Role of Spirituality and Religion in Family Quality of Life for Families of Children with Disabilities

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Abstract: Results from a qualitative inquiry investigating conceptualization of family quality of life are provided. Focus groups and individual interviews were comprised of 187 individuals that included family members (e.g., parents, siblings) of children with a disability, eight individuals with a disability, family members of children without a disability, service providers, and administrators. Data were collected in urban and rural settings to elicit participants' understanding of domains of family quality of life. Themes of spirituality and religion in the context of family quality of life for families of children with disabilities are explored in this article. Families described the importance of spirituality in their lives and their participation in religious communities. Discussion and implications include strategies to enhance family spiritual well being, to provide spiritually sensitive supports, and to promote inclusive religious communities for children with mental retardation and developmental disabilities (MR/DD) and their families.

Despite a long history of quality of life studies, most research efforts have focused on conceptualizing and measuring *individual* quality of life with the notion of *family* quality of life drawing attention only recently (The Accreditation Council, 1995; Bailey et al., 1998; Cummins & Baxter, 1997; Turnbull et al., in press). It is not surprising, therefore, that the conceptualization of family quality of life primarily depends on literature about individual quality of life.

Individual Quality of Life

The definition of individual quality of life has evolved somewhat over the last three decades and has been defined differently depending on the researcher (Brown, 1997; Cummins, 1997; Felce, 1997; Hughes & Hwang, 1996; O'Boyle, 1997; Schalock, 1997, 2000). Regardless of the specific way individual quality of life is defined, researchers generally have included these common concepts: general feelings of well-being, feelings of positive social involvement, and opportunities to achieve personal potential

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(Schalock et al., 2002). They have also agreed that quality of life should include various domains of life and taken together as a whole should encompass the entirety of life (Cummins; Felce & Perry, 1997, Raphael, Brown, Renwick, & Rootman, 1996; Schalock, 1997; Schalock et al.).

Several authors in individual quality of life studies have suggested that quality of life includes six domains and associated indicators (Schalock et al., 2002): (a) physical well-being (e.g., health, nutrition, mobility, and daily living activities); (b) emotional well-being (e.g., happiness, contentment, freedom from stress, self-concept, and religious belief); (c) social well being (e.g., intimacy, friendships, community activities, and social status and roles); (d) productive well-being (e.g., personal development in education or job, leisure and hobbies, choice and autonomy, and personal competency); (e) material well-being (e.g., ownership, financial security, food and shelter, and socioeconomic status); and (f) civic well-being (e.g., privacy, voting, access, civic responsibilities, and protection under the law). The indicators listed here are not an exhaustive index, but instead, provide a dynamic list that may be added to and continuously refined (Cummins & Baxter, 1997; Felce, 1997; Gardner, Nudler, & Chapman, 1997; Hughes & Hwang,

1996; Schalock, 1996).

Family Quality of Life

Although individual quality of life research has produced sufficient momentum to result in an international consensus document (Schalock et al., 2002), family quality of life is at the very beginning of the conceptualization process. It appears that family quality of life should be a natural extension of the work on individual quality of life, especially given the strong emphasis in the disability field on a family-centered service delivery model. Since the mid-to-late 1980s, there has been a growing recognition of the importance of family-centered service delivery characterized by family choice, a family strengths perspective, and the family as the unit of support (Allen & Petr, 1996; Bailey & McWilliam, 1993; Dunst, Johnson, Trivette, & Hamby, 1991; Turnbull, Turbiville, & Turnbull, 2000). Bailey and colleagues (1998) have proposed quality of life of families of children with disabilities as a "useful indicator of outcomes of policy initiatives" (p. 322).

Given the complexity in defining *family* in today's society, in addition to the difficulty of defining *quality of life,* defining *family quality of life* offers even greater challenges. Poston and her colleagues (2003) present the following definition of *family* and *family quality of life:*

> *Family:* people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis.

> *Family quality of life:* conditions where the family's needs are met, family members enjoy their life together as a family, and family members have the chance to do things that are important to them.

Spirituality, Religion and Disability

Most researchers and practitioners agree that there is a difference between spirituality and religion. Many people think of themselves as spiritual people but not as followers of a specific religion. Researchers and practitioners in human service professions define spirituality as a basic aspect of human experience and development and experience, common to all people, cultures and religions (Canda, 2001). It is also defined as the area of life that includes the need to find meaning in our existence; a search for fulfilling relationships between oneself and others, the universe, and reality as one views and understands it; as well as the *way* that we respond to the sacred (Canda, 1999; Fitchette, 1993; Gaventa; 2001). Canda and others (Canda, 1999; Fitchette; Gaventa.) assert that people have a spiritual aspect to themselves along with the biological, psychological and social aspects.

Religion is defined as the institutionalized and organized patterns of beliefs, moral, rituals and social structures that people create to help fulfill their spiritual quest (Canda, 1999; Fitzgerald, 1997). Spirituality is expressed through religion and religious practices, but it can also be experienced through nonreligious and nonsectarian forms (Canda). Spirituality is personal but can also be shared together in communities and religious organizations (Canda).

There is increasing evidence to suggest that it is a person's inner world of values, beliefs and inspiration that helps determine the process of coping (do Rozario, 1997). Additionally, there are hundreds of studies in fields of health, mental health and social work that point to the role that religious and spiritual belief and practices contribute to resilience in people who experience illness or disabilities (Canda, 2001).

Views of illness and disability are intertwined with religious or spiritual beliefs (Zhang & Bennett, 2001). Sevensky (1981) suggested that religion serves three functions for people who are ill: (a) provides a framework to make meaning of their illness, (b) provides practical resources, and (c) provides hope. Zea, Quezada, and Belgrave (1994) indicated that for Hispanic families spirituality, specifically faith in God's will, can lead to positive acceptance of disability. Disability may also be seen as a trial that is to be endured or as punishment for sin or wrongdoing. Zhang and Bennett indicated that families may rely on cultural or spiritual traditions to help them interpret disability, especially in the absence of other information.

Researchers and practitioners have begun to appreciate different approaches to rehabilitation and/or education of persons with disabilities

including spiritual approaches (Byrd, 1997). In medicine, Frank (1975) asserted that there may be too much emphasis on healing the body and not enough on the mind. Byrd posits that one way to change emotional states is to focus on an individual's spirituality. He described research in spirituality and health, and emphasized that spirituality has a positive effect on health and healing; Byrd also endorses spiritual tools (e.g., prayer and worship) being used in conjunction with medical and psychological tools.

Lane (1995), who herself experiences a disability, addressed the topic of anger and disability, including anger at God. She says, "healing begins as we who live with disabilities recognize our anger and give credibility to it" (p. 110). She goes on to challenge people to either "choose to remain angry over what has been lost or never realized, or find joy and grace in what has been given and in what can be" (p. 110). She suggested that part of this journey from anger to joy includes questioning God and working through faith to reestablish that broken relationship with God. She asserts that the spiritual journey enables a person to "live with rather than suffer from" (Lane, 1992, p. 53) a disability.

Given then that spirituality has an important role in individual quality of life and in people's search for wholeness and meaning in life, it is no surprise to find that spirituality and specifically religious practices, have a major focus in family quality of life as seen in the study described in this article. Questions of interest for this research were as follows:

What role do spiritual or religious beliefs and practices play in family quality of life?

How can community organizations contribute to the enhancement of families' spiritual well being?

Method

This research was guided throughout by a participatory action research (PAR) process that involved collaboration with family members, service providers, administrators, and researchers from education, human and social services, and health to insure maximum relevance (Santelli, Singer, DiVenere, Ginsberg, & Powers, 1998;

Turnbull, Friesen, & Ramirez, 1998). We used focus groups and individual interviews for data collection. Focus groups provided a number of advantages, specifically, a responsive context for people who have not traditionally been encouraged to voice their perspectives on sensitive topics (Krueger, 1994; Rubin & Rubin, 1995). Individual interviews were primarily used to gain perspectives of parents who do not speak English at all or who speak English on a limited basis. Individual interviews enabled use of interpreters that would have been difficult to incorporate into focus groups.

Participants

Focus groups. We conducted focus groups in three locations: (a) Kansas City, Kansas (urban), (b) New Orleans, Louisiana (urban), and (c) Granville County, North Carolina (rural). In general, each location had (a) two focus groups of families with children with disabilities, (b) two focus groups of families of children without disabilities, (c) one focus group of service providers, and (d) one focus group of administrators. There was also one focus group of people with disabilities in North Carolina.

In collaboration with local PAR advisors in each site (parent and professional leaders), we used purposive, maximum variation, intensity and convenience sampling strategies to recruit participants (Erlandson, Harris, Skipper, & Allen, 1993; Krueger, 1994; Lincoln & Guba, 1985; Patton, 1990). Additionally we followed their advice about the most appropriate way to configure groups to maximize the participants' comfort and potential for responsiveness. Tables 1 and 2 report the demographic characteristics of family members and professionals respectively.

Individual interviews. We conducted interviews in the Kansas City area with 18 parents for whom English is not their primary language and ten service providers who regularly provide supports and services to families with limited English proficiency. We worked with parent leaders and with agencies that provide direct services to children and families with limited English proficiency (e.g. school-based coordinators of the English as a second language program) to identify participants. Local leaders provided the first contact with families and

TABLE 1

Participant Demographics: Family Members (*n* = 137)

Variable	Families of Children with Disabilities (*n* = 78)	Families who use English as a Second Language (*n* = 18)	Families of Children Without Disabilities (*n* = 33)	Individuals with Disabilities (*n* = 8)
Gender				
Female	55	17	29	3
Male	23	1	4	5
Missing	0	0	0	0
Ethnicity				
African-American	42	0	16	6
Hispanic	3	17	2	0
White	26	0	13	2
Other	4	1	2	0
Missing	3	0	0	0
Age				
10's	2	INA	0	8
20's	9		5	0
30's	24		12	0
40's	25		12	0
50's	10		4	0
60's and older	2		0	0
Missing	6		0	0
Marital Status				
Married	47	INA	20	0
Not married	25		13	8
Missing	6		0	0
Employment Status				
Employed full-time	39	INA	11	0
Employed part-time	10		5	0
Not employed	21		6	0
Full-time student	2		0	0
Missing	6		1	8
Highest level of education completed				
No high school diploma	6	INA	2	8
High school graduate or GED	15		8	0
Some college, or college degree	51		22	0
Missing	6		1	0
Relationship with the child				
Biological parent	51	18	32	N/A
Foster parent	3	0	0	
Adoptive parent	5	0	0	
Other family member	6	0	0	
Missing	13	0	1	
Income				
Low (annual income< $25,000)	17	INA	12	8
Moderate	24		14	0
High (> $50,000)	18		6	0
Missing	19		1	0
Community size				
Metro/urban	49	INA	22	0
Small city/Town	6		8	8
Rural area	7		2	0
Missing	16		1	0

TABLE 1 —(Continued)

Variable	Families of Children with Disabilities (n = 78)	Families who use English as a Second Language (n = 18)	Families of Children Without Disabilities (n = 33)	Individuals with Disabilities (n = 8)
Age range of the child with a disability				
Birth to 5	17	INA	N/A	0
5-13	20			0
13-21	21			8
Over 21	3			0
Missing	17			0
Disability severity of the child with a disability				
Mild	6	INA	N/A	4
Moderate	33			4
Severe/very severe	26			0
Missing	13			0

Note. INA = information not available

assisted us in arranging for interpreters. Demographic summaries for the individual in-terviews are in Tables 1 and 2.

We also interviewed three siblings of indi-viduals with disabilities in Kansas City. We in-terviewed them rather than conducting a focus group because the PAR advisor suggested that she thought interviews would be more comfortable for them. Sibling demographics are included in the summary in Table 1.

Data Collection

Focus groups. We used a semi-structured in-terview guide to provide general direction for the focus group discussion. We used the following grand tour questions with families:

When you hear the words "family quality of life," what first comes to your mind?

Tell us about times when things have gone really well in your family. What helps things go well?

Tell us about times that have been especially tough in your family. What are the things that usually create tough times?

We asked service providers and administrators about quality of life within their own families, as well as questions about their perspectives on factors that contribute to a good quality of life for the families to whom they provide services.

Most focus groups were comprised of 6-12 participants. We conducted focus groups in two rounds with the second round being held 3-4 months after the first round. Each focus group lasted approximately 1 1/2 hours. At the conclusion of the focus groups, the moderator

TABLE 2

Participant Demographics: Professionals (*n* = 50)

Variable	n
Gender	
Female	46
Male	4
Ethnicity	
African-American	5
Hispanic	2
White	43
Other	0
Role	
Administrator	17
Service provider	33
Working field	
Education	19
Human/social services	21
Health care	8
Combination	2

conducted an early member check by summarizing major points and soliciting feedback. All focus groups were recorded and transcribed.

Individual interviews. Nine graduate students conducted the individual interviews with families for whom English is not their primary language. The students followed similar procedures in the individual interviews as already described for focus groups regarding general sequence of questions, tape-recording, and transcription.

Data Analysis

We used the constant comparative method of analyzing focus group and interview data to (a) generate categories, subcategories, and codes; (b) interpret patterns and themes; and (c) ensure rigor (Glaser & Strauss, 1967; Lincoln, 1995; Lincoln & Guba, 1985).

Generating Categories, Subcategories, and Codes

Initially, six members of our research team read two focus group transcripts (representing different types of groups and research sites) to identify text segments that appeared pertinent to the research questions. We met in pairs and discussed initial perspectives on emerging categories. We repeated this process with four more sets of transcripts and formalized the categories into an initial codebook. We continued to read transcripts until all transcripts had been analyzed according to categories and the codebook had been revised seven more times. All six researchers agreed that the 90 codes in version 11 of the codebook had a clear operational definition and represented a comprehensive categorization system. Disagreements among members of the team were resolved through discussion and consensus building; thus, the goal was to develop a credible and inclusive taxonomy representing a synthesis of all members of the research team (Lincoln, 1995).

Interpreting Patterns and Themes

Thirty-five transcripts from focus groups and 30 transcripts from interviews resulted in approximately 1,900 single-spaced pages of transcripts. We placed all of these transcripts into

Ethnograph (5.0), a software program that sorts data by categories. Based on the 11th version of the codebook, we used *Ethnograph* to sort all coded segments and provide printouts of all segments for each code. Through this process of constantly and continuously comparing codes, the research team sorted the data into 10 domains and 139 indicators of family quality of life. This sort formed the basis for the 12th version of the codebook.

Four members of the research team used the 12th and final version of the codebook to recode all 65 focus group and individual interview transcripts. A fifth member of the research team checked 30% of the transcripts to ensure coding completeness and accuracy.

Although this data analysis process is described in somewhat of a linear process, the process of developing and refining codes and then coding and recoding transcripts occurred in a non-linear fashion (Erlandson et al., 1993). The entire process was spread across 16 months.

Ensuring Rigor

We ensured rigor through incorporation of procedures to address credibility, transferability, and dependability (Lincoln, 1995; Lincoln & Guba, 1985). We used three techniques for addressing credibility (accuracy of information) (a) triangulation of data, (b) peer debriefing, and (c) member checking (Erlandson et al., 1993; Lincoln & Guba).

We triangulated data (i.e., the synthesis of multiple sources with the same information) by gathering information (a) from multiple sources (e.g., families of children and youth with and without disabilities, service providers, and administrators), (b) from multiple locations (e.g., Kansas City, New Orleans, and Granville County) and (c) using multiple researchers to collect and analyze data. We incorporated peer debriefing (i.e., inviting peers who are not immersed in the research to reflect and provide feedback on methods and findings) by involving PAR committee members, other research colleagues at the same setting as the researchers, and family leaders. Finally, we used member checking (a) at the end of each focus group (as previously described), (b) at the beginning of the second round of focus groups (sharing a synthesis

from the first round), and (c) by a formal member check conducted at the end of data analysis.

The formal member check included sending an executive summary of the results and a response form to 65 focus group participants. We received a 38% response rate. All responses confirmed the credibility of the summary; three participants provided comments for improving the focus group process (e.g., too much time lapsing between the first and second rounds of the focus groups; focus group location was too crowded).

Although transferability is not a crucial issue for qualitative studies (Maxwell, 1996), we were intentional in seeking to enhance transferability by including (a) different geographic locations to expand the diversity of the sample and (b) diverse participants with a wide variety of characteristics (e.g., families of children and youth with and without disabilities representing different ages and types of disabilities).

Dependability addresses the extent to which the research process is consistent across re-searchers. The research team included 16 people (five assumed primary responsibility) over two years. Using multiple researchers helped ensure that the data were not weighted to reflect any one researcher's perspective (Brotherson & Goldstein, 1992). The research team extensively discussed their agreements and disagreements in working to achieve consensus on categories, subcategories, codes, domains, and indicators. As a research team, we accounted for all changes in the research process and all decisions related to coding by developing an audit trail involving five types of information: (a) raw data (e.g., interview guides, audiotapes), (b) data reduction and analysis products (e.g., *Ethnographic* printouts, peer debriefing notes), (c) data reconstruction and synthesis products (e.g., codebooks, final report), (d) process notes (e.g., decision diary, methodological notes), and (e) products describing intentions and dispositions (e.g., proposal, personal notes).

Limitations of the Study

Our broad research questions focused on a beginning conceptualization of family quality of life. We believe it was entirely appropriate to use qualitative inquiry given the exploratory nature of research on family quality of life. Given the nature of qualitative inquiry, we caution against broad generalizations of these findings to all families -- those with and without children with disabilities.

The major limitation in terms of describing the impact of spirituality on family quality of life is that we did not include participants from a wide range of spiritual and religious backgrounds. We did not recruit participants according to diverse spiritual backgrounds, nor did we ask participants to indicate their spiritual or religious affiliations in the demographic section. It is clear from comments that most of the participants were Christian. Had we recruited a more diverse sample, we might have a wider variety of comments and themes concerning spiritual and religious beliefs and practices.

Results

Themes resulting from participants' comments were organized into 10 domains of family quality of life (Poston et al., 2003). These domains (advocacy, daily family life, emotional well-being, family interaction, financial well-being, health, physical environment, productivity, parenting, and social well-being) encompass the entirety of family quality of life and are described in detail elsewhere (Poston et al.,). The focus of this article, however, is on themes related to respondents' perspectives on spirituality, specifically faith and participating in religious communities.

Due to the importance of spirituality and religion to families, as evidenced by the number and intensity of comments, spiritual well being was originally a separate domain. However, based on input from our PAR committee, spirituality was encompassed into emotional well being. PAR Committee members felt that the presence of and specific form of spiritual and religious beliefs of family members should be private and that any family quality of life model should recognize spirituality, and provide spiritually appropriate supports, but not get into specific belief systems. Although we did not intend to advance a specific spiritual belief system, the presence of spirituality as a domain seemed to indicate that we were advocating for a specifically spiritual component to family quality

of life. It was thought that this might be a concern or be off-putting to some families who did not have a spiritual belief system.

Participant comments concerning spirituality generally fell into two main categories: (a) having spiritual beliefs and (b) participating in religious communities.

Having Spiritual Beliefs

Many participants spoke very passionately about their spiritual beliefs as a contributor to their emotional and overall family quality of life. Although spirituality may encompass many beliefs and practices that are not tied directly to a specific religion (Canda, 1999), most of the participants spoke specifically about spiritual and religious beliefs as practiced in Christian churches. Their comments can be categorized into three areas: (a) having faith, (b) using prayer, and (c) attributing meaning to disability.

Having Faith

Participants in all groups, but mostly parents, spoke about the importance of having faith or believing in something greater than themselves. They indicated that their faith gave them strength and helped them make sense of the events in their lives.

> The most important things in my life? My God. I think without God I don't think any of us, if you don't believe that there's some thing higher than you, I don't think we can make it.

For most participants, their faith ties directly to a reliance on God. Many parents looked to God for help in their lives. They indicated they re lied on God to help remove barriers and to show them the direction they should take. They asked God for strength, patience, and inner peace.

> I have to have at least a strong faith in God so that I can get to the inner peace, and the happiness, and the good environment.

In addition to asking God for what they needed, participants credited God for good things in their lives.

That means when you get up in the morn ing you thank God for Him opening your eyes and making you able to stand on your own two. And you take the rest of the day, and you fill it with everything that you can get. into it. I mean, you don't have no time to waste.

Using Prayer

Participants talked about using prayer as a way to communicate with God and to access their faith.

> Mine is prayer. I believe through prayer things are answered. And my faith and my belief in God, all things are answered. All things are possible. For me, I feel that I do it (pray) all the time, I pray before I go to school to give me the strength and patience and all the deal. Once I pray, I feel the peace. And once I'm at peace, I'm fine. I can do what I need to do.

Some parents talked about when they prayed. This particular family incorporated prayer into a daily routine by praying at the evening meal:

> At home, when we can all sit down and have dinner together that's when we pray. We all pray at our dinner table. That's when all of us are quiet. And everybody's calm, and that's when we have prayer.

Attributing Meaning to Disability

For many families of children with disability, faith and prayer took on an additional role. About half of the families who shared perspec tives on their spiritual life spoke about how they used their faith as a way to make some sense of having a child with a disability. For many, they viewed their child as a gift from God. This gift was viewed either as a blessing or as a test of their faith.

> I have to say for all parents that have kids with disabilities, or exceptionalities, I think you have to look at that as a gift from God, as a blessing, as a test of your faith. If you have faith, it's going to work out.

Some participants might have viewed their child as God's punishment for some perceived failure on their part, but they did not express this view explicitly.

Participating in Religious Communities

Participants spoke about issues connected with participating in religious communities. Generally the comments related to being able to go to meetings or activities sponsored by the religious communities and having connections and relationships with others within the religious community. Several respondents spoke about how their child was accepted into all facets of the religious community. They described their church as a place of acceptance and unconditional love. One mother related how her son joined the choir and sang in church; a father described the joy his daughter finds in the music at church:

> Church experience is just wonderful. I mean, it just take over. I don't know. I mean, once you walk through the door, that's it. And well, she love music, so, that's it. Once she walks in the door she can just about do anything she want to do. She can walk in, she sit on the front, you know, everybody knows where she sits. She goes straight to the front, she can sit on the organ. She doesn't touch the keys or nothing. But she just sit there, long as the organ's playing, she sitting there. She gets up once it stops and get up and go and sit down. And, you know, that's the most, best place I think she's not being, not just tolerated.

About the same number of participants indicated the difficulty they faced when they wanted to attend church activities. Some families felt that their children were not accepted or that they did not have the support to participate fully. One mother comments:

> There's a lot of people (in the church) that don't know how to deal with your autistic child. And I hate to say it, and I have a lot of work to do, but I will have to show them how to really get religious.

Discussion

Results described in the previous section are discussed in this section in terms of (a) impact of spirituality and religion on family quality of life, (b) implications and actions, and (c) resources.

Impact of Spirituality and Religion on Family Quality of Life

As evidenced in participants' comments, spirituality and religion play a major role in many of their lives. Participants' comments echoed the themes found in the literature; they turned to their spirituality and faith to find meaning and purpose in life and they joined religious communities as a way to share and develop their spirituality with others. Most of the comments reflected a sense of strength gained from spiritual well being and participation in religious activities. Spiritual development impacts many other areas of family quality of life. Strength gained from faith and these activities provides a resource that enables family members to meet the challenges they face in everyday life. Challenges from other aspects of life (e.g., financial, health, emotional, social or daily life) can be ameliorated by the strength and sense of well being gained through religious beliefs and social support from members of their religious community.

Families who choose to incorporate spirituality and religion into their individual and family life want to turn to religious institutions for information and support. Religious leaders, in turn, need someone to go to for their information, training, and support as they develop a comprehensive ministry that is responsive to the needs of children with disabilities and their families.

It is clear that there are many families who would probably choose to attend their local church, temple, synagogue or mosque if their children had the appropriate supports. Without the appropriate supports, parents are either reluctant to attend or are unable to benefit from attendance because they spend their time providing direct support to their children with disabilities. Based on the families' comments in this research, we suggest that families are looking for three things from their religious community: (a) acceptance of their child, (b) spiritual and emotional support for themselves, and (c) supports for their child during services so that both their child and themselves can have

meaningful participation in religious activities.

Implications and Actions

Based on a review of the literature and themes heard from families in this research, we propose a series of implications and suggestions for action steps that can be taken by (a) families, (b) religious organizations, and (c) schools and disability organizations. Although participants focused specifically on religious activities, many of these implications and actions are valid for any spiritual practice as well as religious practice.

Families

Families who want support to enhance their spiritual well-being or to participate in their religious community can take several steps to make their desires and priorities known to people who can support them. We suggest three concrete steps that family members can take that might be helpful: (a) set aside time for spiritual or religious practice, (b) ask for support from their religious community, and (c) ask for support from their community disability organization or child's school.

Setting aside time for spiritual or religious practice. Like other activities, prayer, spiritual reading, meditation, or attending community religious activities take dedicated time and effort. It might be helpful to set aside time every day or every week to devote to spiritual or religious practice. Family members who want to make this a priority in their lives might want to ask other family members or extended family for help with child care or schedule respite care so that they can devote their attention for that short time period to their spiritual or religious practice rather than caring for children and all the other tasks that usually overwhelm them.

Reaching out to religious communities. Sometimes it is difficult to share personal and family challenges with others, no matter how understanding they might be. Although it might be difficult at first, families who want assistance in developing their spiritual lives may need to ask for it. Religious leaders are there to help congregants and often there are specific support groups or ministries that can provide supports for

families in need. If a family doesn't feel they have the resources it takes to seek information, perhaps a close friend, family member or educator can be an intermediary with religious leaders to set up appropriate counseling or other supports.

Reaching out to disability organizations. If a family has the commitment for support from religious organizations, but needs information and training to make that commitment a reality, then they can ask for the expertise of community disability organizations (e.g., The Arc, Autism Resource Center, school teacher). Often, disability organizations are more than willing to provide this type of information and training; they just need to be asked.

Religious Organizations

How can religious organizations and communities provide the type of support that children with disabilities and their families want? One church provides supports for children with disabilities and their families through a lay ministry program called Mathew's ministries, named after a young boy with disabilities. This congregation provides an example of how church members can effectively provide supports so that children with disabilities and their families can fully participate in the spiritual and social life of the church.

Mathew's Ministry has the mission of supporting, empowering and enabling people with disabilities and their families to grow in their faith and to contribute their gifts and talents within the Christian community. The ministry's "angel care team" consists of volunteers who are screened and trained to provide supports to children with disabilities within the context of church activities or individually as necessary. Parents and veteran angel care team volunteers conduct training. Mathew's Ministries also sponsors parents' night out for parents of children with disabilities. Congregation teams (e.g., Sunday school classes, youth groups) volunteer to provide supports for the children so that the parents can enjoy an evening out or spend time with their other children. Families of children with disabilities in turn sponsor other congregational ministries such as the annual food drive or perform duties with their children as greeters at worship services. The church employs

one staff person 10 hours a week for administrative support and is celebrating its tenth year of providing support to children with disabilities and their families.

Many religious organizations have a health-related ministry whereby congregants, who are also health care professionals, provide information and support to other congregants on health and wellness issues (e.g., see website at http://www.stpeterlutheranchurchofhallettsville.org/ministries.htm). This health-related ministry might also include educators and focus on disability awareness and issues in addition to health.

Religious leaders can turn to several community resources. Local disability agencies, chapters of The Arc or other disability organizations usually have a community outreach program that provides information and awareness on general disability issues. These organizations may also be able to provide support to religious staff as they support specific children with disabilities. Oftentimes, the parents of children with disabilities are more than willing to share information about their child. Religious leaders can ask if parents would be willing to share information with the congregation at large or with specific people (e.g., teachers, nursery staff) who will be working with their children. Educators may be able to share some information on topics such as adapting curriculum, positive behavior support and social skills.

Many churches have a ministry called Stephen's Ministries or something similar that provides outreach and counseling to church members during times of crises (see website http://www.stephenministries.org). Religious leaders can ensure that Stephen's Ministers have awareness about disability issues and are specifically trained to counsel families of children with disabilities.

Schools and Disability Organizations

School staff can be aware of students' and families' religious preferences and priorities. The IEP can include goals that will enhance a student's and family's ability to participate in their religious community. School staff are frequently the most competent and experienced people in the area of positive behavior support, universal design for learning, and communica-

tions supports that would enable students to participate in their religious community in a meaningful way. Although school staff are usually already stretched to the limit and may not be able to provide individual training and support to religious staff, a partnership can be formed that would benefit both school and religious staff. Such a partnership might include inviting religious organization staff to professional development, offering to trade time or areas of expertise (e.g., religious staff volunteer at school in return for help with universal design of the curriculum), or a religious organization offering to help sponsor school functions.

Community disability agencies can specifically hire staff who are willing to work with religious organizations and to provide support for individuals within a religious activity. With appropriate respite care, families can choose to attend services without their member with a disability, or perhaps more importantly all family members can attend together. As part of the community outreach, these organizations can form a team of spiritually sensitive trainers and coordinators who work with local religious organizations to facilitate inclusion and support for people with disabilities and their families in local religious programs.

Spiritual and religious beliefs impact the way families view disability and education. Professionals and direct support staff need to be aware of and sensitive to families' religious and spiritual belief systems and how they impact their view of disability (Zhang, 2001). Disability organizations can include spirituality and religious awareness into their professional development programs. Service coordinators and case managers can seek training and information on providing spiritually sensitive supports to individuals and families.

Resources

There are currently several resources that families, religious organizations, disability organizations, and schools can access to assist them in enhancing supports for religious and spiritual activities for families. There are websites, books, journals and organizations dedicated to supporting spiritual activities for people with disabilities and their families. Some of these

TABLE 3
Resources for Enhancing Religious Supports and Participation

Resource	Website or Contact Information	Description
American Association on Mental Retardation Division on Religion and Spirituality website	www.aamr.org (main page) http://www.aamr.org/Groups/div/RG/index.html (Division on Religion and Spirituality)	This website provides membership and contact information for the Religion and Spirituality Division of AAMR. It also provides guidelines for certification of pastoral and lay ministers who support people with mental retardation.
Quality Mall "Religion and Spirituality Store"	http://www.qualitymall.org/directory/FMPro?-DB=qmdepts&-Lay=depts&-format=department_1.html&-RecID=100&-Find	This website contains information on products and programs for exploring and supporting the spiritual and religious preferences of individuals with developmental disabilities and their families. There will also be information and resources for support providers, congregations, and service organizations.
Newsletter from IMPACT entitled Feature Issue on Faith Communities and Persons with Developmental Disabilities	http://ici.umn.edu/products/impact/143/default.html	A feature issue of Impact, the newsletter from Institute on Community Integration, that is fully devoted to faith communities and persons with developmental disabilities. This 36-page resource has theme articles, stories, resources, models, and more. To order (first copy is free) contact the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455, 612-624-4512 or see website.
On the Road to Congregational Inclusion: Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families	To order, send check for $15 payable to "The Boggs Center-UAP" to Bill Gaventa at The Boggs Center-UAP, P.O. Box 2688, new Brunswick, NJ 08903 Five or more copies: $10 per copy and $10 for shipping and handling. Phone: 732-235-9304, Fax: 732-235-9330, E-Mail: gaventwi@umdnj.edu	A 125 pp. bibliography and address listing of resources for clergy, laypersons, families, and service providers. The resources are from religious and non-religious organizations, but ones selected because of their potential usefulness for people working on inclusive ministries and congregational supports. It is divided by areas of congregational life, for example, worship, religious education, families, youth groups, outreach, theological and scriptural issues, audiovisuals, etc.
United Methodist Church of the Resurrection, Leawood, KS	http://www.cor.org/devsite/images/matthew_min/matthews_ministries.html	This website contains the mission and vision for Mathew's Ministries of the united Methodist Church of the Resurrection, the church described in this article.
Faith in Action: A Unitarian Universalist Department for Diversity and Justice Website	http://www.uua.org/faithinaction/jtwacc/accessl.html	This website contains suggestions to help congregations become more welcoming to people with disabilities. This is a website of the Unitarian Universalist faith, but applicable to other congregations.

resources are described in Table 3. Perhaps the organization most devoted to the spiritual lives of people with disabilities and their families is the Religion and Spirituality Division of the American Association on Mental Retardation. Their resources and website are included in the table.

Conclusion

Spirituality and religion play important roles in the lives of families of children with disabilities. Religious practice often brings meaning, solace and strength during difficult times. It can also bring friendship, and emotional and practical support through religious communities and organizations. Families of children with disabilities may need supports to be able to benefit from religious practice and activities. Religious and community disability organizations can step up and fill the need for supports. It doesn't take a lot of time or money, just awareness and a willingness to reach out.

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