.3 | 44.0 | 41.8 |
| Participating in a national or international mission activities (e.g., short-term trips) | 89.6 | 0.9 | 1.2 | 6.1 | 2.1 | 24.1 | 39.7 | 36.2 |

*Note.* Percentages are based on the number of participants who completed each item. Missing data range from five to 19 per item (median = 11).

**Table 2.** Spiritual Practices and Person(s) Initiating Each Activity.

| Practice | Frequency of expression (% of responses) | | | | | Initiator (% of responses) | | |
|---|---|---|---|---|---|---|---|---|
| | Never | Daily/ weekly | Monthly | Yearly | Unsure | Child | Both equally | A family member |
| Praying before or after mealtime | 20.6 | 64.0 | 5.7 | 4.8 | 4.8 | 15.2 | 35.1 | 49.7 |
| Reading (or listening) to scripture | 28.7 | 54.0 | 11.5 | 3.2 | 2.5 | 11.5 | 26.4 | 62.2 |
| Praying at bedtime or upon waking up | 28.7 | 50.5 | 4.4 | 1.6 | 14.8 | 21.8 | 32.1 | 46.1 |
| Listening to religious music or radio | 33.5 | 48.0 | 11.8 | 2.8 | 3.9 | 23.3 | 37.4 | 39.3 |
| Praying together with other family members at home | 30.4 | 45.0 | 14.6 | 4.1 | 6.0 | 5.9 | 38.5 | 55.7 |
| Singing or humming religious songs | 32.8 | 44.5 | 13.6 | 2.6 | 6.6 | 35.9 | 38.2 | 25.9 |
| Practicing a weekly day of rest for religious or spiritual reasons (e.g., Sabbath/Lord's day) | 48.8 | 44.2 | 3.3 | 1.2 | 2.6 | 6.0 | 43.3 | 50.7 |
| Referencing religious or spiritual ideas in conversations (e.g., talking about positive events as blessings) | 38.8 | 38.8 | 12.8 | 2.1 | 7.6 | 16.3 | 44.8 | 38.9 |
| Having casual conversations with family members about spiritual issues (not devotions) | 33.0 | 36.3 | 20.1 | 5.5 | 5.1 | 17.3 | 46.2 | 36.5 |
| Contributing money to a religious group or congregation (e.g., tithes, offerings, tzedakah) | 39.4 | 36.3 | 12.0 | 7.4 | 4.9 | 12.3 | 32.8 | 54.9 |
| Participating in personal devotions (other than reading or listening to scriptures) | 58.5 | 26.8 | 7.0 | 1.2 | 6.6 | 19.1 | 28.4 | 52.5 |
| Participating in family devotions (other than reading or listening to scriptures) | 54.9 | 24.8 | 11.4 | 4.2 | 4.7 | 7.3 | 27.1 | 65.5 |
| Watching religious television programs or movies | 36.8 | 23.2 | 21.6 | 12.6 | 5.7 | 20.9 | 32.1 | 47.0 |
| Sharing one's faith or witnessing with people outside the family | 55.4 | 18.0 | 10.2 | 4.8 | 11.5 | 29.4 | 35.0 | 35.6 |
| Choosing to wear jewelry or clothing that expresses spiritual or religious meaning | 64.4 | 15.3 | 11.1 | 5.3 | 3.9 | 40.6 | 32.3 | 27.1 |
| Making connections to the divine through nature | 66.7 | 12.7 | 8.0 | 2.3 | 10.3 | 24.6 | 34.9 | 40.5 |
| Celebrating religious holiday traditions at home | 14.2 | 11.2 | 17.9 | 54.3 | 2.3 | 3.7 | 50.1 | 46.3 |
| Creating art, music, dance, or writing as a spiritual practice | 76.0 | 9.8 | 4.0 | 4.2 | 6.1 | 30.1 | 35.0 | 35.0 |
| Accessing religious websites | 68.2 | 9.1 | 10.3 | 4.0 | 8.4 | 32.3 | 25.0 | 42.7 |
| Praying using items such as rosary beads, icons, mezuzahs, crosses, or other things at home | 89.0 | 5.6 | 2.3 | 0.7 | 2.3 | 15.3 | 37.5 | 47.2 |
| Attending a religious music concert | 57.2 | 4.9 | 7.0 | 27.8 | 3.0 | 10.3 | 34.1 | 55.7 |
| Practicing other physical meditation techniques as a spiritual practice (not including prayer) | 90.1 | 4.6 | 1.8 | 0.7 | 2.8 | 15.9 | 36.5 | 47.6 |
| Following dietary laws as a religious practice | 89.5 | 4.4 | 2.1 | 2.6 | 1.4 | 16.9 | 32.3 | 50.8 |
| Burning candles or incense as a spiritual practice | 89.6 | 2.5 | 3.0 | 3.7 | 1.2 | 14.9 | 35.8 | 49.3 |
| Fasting or denying oneself something as a spiritual discipline | 84.9 | 1.6 | 3.5 | 7.2 | 2.8 | 16.0 | 25.9 | 58.0 |
| Practicing yoga for spiritual reasons | 95.6 | 1.4 | 1.4 | 0.2 | 1.4 | 23.6 | 32.7 | 43.6 |

*Note.* Percentages are based on the number of participants who completed each item. Missing data range from three to 22 per item (median = 9).

**Table 3.** Parent-Reported Strength of Religious Faith Ratings for Youth and Parents.

| Version/items | Percentage responding (%) | | | | M (SD) |
| | Strongly disagree | Disagree | Agree | Strongly agree | |
|---|---|---|---|---|---|
| Youth | | | | | |
| My child enjoys being around others who share his or her faith. | 16.3 | 11.4 | 47.1 | 25.2 | 2.81 (0.99) |
| My child considers himself or herself to be active in his or her faith or congregation. | 19.6 | 19.8 | 37.7 | 22.9 | 2.64 (1.04) |
| My child prays daily. | 20.0 | 23.6 | 34.0 | 22.4 | 2.59 (1.05) |
| My child looks to his or her faith as providing meaning and purpose in his or her life. | 19.4 | 23.6 | 38.3 | 18.7 | 2.56 (1.01) |
| My child's faith affects many of his or her decisions. | 22.2 | 28.0 | 34.0 | 15.2 | 2.44 (1.01) |
| Parent | | | | | |
| I enjoy being around others who share my faith. | 6.3 | 5.6 | 38.8 | 49.3 | 3.31 (0.84) |
| I consider myself to be active in my faith or congregation. | 10.7 | 16.3 | 32.2 | 40.8 | 3.03 (1.00) |
| I pray daily. | 8.8 | 12.5 | 28.5 | 50.2 | 3.20 (0.97) |
| I look to my faith as providing meaning and purpose in my life. | 7.0 | 3.2 | 32.0 | 57.8 | 3.41 (0.85) |
| My faith affects many of my decisions. | 6.5 | 6.7 | 28.9 | 57.9 | 3.38 (0.87) |

*Note.* Percentages are based on the number of participants who completed each item. Missing data range from eight to 25 per item (median = 9).

## Data Analysis

We distributed 599 research packets to interested parents and received 483 in return. We excluded 33 because the child with disability was outside the age range or the family lived outside the state and eliminated another 10 because the entirety of measures related to our analyses was left blank. For the 440 parent reports included in the study, we used descriptive statistics (i.e., frequencies, means, standard deviations) to summarize the reports of congregational activities and spiritual practices for their daughter or son (Tables 1 and 2), their descriptions of who most often initiates each activity or practice (Tables 1 and 2), and their self and proxy ratings of strength of religious faith (Table 3). Missing data were limited (see Tables 1-3) and, therefore, item-level analyses were based on the number of parents completing each item.

To explore factors associated with total number of different congregational activities, total number of different spiritual practices, and perceptions of the strength of religious faith ratings for youth, we used both correlation and regression analyses. First, we computed Pearson correlation coefficients to examine associations between all variables (Table 4). Because three variables were dichotomous (i.e., race/ethnicity, communication mode, autism label), we used point biserial correlations when one variable was dichotomous and a phi coefficient when both were dichotomous. Next, we conducted a linear multiple regression analysis to examine factors associated with each of the three dependent variables (i.e., number of different congregational activities, number of different spiritual practices, overall youth's strength of religious faith). We examined beta weights (standardized multiple regression coefficients) and semipartial (i.e., part) correlations to determine the relative value of each variable (Table 5). The unique predictive value for a given variable is the percentage of variance in the outcome variable accounted for by that predictor variable over and above the variance explained by the remaining predictors in the regression model. For all correlation and regression analyses, we coded variables as follows: number of congregational activities (range = 0-19), number of spiritual practices (range = 0-26), youth's strength of religious faith (range = 1-4), child age (range = 13-21), parent race/ethnicity (0 = not White only, 1 = White only), communication mode (0 = not speech, 1 = speech), challenging behaviors (range = 1-4), support needs (range = 1-5), functional skill deficits (range = 1-4), autism label (0 = not autism, 1 = autism), and parent's strength of religious faith (range = 1-4).

**Table 4.** Bivariate Correlation Matrix for All Predictor and Outcome Variables.

| Variable | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. Number of congregational activities | — | | | | | | | | | | |
| 2. Number of spiritual practices | .70** | — | | | | | | | | | |
| 3. Youth's strength of religious faith | .58** | .65** | — | | | | | | | | |
| 4. Age | .02 | .06 | .07 | — | | | | | | | |
| 5. Race/ethnicity[a] | −.05 | −.08 | .01 | −.03 | — | | | | | | |
| 6. Communication mode[a] | .17** | .14** | .15** | −.01 | .07 | — | | | | | |
| 7. Challenging behaviors | −.11* | −.06 | −.19** | −.07 | .01 | −.14** | — | | | | |
| 8. Support needs | −.19** | −.12* | −.23** | −.01 | .00 | −.49** | .34** | — | | | |
| 9. Functional skill deficits | −.18** | −.12** | −.20** | .05 | −.02 | −.53** | .22** | .66** | — | | |
| 10. Autism label[a] | −.14** | −.01 | −.10* | −.14** | .05 | .04 | .18** | −.04 | −.25** | — | |
| 11. Parent's strength of religious faith | .37** | .43** | .50** | .05 | −.01 | .02 | −.08 | −.04 | −.06 | −.04 | — |

[a]Dichotomous variable.
*$p \leq .05$. **$p \leq .01$.

**Table 5.** Regression Analyses Predicting Youth's Congregational Activities, Spiritual Practices, and Faith Ratings.

| Variable | Number of congregational activities | | Number of spiritual practices | | Youth's strength of religious faith | |
|---|---|---|---|---|---|---|
| | β | r | β | r | β | r |
| Age | −.04 | −.04 | .02 | .02 | .02 | .02 |
| Race/ethnicity | −.05 | −.05 | −.10** | −.10 | .02 | .02 |
| Communication mode | .07 | .06 | .08 | .06 | .04 | .03 |
| Challenging behaviors | .04 | .04 | .05 | .04 | −.07 | −.07 |
| Support needs | −.02 | −.01 | .03 | .02 | −.12* | −.08 |
| Functional skill deficits | −.07 | −.05 | .01 | .01 | −.09 | −.06 |
| Autism label | −.11* | −.10 | .06 | .06 | −.11* | −.10 |
| Youth's strength of religious faith | .49** | .40 | .60** | .50 | — | — |
| Parent's strength of religious faith | .12** | .11 | .12** | .10 | .48** | .47 |

*Note.* $n = 419$. β = standardized beta coefficient. r = semipartial, or part, correlation.
*$p < .05$. **$p < .01$.

## Results

### Involvement in Congregational Activities

Parental reports of the extent to which their daughter or son participates in various congregational activities are summarized in Table 1, arranged from most to least common based on daily or weekly involvement. At least half of the youth with IDD had some degree (i.e., daily/weekly, monthly, or yearly) of participation in three activities: attending worship services (85.5%), attending a Sunday school or religious education class (63.0%), or attending congregational fellowships, potlucks, and other social gatherings (58.7%). The extent to which youth were reported to serve *within* (e.g., choir/music team, usher/greeter) or *beyond* (e.g., local outreach activities, mission activities) the congregation was much less common (typically less than 20%). Likewise, leadership roles within activities (e.g., prayers, scripture readings) were not extensive. On average, youth with IDD participated in 4.96 (*SD* = 3.72) of these 19 congregational activities: 2.30 daily (*SD* = 2.38), 1.31 monthly (*SD* = 1.77), and 1.35 yearly (*SD* = 1.55). Only 12.7% were reported to have engaged in none of these congregational activities.

The person(s) reported to typically initiate each activity varied widely across experiences. For all of the congregational activities, more than half of youth were reported to primarily or equally initiate the activity (range = 53.1%-75.6%). The activities most likely to be initiated primarily by the youth with IDD were serving as an usher or greeter (38.5%), participating in a youth group (37.8%), serving in the choir or on a music team (37.2%), and attending a religious youth retreat, conference, rally, or congress (32.1%). Those activities most likely to be initiated primarily by a parent were attending congregational fellowships, pot-lucks, and other social gatherings (48.0%); leading scripture readings during religious services (46.9%); participating in local outreach activities (46.7%); and attending worship services (43.2%).

## Engagement in Spiritual Practices

Parental reports of the extent to which their daughter or son engages in various spiritual practices are sum-marized in Table 2, arranged from most to least common based on daily or weekly engagement. At least half of the youth with IDD participated to some degree (i.e., daily/weekly, monthly, or yearly) in 11 of the activi-ties: celebrating religious holiday traditions at home (83.4%), praying before or after mealtime (74.5%), reading (or listening) to scripture (68.7%), praying together with other family members at home (63.7%), listening to religious music or radio (62.6%), having casual conversations with family members about spiri-tual issues (61.9%), singing or humming religious songs (60.7%), watching religious television programs or movies (57.4%), praying at bedtime or upon waking up (56.5%), contributing money to a religious group or congregation (55.7%), and referencing religious or spiritual ideas in conversations (53.7%). On average, youth with IDD engaged in 10.19 ($SD = 6.09$) of these 26 different practices: 6.24 daily ($SD = 4.97$), 2.28 monthly ($SD = 2.62$), and 1.67 yearly ($SD = 1.76$). Only 6.4% were reported to have engaged in none of these spiritual practices.

Although the person(s) reported to typically initiate engagement varied widely, parents tended to report initiating these spiritual practices more often than congregational activities. Those practices most likely to be initiated primarily by a parent were participating in family devotions (65.5%), reading (or listening) to scripture (62.2%), fasting or denying oneself something as a spiritual discipline (58.0%), attending a religious music concert (55.7%), and praying together with other family members at home (55.7%). For 16 of the 26 practices, at least half of the youth with IDD were reported to primarily or equally initiate the practice. The practices most likely to be initiated primarily by the youth with IDD were choosing to wear jewelry or clothing that expresses spiritual or religious meaning (40.6%), singing or humming religious songs (35.9%), accessing religious websites (32.3%), and creating art, music, dance, or writing as a spiritual practice (30.1%).

## Strength of Religious Faith

Overall ratings of parents' perceptions of the strength of religious faith for youth approached the midpoint of the scale ($M = 2.62$, $SD = 0.90$; see Table 3 for individual items). Most parents agreed or strongly agreed their child enjoys being around others who share his or her faith (72.3%), considers himself or herself to be active in his or her faith or congregation (60.6%), looks to his or her faith as providing meaning and purpose in his or her life (57.0%), and prays daily (56.4%). Parent ratings of their own religious faith were somewhat higher on all five individual items (Table 3).

## Factors Associated with Religious and Spiritual Expressions

Prior to running our regression, we examined the correlations among all variables (Table 4). Dependent variables included number of congregational activities, number of spiritual practices, and youth's strength of religious faith. Independent variables included child age, parent race/ethnicity, communication mode, challenging behaviors, support needs, functional skill deficits, autism label, parent's strength of religious faith. Overall, communication mode, support needs, functional skill deficits, and parent's strength of reli-gious faith were significantly associated with all three dependent variables. Challenging behaviors and the

presence of an autism label were significantly associated with the number of congregational activities and youth's strength of religious faith.

We used multiple regression analyses to examine factors associated with the three dependent variables. For the number of congregational activities, the regression model accounted for 37% of the variance in ratings, $R^2 = .37$, $F(9, 409) = 26.90$, $p < .001$. For the number of spiritual practices, the regression model accounted for 45% of the variance in ratings, $R^2 = .45$, $F(9, 409) = 37.50$, $p < .001$. For the youth's strength of religious faith, the regression model accounted for 32% of the variance in ratings, $R^2 = .32$, $F(8, 410) = 24.14$, $p < .001$. As shown in Table 5, after simultaneously controlling for other independent variables, all dependent variables had three significantly associated independent variables. Specifically, fewer congregational activities were associated with the presence of an autism label, lower ratings for youth's strength of religious faith, and lower ratings for parent's strength of religious faith. Similarly, fewer spiritual practices were associated with race/ethnicity White, lower ratings for youth's strength of religious faith, and lower ratings for parent's strength of religious faith. In addition, lower ratings for youth's strength of religious faith were associated with higher support needs, the presence of an autism label, and lower ratings for parent's strength of religious faith.

## Discussion

Although the importance and influence of spirituality in the lives of youth and young adults has garnered much attention (King & Roeser, 2009; Smith & Denton, 2005), few studies have focused on the religious and spiritual lives of youth who have disabilities. Our interest was in providing an initial portrait of the place and prominence of faith in the lives of youth with IDD. We asked more than 400 parents about the congregational involvement, spiritual practices, and religious faith of their daughters and sons with disabilities. These findings extend the literature in several ways.

First, the religious and spiritual lives of many youth with IDD are noticeable and multifaceted. Congregational activities were evident for the large majority (87.3%) of youth and this involvement typically spanned multiple activities (e.g., participation in worship services, religious education, social gatherings). Likewise, these youth were reported to engage in a wide variety of spiritual practices at home, many with considerable regularity (i.e., daily or weekly). This combination of religious and spiritual expressions was accompanied by parent descriptions of a religious faith that was perceived to be somewhat strong. In other words, this dimension emerges as a relevant, prominent, and multifaceted aspect of the everyday experiences of many youth with IDD. Such an overall portrait is consonant with studies addressing faith in the lives of adolescents and young adults without disabilities (Smith & Denton, 2005; Smith & Snell, 2009). Moreover, the high proportion of youth with IDD in our sample who attended worship services at least monthly (i.e., 75.6%) resembles the pattern reported by Ault et al. (2013) among a broader range of children, youth, and adults with IDD in multiple states (i.e., 79.7% attended at least once or twice per month in the prior study). However, it greatly exceeded the involvement of adults with IDD (aged 18 years-30 years) who were receiving state-funded services across 24 states (i.e., 46.0% attended at least once per month; Carter et al., 2015). Although these findings collectively affirm the pertinence of faith among youth with IDD, they also advise against making assumptions about the priorities or practices of any particular person. Our findings indicate this dimension of youth's lives can be highly individualized (i.e., no two youth were described as engaging in exactly the very same combination of practices). Likewise, there were some youth for whom these practices had no salience at all (i.e., they were reported to have had none of the expressions we addressed).

Second, some of these religious and spiritual expressions appear to hold a degree of importance in the lives of youth. When they were involved in congregational activities, youth were often described as having an active role in initiating these practices—either mostly on their own or equally with a family member. These patterns held for spiritual practices at home or elsewhere, though to a somewhat lesser extent. At the same time, the initiations of youth varied considerably across activities. Such findings raise interesting questions about the application of self-determination within the domains of religion and spirituality. Adolescence is often a time when many youth come to own and individualize their faith. Although we

emphasize that initiation may not always equate with importance, such findings do align with qualitative descriptions of the spiritual lives of youth with disabilities (e.g., Baldwin et al., 2015; Liu et al., 2014).

Third, congregational involvement tended to be limited to a few select activities—attending worship services, a religious education class, and/or attending socials gatherings. Ault et al. (2013) described a similar pattern, with the participation of children, youth, and adults with IDD being most prominent in religious services (85.3%) and religious education programs (60.8%). Our study found that involvement in youth groups was much more limited for transition-age youth. This may represent missed opportunities for relationships and learning for a group of adolescents and young adults who tend to have few friendships and infrequent community involvement (Lipscomb et al., 2017). We also noticed that involvement in leadership roles and service opportunities was fairly limited. Similarly, Ault et al. (2013) reported that just 16.2% of children, youth, and adults with IDD were involved in volunteer work. These findings may reflect the struggle many congregations experience in moving from a primary posture of "ministry to" people with disabilities toward one emphasizing "ministry by" people with disabilities (Carter, 2016). The reasons for this limited involvement could be multiple (e.g., particular opportunities are not offered in their congregation, families are unaware of these opportunities or consider them to be unimportant, youth generally do not participate in these activities). For families and ministry leaders, the primary gap to address lies between individual interest and actual involvement.

Fourth, several factors were strongly associated with the number of congregational activities in which youth were involved and the number of different spiritual practices. Not surprisingly, parental perceptions of the strength of their child's faith were associated with both areas of expression. Likewise, parental faith was associated with both areas of expressions, though to a lesser degree. This connection between the faith of parents and children has also been found among youth without disabilities, which may be indicative of the ways in which parents can be socializing agents of religious and spiritual practices during adolescence (e.g., Barry, Nelson, Davarya, & Urry, 2010; Gunnoe & Moore, 2002). Although youth with autism were reported to have less congregational involvement and lower ratings of religious faith, we were surprised by the more muted extent to which other characteristics (e.g., challenging behaviors, communication mode, functional skills) were associated with participation in multiple practices. Such factors tend to present substantial barriers for the involvement in other school, work, and community activities (e.g., Carter, Austin, & Trainor, 2012; Lauderdale-Littin, Howell, & Blacher, 2013).

## Limitations

Several limitations should be considered alongside these findings. First, our study addressed only some aspects of the religious and spiritual lives of youth (cf. Pearce et al., 2017). Although our study provides new insights into congregational and personal practices, much more should be said about the beliefs, values, meanings, experiences, commitments, and preferences of youth with IDD in this area of their lives. We encourage researchers to pursue a combination of qualitative, observational, and survey studies that could provide a richer portrait of the practices and priorities of youth with IDD. Second, we relied on parents as the only informants in this study. Although we focused our measures on observable activities and practices, there are other private practices and perspectives that would not be noticed by parents. Our field has long struggled to capture the views of students with complex communication needs. Nearly one fifth (17%) of the youth in this study did not use speech as a primary communication mode and many were described by their parents as having substantial support needs and limitations in functional skills. More participatory research methods that incorporate both creative interviews and sustained engagement may be needed to better understand this dimension of youth's lives. Third, we relied on "initiations" of religious and spiritual practices as one potential indicator of their importance to youth with IDD. However, there are multiple reasons that one's initiation of a particular activity could underestimate or overestimate its importance to the person. Moreover, not every outlet for spiritual expression will be of equal importance for youth with disabilities and it will be important to discern which are most valued by individuals. Fourth, we do not know about the degree to which congregational activities were integrated (i.e., took place alongside others who did not have similar disability labels).

The opportunities for developing relationships and experiencing belonging differ substantively across inclusive versus specialized ministry models. As with other areas of society, many congregations have struggled to adopt inclusive programming in widespread ways. Fifth, our sample was drawn from a single state within the United States with a particular religious backdrop. For example, a national survey of Americans undertaken close in time to our study found that 82% of Tennessee respondents considered themselves to be moderately or very religious; responses across other states ranged from 43% to 90% ($M = 71\%$). Studies should also be carried out in other states and countries to better understand the extent to which the experiences of youth with IDD are similar or different.

### Implications for Practice

Our findings have implications for families, congregations, and service systems committed to supporting the spiritual and religious lives of individuals with IDD. First, given the prominence of spiritual practices taking place at home, families may benefit from receiving guidance on how they can best nurture the faith formation and spiritual development of their children with disabilities as they enter adulthood. Presently, most resources in this area focus broadly on parenting children with IDD (e.g., Bradley, 2015; Mazza & Bundy, 2014) and little guidance is available on spiritual formation.

Second, congregations may need guidance on how best to support the participation of youth with IDD in the worship, learning, service, and social activities that comprise their faith communities. Prior studies suggest attitudes and the availability of supports may be uneven across churches, synagogues, and other places of worship (e.g., Amado, Degrande, Boice, & Hutcheson, 2012; Carter, Boehm, Annandale, & Taylor, 2016; Larocque & Eigenbrood, 2005). Likewise, seminary curricula give only limited attention to the topic of disability (Annandale & Carter, 2014), leaving many future clergy with limited experience or training upon which to draw. A growing number of local and parachurch ministries now exist to support congregations in building their capacity and commitment to support individuals with disabilities. Additional work is needed to raise the commitment, confidence, and capacity of congregations to support these youth.

Third, national organizations such as the Arc, the American Association on Intellectual and Developmental Disabilities, and TASH have issued strong position statements affirming the importance of supporting the spiritual lives of people with disabilities. For example, the resolution from TASH (2003) affirms

> . . . that all people with disabilities have the right to spiritual expression including the reflection upon and sharing of spiritual purposes for their lives. TASH 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.

For adolescents, families will have the most active role in supporting religious and spiritual expressions. But as youth transition to adulthood and receive support from residential agencies, the commitment and preparation of staff in this area of support will be important to discern. As with other dimensions of these youth's lives, this is not a place for presumptions or prejudices; instead, good questions must be asked. Carter (2013) advocated for the development of person-centered approaches focused on identifying the spiritual interests, practices, and desired connections of people with IDD. Although a growing number of agencies now incorporate such assessments into their individualized planning (Gaventa, 2016; Merrill, 2012; New York State Office for People with Developmental Disabilities, 2011), much more development of these assessment and planning approaches are needed.

### Implications for Research

Amid these findings, several directions for future research emerge. First, the spiritual development of youth with IDD is not static, but instead emerges over time. Adolescence and early adulthood is a period in which the spiritual priorities and practices of youth often change. Yet, prior studies—including the present study—offer only a snapshot in time. Longitudinal research that follows the religious and spiritual trajectories of youth with IDD over time could provide much-needed insight into how families and communities can best

support faith formation across adolescence and early adulthood. Second, there is an enduring need for reliable, valid, and diverse measures that can be used within this area of research. When planning this study, we were struck by the paucity of assessments designed for this particular group of youth. We encourage future researchers to explore the ways in which existing faith-related measures can be adapted to capture the experiences of students who experience cognitive impairments, communication deficits, reading difficulties, or difficulties understanding complex or abstract constructs. Third, the literature is replete with examples of effective instructional approaches, curricula, and formal programs aimed at enhancing the social, academic, behavioral, self-determination, and vocational skills students with IDD need to flourish in adulthood. However, comparatively little is known about how best to address the spiritual growth and congregational connections of these youth during this important period of transition.

## ORCID iD

Erik Carter https://orcid.org/0000-0001-7153-2782

## References

Abells, D., Burbidge, J., & Minnes, P. (2008). Involvement of adolescents with intellectual disabilities in social and recreational activities. *Journal on Developmental Disabilities*, *14*, 88-94.

Amado, A. N., Degrande, M., Boice, C., & Hutcheson, S. (2012). Accessible congregations campaign: Follow-up survey of impact on individuals with intellectual/developmental disabilities (ID/DD). *Journal of Religion, Disability & Health*, *16*, 394-419. doi:10.10 80/15228967.2012.731909

Annandale, N., & Carter, E. W. (2014). Disability and theological education: A North American study. *Theological Education*, *48*, 83-102.

Ault, M. J. (2010). Inclusion of religion and spirituality in the special education literature. *The Journal of Special Education*, *44*, 176-189. doi:10.1177/0022466909336752

Ault, M. J., Collins, B. C., & Carter, E. W. (2013). Congregational participation and supports for children and adults with disabilities: Parent perceptions. *Intellectual and Developmental Disabilities*, *51*, 48-61. doi:10.1352/1934-9556-51.01.048

Bachman, J. G., Johnston, L. D., & O'Malley, P. M. (2014). *Monitoring the future: Questionnaire responses from the nation's high school seniors: 2012*. Ann Arbor, MI: Institute for Social Research.

Baldwin, P. J., Evans, J., Etherington, N., Nichols, M., Wright, V., & McDougall, J. (2015). Youth with disabilities talk about spirituality: A qualitative descriptive study. *The Qualitative Report*, *20*, 941-958.

Barry, C. N., Nelson, L., Davarya, S., & Urry, S. (2010). Religiosity and spirituality during the transition to adulthood. *International Journal of Behavioral Development*, *34*, 311-324. doi:10.1177/0165025409350964

Baylor University. (2005). *The Baylor religion survey*. Waco, TX: Baylor Institute for Studies of Religion.

Bradley, L. (2015). *Special needs parenting: From coping to thriving*. Edina, MN: Huff.

Buttimer, J., & Tierney, E. (2005). Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of Intellectual Disabilities*, *9*, 25-42. doi:10.1177/1744629505049728

Carter, E. W. (2007). *Including people with disabilities in faith communities: A guide for service providers, families, and congregations*. Baltimore, MD: Paul H. Brookes.

Carter, E. W. (2013). Supporting inclusion and flourishing in the religious and spiritual lives of people with intellectual and developmental disabilities. *Inclusion*, *1*, 64-75. doi:10.1352/2326-6988-1.1.064

Carter, E. W. (2016). A place of belonging: Research at the intersection of faith and disability. *Review & Expositor*, *113*, 167-180. doi:10.1177/0034637316637861

Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies*, *23*, 50-63. doi:10.1177/1044207311414680

Carter, E. W., Boehm, T. L., Annandale, N. H., & Taylor, C. (2016). Supporting congregational inclusion for children and youth with disabilities and their families. *Exceptional Children*, *82*, 372-389. doi:10.1177/0014402915598773

Carter, E. W., Kleinert, H. L., LoBianco, T. F., Sheppard-Jones, K. A., Butler, L. N., & Tyree, M. S. (2015). Congregational participation of a national sample of adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *53*, 381-393. doi:10.1352/1934-9556-53.6.381

Denton, M. L., Pearce, L. D., & Smith, C. (2008). *Religion and spirituality on the path through adolescence: Research report number 8*. Chapel Hill: National Study of Youth and Religion, The University of North Carolina at Chapel Hill.

Fetzer Institute. (2003). *Multidimensional measurement of religiousness, spirituality for use in health research: A report of a national working group*. Kalamazoo, MI: Author. (Original work published 1999)

Gaventa, W. (2016). Disability and spirituality: Re-membering wholeness in services and supports. *Journal of Disability & Religion*, *20*, 307-316. doi:10.1080/23312521.2016.1239155

Gunnoe, M. L., & Moore, K. A. (2002). Predictors of religiosity among youth aged 17-22: A longitudinal study of the National Survey of Children. *Journal for the Scientific Study of Religion*, *41*, 613-622. doi:10.1111/1468-5906.00141

Hill, P. C., & Hood, R. W. (Eds.). (1999). *Measures of religiosity*. Birmingham, AL: Religious Education Press.

Jacober, A. (2011). *The adolescent journey: An interdisciplinary approach to practical youth ministry*. Downers Grove, IL: Intervarsity Press.

King, P. E., & Roeser, R. W. (2009). Religion and spirituality in adolescent development. In R. M. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology: Individual bases of adolescent development* (pp. 435-478). Hoboken, NJ: John Wiley. doi:10.1002/9780470479193.adlpsy001014

Larocque, M., & Eigenbrood, R. (2005). Community access: A survey of congregational accessibility for people with disabilities. *Journal of Religion, Disability & Health*, *9*, 55-66. doi:10.1300/J095v9n01_04

Lauderdale-Littin, S., Howell, E., & Blacher, J. (2013). Educational placement for children with autism spectrum disorders in public and non-public school settings: The impact of social skills and behavior problems. *Education and Training in Autism and Developmental Disabilities*, *48*, 469-478.

Lee, S. H., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., & Little, T. D. (2008). Self-determination and access to the general education curriculum. *The Journal of Special Education*, *42*, 91-107. doi:10.1177/0022466907312354

Lifshitz, H., Weiss, I., Fridel, S., & Glaubman, R. (2009). Why individuals with intellectual disability turn to religion: Behavioral and psychological motives of adolescents and adults. *Education and Training in Developmental Disabilities*, *44*, 196-206.

Lipscomb, S., Haimson, J., Liu, A. Y., Burghardt, J., Johnson, D. R., & Thurlow, M. L. (2017). *Preparing for life after high school: The characteristics and experiences of youth in special education*. Washington, DC: U.S. Department of Education.

Liu, E. X., Carter, E. W., Boehm, T. L., Annandale, N. H., & Taylor, C. E. (2014). In their own words: The place of faith in the lives of young people with autism and intellectual disability. *Intellectual and Developmental Disabilities*, *52*, 388-404. doi:10.1352/1934-9556-52.5.388

Mazza, D., & Bundy, S. (2014). *Another kind of courage: God's design for fathers of families affected by disability*. Agoura Hills, CA: Joni and Friends.

Merrill, L. (2012). Strategies for supporting the spiritual lives of individuals with disabilities. *TASH Connections*, *38*(1), 21-23.

National Survey of Children's Health. (2011/2012). *Data query from the Child and Adolescent Health Measurement Initiative*. Data Resource Center for Child and Adolescent Health. Available from www.childhealthdata.org

New York State Office for People with Developmental Disabilities. (2011). *Spiritual indicator guide*. Albany, NY: Faith-Based Initiative Program.

Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders*, *34*, 245-256. doi:10.1023/B:JADD.0000029547.96610.df

Pearce, L. D., Hayward, G. M., & Pearlman, J. A. (2017). Measuring five dimensions of religiosity across adolescence. *Review of Religious Research*, *59*, 367-393. doi:10.1007/s13644-017-0291-8

Plante, T. G., Vallaeys, C. L., Sherman, A., & Wallston, K. A. (2002). The development of a brief version of the Santa Clara Strength of Religious Faith Questionnaire. *Pastoral Psychology*, *50*, 359-368. doi:10.1023/A:1014413720710

Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatrics and Adolescent Medicine*, *165*, 141-146. doi:10.1001/archpediatrics.2010.279

Shogren, K., & Rye, M. (2005). Religion and individuals with intellectual disabilities: An exploratory study of self-reported perspectives. *Journal of Religion, Disability & Health*, *9*, 29-53. doi:10.1300/J095v09n01_03

Smith, C. (2003). Theorizing religious effects among American adolescents. *Journal for the Scientific Study of Religion*, *42*, 17-30. doi:10.1111/1468-5906.t01-1-00158

Smith, C., & Denton, M. L. (2005). *Soul searching: The religious and spiritual lives of American teenagers*. New York, NY: Oxford University Press.

Smith, C., & Snell, P. (2009). *Souls in transition: The religious and spiritual lives of emerging adults*. New York, NY: Oxford University Press.

Storch, E. A., Roberti, J. W., Bagner, D. M., Lewin, A. B., Baumeister, A. L., & Geffken, G. R. (2004). Further psychometric properties of the Santa Clara Strength of Religious Faith Questionnaire—Short form. *Journal of Psychology and Christianity*, *23*, 51-53.

Storch, E. A., Roberti, J. W., Bravata, E., & Storch, J. B. (2004). Psychometric investigation of the Santa Clara Strength of Religious Faith Questionnaire—Short-form. *Pastoral Psychology*, *52*, 479-483. doi:10.1023/B:PASP.0000031526.64795.41

Swinton, J. (2002). Spirituality and the lives of people with learning disabilities. *Tizard Learning Disability Review*, *7*, 29-35. doi:10.1108/13595474200200037

TASH. (2003). *TASH resolution of spirituality*. Baltimore, MD: Author.

Turner, S., Hatton, C., Shah, R., Stansfield, J., & Rahim, N. (2004). Religious expression amongst adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *17*, 161-171. doi:10.1111/j.1468-3148.2004.00192.x

Zhang, D., & Rusch, F. R. (2005). The role of spirituality in living with disabilities. *Journal of Religion, Disability & Health*, *9*, 83-98. doi:10.1300/J095v09n01_06

## Author Biographies

**Erik W. Carter** is Cornelius Vanderbilt Professor of Special Education at Vanderbilt University. His research and writing focus on promoting inclusion and valued roles in school, work, community, and congregational settings for children and adults with intellectual disability, autism, and multiple disabilities.

**Thomas L. Boehm** is Ann Haskins Assistant Professor of Special Education at Wheaton College. His research and writing focus on building inclusive community within schools and congregations to improve family quality of life for both people with and without disability.