Congregational Participation and Supports for Children and Adults with Disabilities: Parent Perceptions

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Abstract

Although religion and spirituality have received relatively limited attention in the literature addressing people with disabilities, each is strongly associated with a host of positive outcomes, including enhanced quality of life. One way to participate in religious activities and enhance spirituality is to participate in a faith community. In this article, we report findings from a survey of 416 parents exploring the ways in which they and their children with disabilities participated in their congregations and examining factors associated with participation and inclusion in those communities. Consistent with findings from general social surveys, the majority of parents indicated their faith was important to them and many—along with their sons or daughters with disabilities—participated in congregational activities. Although parents reported their sons and daughters with disabilities participated in somewhat fewer types of activities than they did, this involvement occurred most often in activities involving peers without disabilities. However, parents generally were not satisfied with the level of supports provided by faith communities, and they highly valued a welcoming and supportive attitude by the community. We discuss implications for extending inclusive efforts into congregational contexts and suggest future research directions.

Key Words: religion; spirituality; disabilities; faith communities

Since the 1990s, the concept of quality of life has been increasingly applied in the field of intellectual disability as a framework for understanding and addressing what matters most in the life of any individual. Indeed, the American Association on Intellectual and Developmental Disabilities (2009; AAIDD/The Arc) issued a policy statement saying, "people with intellectual and/or developmental disabilities must be able to live the lives they choose and have a good quality of life" (para. 1). There is now broad recognition that having a disability should not prevent people from having the supports and opportunities to participate in relationships and activities that bring personal satisfaction and meaning.

One construct that may contribute to quality of life is the expression of one's spirituality and/or participation in religious activities (AAIDD/The Arc, 2010; TASH, 2000). Religion and spirituality are separate, yet interrelated, constructs. Spirituality usually is characterized as a personal experience

of an individual searching for meaning, a higher power, or "the sacred" that is accomplished through "inner peace, harmony, or connectedness to others" (Boswell, Kahana, & Dilworth-Anderson, 2006, p. 593; Testerman, 1997). Religion includes practices that involve rituals and traditions, association, and membership with a particular denomination or dogma (Hay & Hunt, 2000). Spirituality—although often considered a more personal experience—can be affected by the social, cultural, and historical contexts in which an individual lives. Religion—a more public experience—is often, although not always, one of the contexts in which individuals develop their spirituality (Testerman, 1997).

Quality of life assessments for persons with disabilities often include items directly or indirectly referencing spirituality or religious participation, such as the widely used Quality of Life Questionnaire (Schalock & Keith, 1993). More recently, Schalock et al. (2002) published a paper highlighting the work of an international special interest group of

researchers who collectively identified eight core domains of quality of life for persons with disabilities. Participation in religious experiences and fostering of spirituality may be associated with quality of life in at least six of those domains, including emotional well being, physical well-being, interpersonal relations, personal development, self-determination, and social inclusion (Ault, 2010).

AAIDD/The Arc (2010) highlighted the importance of spirituality for people with an intellectual disability in a position statement observing, "Spirituality is an important part of human experience that may be expressed both through religious practice and through expressions of personal meaning and values" (para. 2). Although spirituality and religious participation are considered a fundamental human right, there are also well-documented benefits associated with these expressions for people with disabilities and their families. For example, Shogren and Rye (2005) interviewed 41 adults with mild and moderate intellectual disabilities. Most adults (76%) reported attending worship services, and the majority reported believing in God and using positive religious coping strategies. Similarly, Minton and Dodder (2003) interviewed 25 adults with intellectual disability about the churches they attended. All the adults indicated that church was a place to be welcomed, to visit with others, and to be recognized. For parents and caregivers, reported benefits have included receiving support from faith communities (Fox, Vaughn, Wyatte, & Dunlap, 2002; Lin, 2000; Rogers-Dulan, 1998), gaining new social and learning experiences for their sons or daughters (Bailey et al., 2006; Dunst, Hamby, Trivette, Raab, & Bruder, 2000), and renewing or beginning their own spirituality (Artson, 2007; Auluck, 2007; Barua, 2007; Naseef, 2002).

Despite these potential benefits, people with disabilities may participate in religious activities substantially less often than people without disabilities. Findings from a recent interview survey of a national cross-section of 1,001 individuals with disabilities or their proxy indicated that people with disabilities (50%) were less likely than people without disabilities (57%) to attend religious services at least once a month (Kessler Foundation/National Organization on Disability, 2010). For people with more significant disabilities, this participation gap was substantially wider. Other descriptive studies confirm these diminished levels of involvement (Abells, Burbidge, & Minnes, 2008;

Orsmond, Krauss, & Seltzer, 2004; Wagner, Cadwallader, Garza, & Cameto, 2004).

Although few studies have focused on the congregational experiences of families who have children with disabilities, available research suggests many salient barriers to meaningful participation exist (Speraw, 2006; Treloar, 2000a). For example, Turnbull and Ruef (1997) conducted interviews with 17 families of children who had challenging behavior. Over half of the respondents indicated they could not participate in their place of worship as they would like. They perceived that congregational staff were not competent or held negative attitudes toward including their children, the formality of worship services might set the occasion for their children's behavior to disturb others, training provided to congregation members was inadequate, and the groups in which their children were included were not age appropriate. In their focus groups of parents of people with disabilities, Poston and Turnbull (2004) identified both spirituality and religion as prominent themes. Although some parents reported their faith community was a place of acceptance for their child, a similar number of families indicated their children were not accepted and lacked the support needed to participate fully in religious activities.

Recognizing the need and desire of families to participate in their faith communities, the benefits that such expressions hold for both them and their children, and the right for people with disabilities to make choices about their spirituality and religious participation (Gaventa, 2005), it is essential that people with disabilities have the supports and opportunities to be included into their faith communities to the extent they wish to be. However, there remains a paucity of data describing the experiences of families of children with disabilities within faith communities and limited exploration of the factors that may facilitate (or hinder) the participation of parents and their sons and daughters in the life of a congregation. Prior studies generally have been limited by small samples, restricted to single locales, or focused on a narrow dimension of spiritual expression.

The purpose of this study was to survey parents and caregivers of people with disabilities about their own (and their sons' or daughters') congregational participation and to explore factors associated with such participation. Specifically, we sought to answer the following research questions:

- 1. In what ways do families with sons or daughters with disabilities participate in their congregational communities?
- 2. In what ways do the sons or daughters with disabilities participate in these same communities?
- 3. What factors do parents identify as affecting their participation—and the involvement of their sons or daughters with disabilities—in their congregation?

Method

Participants

Participants were 416 parents or caregivers (referred to hereafter as parents) of individuals with disabilities of any age who were attending-or had previously attended—a faith community. Most of the respondents were from an east, south central state (38.3%) and a north central state (23.7%) in the United States; however, the researchers gathered responses from a total of 35 states and the District of Columbia. Mothers completed most of the surveys (88.1%). Comparable with national estimates, the majority of respondents identified as being Protestant or Catholic (89.5%). Less than 5% of respondents identified as being Jewish, Mormon, or Buddhist; no one identifying as Muslim or Hindu participated. A little less than half of the sample (46%) attended smaller faith communities (i.e., less than 300 people attending). Slightly more than half of the sample (52.2%) attended larger communities (300 or more people attending).

Consistent with our efforts to focus on the experiences of families of children with intellectual and developmental disabilities, the majority of parent respondents identified their sons and daughters as having an autism spectrum disorder (ASD; 29.3%), moderate to severe intellectual disabilities (MSID; 22.5%), mild intellectual disability (MID; 19.6%), or developmental disabilities (9.8%). Respondents reported other disability categories (e.g., hearing impairment, visual impairment) less than 3% of the time. The majority (88.2%) of the respondents' sons and daughters was under the age of 18. Table 1 provides additional demographics of the respondents and their sons or daughters.

Instrument

We developed a print and Web-based survey composed of 29 questions: 24 with a close-ended

response format and 12 with an open-ended response format (some questions included both response formats). Survey items were drawn and adapted from national studies of congregational participation including the Baylor Religion Survey, 2005 (Association of Religion Data Archives [ARDA], 2005a), the General Social Survey, 2006 (ARDA, 2006), and the Faith and Family in America Survey, 2005 (ARDA, 2005b); as well as our own review of the extant literature (Poston & Turnbull, 2004; Speraw, 2006; Turnbull & Rueff, 1997).

First, we asked parents to respond to a series of demographic questions addressing their family, their sons or daughters with a disability, their congregational involvement, and the importance of their faith.

Second, we asked parents to provide information on (a) the overall frequency with which they and their sons or daughters participated in religious services and activities outside their home (i.e., more than once a week, once a week, once or twice a month, several times a year, hardly ever, never); (b) whether or not they and their sons or daughters participated in each of 13 religious activities during the past year (see Figure 1); (c) the extent to which their sons or daughters were included in congregational activities involving peers without disabilities (see Table 2 for response options); (d) whether or not each of nine accessibility features were available at their congregation (i.e., not available, available, don't know; see Figure 2); and (e) the degree to which each of the same nine accessibility features would be considered helpful to their (or their sons' or daughters') congregational participation (i.e., not very helpful, somewhat helpful, helpful, don't know).

Third, we asked parents to respond to a series of questions addressing their perceptions of the supportiveness of their congregation and their own responses to this support. Specifically, we asked parents the following:

- 1. Have you found places of worship to be supportive of including your child in religious activities?
- 2. Have you ever changed your place of worship because your child was not included or welcomed?
- 3. Have you ever refrained from participating in religious activities because your child was not included?

Table 1 Respondents and Sons' or Daughters' Characteristics

Characteristic	Valid %	n
Relationship to son/daughter		
Mother	88.1	364
Father	9.9	41
Other (e.g., guardian/grandparent)	1.9	8
Importance of faith to parent		
Important	85.5	353
Somewhat important	12.1	50
Not very important	1.5	6
Do not know	0.5	2
Do not have a religion or faith	0.5	2
Size of faith community		
Less than 100 people	15.4	55
100–299 people	31.0	111
300–799 people	30.7	110
800 or more	21.5	77
Not attending	1.4	5
Disability category		
Autism spectrum disorder	29.3	120
Moderate to severe intellectual disability	22.5	92
Mild intellectual disability	19.6	80
Developmental delay	9.8	40
Visual impairment or blindness	2.9	12
Attention deficit/hyperactivity disorder	2.7	11
Emotional or behavioral disorder	2.4	10
Traumatic brain injury	2.4	10
Hearing impairment or deafness	2.2	9
Orthopedic impairment	2.0	8
Significant health impairment	1.7	7
Learning disabilities	1.2	5
Speech or language impairment	1.2	5
Age of son or daughter		
0–2 years	4.6	19
3–5 years	14.6	60
6–10 years	21.1	87
11–13 years	14.6	60
14–18 years	23.3	96
19–30 years	18.2	75
31 years and over	3.6	15

Note. Valid percentages are based on number of respondents providing information on each item.

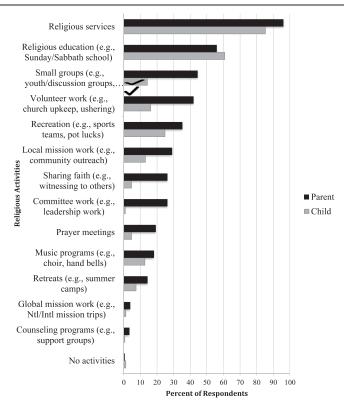


Figure 1. Percentage of respondents reporting participating in various congregational activities by parents and sons or daughters.

- 4. Have you ever kept your child from participating in a religious activity because support was not provided?
- 5. Have you ever been asked or expected to stay with your child at a religious activity so he or she could participate?
- 6. Have you ever been asked by people at a place of worship the best way to include your child in religious activities?

Response options included yes, no, I don't know, or I don't attend a place of worship. When providing an answer of yes, we asked parents to indicate how long ago each issue occurred. In addition, space was available for open-ended comments.

Finally, we invited parents to provide responses to three open-ended questions: (a) What, if anything, has prevented you or your child from

Table 2
Approach Used to Include Sons or Daughters with Disabilities in Congregational Activities

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Approach to participation	%
Regular activities with same-age peers with support	33.6
Regular activities with same-age peers without support	26.9
Does not participate in any activities	21.0
Regular activities with younger peers with support	8.3
Segregated activities with others with disabilities	6.2
Regular activities with younger peers without support	3.8

Note. N = 338 respondents.

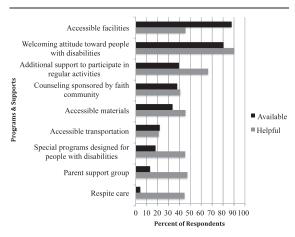


Figure 2. Percentage of parents rating each accessibility feature as available in their congregation and potentially helpful to their son's or daughter's participation.

participating in a religious community as much as you would like? (b) What, if anything, has helped you or your child participate in a religious community? and (c) If there is anything you want to add that we did not cover in the survey, please let us know here. The complete survey is available from the first author on request.

Procedures

Because comprehensive lists of parents of children with developmental disabilities are not readily available, we used nonprobability sampling specifically judgment and snowball sampling—to identify these 416 respondents. To recruit participants, we identified and contacted groups likely to be frequented by parents of children with disabilities (e.g., a Down syndrome association, learning disability association, and autism society) and asked them to distribute to their members an invitation to participate in the survey. We also distributed invitations through professional groups in contact with parents who could distribute the invitation (e.g., American Council on Rural Special Education, State TASH, Quality Indicators of Assistive Technology listsery, state transition listserys). Based on the capacities and preferences of the organizations, several methods of distribution were used including professional and parent listservs (n = 17), e-mail lists and parent meetings (n = 11), announcements on Web sites (n = 6), professional and parent newsletters (n = 3), and flyers

distributed at state special education conferences (n = 3). Most distribution venues—with the exception of the professional special education conferences—were located in either an east, south central state or a north central state based in proximity to the researchers.

The survey was self-administered and available in both an online and paper format. We created and distributed the online version using a secure Web-based platform, and responses were completely anonymous. To reduce the chance of duplicate responses from the same respondent, we set the software to allow only one response from the same IP address. A paper-based version was available for those who did not have access to the Internet or preferred to respond using paper. All, but one, of the surveys were submitted electronically. We estimated the survey took approximately 15 min to complete.

Although respondents submitted 463 surveys, we excluded 47 from our analyses because responses for major sections of the survey were omitted. This resulted in a final total of 416 valid responses.

Data Analysis

We used descriptive and correlational statistics to summarize close-ended sections of the survey. First, we conducted descriptive analyses (i.e., frequencies, percentages) for each variable to characterize the respondents, their activities, and their perceptions. Second, we conducted cross-tabulations and chisquare tests of statistical significance to examine whether responses differed based on selected variables. Specifically, we were interested in whether type of disability, age, congregational size, degree of inclusion, and perceptions of congregational supportiveness were associated with differences in the frequency of parent and child participation; the type of inclusion the sons or daughters experienced (e.g., segregated or regular activities); and specific actions taken by families and faith communities (e.g., had ever changed their places of worship, refrained from participating, or were asked the best way to include their sons or daughters). We selected these specific variables for analysis based on our prior review of the literature (e.g., Ault, 2010; Carter, 2007) and our initial review of qualitative responses on this same survey. We used an alpha level of .05 for all statistical tests. Third, we coded open-ended responses using a constant-comparative method (Lincoln & Guba,

1985). Because of their depth, findings from our qualitative analyses of open-ended survey items and follow-up individual telephone interviews are presented elsewhere (Ault, Collins, & Carter, 2012). Missing data varied across sections and total numbers of respondents are displayed in table and figure notes.

Results

In What Ways do Parents and Their Sons or Daughters with Disabilities Participate in Their Congregational Communities?

Frequency of participation. As shown in Table 1, nearly all (97.6%) of the participating parents reported their faith was important or somewhat important to them. Most of the parents (88.1%) and sons or daughters (79.7%) were categorized as frequent participants (i.e., at least once or twice a month) in religious services or activities outside of their home. The sons or daughters attended services and activities somewhat less often than did their parents. While only 1.1% of the parents reported they never attended services and activities, 5.5% of the sons or daughters were reported to never be attending.

Types of activities. The five most frequently reported activities in which parents themselves participated were religious services (96.1%), religious education programs (56.0%), small group meetings (44.5%), volunteer work (42.0%), and recreational activities (35.3%). On average, parents participated in 4.2 types of activities over the course of the past year (range = 1-13). The most frequently reported activities in which parents reported their sons or daughters participating were religious services (85.3%), religious education (60.8%), recreational activities (24.8%), volunteer work (16.2%), and small group meetings (14.2%). On average, the sons or daughters participated in 2.5 types of activities over the course of the past year (range = 1-10). Comparisons of reported involvement in each of the 13 religious activities for both parents and their sons or daughters are shown in Figure 1. A higher percentage of parents participated in activities than did their sons or daughters in every category except religious

Type of inclusion with peers. The majority of parents indicated their sons or daughters participated in regular activities with same-age peers with or without support (60.7%), while 12.1% of the

sons or daughters participated in regular activities with younger peers with or without support (see Table 2). Those participating with support were the sons or daughters who required support beyond what was normally provided for typically developing children. Although vounger children require more support than older children in general, support in this survey referred to those who needed support above and beyond what was provided for other children of the same chronological age. Therefore, 72.8% of the sample were participating in regular activities in their congregations, whereas only 6.2% were participating in segregated activities designed only for individuals with disabilities. Of those participating in segregated activities (n =21), most (43.8%) were individuals with ASD; most (69%) were between the ages of 11 and 30 years; and most (80%) attended larger churches (i.e., those with 300–800 or more people attending services).

Although the majority of sons or daughters in the sample was participating within regular activities, parents reported that more than one fifth (21%) were not participating in any activities.

Among these individuals, most were identified as having MSID (35.3%) or ASD (26.5%); 31.3% were between the ages of 14 and 18 years; 57% were of the Protestant faith; and 42.7% attended smaller churches with attendance between 100 and 299 people.

What Factors Are Associated with Congregational Participation?

Accessibility features available and considered helpful. Parents reported the accessibility features most often available were accessible facilities (89.3%), welcoming attitudes toward people with disabilities (81.8%), and additional support to participate in regular activities (40.2%). Overwhelmingly, parents rated a welcoming attitude toward people with disabilities as helpful (91.5%), followed by the provision of additional support to participate in regular activities (67.3%), parent support groups (48.1%), accessible materials (46.3%), and accessible facilities (46.3%). Parents' ratings of all nine accessible features are shown in Figure 2. For every program or support listed, except accessible facilities and accessible transportation, parents rated the helpfulness of the program or support higher than their actual availability. The largest discrepancies between programs that respondents rated as helpful and those that were actually available were parent support groups and respite care.

A total of 81 respondents wrote in other programs or supports they would find helpful in participating in a place of worship. The codes and definitions assigned and the percentage of responses were (a) supports for inclusion of the child, in which parents named programs or supports that would help promote better inclusion of their sons or daughters in the ongoing programs of their faith communities (36.7%); (b) education, in which parents indicated a need for education and training of staff members, peers, the congregation, or volunteers (16.7%); (c) accepting attitudes, in which parents indicated that welcoming, accepting, and flexible attitudes would be helpful to their participation (11.1%); (d) supports for parents in the form of child care or respite during services so parents could attend worship times (7.8%); (e) segregated programs, in which parents named programs serving only individuals with disabilities as helpful (6.7%); and (f) physical accessibility of the facility, such as wheelchair accessibility or a room specifically designed to take children to when displaying inappropriate behaviors (6.7%).

Parent perceptions of supportiveness. Parents did not perceive a high degree of supportiveness of including their sons or daughters within the places of worship they attended. Only 42.5% described

their congregations as supportive; 41.1% described their congregations as sometimes supportive; 12.7% indicated they were not supportive; 0.3% said they did not attend a congregation; and 3.4% reported that they did not know. Responses to other items addressing congregational support are displayed in Table 3. Almost one third of parents reported having changed their place of worship because their child had not been included or welcomed; almost half had refrained from participating; more than half had kept their sons or daughters from participating in a religious activity because of a lack of support; and more than half had been expected to stay with their sons or daughters in order for participation to occur. Finally, more than half of parents reported they had never been asked about the best way to include their sons or daughters in religious activities.

Factors affecting parental attendance. We conducted chi-square tests to examine differences in the congregational attendance rates of parents based on their sons' or daughters' disability category, age, the type of inclusion with peers, and whether or not they felt the congregation supported inclusion of their sons or daughters. To ensure cell sizes were greater than 5, we collapsed some categories prior to analysis. We combined the frequency of attendance into two categories: frequent attendees (i.e., those attending at least

Table 3
Parents' Perceptions of the Supportiveness of Their Congregations

	% of responses		
Perception	Yes	No	I don't attend/participate in places of worship
Have you ever changed your place of worship because your child was not included or welcomed?	32.3	66.6	1.1
Have you ever refrained from participating in a religious activity because your child was not included or welcomed?	46.6	52.5	0.8
Have you ever kept your child from participating in a religious activity because support was not provided?	55.8	43.7	0.6
Have you ever been expected to stay with your child at a religious activity so your child could participate?	55.3	43.3	1.4
Have you ever been asked by person at a place of worship the best way to include your child in religious activities?	53.5	46.2	0.3

Note. N = 351 to 356 respondents.

once or twice a month) and infrequent attendees (those attending several times a year or less). We collapsed the sons' or daughters' age categories into three categories: young children (i.e., birth to 5 years), school-age children and youth (i.e., 6-18 years), and adults (i.e., 19-31 years and over). We collapsed the type of inclusion into three categories: (a) those sons and daughters participating in segregated activities, (b) those participating in regular activities with same-age peers, and (c) those participating in regular activities with younger peers. We specifically focused on sons and daughters with category disabilities of ASD, MSID, and MID to meet cell-size requirements. None of these variables was associated with the frequency of parental attendance, except a significant relationship was found between frequency of attendance and the availability of support for sons or daughters (i.e., parents reporting the community supported inclusion of their sons or daughters versus parents reporting the community did not support inclusion of their sons or daughters), χ^2 (1) = 6.624, p < .05. In other words, parents who were frequent attendees were significantly more likely than infrequent attendees to respond that their child was supported.

Factors associated with sons' or daughters' attendance. We conducted chi-square tests to determine if there was a relationship in the attendance rates of the sons or daughters at their faith communities with their disability category, their age, the type of inclusion with their peers, and whether or not their parents felt supported at their community. We found no significant relationships except, as with parental attendance, sons or daughters who attended frequently had parents who were significantly more likely to respond that their sons or daughters were supported in the place of worship than were not supported, χ^2 (1) = 14.375, p < .05.

Factors associated with inclusion approach. We examined the relationship between the approach used to include sons and daughters and the factors of disability category, age, congregation size, and parents' perception of supportiveness. None of these variables was significantly associated with the approach to inclusion except the size of the congregation. Sons or daughters who participated in segregated activities were significantly more likely than those who participated in regular activities with younger children to attend large faith communities, χ^2 (1) = 5.794, p < .05. Similarly, sons or daughters who participated in

segregated activities were significantly more likely than children who participated in regular activities with same-age peers to attend large faith communities, χ^2 (1) = 4.997, p < .05.

Factors associated with perceptions of supportiveness. We examined the relationship between parents' perceptions of the supportiveness of their congregation and the factors of sons' or daughters' disability category, age, and the size of their congregation. A significant relationship was found between the parents' perceptions of supportiveness and the disability category of the sons or daughters. To pinpoint the differences, we conducted a series of 2×2 cross-tabulations, and the results indicated that both parents of sons or daughters with MID and MSID were significantly more likely to report that places of worship were supportive of their child than were parents of sons or daughters with ASD, χ^2 (1) = 4.992, $p < .05 \text{ and } \chi^2 (1) = 5.785, p < .05, \text{ respectively.}$

Discussion

The rights of people with disabilities to participate in religious activities and express their spirituality in ways and contexts that are personally valued have been clearly affirmed by professional and global organizations (AAIDD/The Arc, 2010; Carter et al., 2012; United Nations, 1948). Moreover, spiritual expression and religious participation are strongly associated with quality of life for individuals with and without disabilities. Yet, relatively little is known about the involvement of parents and their sons or daughters with disabilities in congregational life and the degree to which supports are available to enhance their participation. This study contributes to the literature by exploring parental perspectives of the ways in which families participate in their faith communities, and it contributes new insights into factors associated with their participation and inclusion in places of worship. A number of points can be made based on the results of the survey.

First, parents reported participating in a range of activities within their congregation (i.e., an average of four categories during the past year), while their sons or daughters participated in a somewhat more narrow bandwidth of activities (i.e., primarily religious services and religious education). These data indicate sons and daughters with disabilities were not participating in additional activities that

could provide meaningful avenues for expressing their spirituality (e.g., sharing their faith, taking part in prayer meetings) or serving others (e.g., doing volunteer work, engaging in mission work). It is unclear whether such opportunities for deeper involvement were not considered or not offered to individuals with disabilities in ways naturally available to others without disabilities (i.e., barriers of opportunity or access; Carter, 2007), that younger children tend not to participate in the same breadth of activities as adults, or that other factors accounted for these differences. Recommended educational policies and practices emphasize the importance of ensuring that children and youth with significant disabilities have access to the same range of opportunities available to their peers without disabilities (Browder & Spooner, 2011; Kim & Turnbull, 2004) and are provided the opportunities to make their own choices and to set their own goals regardless of their disability (Carter, Owens, Trainor, Sun, & Swedeen, 2009). Within congregational contexts, adopting this same principle should lead to individuals who are provided the opportunity not only to participate in activities others have deemed as appropriate for them, but also to participate in those activities they personally prefer. For example, people with disabilities have traditionally been the focus of "service" or support. By considering and providing opportunities for the full range of congregational activities, these individuals may take on a role as a supporter or server of others.

Second, in terms of the primary approaches used to support children with disabilities in congregational activities, almost three fourths of sons and daughters participated in regular activities-most often with their same-age peers-less often with younger peers. Only 6.2% participated in segregated activities designed only for people with disabilities. It is encouraging that these data seem to indicate that individuals with disabilities are being included with others without disabilities in the community. On the other hand, it is of concern that more than one fifth of respondents indicated their sons or daughters participated in no activities at all. Because we did not ask parents to expound on the reasons why their sons or daughters did not attend, additional research is needed to explore the factors hindering such participation. Interestingly, our findings indicated that people with disabilities attending larger congregations were more likely to participate in segregated activities. It may be that larger faith communities simply have the numbers

of individuals to form into groups, allowing them to compartmentalize their members by certain characteristics (e.g., age, marital status, disability). Smaller congregations do not have the numbers of individuals to do this and so may be more likely to have their members with disabilities participating in integrated activities. Current best practice within schools supports the inclusion of people with disabilities in their neighborhood schools so that the natural proportions of people with significant disabilities is reflected in the total school population (Jackson, Ryndak, & Wehmeyer, 2008/2009). Large congregations, especially those providing segregated programs designed for people with disabilities, may become identified as a community with such a program, thereby attracting large numbers of families that results in an unnatural proportion of people with disabilities attending there.

Third, a large proportion of parents indicated the supports needed to adequately support the participation of their families in congregational activities were not fully available. This finding is supported by other research in which parents have reported some dissatisfaction with the level of support provided within their places of worship (e.g., Poston & Turnbull, 2004; Speraw, 2006). For example, more than two thirds of parents desired additional support for their sons or daughters to participate in regular activities. In addition, supports for inclusion were available in only 40% of congregations, and accessible materials were available in only 34% of congregations. Parents ranked all other programs as potentially helpful, but less often available.

Fourth, the absence of some simple—but key supports in some congregations also affected the actions of the broader family. Many parents had been required to stay with their sons or daughters or had prevented them from attending an activity because of a lack of support. Perhaps the most telling sign of a lack of appropriate supports was that one third of the respondents reported they had changed their places of worship specifically due to a lack of welcome or support for their sons or daughters. These findings indicate faith communities may benefit from (a) training to understand the best way to include individuals with disabilities, (b) leadership knowledgeable in disability theology and support (Treloar, 2000b), and (c) accepting congregational attitudes that all people are valued and can contribute to a faith community (Brown, 2001).

Fifth, of the multiple factors we explored, parents' perceptions of how supportive their faith communities were in including their sons or daughters may be among the most salient. Parents and children who attended their faith communities frequently were more likely to respond their community was supportive of including their sons or daughters. In addition, parents who had sons or daughters with ASD were more likely than parents of sons or daughters with mild or severe intellectual disabilities to feel less supported in their faith community. Given that some individuals on the autism spectrum can exhibit challenging behaviors (e.g., not sitting still, making noises), it may be that faith communities are uncomfortable with or untrained in working with those individuals, resulting in parents not feeling the support of the community.

Finally, the attitudes expressed within a faith community may play an important role in facilitating the participation of families of children with disabilities. Given the importance parents in this sample placed on a "welcoming attitude" (91.5% rating as helpful), it is important to consider what this phrase really means and how best to foster it within faith communities. A welcoming attitude is a complex construct that is made up of social behaviors and is not yet well defined and has, as of yet, not been demonstrated clearly (LaRocque & Eigenbrood, 2005), although some congregations are making efforts toward inclusive communities (Collins & Ault, 2010). Future researchers should examine this construct of welcoming attitudes and empirically validate the behavioral components that could then be used to provide an accurate definition and yield accurate measurement of "welcoming" so that faith communities could put these behaviors into place and their effects could be evaluated (Wolf, 1978).

Limitations and Future Research

This investigation is one step in describing and exploring factors influencing the participation and inclusion of families with disabilities into their places of worship. Readers should carefully consider our sampling process when determining the extent to which these findings may be applicable to samples of parents from other locales and contexts. However, these findings can be used as a starting point for future investigations and to corroborate findings from other investigations.

Future research is also needed that pinpoints key variables contributing to the participation and inclusion of families in the faith community of their choice. First, additional analyses related to age (e.g., breaking out an analysis of 14 to 22 year olds and 23 to 30 year olds) was not conducted in this study but may be important for future study. Second, similar research should be conducted with samples of different characteristics. Samples with higher incidence of religions other than Christianity will be important to study as well as those representative of other disability categories. Third, respondents who are individuals with disabilities themselves should have the opportunity to respond to similar questions as were presented to their parents in this study. Researchers should focus on developing questionnaires and methods that would allow individuals with complex communication and cognitive challenges to voice their perspective on these issues. Fourth, the vantage point of faith communities on these same topics is critical to understanding the complexity of these issues. Fifth, factors contributing to parents' levels of satisfaction with their faith communities should be examined. Sixth, educational programs should be developed and implemented for faith communities and for parents to assess the effects on the inclusiveness of the community. Seventh, methods should be developed and studied to determine the effects on the attitudes of the community toward people with disabilities. Finally, it is interesting to note that a small percentage of the respondents were fathers. Obtaining perceptions from a larger sample of fathers may provide additional findings not revealed in this study.

As evidenced in the inclusion of religion and spirituality within most conceptualizations of quality of life and human flourishing, people with disabilities should have the opportunity to fully participate in this area of their lives if they so desire. Findings from this investigation indicate that respondents whose faith is important to them highly value participation and inclusion in their faith communities. Faith communities that can provide appropriate supports, welcoming and accepting attitudes, and members and leaders educated in inclusive practices can contribute to enhanced quality of life for families and their children with disabilities. With continued research in this area, people with disabilities can develop their spirituality and congregational connections to the degree they desire and in ways comparable ways to individuals without disabilities.

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.
- American Association on Intellectual and Developmental Disabilities. (2010). Spirituality [White paper]. Available at http://aaidd.org/content_155.cfm?navID=31
- American Association on Intellectual and Developmental Disabilities/The Arc. (2009). *Quality of life* [White paper]. Available at http://aaidd.org/content_143.cfm
- Artson, B. S. (2007). Jacob who loves the Sabbath. Journal of Religion, Disability, and Health, 10, 243–246. doi:10.1300/J095v10n03_16
- Association of Religion Data Archives. (2005a). Baylor religion survey, 2005 (Data file). Available at http://www.thearda.com/Archive/Files/Codebooks/BRS2005_CB.asp
- Association of Religion Data Archives. (2005b). Faith and family in America, 2005 (Data file). Available at http://www.thearda.com/Archive/Files/Codebooks/FAITHFAM_CB.asp
- Association of Religion Data Archives. (2006). General social survey, 2006 (Data file). Available at http://www.thearda.com/Archive/Files/Codebooks/GSS2006_CB.asp
- Ault, M. J. (2010). Inclusion of religion and spirituality in the special education literature. *The Journal of Special Education*, 44, 176–189. doi:10.1080/15228961003622195
- Ault, M. J., Collins, B. C., & Carter, E. W. (2012). Factors associated with participation in faith communities for individuals with developmental disabilities and their families. Manuscript submitted for publication.
- Auluck, S. (2007). Life is strange. Journal of Religion, Disability, and Health, 11, 23–28. doi:10.1300/J095v11n02_04
- Bailey, D. B., Bruder, M. B., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C., ... Barton, L. (2006). Recommended outcomes for families of young children with disabilities. *Journal of Early Intervention*, 28, 227–251. doi:10.1177/ 105381510602800401

- Barua, M. (2007). Lessons from Neeraj, my son with autism. *Journal of Religion*, *Disability*, and *Health*, 11, 29–40. doi:10.1300/J095v11n02 05
- Boswell, G., H., Kahana, E., & Dilworth-Anderson, P. (2006). Spirituality and healthy lifestyle behaviors: Stress counter-balancing effects on the well-being of older adults. *Journal of Religion and Health*, 45, 487–602. doi:10.1007/s10943-006-9060-7
- Browder, D. M., & Spooner, F. (2011). *Teaching students with moderate and severe disabilities*. New York, NY: Guilford Press.
- Brown, R. D. (2001). Examining the beliefs of involved adults concerning the moral and religious development of individuals with mental retardation. *Journal of Religion, Disability, and Health, 5*, 5–28. doi:10.1300/J095v05n01_02
- 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., Owens, L., Trainor, A. A., Sun, Y., & Swedeen, B. (2009). Self-determination skills and opportunities of adolescents with severe intellectual and developmental disabilities. American Journal on Intellectual and Developmental Disabilities, 114, 179–192. doi:10.1352/1944-7558-114.3.179
- Carter, E. W., Taylor, C., Ault, M. J., Collins, B. C., Kleinert, H. L., & Tyree, M. (2012, Winter). Recent research on spiritual supports: What we know and where we might go. TASH Connections, 38(1), 31–34. Available at https://netforum.avectra.com/eweb/DynamicPage.aspx? Site=TASH&WebCode=v37i1
- Collins, B. C., & Ault, M. J. (2010). Including people with disabilities in the religious community: Program models implemented by two churches. *Journal of Religion*, *Disability*, *and Health*, 13, 113–131. doi:10.1080/15228961003622195
- Dunst, C. J., Hamby, D., Trivette, C. M., Raab, M., & Bruder, M. B. (2000). Everyday family and community life and children' naturally occurring learning opportunities. *Journal of Early Intervention*, 23, 151–164. doi:10.1177/ 10538151000230030501
- Fox, L., Vaughn, B. J., Wyatte, M. L., & Dunlap, G. (2002). "We can't expect other people to understand": Family perspectives on problem behavior. *Exceptional Children*, 68, 437–450.
- Gaventa, W. (2005). A place for all of me and all of us: Rekindling the spirit in services and

- supports. *Mental Retardation*, 43, 48–54. doi:10. 1352/0047-6765(2005)43<48:APFAOM>2.0. CO:2
- Hay, D., & Hunt, K. (2000). Understanding the spirituality of people who don't go to church: A report on the findings of the adults' spirituality project at the University of Nottingham. Available at http://spiritualjourneys.org.uk/
- Jackson, L. B., Ryndak, D. L., & Wehmeyer, M. L. (2008/2009). The dynamic relationship between context, curriculum, and student learning: A case for inclusive education as a research-based practice. Research and Practice for Persons with Severe Disabilities, 33/34, 175– 195. doi:10.2511/rpsd.33.4.175
- Kessler Foundation/National Organization on Disability. (2010). Survey of Americans with disabilities. Available at http://www.2010disability surveys.org/indexold.html
- Kim, K., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. Research and Practice for Persons with Severe Disabilities, 29, 53–57.
- LaRoque, M., & Eigenbrood, R. (2005). Community access: A survey of congregational accessibility for people with disabilities. *Journal of Religion*, *Disability*, *and Health*, 9, 55–66. doi:10.1300/J095v9n01_04
- Lin, S. (2000). Coping and adaptation in families of children with cerebral palsy. *Exceptional Children*, 66, 201–218.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Minton, C. A., & Dodder, R. A. (2003). Participation in religious services by people with developmental disabilities. *Mental Retardation*, 41, 430–439. doi:10.1352/0047-6765(2003)41<430: PIRSBP>2.0.CO;2
- Naseef, R. (2002). When the bough breaks. *Journal of Religion*, *Disability*, and *Health*, 6, 75–87. doi:10.1300/J095v06n01_06
- 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
- Poston, D. J., & Turnbull, A. P. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities.

- Education and Training in Developmental Disabilities, 39, 95–108.
- Rogers-Dulan, J. (1998). Religious connectedness among urban African American families who have a child with disabilities. *Mental Retardation*, 36, 91–103. doi:10.1352/0047-6765(1998) 036<0091:RCAUAA>2.0.CO;2
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., ... Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40, 457–470. doi:10.1352/0047-6765(2002)040<0457: CMAAOQ>2.0.CO;2
- Schalock, R. L., & Keith, K. D. (1993). Quality of life manual. Worthington, OH: IDS.
- Shogren, K. A., & Rye, M. S. (2005). Religion and individuals with intellectual disabilities. *Journal of Religion*, *Disability*, *and Health*, 9, 29–53. doi:10.1300/J095v09n01 03
- Speraw, S. (2006). Spiritual experiences of parents and caregivers who have children with disabilities or special needs. *Issues in Mental Health Nursing*, 27, 213–230. doi:10.1080/01612840500436974
- TASH. (2000). TASH resolution on supports in the community [White paper]. Available at http://www.tash.org/advocacy-issues/community-living/
- Testerman, J. K. (1997). Spirituality vs. religion: Implications for healthcare. Available at http://circle.adventist.org/files/CD2008/CD1/ict/vol_19/19cc_283-297.htm#_edn2
- Treloar, L. L. (2000a). Spiritual beliefs, response to disability, and the church—Part 1. *Journal of Religion*, *Disability*, and *Health*, 3, 5–32. doi:10. 1300/J095v03n04_02
- Treloar, L. L. (2000b). Spiritual beliefs, response to disability, and the church—Part 2. *Journal of Religion*, *Disability, and Health*, 4, 5–31. doi:10. 1300/J095v04n01_02
- Turnbull, A. P., & Ruef, M. (1997). Family perspectives on inclusive lifestyle issues for people with problem behavior. Exceptional Children, 63, 211–227.
- United Nations. (1948). The universal declaration of human rights. New York, NY: Author.
- Wagner, M., Cadwallader, T. W., Garza, N., & Cameto, R. (2004). Social activities of youth with disabilities. *NLTS2 Data Brief*, 3(1), 1–4.

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis*, 11, 203–214.

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