CE 2.5 contact hours

Disability and the Church: How Wide Is Your Door?

Many families find places of worship to be inaccessible and unwelcoming to people with disabilities.

BY JILL L. CUNNINGHAM, BEVERLY A. MULVIHILL, AND PATRICIA M. SPECK

Jill L. Cunningham, DNP, FNP-BC, is Assistant Professor of Nursing at Samford University in Birmingham, Alabama.

Beverly A. Mulvihill, PhD, is Associate Professor of Maternal and Child Health in the School of Public Health at the University of Alabama at Birmingham.

Patricia M. Speck, DNSc, FNP-BC, FAAN, is Assistant Professor of Nursing at the University of Tennessee Health Science Center in Memphis.

An estimated 10.2 million children (13.9%) ages 0 to17 years in the United States have one or more disabilities—a prevalence of 10% to 18.5% of all the children across America. This means that one in five households (8.8 million families) have at least one child with a disability (Child and Adolescent Health Measurement Initiative [CAHMI], 2007).

Sadly, families of children with disabilities additionally experience an increase in the occurrence of secondary conditions including medical, social, emotional, and community disparities (U.S. Department of Health and Human Services [HHS], 2000). These conditions result in increased vulnerability and decreased overall health and well-being compared with the general population (Table 1). The quality of life experienced by these families often is adversely influenced due to lack of access to many community activities and services (HHS, 2000). In fact, the National Organization on Disability (2007) reports large differences in levels of participation in most basic life activities between people with and those without disabilities.

In response to these disparities, goal six of Healthy People 2010 was developed to "promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population" (HHS, 2000, p. 6-3). This goal aims to improve the quality of life and the number of healthy years for people with disabilities and their families through their

a Glance

- **As many as** *18.5% of all children in the United States have disabilities along with myriad resultant secondary conditions.*
- **The faith** *community is one key to meeting the needs of these families; however, families with children with disabilities often are excluded.*
- **Barriers to** *inclusion include architectural and financial issues, lack of awareness and knowledge, limited attitudes and fears, discomfort, and avoidance.*
- **Nurses are** *uniquely qualified to lead a disability inclusion ministry and help overcome the barriers.*

increased participation and inclusion in community activities and services.

Six additional objectives contained in the Healthy People 2010 goals relate specifically to children with disabilities and their families. To achieve these objectives, spiritual, physical, social, and emotional support must be provided for families that have children with disabilities. The opportunity to participate in regular social activities such as attending church or community events and socializing with friends and family is needed to improve functional status and well-being (HHS, 2000).

The faith community is one key for providing support and leadership to meet the needs of these families and to reduce their incidence of secondary conditions. Faith communities are increasingly welcomed as partners in public health and health promotion (Institutes for Public Health and Faith Collaborations, 2007). However, despite the potential of faith communities as health advocates, many families find places of worship to be inaccessible and unwelcoming to people with disabilities (Poston & Turnbull, 2004; Treloar, 2002). In fact, most churches lack programs to reach the disability community, and congregations include few individuals with disabilities (Table 2).

This article aims to demonstrate the importance of disability access and inclusion of people with disabilities as integral to the mission of faith communities, to explore the multiple barriers against inclusion of people with disabilities in faith communities, to provide practical examples and resources to help nurses and members of the faith community increase disability access and inclusion, and to emphasize the importance of including this population as a national public health imperative.

DISABILITY, INCLUSION, AND THE CHURCH

Disability is defined by Mulvihill, Cotton, and Gyaben (2004) and the Maternal and Child Health Bureau's Division of Children With Special Health Care Needs (McPherson et al., 1998) as the risk for chronic physical, developmental, emotional, or behavioral conditions experienced by children who require health and related services beyond those required by children in general of the same age. As stated by Mulvihill et al. (2004), this definition consistently yields prevalence estimates of 15% to 20%.

Inclusion is defined as participation by children with disabilities in activities designed for typically developing children without special needs (Mulvihill et al., 2004). The education system currently offers the best examples of inclusion. Within educational settings, children with disabilities typically attend the school and classroom they normally would attend if they had no disabilities. Children may spend

Table 1. Secondary Conditions of Disability

Children with disabilities
- account for 40% or more of medical expenditures for children overall (CAHMI, 2007)
- are subject to abuse 10 times more frequently than typical children (HHS, 2000).

Among children with disabilities
- 25% have three or more diagnosed medical conditions (CAHMI, 2007)
- 28% have three or more functional difficulties (CAHMI, 2007)
- 31% ages 4 to 11 years are reported to be sad, unhappy, or depressed (HHS, 2000).

- People with disabilities have the highest incidence of poverty, homelessness, unemployment, and suicide (Zachariah's Way, 2004).
- Four of five (80%) marriages that include a family member with disabilities end in divorce (Zachariah's Way, 2004).

Table 2. Lack of Faith Inclusion Programs and Participation

- Only 5% of evangelical churches have programs to reach people with disabilities (Zachariah's Way, 2004).
- Of all families experiencing disability, 50% are outside any organized religion (Zachariah's Way, 2004).
- Less than 14% of the population with disabilities claims to be Christian (Zachariah's Way, 2004).
- Finding quality childcare for children and youth with disabilities and special healthcare needs is almost impossible (MDDC, 2004).

all (full inclusion) or part (partial inclusion) of their day in the regular classroom with their peers who have no disabilities (National Information Center for Children and Youth with Disabilities [NICHCY], 1995).

Everyone benefits when all children are able to learn, worship, and play together (Center for Children with Special Needs, 2007). Inclusion offers the experience of an environment in which the effects of segregation are limited and role models exist to foster the development of adaptive skills through imitation (Wolery & Wilbers, 1994). Children gain skills in social interactions and develop friendships with their peers that help them prepare to live more successful lives in the community. In addition, inclusion allows whole families the opportunity to develop meaningful relationships with others and reduces feelings of isolation (Guralnick, 2001; Thompson et al., 1993; Wolery & Wilbers, 1994).

Inclusion reflects our larger community, in which people with and without disabilities live, work, learn, and play together. "Inclusion contributes to acceptance, improved socialization, and understanding of individual differences" (Center for Children with Special Needs, 2007, p. 2). This offers the opportunity for typically developing children to gain a realistic understanding of disabilities; acquire an appreciation for others different from themselves; learn altruistic behaviors such as kindness, patience, and respect; and build social skills, self-esteem, and principles of responsibility for others (Staub, 1996; Thompson et al., 1993; Wolery & Wilbers, 1994).

For the Church, inclusion of children with disabilities offers an opportunity to minister to whole families who may have limited options for worship and expression of their spirituality with others. Welcoming children with disabilities benefits the children, their families, and the congregation:

> *The opportunity to minister to special-needs people is a blessing, not a burden. Special-needs people are inherently blessed in very special ways by God, and it is the unique privilege of those who get to know them at a deeper level to see God's grace manifested in them. Ministry to special-needs people always results in extraordinary and, in most cases, total life-changing blessing to those who minister—the grace of God is never more real. (Zachariah's Way, 2004, p. 27)*

SPIRITUALITY, COPING, AND HEALTH

Families experiencing disability face a dynamic ongoing process of dealing with coping, adapting, adjusting, and learning to live healthy lives within their communities (HHS, 2000). Coping with health-related issues incorporates many spiritual elements. Moltmann (1983) described health as it relates to spirituality by stating: "True health is the strength to live, the strength to suffer, and the strength to die. Health is not a condition of my body; it is the power of my soul to cope with the varying conditions of that body" (p. 142).

Spirituality and religion play major roles in the lives of families of children with disabilities. Family involvement in religious practices helps to bring meaning and purpose as well as solace, strength, friendships, and emotional and practical support. The strength and sense of well-being gained through religious belief and practice enhances the ability of families to meet the challenges they face in other aspects of their everyday lives (Poston & Turnbull, 2004).

Studies in various fields of health have shown that spiritual belief and practices contribute to resilience in people with illness or disability (e.g., Canda, 2001). Views of illness and disability correlate with religious and spiritual beliefs. Families often rely on their spiritual traditions to help them interpret disability (Zhang & Bennett, 2001). Moreover, families who participate in religious activities tend to have better coping skills in dealing with the added stress of a family member with disabilities (Todis & Singer, 1991). Furthermore, the emotional support and relationships derived from a social support system, such as a church family, helps a person cope with stress and provides a protective factor in various life situations (Novack & Gage, 1995).

ACCOMMODATING DISABILITY

Historically, disability has been viewed in terms of a medical model,

which concentrates mainly on the impairments and not on the person (Bricher, 2000). This view emphasizes disability as intrinsic to the individual and inspires pity and fear. A more contemporary view follows the social model, which suggests that disability is a social construct and that problems exist mainly within the environment rather than in the person. This view emphasizes dignity, independence, and choice by placing the person first. The social model focuses on the fact that in many cases, society disables people. The way we organize our culture or community can limit and restrict what some of its members can do. These barriers exist in the physical, organizational, and personal aspects of our communities (Bricher, 2000).

Two key pieces of legislation guarantee the civil and educational rights of people with disabilities: (1) the Americans With Disabilities Act (ADA) and (2) the Individuals With Disabilities Education Act (IDEA). Signed into law in 1990, ADA is a comprehensive civil rights law protecting individuals with mental or physical disabilities from discrimination (United States House of Congress, 1991). The IDEA ensures educational rights, giving the states the responsibility of providing a free appropriate public education to all children (NICHCY, 2006). The consistent concept embedded in these mandates is that individuals with disabilities must have the opportunity to participate equally in all community activities alongside their peers without disabilities.

Churches and places of worship are exempt from ADA and IDEA (Pridmore, 2006) and can decide how or whether accommodations are made for members or visitors with disabilities. However, Jesus' words "Love your neighbor as yourself" (Matthew 22:39, NIV) tell us that we should love and include everyone. Zachariah's Way (2004), an organization that helps churches minister to people with special needs, summarizes Christ's words:

> *Jesus tells us that all the law can be crystallized down to simply loving God supremely and others as ourselves. Jesus said relationships, with him and with people, are what we as Christians are to be primarily concerned. Further, it should be noted that Jesus commands us to love all of our "neighbors"—everyone, not just people who look, talk, dress, and respond as we do. According to the Word of God, an authentic body of believers will ultimately be concerned with fulfilling this commandment as Jesus instructed and will be a church based on relationships. (p. 29)*

As Christians live by Christ's teaching, they love, accept, and recognize each person's unique gifts and abilities. "All children should have access to full inclusion in religious education programs, regardless of their faith or their disability" (Collins, Epstein, Reiss, & Lowe, 2001, p. 53). Zachariah's Way (2004) notes, "Jesus spent the majority of his time on this earth ministering to the needs of the lame, blind, and infirmed—why should his church today be different?" (2004, p. 27).

> CHRISTIAN NURSES ARE UNIQUELY EMPOWERED TO SERVE THE NEEDS OF FAMILIES EXPERIENCING DISABILITY.

BARRIERS TO ACCOMMODATION

What are barriers that impede disability access and inclusion in faith communities? Churches commonly refer to tangible barriers such as architectural and financial issues. However, more common barriers are those related to social constraints such as lack of awareness and knowledge, limited attitudes and fears, and discomfort and avoidance (Table 3).

Many churches are simply unaware of how many families are affected by disability. For example, 65% of churches without a disability ministry have few, if any, persons with disabilities in their congregations (Zachariah's Way, 2004). Although some churches claim to have disability programs, activities are set up as exclusive programs, and most of the congregation is unaware that the ministry exists. Some churches relegate people with disabilities to a separate class or building, and they may be denied access to typical classes, worship, and fellowship times (Zachariah's Way, 2004).

It is not uncommon for parents and church staff to place children with disabilities in a classroom that is not age appropriate. When access to an age-appropriate classroom is possible, the extra support children with disabilities need typically is not available. Without the appropriate supports, parents are reluctant to attend services because they are concerned

Table 3. Barriers to Inclusion

Statement	Family Care Providers Who Agree (%)	Group Program Providers Who Agree (%)
Childcare providers are concerned with safety factors such as lifting larger children and using medical equipment.	74	84
Children with aggressive behaviors (social/emotional problems) cannot receive the attention they need in a typical childcare setting.	65	72
There are many liability issues caring for children with disabilities.	82	77
Providers do not have sufficient knowledge about disabilities.	77	85
Providers are uncomfortable diapering or assisting with toileting a child outside the typical age for such support.	59	72
The childcare community does not have sufficient knowledge about childcare regulations and the effect on children with special needs.	66	69

Notes. Data from Maryland Committee for Children survey (Maryland Developmental Disabilities Council, 2004, p. 10). "Family care providers" include families caring for children with disabilities. "Group program providers" are nonfamily caregivers.

whether the needs of their child can be safely met (Cunningham, 2008).

Church staff and volunteers can be reluctant to accept children with disabilities because they feel inadequately trained to provide care or have fears and misconceptions resulting from insufficient information and experience. Staff and volunteers typically have incorrect assumptions about the children with disabilities and the effect on the workload and childcare setting. These fears and misconceptions ultimately lead to a lack of staff and volunteers to provide the additional assistance needed by children and youth with disabilities (Table 3) (Maryland Developmental Disabilities Council [MDDC], 2004).

Other barriers relate to medical and behavioral issues of individuals with disabilities. Most staff and volunteers are uncomfortable with children who have health issues or use medical equipment and are not trained regarding disabilities or appropriate care. This lack of training ultimately results in deficits and barriers for even basic care, such as toileting and feeding. Unusual behavioral patterns often seen in children with disabilities are a barrier as well because most programs do not have support plans for dealing with challenging behaviors (MDDC, 2004).

As a result of complex medical and behavioral issues, concerns of liability increase. Many faith communities fear that developing a disability ministry will put them at increased risk of liability if something were to happen while a child is in their care. "Child care providers incorrectly believe that they must have increased liability coverage if they care for a child with a disability" (MDDC, 2004, p.11).

MAKING A DIFFERENCE

Despite barriers, some families turn to religious institutions for support, information, and development of their spirituality and faith. They need additional support for their child with disabilities to have the opportunity for social inclusion and worship. In turn, religious organizations need information, training, and support to overcome barriers and develop a comprehensive program that ministers to the needs of these children and their families (Poston & Turnbull, 2004).

In 2004, agencies in Alabama collaborated to conduct a forum style needs assessment of families with children who have disabilities (Mulvihill & Johns, 2004). The participants reported that churches in their communities often were unwilling to include their children and families. To increase awareness and provide support and training for the faith community, a funded project was implemented in the state of Alabama. The project, titled Faith-Based Inclusion for People With Disabilities, was a collaborative effort supported by the Alabama Council for Developmental Disabilities, the Alabama Governor's Office on Faith-Based Initiatives, and the University of Alabama at Birmingham's School of Public Health.

The objectives of the project were to improve awareness of the need for inclusion of children, youth, and adults with disabilities and their families in faith-based programs, to increase the number of faith-based programs with knowledge of best

practice for inclusion of persons with disabilities, and to provide resources for collaboration and expertise for inclusion of persons with disabilities in faith-based programs.

Over the course of the project, several statewide workshops were conducted to provide information to church members and leaders, nurses, and families on the importance of including persons with disabilities and how to implement ministry programs within their religious organizations. The programs were free of charge and open to all. Free on-site childcare was available for children with and those without disabilities. Continuing education credits were offered to nurses.

Each workshop included basic disability awareness training, developmentally appropriate care and practices, best practices for inclusion (Table 4), identification and removal of barriers (affordable and creative alternatives), and information on community and disability resources. Each training program featured experts in disability inclusion ministry who offered valuable examples, policies, and procedures of their programs and answered specific questions regarding faith-based inclusion of persons with disabilities.

MINISTRY IN ACTION

Hearts and Hands is an example of an ideal inclusive ministry whose coordinator participated in many of the project trainings described above. The program coordinator chose this name because "we love with our hearts; we serve with our hands." The program's slogan is "so that *all* may worship Him" (L. Difatta, personal communication, March 29, 2008).

The mission of Hearts and Hands is to provide a means of inclusion and support for children with disabilities and their families and to share the love of Christ through service, encouragement, and support. Inclusion of persons with disabilities is achieved by assigning a volunteer "buddy" to provide needed assistance to a child with disabilities. This allows the child's parents and siblings to attend Sunday school and worship comfortably and confidently, knowing that their child is getting the extra assistance she or he may need. The program is staffed by lay volunteers, not trained professionals. The ministry does not provide direct healthcare services, however, a unique plan to respond to emergencies is approved by each family. Any child may be served whether a church member or not and regardless of the disability. Any child with a physical or developmental impairment, short- or long-term, is eligible to participate at no cost to his or her family (Hearts and Hands, n.d.).

In an attempt to minimize barriers, Hearts and Hands has developed written policies and procedures, which are provided to volunteers and parents participating in the program. These guidelines include orientation procedures, volunteer schedules and responsibilities, on-call procedure for unexpected visitors, a child information form called Getting to Know Me, behavioral support plans, and a liability waiver form signed by parents or legal guardians of participating children (Hearts and Hands, n.d.).

NURSING IMPLICATIONS

Christian nurses are uniquely empowered to serve the needs of families experiencing disability. According to Treloar (2002), "Professionals who assist people affected by disability to achieve spiritual well-being promote health that transcends physical, cognitive, or emotional limitations" (p. 601). Christian nurses possess not only the knowledge to care for children with disabilities, but also the love, compassion, and understanding of Jesus to share with these families. Consistent with their holistic caregiving nature, nurses tend to be mission-minded and enjoy the chance to provide a needed ministry right in their own communities.

Nurses can serve as missionaries to families experiencing disabilities. They can serve as a "buddy" volunteer, provide respite care for families, conduct workshops and training, develop and coordinate disability ministries, facilitate a faith-based small group that promotes networking of families and resources, and encourage religious institutions to address disability issues openly.

In practice, nurses encourage communication regarding disability and spiritual needs and allow opportunities for sharing feelings and concerns. Nurses collaborate with spiritual leaders in their community to address spiritual issues the family may be experiencing. Nurses are familiar with their community's network of

Table 4. Best Practices for Inclusion

- Written program philosophy
- Written plan for inclusive programs
- Strong leadership
- Disability awareness for staff and children
- Training and support of staff
- Sufficient staff/volunteers to meet the needs of all children in planned programs
- Communication and collaboration
- Adapted setting, activities, and time
- Collaboration with families
- Evaluation plan

Note. From Mulvihill, Cotton, & Gyaben, 2004.

Web Resources

- National Organization on Disability (www.nod.org)
- Zachariah's Way (www.zachariahsway.com)
- The Center for Religion and Disability (www.religionanddisability.org)
- Pathways Awareness Foundation (www.inclusioninworship.org)

resources that demonstrate acceptance and support of people with disabilities. For these reasons, nurses may choose to be involved in programs or agencies that provide services, leadership, and expertise for the community with disabilities. In addition, nurses practicing family-centered care develop plans with the family rather than for the family. Furthermore, nurses in practice who are aware of their own personal attitudes and understanding of disabilities are sure to demonstrate compassion rather than pity when working with families of children with disabilities (Treloar, 2002).

CONCLUSION

People with disabilities are essential to the wholeness of Christian community, and ministry with them is an integral part of fulfilling the mission of the church. Everyone should have the opportunity to be full participants and contributors in the church community. Faith leaders open to the total community recognize that the failure to include persons with disabilities in the church evolves from social stigma and lack of knowledge in members and leaders of the church rather than in the person with a disability.

In the current culture, human life is devalued, and many people worship physical perfection. However, all humans are created in God's image (Genesis 1:27) and thus possess dignity, value, and purpose. Churches protect this vulnerable population and extend open arms of invitation and fellowship for *all* of God's people with programs that are inclusive for the persons with disabilities.

Nurses can play a major role in providing inclusive religious opportunities for children and youth with disabilities and ensuring that the spiritual needs of entire families are met. In fact, nurses are key contributors toward building faith communities in which *all* people experience health, well-being, and an overall improvement in their quality of life.

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