From the Editors

"A basic component of human rights is freedom of religious expression. Individuals with disabilities have the right to choose their own expressions of spirituality, to practice those beliefs and expressions, and to participate in the religious community of their choice or other spiritual activities." This is the opening of the policy statement on Spirituality and Religious Freedom recently approved by the American Association on Mental Retardation (AAMR). It goes on to note that individuals with developmental disabilities and their families still experience mixed responses to their presence, gifts, and needs from congregations, and limited support for religious participation on the part of disability service providers. In this issue of Impact, we seek to address that mixed response by continuing the dialog about inclusion that has already begun between persons with disabilities, faith communities, and the disability services system. The articles provide theological frameworks for inclusion, practical tips for welcoming individuals with disabilities into congregations, ideas for service providers seeking to support religious expression, and success stories from around the country. We hope that it will contribute to the dismantling of the remaining barriers between persons with developmental disabilities and their chosen communities of faith.

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Gifted, Called, and Differently-Abled

by Rev. Lisa Thogmartin-Cleaver

Because I was born with a disability and it has always been part of who I am, for many years I didn’t spend too much time thinking about it. I found that as a person who is differently-abled I had one of two choices to make: I could choose to acknowledge my disability and interact with my environment in the unique and best ways possible for me, or I could choose to ignore my disability, try to “fit in” and live as “normal” a life as possible. I made the second choice and spent the first 30 years or so of my life telling myself and being told by others that I was a gifted person with a lot to offer to others “in spite of my disability.”

My relationship with God and with the Lutheran Church has always been there. I grew up in a small town church in central Ohio. For many years the church was not accessible in terms of physical accessibility (wheelchair ramps, elevators, widened bathroom stalls, etc.), but that didn’t seem to be a huge issue for me. Being differently-abled and using a wheelchair was a part of my existence and I got along fine “in spite of it.” I was as active at church as I was able to be, serving as the president of my youth group, singing in the choir, and eventually serving as the president of the women’s organization. Church was a very satisfying part of my life and there came a time when I wanted more involvement in that world.

I suppose on some level I always felt a call to the ministry. As I approached college I

[Cleaver, continued on page 34]
Liberation, Inclusion, and Justice: A Faith Response to Persons with Disabilities

by Nancy Eiesland

I recently read an article entitled “Disability for the Religious” in the Disability Rag, a magazine primarily for disability rights activists. The article implied that religion offers no relevant answers to the query “What is disability?” According to the article’s author the answers available are the following: Disability is (a) a punishment; (b) a test of faith; (c) the sins of the fathers visited upon the children; (d) an act of God; or (e) all of the above (Majik, 1994). If these were the only choices offered by religion, I would agree that it has no relevant answers.

Religion, in particular Christianity, has often been cited as the source of destructive stereotypes about people with disabilities. For example, the introduction to a collection of essays by mostly Canadian women with disabilities includes this statement: “Many people, including the disabled, still believe the traditional myths about the disabled. Some of these negative attitudes have their origins in ancient religious beliefs that regarded the disabled as devil possessed, or as corporeal manifestations of family guilt” (Israel & McPherson, 1983). This statement may be true, but it is only partial truth that fails to acknowledge a growing movement of people with disabilities who have begun to articulate a liberatory theology of disability, and to address the particularities of religious and cultural milieus in which negative myths and beliefs about people with disabilities emerged. For example, the well-known historical theologian Carolyn Walker Bynum has recently contended that Christianity in the Middle Ages did not specifically distinguish impairments from ordinary life. She writes, “Infirmity [impairment] was part of God’s varied creation – the order of things. The response to difference was charity, spirituality and morality” (Bynum, 1995). She goes on to argue that it was not necessarily ancient religious beliefs that shaped the contemporary attitudes toward disability, but rather it was widespread Christian acceptance of the quest to control difference born of Enlightenment medical views.

If, indeed, this is the case, it may be possible to find within Christian sources and history glimpses of more adequate answers to the query: what are the theological responses to people with disabilities in our midst? Thus, the challenge for people of faith is first to acknowledge our complicity with the inhumane views and treatment of people with disabilities, and second, to uncover the hidden, affirming resources in the tradition and make them available for contemporary reflection, finding new models of the church in which full participation is a sign of God’s presence.

As in all theological endeavors, this liberatory theology of disability is situated within a context and a biography. Although I have a master’s degree in theology from Candler School of Theology at Emory University, my Ph.D. and my professorship are in sociology of religion. Yet, I am a theologian by necessity. As a person with a disability, I could not accept the traditional answers given to my own query of “What is disability?” Since I have a congenital disability, I have had opportunities to hear and experience many of these so-called answers through the years. They included “You are special in God’s eyes, that’s why you were given this painful disability.” Imagine it didn’t seem logical. Or “Don’t worry about your pain and suffering now, in heaven you will be made whole.” Again, having been disabled from birth, I came to believe that in heaven I would be absolutely unknown to myself and perhaps to God. My disability has taught me who I am and who God is. What would it mean to be without this knowledge? I was told that God gave me a disability to develop my character. But by age six or seven, I was convinced that I had enough character to last a lifetime. My family frequented faith healers with me in tow. I was never healed. People asked about my hidden sins, but they

(d) must have been so well hidden that even I misplaced them. The theology that I heard was inadequate to my experience. However, in my teen years, I became actively involved in the disability rights movement, the worldwide movement that has sought basic human rights for the now approximately 600 million persons with disabilities worldwide:

- 300 million of whom live in Asia (including 70 million children);
- 50 million who live in Africa;
- 34 million who live in Latin America;

*Note: The discrepancy between the total and the regional statistics given is due to missing statistics for some regions and countries.

For a long time, I experienced a significant rift between my participation in the disability rights movement and my faith.

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But by age six or seven, I was convinced that I had enough character to last a lifetime.

Within the disability rights movement I came to understand why we people with disabilities have such depreciated views of ourselves and why so many of us are lacking in genuine convictions of personal worth. I began to see the “problem” not within my body or the bodies of other people with disabilities, but with the societies that have made us outcasts and viewed and treated us in demeaning and exclusionary ways. In the U.S., I was among those who organized sit-ins to achieve access to public transit, to seek access to public facilities, and to promote human and civil rights legislation. I became passionately committed to the view that society must be changed in order for our full value as human beings to be acknowledged.

Yet while the disability rights movement and activism addressed my experience, it didn’t always respond to my more spiritual and theological questions such as, “What is the meaning of my disability?” For a long time, I experienced a significant rift between my participation in the disability rights movement and my Christian faith. The movement offered me opportunities to work for change that were unavailable in Christianity, but my faith gave a spiritual fulfillment that I found elusive in the rights movement. Yet, I also had to name the ways in which Christian communities participated in our silencing. Within the church, often other people with disabilities were uninterested in political and activist matters. In the rights movement, fellow participants saw religion as damaging or at least irrelevant to their work.

Although I began to answer my own question of the meaning of my disability by articulating God’s call for justice for the marginalized, thus including people with disabilities, I nonetheless felt spiritually estranged from God.

However, the return path towards intimacy with God began to be cleared as I read a passage from the Gospel of Luke after an encounter with several other people with disabilities. The setting was the Shepherd Center in Atlanta – a rehabilitation hospital for people with spinal cord injuries. I had been asked by its chaplain to lead a Bible study with several residents. One afternoon after a long and frustrating day, I shared with the group my own doubts about God’s care for me. I asked them if they could tell me how they would know if God was with them and understood their experience. There was a long silence, then an African-American young man said, “If God was in a sip/puff maybe He would understand.” We talked about the image for awhile and concluded.

Several weeks later, I was reading the gospel passage in Luke 24:36-39. It is set within the account of Jesus’ death and resurrection, but its focus is really on his followers who are alone and depressed. The passage reads: “While they were talking about this, Jesus himself stood among them. They were startled and terrified, and thought that they were seeing a ghost. He said to them, ‘Why are you frightened, and why do doubts arise in your hearts? Look at my hands and my feet; see that it is I myself. Touch me and see.’” It wasn’t God in a sip/puff, but here was the resurrected Christ making good on the promise that God would be with us, embodied, as we are – disabled and divine. Reading this passage, I realized that here was a part of my hidden history as a Christian. The foundation of Christian theology is the resurrection of Jesus Christ. Yet seldom is the resurrected Christ recognized as a deity whose hands, feet, and side bear marks of profound physical impairment. In presenting his impaired body to his startled friends, the resurrected Jesus is revealed as the disabled God. Jesus, the resurrected Savior, calls for his frightened companions to recognize in the marks of impairment their own connection with God, their salvation. In so

*Note: A “sip/puff” refers to wheelchairs and other assistive technologies that are maneuvered by sipping from or puffing into a straw-like apparatus.*

Disability and Faith
Resources: Organizations

**National Organization on Disability, Religion and Disability Program.** Works with local congregations, national denominational groups, and seminaries to remove barriers of architecture, communication, and attitudes that prevent people with disabilities from full and active religious participation. FFI call 202/235-9500 or visit www.nod.org.

**American Association on Mental Retardation, Religion and Spirituality Division.** Offers publications, resource persons, and an annual conference to foster spiritual growth for persons with developmental disabilities. FFI call 732/235-9304 or visit www.aamr.org.

**Council for Jews with Special Needs, Inc.** Works to ensure that all Jewish young people with disabilities have the opportunity to fully participate in the richness of Jewish religious, cultural and social life. It offers a variety of programs, services, and materials. FFI call 602/277-4243 or visit www.cjsn.org.

**National Apostolate for Inclusion Ministry.** Promotes the full incorporation of persons with mental retardation and their gifts into the Catholic Church. Offers annual conference for persons with mental retardation, families, pastors, religious teachers and others; publications; and contacts nationwide. FFI call 301/699-9500 or visit www.nafim.org.

**National Christian Resource Center.** Provides educational resources to people with mental retardation, their families, pastors, volunteers and disability professionals. Operated by Bethesda Lutheran Homes and Services. FFI call 800/369-4636 or visit www.blhs.org/congregations/n_crc.

The resources above are presented for readers’ review; no endorsement is implied. For additional resources order Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families: A Bibliography and Address Listing of Resources (2000), from The Boggs Center on Developmental Disabilities, 732/235-9500.
Respecting the Urge to Join

by Rev. James F. McIntire

I once read of a medical theory that suggests that cell fusion – the linking together of two independent cells – may be part of our original code, the map which allowed human beings to evolve from our original primordial existence. If that is true, the theory suggests, such union may account for our tendency to want to form attachments to each other even now. We all want to belong to something. That urge to join together, the desire to belong to a larger group so that we’re not alone, is very basic.

Yet, it’s also true that once we get together it seems sometimes that there is an equally basic urge to want keep out others who are different. In our worshiping communities, we have developed this “keeping out” mode into an art form. We all want to belong to something, but we each want something different to belong to and we want to decide who else is allowed to belong.

The Pull Toward Belonging

Religious communities have historically and continually denied people with disabilities access to buildings, to worship, to fellowship, to leadership, to any kind of participation, because they are “different.” It has usually been assumed that people with disabilities need to be cared for rather than be included as those who offer the care. Yet despite this historic marginalization of people with disabilities, there is still something at the center of our human existence that pulls us toward wanting to belong. And so I have heard adult friends with developmental disabilities express their very personal urge to join up together. “I want to belong to a place where people say hello when I walk in,” one person told me. Another was a little more specific: “I just want to go to a church where I’m allowed to sing in the choir.” Those are pretty basic requests and the message can’t be any clearer. These are people that have felt excluded for most of their lives. They are feeling like they are on the outside of something which I just don’t understand as having an inside and outside. Maybe society in general feels like it has some right to exclude people who are different from the majority, but I just can’t see how a community of faith possibly can.

This urge to join up together is so basic to our human design that we just want to belong. And why not? It is in our faith communities that we find others who are struggling with the same basic life issues that we are. It is in these communities that we can – if they are what they claim to be – openly shed tears and laugh out loud, pray with those who know our pain, and hold hands with others who can bring us closer to wholeness. And when it comes down to it, the foundation of any community of faith is rooted in an insistence on inclusion for the purpose of wholeness and community and healing and re-alization of God’s presence. There is something in our human understanding of the divine that urges us to join together to share our faith questions.

Maria’s Faith

“It was really important to me to have my children baptized, but for years the rejection of my church had been stopping me. [My one son] couldn’t receive communion or be baptized because of his autism – because he can’t understand...blah, blah, blah, blah.” Maria is a young mother of two boys whose disability resulted from damage caused by a cerebral brain hemorrhage two years ago. “I can feel, but not do,” she says of her physical disability. Her younger son, Nicholas, has autism and though she has often met with resistance, she has advocated for his baptism and full inclusion in the church even before the onset of her own disability.

“I was raised, not as an atheist, but to disregard God,” she says, “to believe that God is there but, ‘Oh well, what’s he gonna do for me?’ It’s hard to be raised without faith, to not have a foundation. I was in a free-fall my whole life. My wheelchair is now a symbol of grounding – a foundation. The chair is a prison in some ways, but it is also a support. Without it I couldn’t do anything. With it I have the freedom to change at least some of my environment.”

Part of that freedom included moving ahead with Nicky’s baptism, and Maria’s initiative brought about the possibility of baptism for both of her children. “I began to believe that God could forgive a person like me. The forgiveness was a real gift. Baptism was a show of love to Jesus for what he did for me. I wanted to show the world how much the Lord meant to me and that they could turn to him too – not to proselytize but to lead by example. Despite what happened to me I wanted to show the world I still love God.”

Both children, and Maria herself, were baptized during worship at the wheelchair community where Maria now lives. “I never thought I myself would be baptized, but when I had my transforming experience after having my disability – I was no longer afraid.” Now she feels like she belongs and that both her children are a part of a larger, universal faith community that in some ways might not be totally accepting of her son’s autism, but at least it’s trying.

Seth’s Bar Mitzvah

“The whole [evening of the Bar Mitzvah] focused on Seth’s abilities and not his disabilities,” say his parents Steve and Sharon. “After the Bar Mitzvah, Seth made several long-awaited physical and mental strides – it was almost as if he was saying, ‘You invested the time into me, now I’m going to do what you expected of me.’” Seth is a young man with Angelman’s Syndrome who had reached the age of re-

responsibility in Jewish tradition when most become Bar/Bat Mitzvah, “children of the commandment.” But because of his developmental disability, Seth does not learn or understand like some typical children. Yet, with his congregation’s and family’s encouragement and assistance, he celebrated this milestone in glorious tradition.

On the bimah (stage), his parents, his brother, and his communication device all verbalized the words that he could not. Yet it was definitely Seth’s presence that spoke more to the congregation than any human words possibly could. Seth’s dad says, “I know several members of our congregation who have witnessed Seth grow up were so proud to be there. Many people came up to us over the next few weeks telling us how moving they thought the whole affair was and how touched and privileged they were to have witnessed it. In addition, our family members saw that maybe he will be able to ‘amount to something’ and I think it put Seth’s whole life into a new perspective for them.”

Heather’s Creed

“It began in September, 2000, when we were given the list of ‘expectations’ from the church on how our daughter will be required to participate in various activities and study groups in order to be confirmed,” says Kim. “However, there was one problem: The curriculum was not designed for a developmentally delayed child who cannot read or write. The first task was to find a mentor for our special needs confirmand.” They were successful in finding someone to help, a special education teacher who was a church member. But, could a process designed for those with typical intellectual abilities work for Heather?

“One of the steps of the journey was to write a creed. Well, my daughter has reached the teenage milestone and has become very fond of boys and TV programs. So, her creed started with thanking God for the animals, friends and for Kevin on the bus...I was beginning to feel more that Martin [Heather’s dad] was right [in wondering if Heather would ever understand enough to become a church member]. Then one day while we were taking our dog for a ride in the car Heather was sitting up front with her dad and said, ‘Dad, why do people cut down trees?’ Martin said, ‘I guess they don’t want to take care of them any more.’ Heather then said, ‘They should respect God’s gift and don’t cut them down.’ She then added that maybe she will put posters up to say just that! Well, if I ever had a light bulb moment that was it! That was to be Heather’s Creed. A picture of a tree and her message ‘Respect God’s Gift.’”

Can we learn a lesson from Heather and use whatever God’s gifts are to respect that basic urge to join together? Can we adapt our religious traditions and theologies so that all are welcome?

Lindsay’s Membership

My daughter, Lindsay, is now at the age that a young person in the Christian tradition would consider confirmation, that rite of passage that would have her become a full member of her congregation. But Lindsay’s developmental disabilities limit her intellectual understanding and cognitive abilities. She will not be able to learn the lessons like the other children, she won’t attend the regular classes with those of her same chronological age, she won’t stand in front of the congregation and answer the traditional questions about her faith. She was baptized as an infant as a sign of God’s grace in her life and her parents and others affirmed their responsibility for raising her in faith, but Lindsay will not confirm that act through a personal profession of faith.

But the congregation where she finds a home is the place where she has been nurtured, loved, cared for; it has been a place where she has taught as much as she has learned. This congregation is where she walked on her own for the first time at age nine; this congregation has prayed for her during medical crises; this congregation has embraced her and she them. It is the community which makes sure she has her favorite chocolate milk at Sunday School while the other children drink apple juice; the congregation which presented her with a Bible video when the others her age ceremoniously received a printed Bible. So, she is already a part of that community, and as the time for confirmation nears that congregation will, with the help of Lindsay’s parents and with God’s grace, find a way to announce to the world that she is in some new way a unique part of a unique group of people. I have no idea what goes on in the mind of this little girl – oops, young woman! – and I have no idea how God moves within her soul, but I do know that she wants to be included and she will be.

Deciding for Inclusion

Can we make changes that make our worshipping communities more welcoming of people with developmental and other disabilities? The key is in the fact that I have not once in this article mentioned installing a ramp or elevator or other renovation that creates a financial red-flag for many of us. Each time inclusion happened in these stories, it happened with very little cost but with much determination – individuals, families, friends, congregation, and clergy. Once we all decide together that attitudes are going to change, they’re going to change. When congregations decide that it’s time to recognize and respect everyone’s urge to join up together, inclusion is going to happen.

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The broad vision of inclusive communities encompasses inclusion in all aspects of life – home, work, recreation, and worship. Although various efforts have greatly expanded the physical presence of individuals with developmental disabilities in many community locations, there is still a significant distance to go toward full social inclusion. Even though individuals with disabilities may live in ordinary neighborhoods, attend regular schools, and have community jobs, many are still socially isolated and friendless. Most nondisabled community members do not have any friends who have developmental disabilities.

While different initiatives in supported community living continue to expand social inclusion of individuals with developmental disabilities, inclusion through places of worship presents unique and extraordinary opportunities.

While different initiatives in supported community living continue to expand social inclusion of individuals with developmental disabilities, inclusion through places of worship presents unique and extraordinary opportunities. Many community bridge-building efforts have found various churches, synagogues, and other congregations to be some of the most accessible avenues for true inclusion. More than any other community group, people of faith in all types of congregations have immediately grasped the message of full inclusion and extended themselves in significant ways to include, value, and befriend persons with developmental disabilities.

For those congregations just starting down that path, as well as for those seeking to do more, this article discusses inclusion in faith communities at various stages of the individual’s lifespan. Also addressed are ways in which congregations can further the inclusion of individuals with developmental disabilities in the broader social community.

Preschool Age Programs
When selecting nursery school and daycare programs for their young children, parents often look to their faith communities. As more synagogues, churches and mosques establish these programs, parents tend to choose familiar settings where they are comfortable with program content and the values that are being taught. At the time when parents of young children with disabilities approach their congregation in order to enroll their children in classes, they are frequently overwhelmed by doctors’ appointments, therapy and counseling sessions, and the stresses of caring for their child with special needs. All too frequently, they are told that the program cannot accommodate the child and that they must look elsewhere. Many parents see this as being cut off and cast out from the source of their spiritual support – and many bitterly opt out of their association with a congregation.

However, that picture is slowly changing. The current public education environment has shaped education in religious settings, as well. The landmark 1975 Education for All Handicapped Children Act (Public Law 94-142), revised in 1997 as the Individuals with Disabilities Education Act (IDEA), requires that children with special needs be educated in their public schools in the most appropriate and least restrictive environment possible. Although faith communities are not subject to the same legal obligations as public schools, there is a strong moral mandate that entitles every family to find a place within the religious setting of their choice.

Early childhood programs, in particular, lend themselves to welcoming and accommodating children with disabilities. Increasing numbers of young children with disabilities are becoming part of regular congregational nursery school or daycare programs, either through the availability of part-time programs to supplement the clinical or public school early childhood special education programs, or through provision of the necessary supports by specialists within the religious institution’s own program. In these programs, the presence of a classroom aide often helps the child’s integration and also helps the classroom teacher.

Young children are curious about other girls and boys. They see each other’s external appearances, interests, strengths, and challenges. They learn social skills and how to interact appropriately from each other. Youngsters with “differences” are often quickly befriended and accepted naturally and without reservation. The ongoing presence of families with children with special needs in early childhood and congregational activities tends to ease the anxiety of congregants who are not accustomed to individuals with disabilities – and the early childhood classmates are often model advocates of inclusion.

Elementary Through High School
When children with disabilities reach elementary school age, the situation can become both easier and harder. Al-
though elementary age students are supposedly more sophisticated, academic demands increase and social issues become more complex. In addition, many teachers in religious school programs are not trained educators and most have had little to no experience instructing students with special learning needs. They often become frustrated and unwilling to devote extra effort to including these youngsters in class activities.

Even with the best of intentions, any given learning environment may be restrictive for an individual student unless a continuum of options is available. These options include support for the regular teacher to help him or her build-in accommodations and modifications for the student with learning differences through consultation with his/her secular school teacher; resource help through specific skill instruction geared to individual needs; team-teaching by special education and regular classroom personnel; and, if necessary, specialized self-contained classes that provide intensive, highly individualized instruction with a low student-teacher ratio. Having a trained aide in the classroom to assist the youngster with disabilities as well as the teacher can make the difference between the ability to attend a congregational program and exclusion.

Besides congregational Sunday schools and religious schools, parochial day schools can also offer a range of supports for students with disabilities. Sadly, very few parochial schools currently accept students with developmental disabilities. Once again, exclusion of children with disabilities has a spiritual impact on families. Although most of the teachers have had pedagogic training, parochial schools often are constrained by budgetary limitations, additional expenses, and the intensity of the curriculum. However, a variety of development programs can be offered that enable educators to understand the nature and needs of diverse learners. Expanding beyond the concept of “special education” as involving only a small segment of the population, educators can broaden their understanding of the individual learning needs of all children. While it may appear to be a costly undertaking, the concept of inclusion is in keeping with religious precepts.

The religious/parochial school classroom is a living laboratory for implementing the religious values of dignity of the individual and acts of loving kindness. By creating a “caring community” within the classroom, students get to actually practice reaching out to others and collaborating to make it possible for everyone to function effectively and comfortably. Classmates can be helped to appreciate individual differences as a religious value and the youngsters with disabilities benefit from interacting with typical peers.

In addition, as children with developmental and other disabilities approach the times for celebrating the usual religious milestones of young people, they can be involved in learning the rituals and prayers that will enable them to take their rightful places in their congregations. By starting early and breaking down the material into smaller components that can be rehearsed and mastered, they can participate in the worship services to the best of their abilities. Fortunately, it is rare these days to find a congregation that will not allow them to celebrate becoming a Bar or Bat Mitzvah, or receive communion or confirmation.

Supports for Adults

While many students experience inclusion in their regular school classrooms and in religious programs, once a child graduates he or she often becomes more isolated. Upon graduation, school friends often go off to college or other lives. There is no adult social structure comparable to school in which everyone of the same age participates.

Faith communities can play a major role in the valuing and inclusion of adults with developmental disabilities in at least two significant ways. First, true inclusion takes more than an individual simply attending weekly services, and takes more than providing classes which separate people with disabilities from the rest of the church community. Congregations can provide opportunities for full participation through their regular adult committees or groups, such as men’s groups, women’s groups, choir, church decorating, ushers, etc. – in other words, opportunities for people to build deeper and more personal connections with one another.

Secondly, congregation members can extend themselves in individual friendships, both within the church and the wider community. Social ministry programs can identify more isolated congregation members and provide fellowship and friendship. Structured programs like Robert Wood Johnson’s Faith in Action initiatives have provided many opportunities for true friendship, which others can emulate even without a structured program. Sometimes adults with disabilities who live with their parents remain somewhat isolated within the family structure. Other congregation members can reach out to support expansion of the social networks of these individuals.

Conclusion

Congregations play a key role in promoting inclusive communities. Supporting inclusion through faith communities reinforces wholeness on the individual and societal levels. An individual’s wholeness depends on addressing all their needs, including spiritual needs. A community’s wholeness depends on the valuing, participating, and belonging of all its members.

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Overview

You Are Not Alone! Resources for Inclusive Ministries and Spiritual Supports

by Rev. Bill Gaventa

Assumption #1: You are reading this article as a provider of disability services, advocate, family member, layperson, or clergy who has seen a need to address the spiritual and religious needs and hopes of people with developmental disabilities. Assumption #2: You perhaps have tried some things in the past, not had much response, had trouble finding resources, or, even worse, encountered attitudes or outright actions that were apathetic at best or intensely painful at worse. Or, you may have helped some good things to happen, but you are not aware of others who share both your joys and struggles. Where to begin when you feel like you are starting from the ground up?

First, know that whatever kind of support you can imagine for and with people with developmental disabilities within the faith community, somewhere, someone is doing it already. That includes worship, religious education, recreation, advocacy, housing, circles of support and friendships, respite care, service to others, and many more. It can be done and someone is doing it. Second, know that there are growing numbers of resources that can be a support to you. Let’s look at some.

Principles of Practice

In both religious networks and service systems, there are clear rationale and foundations for inclusive spiritual supports. In “secular” and “public” health and human service systems, there is increasing research and practice that points to the importance of addressing spiritual needs and preferences as part of holistic services and supports. In the developmental disabilities field, researchers and practitioners are beginning to articulate ways that effective spiritual supports are connected to effective services, person-centered planning, cultural competence, and self-determination. The recently adopted policy statement on religious freedom and spiritual supports by the American Association on Mental Retardation (AAMR) is an example (available at www.aamr.org under “Policy Statements”).

The sources of principles that form the foundation of inclusive religious practice, though, are clearly within the religious community. In recent years, national religious organizations such as the Catholic Conference of Bishops, National Council of Churches of Christ, and Union of American Hebrew Congregations have adopted new or updated position papers or statements on ministry and people with disabilities. A number have national resource offices whose portfolio of responsibilities includes resources, networking, and guiding congregational supports with people with disabilities. One of the strongest recent policy statements, titled “The Accessible Church: Toward Becoming the Whole Family of God,” comes from the many faith groups who are members of the Massachusetts and Rhode Island Councils of Churches (it can be found at www.masscouncilofchurches.org/docs/accessibility.htm).

Thus, as you get started, find out what the leading-edge practice in your profession is and what the national bodies with whom you are connected have already done. You can find others who are paving the way.

Ecumenical and Interfaith Resources

As you research the resources within your own faith community or that of a congregation with whom you are seeking to collaborate, a second major group of resources are ecumenical and interfaith organizations specifically focused on strengthening ministries and spiritual supports and services with people with disabilities and their families. These include two that are interfaith, connected to professional and advocacy organizations, and a number of ecumenical organizations:


• National Organization on Disability, Religion and Disability Program (202/293-5960, www.nod.org). Sponsor of “That All May Worship” conferences around the country, and leader of the Accessible Congregations Campaign.

• Consortium of Jewish Special Educators (212/245-8200 x385). A network of coordinators of special services in Jewish education agencies, federations, and community centers.

• National Council of Churches, Committee on Disabilities (800/222-3872, www.ncccusa.org). A committee connecting resource offices and programs within a number of mainstream Christian denominations.

• National Apostolate for Inclusion Ministry (301/699-9500, www.nafim.org). Primarily Catholic, but also including other traditions, it focuses on developmental disabilities and inclusion within congregations.


• Networks that focus on inclusive religious education, including the Network for Inclusive Catholic Education

(937/229-4356), and Friendship Ministries (616/246-0842). Again, while based in particular traditions, their resources are used in a number of Christian denominations.

So, how are these helpful to you? They can connect you to resources that are already developed and to people engaged in similar forms of ministry or service. Some offer a formal process for individual congregations who want to explore and strengthen inclusive ministries and supports. And, the national conferences and leadership of these organizations can assist you in your community by helping to sponsor or lead workshops that bring together religious networks and service providers.

**Regional and State Resources**

In a number of areas around the country, regional and state initiatives are developing new strategies for supporting congregations and disability service providers. They include:

- Interfaith coalitions and resource offices, such as the Interfaith Disabilities Network in Atlanta (404/881-9777 x222, www.aadd.org), the Center for Spirituality and Disability (267/257-9541) in Philadelphia, and Pathways Awareness Foundation in Chicago (800/955-2445).
- Area-wide ministries and programs that provide a variety of supports and services that connect communities and people with developmental disabilities. One example is Bridge Ministries in Seattle (425/828-1431, www.bridgemin.org), which has programs that include counseling, adaptive equipment, circles of support, guardianship, and more. The Bridges to Faith committee (508/992-1848) in Massachusetts recruits “Faith Companions” to help include people with developmental disabilities within the congregations of their choice. Metro area Jewish federations and centers for education, and organizations like the Council for Jews with Special Needs (602/277-4243, www.cjsn.org) coordinate a number of projects that support initiatives within individual synagogues while also guiding collaborative projects. In many places, chaplains who formerly served primarily as pastors within the world of an institution are increasingly focused on supporting inclusive congregational ministries.

**“That’s nice, but we need money”**

Sources of financial support for inclusive congregations include religious organizations, state offices on developmental disabilities, Developmental Disabilities Councils, private foundations, the Faith in Action Program of the Robert Wood Johnson Foundation, and reshaped or redirected chaplaincy services. There may be other forms of public funding available under new “faith-based initiatives” at the federal and state levels. For initiatives within individual congregations, a new publication from the Alban Institute and the Religion and Disability Program of the National Organization on Disability titled *Money and Ideas* summarizes the creative initiatives of 50 congregations.

But, do you really need money? It is also crucial to recognize that most forms of inclusive ministry and spiritual supports involve the determination and will to include, rather than a first expenditure of funds. You don’t have to start with a “program.”

**Putting It Together**

Making this work in your congregation, agency, community, or state is certainly not a given, and, as you know, depends on effective planning, partnerships, training, and organization. It may first depend upon families, advocates, and people with disabilities summoning the courage, and overcoming past wounds, to approach and ask their faith community once again. Most creative initiatives in this area began around individuals.

Consultation, collaboration, friendly competition, and creative coaching are all words that get overused but are crucial in the development of these initiatives. Think, for example, in creative ways about planning: Have spiritual assessments and supports been part of IEP, IHP, or person-centered planning processes? When was the last time a representative from someone’s faith community or tradition was invited to participate? Think about training. To help clergy and congregations, you are going to have to go where they go, meet them on their ground. To help agency staff and professional staff, include spirituality and spiritual supports in preservice and inservice training. Think of how the gifts of individual agency staff can be used to support initiatives in this area, no matter what their job description, and/or how congregations can use the skills and knowledge of professionals and families within their congregations to train and coach others.

**Help Us All Learn!**

As you work within this area, let others know what you are doing. Connect with national networks and their newsletters. Write about what you are doing, and the resources or models you develop. Consider writing for the *Journal of Religion, Disability, and Health*; we need the same kind of intensive, systematic, and disciplined research and writing in the area of faith and developmental disabilities as is happening within other areas of health and human service. The spiritual needs and gifts of people with developmental disabilities have too long been hidden. To help them help us, don’t hide your light under a bushel!

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Overview

Disability Through a Lens of Inclusion: A Theological Framework for Welcoming All

by Rev. Rosalie Norman-McNaney

What does the term “all are welcome” mean relative to faith communities and persons with developmental disabilities? Does it mean individuals with developmental and other disabilities are affirmed and valued as active, contributing participants in the daily life of the faith community? Or does it instead mean they are primarily recipients of “charity” and attitudes and actions that may be experienced as patronizing, condescending, or even shaming? Does it mean they have access physically and programmatically to all aspects of the community’s life – including participation in sacramental or passage rites such as Bat/Bar Mitzvah, communion, baptism, membership – or must they stay on the fringes, isolated by segregated seating and restricted to self-contained faith development educational classes?

The response of a congregation – be it a synagogue, church, mosque or temple – to persons with developmental disabilities will vary based on people’s knowledge of and sensitivity toward individuals with developmental disabilities, as well as on the theological lenses through which their beliefs are filtered. Every religious tradition is pluralistic, with a wide range of interpretations of sacred texts; the practice of sacraments, rituals, and rites of passage; and other aspects of belief and practice that serve to either marginalize or include persons with disabilities.

How do we understand “all are welcome,” and what will we do to ensure that it is so?

Reference


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by Rev. Bill Gaventa

Determining a person’s interest in spiritual expression and religious activities should be part of any person-centered planning process. And while it involves more than asking whether someone wants to go to worship services or not, it does not have to be complicated.

Over the years, chaplains and agencies have developed forms called by names such as “Individual Faith Profile.” Common items covered are faith traditions, congregation membership, rites or sacraments that have been received or desired, faith involvement (worship, religious education, congregational programs, prayer, etc.), and areas of support needed for effective inclusion. More thorough “spirituality” profiles have described the spiritual interests and needs of an individual and then outlined an individualized plan for supporting a healthy spirituality. Additionally, there are literally hundreds of versions of spiritual needs assessments developed by hospitals and health care services as they recognize the importance of addressing spiritual needs and interests as part of holistic health care.

One very simple format for a spiritual assessment has been developed by Christina Puchalski, M.D., and others (Puchalski, 2000). She uses the acronym “FICA” to signify the format for initial exploration:

- F: Faith or Beliefs. What is a person’s faith or belief? What gives meaning? Does this person consider himself/herself to be spiritual or religious?
- I: Importance. How important is spirituality for this person?
- C: Community. What kind of communal expression does this take, or would the person want it to take?
- A: Address. How does this person/family want us, as health and human service providers, to address these needs and interests?

Another format developed by an interdisciplinary team in healthcare settings is George Fitchett’s “7x7” Model for Spiritual Assessment. This particular model outlines seven dimensions of holistic assessment: psychological, family systems, medical, psychosocial, cultural, spiritual, and social issues (e.g. poverty). In the spiritual dimension, seven areas are explored: belief and meaning, vocation, experience and emotions, courage and growth, ritual and practice, community, and authority and guidance (Fitchett, 1993).

More important than the particular assessment tool, though, is the sensitivity and commitment by service providers to this area of individual and family life. Why? For the following reasons:

- Opening this area of inquiry is opening an area that can have profound feelings and experiences associated with it. Asking an individual with a disability to “tell me your faith story,” in my experience, does not usually elicit a lukewarm response. Faith and congregations have been very important, either in a positive way or because of painful experiences and a lack of response to an individual’s hopes and needs. A process like the one above, adapted to your setting, is one that can be non-invasive, and can get more detailed and thorough depending on the person’s interests and wishes.
- Agencies often avoid spiritual supports because of a fear of proselytizing or a concern about “church/state” separation. A thoughtful and sensitive process and policy can help an agency avoid problems in those areas while addressing needs.
- A spiritual assessment could also be a way to involve community clergy and/or congregational volunteers. An agency which says, “We are not sure how to do this, but we know it is important. Could you help us?” might actually take the first significant steps towards collaboration with faith communities and supports. Or, stated another way, how often does your agency ask if someone might want their pastor, priest, rabbi, or someone else from their congregation to come to their IHP or person-centered planning meeting?

Thus, spiritual assessments should be more than a record-keeping exercise. They are a significant dimension of person-centered supports and community participation. A shortcoming of the process is that many people with developmental disabilities may not have had enough opportunity to provide “informed” answers because of limited experience with faith communities. Thus, the process needs to assess hopes, as well as past and current experience.

Finally, the spiritual assessment process requires commitment and follow-through from service providers — commitment to addressing an area that can touch people deeply, along with the determination to work with congregations to do what it takes to help find and/or build the supports that may be needed for participation in a faith community.

References


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Children with Autism and the Mass: Tips for Parents and Teachers

by Katie Blatz, Doris Anne Mercer, and Anita Stephens

The following is from the newsletter of the group God’s Love Embraces Autism in the Diocese of Pittsburgh. Written by parents of children with autism, it is designed to assist other parents and teachers in the religious education of the child with autism. In this article, three mothers share what they’ve learned about including their sons in the Mass, the Roman Catholic service of worship.

We started with the assumption that if our children with autism were acting up at Mass, it was not necessarily due to bad behavior. Taking into consideration the “sensory” and “rigidity” issues that accompany autism, acting up could be due to our children’s unfamiliarity or discomfort with their surroundings. Churches, most often, are large, cavernous, “echo-y” places which can create all kinds of auditory processing discomfort for our kids.

We found that it helped if we took our sons into the empty church and let them wander freely and touch everything. Of course they were drawn to the altar area, which should be the focus, but is also an area deserving of great reverence. Since our children show their reverence in non-typical ways, a talk with parish priests is a good idea before letting the kids loose. We found that one visit like this is far from enough. Often, you’ll need to visit over and over before the child is comfortable.

Doris’ Experiences with Michael

Doris is a cantor at her church. While she rehearsed with the organist, her sons, E.J. and Michael roamed around the altar area (Michael has autism). After that exposure, she noticed a marked difference in Michael’s comfort level and calmness at Mass. Of course, Doris, right from the beginning would reinforce the concept: “At practice, we are on the altar. At Mass, we sit in the pew.”

She also discovered that Michael’s behavior was much better if they sat in the first row, with no other people or distractions between him and the altar. The front pew is not necessarily the first place a family who has a child with autism would pick. But it can truly make a difference in the child’s ability to focus and thus participate in the Mass. Again, a talk with the parish priests, Eucharistic ministers, lectors, ushers, etc. is a good idea to garner support and understanding for your child’s attendance at Mass. Also, Doris found that Michael was less “fidgety” if he had something in his hands. She’d bring a small packet of “fidget items” – rosary beads, a decade, a worry stone. You could also include a “koosh” ball or other item for variety.

Anita’s Experiences with Michael

Anita, mother of Michael and Jason, introduced them to their church a bit differently (Michael has autism). She also wanted Michael to be more familiar with the church and would bring him for explorations in the empty church. She found it helpful to bring a list of items for him to find. This list helped him to focus on where he was. The list might be something like find the altar, find the pulpit, find the Bible, find the chalice, etc. This list could be as long or as short as the child’s attention span. Lists could vary from visit to visit. Some children may need the interaction of placing a sticker or checkmark after each item found. If a child doesn’t read, a picture list could be made. You could individualize a list for your own child.

Anita found that here Michael didn’t respond as well to “fidget items” in his hands as he did to books. He was fascinated with books, even before he could read. She shopped around and found a variety of beginner Bibles and “easy-read” religious stories for him. The books, as well as sitting near the front of the church or close to the choir or organ music, helped Michael to focus and par-
form of prayer, we like to think).

When Bill developed language, our true problems at Mass began. Bill’s language is a mixture of appropriate verbal remarks and completely inappropriate, repetitive “chatter.” This chatter can be constant and is at one volume setting: LOUD! Bill could not lower his voice more than a few seconds at a time. As much as we wanted Bill to be at Mass, we also didn’t want to overwhelm the rest of the congregation. We spoke with our parish priest and he suggested that we try a combination of things. We started by putting Bill in the babysitting program at the 10:00 Mass, even though he was technically too old. Then we’d bring Bill into the church for Communion and the end of Mass. (We did have to give the babysitters a crash course in autism!)

As Bill got older, we dropped the babysitting program and moved into the family room. To focus on the Mass from the family room, Bill often needs more than books. We noticed that he was quieter if he had a more interactive kind of Mass book. We made him a Velcro™ “Mass activity book” that involved matching pictures with parts of the Mass as we went along. We even put Velcro™ on a picture of him so he could put himself next to a picture of the Consecration of Jesus. Also, Bill loves doing puzzles with a religious theme during the Homily.

Father suggested that Bill could go back and forth between the family room and the regular congregation as needed.

His loud and exuberant commentary has necessitated that we stay mainly in the family room. We always come out for Communion though, and this can be quite an experience. We never know what Bill may say on his way down the aisle. He may say bits of prayers, which he often combines with his favorite topics – Disney characters and Star Wars. I think his image of the Blessed Mother is a mixture of the traditional “Our Lady in Blue,” Snow White and Cinderella. But he is filled with excitement when he receives the Host. He may jump up and down and loudly proclaim: “My Lord and my God, yup, I ate Jesus!”

Over the years, many people in our parish have become supportive of Bill. Everyone still watches Bill in church (it truly is hard not to). Usually, our family is okay with this, but sometimes it is still hard.

**Conclusion**

All three of us mothers have also practiced parts of the Mass with our sons at home so that they become routine: repeating and memorizing the Our Father, the Creed and other prayers that stay the same, hand-over-hand practice of the Sign of the Cross or the “thumb crosses” before the Gospel, even re-enacting the washing of the hands, going to Communion, etc. It does help them focus on these parts during the Mass.

Learning the Mass and participating in the Mass is a life-long journey for all of us. Families who have children with autism just have to be a little more creative as they travel down the path.

Adapted and reprinted with permission from the newsletter of God’s Love Embraces Autism (January 10, 2001), published by the Diocese of Pittsburgh, Secretariat for Education, Department for Persons with Disabilities, 135 First Avenue, Pittsburgh, PA 15222. For additional information, contact Grace Harding at 412/456-3119 or by e-mail at gharding@diopitt.org. The newsletter is available on the Web at http://www.diopitt.org/education/gleanews.htm.

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**Disability and Faith Resources: Religious Education Materials**

**Rose Fitzgerald Kennedy Program Improve Catholic Religious Education for Children and Adults with Mental Retardation.** Curriculum and guide with 260 lesson plans and prayer services. Written for students with mild to moderate mental retardation, it can be modified for those with more severe disabilities. For use in inclusive or specialized classes or at home. Spanish and English versions. Adaptable to other Christian denominations. FFI contact Grace Harding, Diocese of Pittsburgh, Department for Persons with Disabilities, 412/456-3119.

**Guide for Teachers of Persons with Mental Retardation.** A curriculum with one guide for use with children in inclusive classes, and one for use with youth and adults in self-contained classes. FFI contact United Methodist Publishing House, Church School Publications, 800/251-8591 or 615/749-6447.

**Dignity and Disability: A Jewish Discovery Kit.** This and other materials of use for congregational schools (including "The Special Passover Haggadah" and "Teaching Hebrew Reading to Students with Learning Disabilities") are available. FFI contact the Board of Jewish Education of Greater Washington, Special Needs Department, 301/255-1952.


The resources above are presented for readers’ review; no endorsement is implied. For additional resources order Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families: A Bibliography and Address Listing of Resources (2000), from The Boggs Center on Developmental Disabilities, 732/235-9500.
Jewish Life Cycle Events: Including Children With Developmental Difficulties

by Becca Hornstein

“Blessed is the Lord our G-d, Creator of a variety of Creations” (traditional blessing which is spoken upon encountering a person with disabilities).

Stepping up to the Torah, the young teenager looks out at a sanctuary full of family and friends, all waiting eagerly for him to begin. He lifts the pointer to the first Hebrew letters of his assigned portion in the scroll, takes a deep gulp of air, and begins to chant the words and phrases which bind him to a 4000 year old tradition of Judaism. Today he will become a responsible adult in the eyes of his religious community. Today is his Bar Mitzvah.

Years of study in English and in Hebrew, learning the history, literature, commandments, holidays, and prayers have culminated in this moment. Different Jewish denominations require different degrees of participation in the Bar Mitzvah service. In some, the child will chant a portion of the Torah (five books of Moses) and Haftorah while in others, the child will lead the entire Sabbath morning service for two to three hours. For all children, it is a moment of both terror and exhilaration; for all parents, it is a moment of unbridled pride and joy. However, until fairly recently, children with developmental disabilities were seldom included in preparations for Bar or Bat Mitzvahs.

Along with the baby naming ceremony and marriage, the Bar Mitzvah (“son of the commandments”) or Bat Mitzvah (“daughter of the commandments”) is the best known Jewish life cycle event. When my son Joel, who has autism, was around 10 years old, I confronted the question of whether or not to pursue a Bar Mitzvah for him. Because of his disability, Joel had only been speaking for a couple of years; why would I want to add the burden of learning prayers in another language as well as expecting him to “perform” before a sanctuary full of people? At that time, no one expected a child with a significant disability to have a Bar Mitzvah and very little Jewish special education existed. Nonetheless, I wanted a chance to declare Joel’s value and dignity before G-d, my family and friends, and the people who had helped Joel fight his way out of the solitude of autism. Luckily, I found a remarkable rabbi and congregation. In May of 1987, Joel stood before over 200 people and recited all of his prayers and Torah portion in English and in Hebrew.

To prepare for a moment like this takes a cooperative effort by both parents and religious educators. In the past 12 years, I’ve been blessed with the opportunity to help dozens of Jewish families prepare their child who has special needs for his or her Bar or Bat Mitzvah. Together, we’ve all discovered the amazing degree of determination our children can exhibit as well as the equally amazing degree of flexibility rabbis, cantors, and teachers can explore. For every “challenge” a child with a disability presents, there is a creative response:

• Cannot learn to read Hebrew: For the child who simply cannot learn to read Hebrew, a language that has a different alphabet and reads from right to left, one option is to write the “script” in transliteration (phonetic English). Another option is to prepare an audio tape with all of the prayers in Hebrew and English. Hours of listening to the tape will help the child memorize the prayers.

• Cannot verbalize: Some children cannot verbalize and must “speak” in other ways. Most congregations will accept sign language or augmentative communication devices to express the prayers and Torah portion. One of the most touching Bar Mitzvahs I attended included a girl who was an elective mute. Eventually, she was comfortable enough with the teacher and cantor to whisper her Torah portion and prayers in Hebrew to them to prove her ability. However, at the Bat Mitzvah service which she shared with her best friend, she was silent. Unable to speak out loud her interpretation of her Torah portion, she had painted a picture to explain her thoughts. Another very special moment came in a Bar Mitzvah for a boy who was profoundly multiply disabled and had absolutely no communication skills. He sat on his father’s lap, his fingers lovingly curled around the wooden handles of the scroll, as his father chanted the Hebrew in his son’s honor.

• Cannot stay in one place for long: Recently I read a Canadian news article about a hyperactive, non-verbal boy’s Bar Mitzvah. Knowing the boy might wander the room during the Sabbath service, the rabbi explained to the congregation, “Today is Ben’s day. This entire chapel is his bimah (stage) and he can move in it as he wishes and he can express himself and communicate with G-d in his own way.” Another rabbi in Pennsylvania kept a footloose fellow seated right next to him throughout most of the ceremony, explaining that he thought G-d would understand the need to modify this child’s obligation to stand for certain prayers. During the services, the rabbi invited the child’s best friend to come up and sit beside him. Having his friend who was in a wheelchair beside him both reassured and calmed the Bar Mitzvah boy.

• Cannot be quiet for long: Many parents fear their child with special needs may speak out loudly or inappropriately.

[Hornstein, continued on page 35]
An Ecumenical Appeal for Inclusion: The First U.S. Regional Initiative

by Rev. Betsy J. Sowers

Over the past 25 years, the local church has been the focus of inclusion of people with disabilities in the religious community. Now inclusion is emerging as a global and ecumenical movement. Reflecting this direction, the first regional, ecumenical initiative in the United States was begun by Rev. Diane Kessler, Executive Director of the Massachusetts Council of Churches, and Rev. James Miller, former Executive Director of the Rhode Island State Council of Churches. It is offered here as a model for others who are building networks between faith communities.

The initiative began in 1999 with the convening of an ecumenical group of people from Massachusetts and Rhode Island involved in disability services and advocacy, and in inclusion in faith communities. The group turned out to be a welcome haven of support, networking, and resource sharing among people who often felt isolated and alone in their local settings. Simply gathering together to share successes and frustrations was empowering. New friendships and working relationships emerged across denominational lines.

A key insight soon emerged from our conversations. When people with disabilities are unable to enter church facilities because of physical barriers, or when a congregation fails to welcome all as equal members, there is more at stake than civil rights or hurt feelings. When people are excluded from churches, something is theologically amiss, with painful consequences for those excluded and for those inside the church whose faith community is incomplete. Likewise, churches that reflect the diversity of God’s children embody a deeper understanding of their faith, which permeates their entire ministry. Physical and programmatic accessibility alone do not result in inclusion unless the theological piece of the puzzle is in place.

Out of a desire to communicate this insight to the larger religious community the ecumenical group charged a committee to draft “The Accessible Church: Toward Becoming the Whole Family of God.” It is an appeal to churches “to re-examine our ideas about disability and how our attitudes, expectations, behavior, communication, and architecture often create barriers for people with disabilities. It is a call to be reconciling communities of faith, committed to making our worship, programs, and physical structures fully accessible so that all can participate.”

The process of crafting and approving the appeal was designed to draw in a wide constituency within the ecumenical community. Carolyn Thompson, Disability Project Coordinator for the city of Cambridge, Massachusetts, drafted the appeal, with assistance from an ecumenical committee, and editorial suggestions from theologians of the Orthodox, Protestant, and Roman Catholic traditions. Next, the document was presented to the Boards of Directors of the Massachusetts and Rhode Island Councils of Churches for discussion and vote. It was circulated to the heads of denominational and ecumenical organizations in both states, and received endorsement from more than 30 religious leaders. Finally, it was distributed to over 6,000 congregations and individuals via newsletters, placed on the Massachusetts Council of Churches Web site, and released to the secular press. The entire process took over a year, and resulted in drawing hundreds, perhaps thousands, of people, into the conversation.

Response to the appeal has been as intimate as a telephone call from a mother of twins with Down syndrome, sharing her gratitude that others had named the source of her pain at her church’s inability to welcome her children; she was heartened to have a tool to help that church change. It has included requests for information from across the country. It has been as global as the invitation to Carolyn Thompson, chief architect of the appeal, to travel to Geneva to consult with leaders of the World Council of Churches on its disability strategy.

The ecumenical group continues to meet annually. It has created an e-mail network to keep members connected for sharing resources, support, and prayer. It is developing a list of speakers who are willing to visit congregations. It has provided workshops at Council of Churches and denominational meetings, and is in the initial stages of planning a conference for church leaders in 2003. Local congregations continue to be the focus of our efforts, but those efforts are no longer confined to the local congregation. Caring individuals are reaching out across denominational and geographical lines with a shared goal: churches where all God’s children are welcomed.

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When the Religion and Disability Program was founded in 1989, those of us at the National Organization on Disability (N.O.D.) were filled with can-do optimism. Our goals were clear: first to transform America’s congregations of all faiths into places of welcome for 54 million children and adults with physical, sensory and mental disabilities; and second, to support people with disabilities and their families who seek to be full participants in their congregations. Today, while holding to those same goals, we have a greater understanding of the multiple responsibilities of congregations as well as a greater appreciation of the many gifts and talents that people with disabilities are able to share with them. We have come to understand that congregations and their leaders want to be welcoming, but do not always know how to do it — how to relax around and truly enjoy a child or adult with disability, how to empower their leadership skills, and how to work to change old attitudes and stereotypes. And although many national faith and denominational groups have provided congregations with curricula and video resources, staff assistance, and in some cases low-interest loans, welcoming people with disabilities has not yet become a social justice priority.

In addition, people with disabilities themselves have not always clearly expressed their unique needs and hopes, many times retreating from their congregations in frustration or anger. This is discouraging for everyone.

Over the years, N.O.D.’s Religion and Disability Program has provided a variety of resources and services. Our three popular guides (That All May Worship, Loving Justice, and From Barriers to Bridges) have sold over 70,000 copies. A new booklet, Money and Ideas: Creative Approaches to Congregational Access, has been published in cooperation with the respected Alban Institute. Since 1993, a total of 143 “That All May Worship” community-building conferences have been held around the country. Our Web site (www.nod.org) includes creative features such as “Journey of a Congregation” and “Audit of Barriers.” And we have compiled the N.O.D. Interfaith Directory of Religious Leaders with Disabilities. The directory lists contact information for religious leaders with physical, sensory or mental disabilities. Our hope is that it fosters communication among ordained clergy, religious educators, seminary faculty, and seminarians who have similar disability experiences.

In anticipation of the millennium, N.O.D. established the Accessible Congregations Campaign (ACC) with the very specific goal of enrolling 2,000 of America’s congregations that were willing to identify and remove barriers to the full participation of people with disabilities. We asked congregations to sign a commitment form which acknowledged that “People, with and without disabilities, are encouraged in our congregation to practice their faith and use their gifts in worship, service, study and leadership.” One by one, small and large churches and parishes, synagogues and temples returned their ACC Commitment Forms to us. On May 3, 2001, the 2,000th committed congregation (the First United Methodist Church of Germantown in Philadelphia) was acknowledged and thanked at a press conference at Adas Israel Congregation in Washington, D.C.

The leaders of some congregations enrolled in the campaign, like the National Presbyterian Church in Washington, D.C., expressed the view that barriers of attitudes were often more difficult to remove than barriers of architecture. The Reverend M. Craig Barnes said just that in his sermon, “Called to Make Room” on July 22, 2001: “The greatest barriers that we find are not architectural, but barriers of the heart.”

As mothers of adult sons with mental retardation (Ginny’s son Peter of the Christian faith, Lorraine’s son Adam of the Jewish faith), we were particularly excited when religious leaders told us of children and adults with developmental disabilities who were full participants in congregations. Their letters and e-mails were filled with words like “dignity,” “respect,” “inclusion” and “blessing.” These congregations took seriously the ACC theme, “Access: It Begins in the Heart.”

A temple in Gary, Indiana was one of the first congregations to enroll in the campaign. The rabbi stated that al-
On May 3, 2001 the 2,000th congregation was enrolled in the Accessible Congregations Campaign of the National Organization on Disability.

Form. His concluding words were, “We take seriously the value of every individual in our community and what their special needs may be. We continue to work very hard at resolving those needs as they come to our attention.”

It was from the Council for Jews with Special Needs, Inc. that we first learned of the welcoming temple in the Reform tradition in Phoenix, Arizona. When they enrolled in the Accessible Congregations Campaign, we learned that their worship space and religious school were totally accessible. We also learned that a group of young adults with developmental disabilities had held their high school prom at the temple.

Recently we received a letter from a Catholic church in Sioux Falls, South Dakota. It began with these words: “We were excited to be part of the Accessible Congregations Campaign and wanted to update you as to what we have done in our church.” That update included the fact that “parishioners with disabilities serve in all capacities, including greeters and gift bearers and participants in the homily and music.”

One of the most welcoming congregations we have discovered is a non-denominational church in Marin County, California. Presently, it has about 15 members with developmental disabilities. Some are regular ushers, some are members of the men’s and women’s groups, some have joined committees, one man leads the hospitality committee, a few have attended weekend retreats, and several have provided music during the Sunday worship service. In addition, a number of families have befriend members with developmental disabilities and included them in weekend and after-church activities. This committed congregation has come to realize that the most important accommodation we can offer someone with disability is the gift of friendship.

We close with one final thought. The Accessible Congregations Campaign is proof that inclusive, welcoming, committed congregations of many faiths exist throughout the nation. They recognize that all of us, with and without disabilities, have gifts and talents to share. They recognize that as there are no barriers to God’s love, there should be no barriers in God’s House.

Ginny Thornburgh is Director of the Religion and Disability Program, and Lorraine Thal is Coordinator of the Accessible Congregations Campaign, both with the National Organization on Disability, Washington, D.C. They may be reached at 202/293-5960, 202/293-5968 (TDD), or by e-mail at Thal@nod.org. The Web address is www.nod.org.

Disability and Faith Resources: Guides to Inclusive Congregations

That All May Worship. An interfaith guide to assist congregations, denominational groups, and seminaries in welcoming people with disabilities. Also available are “Loving Justice,” a guide that clarifies the relationships between the Americans with Disabilities Act, other disability laws, and the religious community; and “Money and Ideas: Creative Approaches to Congregational Access”. Published by the National Organization on Disability. FFI call 202/293-5960, 202/293-5968 (TDD).


Resource Packet on Disability, Spirituality and Healing. By Rev. Nancy Lane, Ph.D., and her organization, A Healing Ministry, this packet contains materials related to biblical, theological and spiritual issues of disability, as well as the roles of individuals with disabilities in spiritual leadership. Distributed on the Web site of the Center on Human Policy, Syracuse University, http://soeweb.syr.edu/thechp/spirituality.html.

Journal of Religion, Disability and Health. Written for religious and human services professionals, it seeks to create an interdisciplinary, interfaith, and multicultural forum for exploration of disability in relation to religion. FFI contact Haworth Press, 800/895-0592 or 607/722-5857, ext. 321.

The resources above are presented for readers’ review; no endorsement is implied. For additional resources order Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families: A Bibliography and Address Listing of Resources (2000), from The Boggs Center on Developmental Disabilities, 732/235-9300.
What is it that draws us to our community of faith? Is it only our need to worship with people whose beliefs mirror our own? Is it the comfort of participating in the traditions that are familiar to us? Or perhaps it is the connection we feel to not only the way we worship, but also the people who worship alongside of us. The desire to experience some or all of these things is what many of us need in response to our own spirituality or quest for our relationship with God. This need, of course, is the same for many people with disabilities.

For individuals with developmental disabilities, finding membership in our faith communities continues to be a struggle. In response to the need of people to not only practice their faith, but also to connect with others in a more personal way, it seems only natural that we would turn to our faith communities. They can provide a welcoming place for people to feel valued and included. However, not knowing how to realize this welcoming environment and make these connections with people with disabilities often leaves clergy and congregations uncertain and paralyzed.

In response to this need for direction and resources, Bridges to Faith was formed. Bridges to Faith is a collaborative, interfaith effort whose mission is to provide opportunities for persons with developmental disabilities to worship in the faith communities of their choice and to provide support to the faith communities who welcome them. The committee works to accomplish this goal by acting as a referral source for individuals who would like to attend worship services, working with congregation members who want to become Faith Companions to support the person’s participation within that congregation, and by providing education and guidance to faith communities in their ongoing ministry to welcome all people into the life of their congregation.

The committee’s membership is made up of the Massachusetts Department of Mental Retardation, the Inter-Church Council of Greater New Bedford (which currently has 43 member congregations), Catholic Social Services’ Apostolate for Persons with Disabilities Office, human service professionals from social service provider agencies, partner congregations, and individuals who have been or want to be connected to a faith community.

Each of the members of the Bridges to Faith committee contributes in a unique and productive way in the process of connecting individuals with developmental disabilities to their faith community of choice. The primary role of clergy on the committee is to make connections with local congregations that will lead to faith companionships for people. Their peer relationship with the congregation leaders gives the work of the committee credibility and reduces some apprehension on the part of clergy about responding to requests made by the committee. The secondary role of clergy on the committee is to affirm the vision of Bridges to Faith, which is to embrace and appreciate the diversity of all people and welcome them into the life of the congregation. It is a ministry that all communities of faith are able to share. From a human service perspective, this effort could easily be seen as another “program” to support the individuals for whom we work. What our clergy membership teaches us is that we are not facilitating volunteer recruitment, but acting as a resource to congregations in their efforts to expand their ministry of hospitality.

The human service professionals on the committee have direct involvement with many of the individuals who have expressed the desire to attend worship services. They offer discreet support to congregations about the type of support a person may need to attend services. This kind of communication reduces the anxiety about the disability and puts an end to the myth that only people who have formal “training” can form a relationship with a person with a disability. They also assist in disseminating information within their agencies about the committee, and coordinate with direct support staff the details of the person’s participation in their faith community.

Our partner congregations offer testimony that diminishes the fears and stereotypes and helps open doors for additional congregations to welcome persons with disabilities. Members from our partner congregations who are active committee members take part in presentations at other congregations, telling of how positively this ministry has affected the whole congregation and demonstrating how little it takes to make such an important change in a person’s life.

People who are now attending worship services or who are waiting to be connected teach members how to improve the process and reinforce the value of the effort by sharing what their membership means to them. They keep us focused on the need to persevere.

Since 1995, the committee has made connections to faith communities based on requests from individuals living in
the New Bedford area. Funded by the Massachusetts Department of Mental Retardation, a part-time network coordinator begins the process by receiving a referral and meeting with the individual to discuss his or her worship preferences. In most instances, people have an identified faith community or denomination in which they wish to participate. For those who are exploring their spirituality or faith, it is not the role of the coordinator to identify a particular denomination of faith for a person. However, the coordinator is available to discuss information about the variety of denominations that are in the community and offer suggestions on ways to assist someone to choose what would be best for them. Once that decision has been made, contact with the chosen faith community is made. Clergy leaders are asked to think of members from the congregation who would like to become Faith Companions. Sometimes, certain members of a community come to mind right away, but other times it takes a little more persistence. Each congregation has its own way of going about identifying members who wish to participate. Again, if the congregation needs assistance, the coordinator is available, along with other committee members, to do presentations for groups in the congregation, provide written information for bulletins, or speak directly to potential Faith Companions. To help congregations and members to better understand what being a Faith Companion entails, Bridges to Faith produced a video describing the committee's work coordinator and the Faith Companion allows the companion to begin to understand the new member and facts about the disability in a non-threatening way. Once misunderstanding and fear are replaced by understanding and ease, inevitably friendship and respect grow. The Faith Companion acts as a bridge between the new member and other members of the congregation, expanding friendships, membership, and understanding in a natural way. Many of the companionships mature into friendships with people doing more than just attending worship services together. The Faith Companions often share participation in other activities within the congregation and outside of it. Many of the people connected to communities of faith this way have said they feel like they belong to a family.

Bridges to Faith is the second of four similar committees active in Massachusetts. The first committee was Spiritual Connections in Fall River, Massachusetts. Its success led to its replication in New Bedford’s Bridges to Faith. The same resources can be found in most cities to establish this type of committee, and facilitate greater connection between individuals with developmental disabilities and local faith communities.

Colleen Perkins is Coordinator of Educational Support, Massachusetts Department of Mental Retardation, and Chair of the Bridges to Faith Committee, New Bedford. She may be reached at 508/992-3848 x334 or by e-mail at colleen perkins@dmr.state.ma.us. To obtain a copy of the Bridges to Faith video describing the committee’s work, call the number above or visit their Web site at www.Bridgesto faith.org.

Published on the Web site of the Institute on Community Integration (http://ici.umn.edu/products/impact/143/).
Finding Love and Friendship:
First Unitarian Universalist Fellowship

by Doris and Eric Spencer

When asked what he likes about being part of the First Unitarian Universalist Fellowship of Hunterdon County, my son Eric says, “I especially like making friends. I respect all members of the church and they respect me. Sunday morning is the best time of the week for me because I am with my friends.” And he adds, “The thing I like best about being part of the Fellowship is believing in God!!” For Eric, a man of few words who has been diagnosed with autism, membership in the Unitarian community has helped him open up to others in surprising ways, and become a valued member of the community. In this article, we hope to share some of the ways membership in the Fellowship has enhanced his life, and he their’s.

Eric and I joined the Unitarian Fellowship at the same time, approximately three years ago, and shortly afterward he moved from our family home to a home of his own. He lives in a one-bedroom condominium in a small town, and works as a data entry clerk in the scientific library of a major pharmaceutical firm. He is a participant in a unique program, the New Jersey Division of Developmental Disabilities Self-Determination Initiative, which provides support for Eric’s independent living – support that he and the family believe he needs and that he and the family choose. Additional support for Eric’s community program is provided by the Princeton Child Development Institute, a well-known program for persons with autism. Eric attended the institute’s school program from age seven and has been involved with their adult life skills program since age 21. The institute’s life skills coaches visit Eric several hours each week to help him gain and maintain the skills needed to live successfully in the community.

As important as paid staff are to Eric’s progress, his “self-determination” program would not be successful without friends and family. And membership in the Fellowship has been a key element in Eric’s community life. The warmth, spirit, and intelligence of the small congregation – which truly has the feeling of family – are compelling.

I came to the Unitarian Fellowship in part through my friendship with Reverend Sue Henshaw, its Community Minister, who also works at The Boggs Center on Developmental Disabilities at the University of Medicine and Dentistry in New Jersey. “Reverend Sue” and her colleague at the center, Reverend Bill Gaventa, work to promote community inclusion of individuals with developmental disabilities and to educate families, professionals, and community members about New Jersey’s Self-Determination Initiative. Of particular interest to Sue is the role religious communities can play in the successful integration of persons with developmental disabilities in the community.

Shortly after my first visit I invited Eric to accompany me. The church’s services are structured so that children participate in the church service for the first 10-15 minutes with their families and then leave the church to go to religious education classes. Initially, Eric attended Fellowship services with me. As an adult member of the community he remained in the church after the children and their teachers left. Sue Henshaw, whom he had known for some time, also left to teach. The church service was somewhat daunting for Eric. The sermons, guest speakers, and discussions were often difficult for him to attend to and follow. But he loved the community and enjoyed seeing the families, especially the children, at the coffee hour after services. Within a short time, Eric asked if he could go with Sue and the children when they left for religious education. I talked with Sue and another religious education instructor about whether Eric could have a role as a volunteer. Quickly, this was arranged and Eric was overjoyed. During his first year as a religious education volunteer, he found his own unique ways to participate. From early childhood Eric has had a fascination with letters, numbers, and words. He has excellent graphic abilities, and, given construction paper and scissors, can quickly cut out letters and names freehand. Before long, Eric had cut out the name of every child in the religious education program, and the walls of Dodd Hall, where classes meet, were papered with his handiwork. In the room where very young children played, Eric cut out the alphabet, upper and lower case, and numbers from 1-20, to help teach them to the children. After services, he interacted with the adults in his own style and with his own language – by fulfilling their requests to cut out letters using different typefaces. The following year, Eric was given the task of creating the sign announcing the topic for the week’s sermon, and placing it outside the church. Today, these are some of his favorite activities. As he says, “I like to make the letters of the alphabet and the numbers, and teach children to read them and to count. I like to help with crafts projects. I especially enjoy making the signs for the Sunday service and putting them outside the church for all to see so they will know what’s happening at UU.”

Prior to joining the Unitarian Fellowship, Eric was very withdrawn socially. He rarely talked spontaneously to others, often remaining aloof in social gatherings, and removing himself to isolated areas. Gradually, over the first year, we noticed that he was changing. He began to approach members, adults and children, to introduce himself and ask their names. And he remembered the names, often better than I did. Eventually he began to share during the “Celebrations and Concerns” part of the service, and one day he spontaneously invited the congregation to a holiday party at his condominium. Last year, he participated in a religious education talent show, doing a scene from a Monty Python movie with one of the teens. This year he has plans to direct a skit using scenes from the musical “Free to Be You and Me.” He regularly attends covered dish suppers and concerts, and is also involved in a variety of volunteer activities: “I have gone to nursing homes and cut out the names of residents for their doors. This year I made all the signs for the UU float in the local Christmas parade. The children dressed in costumes from all nations. I rode on the float with them and was a Frenchman. I also have a team in Walk Far for NAAR, a walk to benefit autism research. I do this every year and we raise money to help. I have also gone to conferences with my friend Sue Henshaw and my mother and father, and talked about living on my own and how much I like it.” Three years ago this degree of outgoing behavior would have been unimaginable.

Some of the unique qualities of Unitarian Universalism that have made Eric’s experience as a Fellowship member so meaningful are part of its philosophy: affirmation of the inherent worth and dignity of every person; justice, equity and compassion in human relations; acceptance of one another; a free and responsible search for truth and meaning; the use of democratic process within the congregation and in society; the goal of world community and peace, liberty, and justice for all; and respect for the interdependent web of all existence. The religion respects differences between people and affirms every person as an individual. In addition, Unitarian Universalists tackle social issues with great gusto, seeking to act as a moral force in the world, believing in ethical living as the supreme witness of religion. The congregation has encouraged Eric’s moving out and becoming involved in other community volunteer activities and social action.

Reverend Sue Henshaw says, “I’ve known Eric long enough and well enough to see the difference before and after he became involved with our congregation. My best memory of his change from a quiet and very isolated person to the man I know now happened after a potluck dinner during the first year he was with us. I was driving Eric home and had become quite accustomed to his silence unless I spoke first. After a period of silence he said, ‘I really liked the chicken. Who made it?’ I almost drove off the road and tried not to get too excited as we talked about the food that was at the potluck. Given how seldom Eric initiated any conversation, every word was a big step for him.”

It’s important to stress that Eric is not a “special” person in our congregation. He’s a member like everyone else, with his own distinctive personality and traits. One measure of how valued those traits are is Eric’s nomination by members of the congregation for the Individual Achievement Award of the New Jersey Council of Schools and Agencies for the Autistic. Eric received this award in May, 2001, and proudly brought it to the congregation during sharing time.

When asked what the Unitarian Fellowship means to him, Eric talks of love and friendship, of the children he works with and cares deeply about, and the adults: “They are all my friends.”

Doris and Eric Spencer live in Hunterdon County, New Jersey, attending First Unitarian Universalist Fellowship of Hunterdon County, Baptistown. Rev. Sue Henshaw (pictured with Eric) may be reached at 732/235-9300 or henshasu@umdnj.edu.

Disability and Faith Resources: Guides to Community Building

Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families. A 135-page guide to resources on inclusive ministries and community building for use by congregations, service providers, and others. FFI contact The Boggs Center at 732/235-9300.


Building Communities From the Inside Out: A Path Toward Finding and Mobilizing a Community’s Assets. By John Kretzman and John McKnight. Includes a section on working with the religious community. Also available is a video series based on this book. FFI contact ACTA (Assisting Christians to Act) Publications, Chicago, 800/397-2282.


Impact: Feature Issue on Social Inclusion and Persons with Developmental Disabilities. Strategies and success stories related to social inclusion in a variety of community settings, including spiritual communities. FFI call the Institute on Community Integration at 612/624-4512 or visit http://ici.umn.edu.

The resources above are presented for readers’ review; no endorsement is implied. For additional resources order Dimensions of Faith and Congregational Ministries with Persons with Developmental Disabilities and Their Families: A Bibliography and Address Listing of Resources (2000), from The Boggs Center on Developmental Disabilities, 732/235-9300.
The Greater Washington Jewish Community: A Community-Wide Response to Inclusion

by Cathy Silberman

For over 25 years the Greater Washington Jewish Community has been a leader in creating a caring community that welcomes, supports, and provides services to individuals with disabilities and their families. Historically, the Jewish Federation of Greater Washington has served as the community planning body and was one of the first Federations to address and consider a communal response to the needs of area Jews with disabilities. In a pioneering effort in 1978, the Federation undertook a comprehensive study to ascertain the extent and nature of the needs of individuals with disabilities. The study recommended that the community adopt an integrated, interagency approach for the delivery of services to persons with disabilities and their families, to ensure a continuum of service from birth to adulthood. This interagency coordination of services was formalized through the creation of the Parallel Professional Advisory Committee (PPAC) for Special Needs, an interagency professional committee operating under the auspices of the Jewish Federation of Greater Washington and staffed by the Federation’s planning department. PPAC members include supervisory and programmatic agency professionals responsible for delivering and supervising services to special needs populations. Some of the agencies represented are: the Board of Jewish Education, the Jewish Foundation for Group Homes, the Hebrew Home of Greater Washington, the three area Jewish Community Centers, the Jewish Information and Referral Service, the Jewish Social Service Agency, Hillel of Greater Washington, and the Washington Board of Rabbis.

The PPAC has been meeting bi-monthly for over 20 years to brainstorm, share resources, and work collaboratively on behalf of the community’s special needs population. One of its first efforts was to develop an outline for a continuum of services that are now provided by a consortium of agencies. Services include family support, ongoing testing and consultative services, screening programs, a community supplementary school, teacher training, professional resource teams, socialization programs, youth groups, camping, and residential group homes/apartments.

As a professional/interagency consortium, the PPAC strives to identify those unmet communal needs that are beyond the capacity of any one agency to fulfill, but when addressed holistically, provide a continuum of care that benefits the entire community. PPAC recommendations for new services are considered by the appropriate agency for inclusion in their budget. The following represents examples of successful collaborative efforts by the PPAC:

- The PPAC for Special Needs applied for and secured funding from the Federation’s Endowment Fund in 2000 for a Jewish Community Newsletter – Kesher Connection – published three times a year, featuring Jewish community events, and courses and programs for individuals with special needs. It is mailed to all people using the special needs services offered by Jewish Community agencies and synagogues. Additionally, copies are distributed via agency special lists, local synagogues, therapist’s offices, schools and other places that work with individuals with special needs. A total of 2000 copies are disseminated.

- Funding from the Federation’s Endowment Fund was also awarded in 2000 for creation of a Jewish Community Web site for individuals with special needs. The Web site (www.kesherconnection.org) constitutes a complete listing for the community of all relevant programs. Its goal is to enhance community awareness and provide a one-stop place for all community information regarding individuals with special needs.

- The Jewish Foundation for Group Homes was created 20 years ago, in part as a result of the PPAC’s recommendation. It now operates 18 group homes for four to five residents each, as well as numerous apartments, serving a wide range of individuals with disabilities. Residents receive vocational training, are integrated into their communities, and have the opportunity to participate fully in local Jewish activities.

The Greater Washington Jewish Community has been successful in providing a seamless continuum of services to the special needs community, in part because of the success of the PPAC structure. By affording opportunities for professionals to meet, network, and share planning ideas and resources in a neutral, positive setting, the PPAC promotes and facilitates interagency cooperation and service coordination. It also serves as a vehicle for community evaluation of programs and services, and as a catalyst for community forums and workshops. The Federation’s ongoing involvement and support provide a broad communal picture, maximize distribution of resources, and ensure the integration of Jewish values into support for persons with disabilities and their families.

Cathy Silberman is Senior Planning Associate with the Jewish Federation of Greater Washington, D.C. She can be reached at 301/230-7244 or by e-mail at csilberman@jewishfedwash.org.
Jewish Residential Living: The Jewish Foundation for Group Homes

by Marcia F. Goldberg

The Jewish Foundation for Group Homes (JFGH) is a nonprofit organization with 18 residential homes and 44 apartments in suburban Washington, D.C. that provide community residential services, and enhanced independent living skills, for adults with disabilities. The organization also makes it possible for those using its residential services, 80 percent of whom are Jewish, to live in a Jewish environment in a kosher home.

Many of the Jewish residents of JFGH group homes have had limited religious education and experiences in their early years. While some grew up with Jewish traditions within their families – such as holiday celebrations, some synagogue attendance for religious services, and formal religious education and Bar or Bat Mitzvah – not all come from Jewish families that observed the traditions. In addition, observant families may have found it difficult to find a proper religious educational setting for their child with a disability. Now, these individuals are living in homes that have kosher kitchens, and they are regularly participating in Jewish holiday celebrations and life cycle events.

In each home, Shabbat (Sabbath) is welcomed on Friday evenings with the lighting of candles and blessing of grape juice and hallah (braided bread). In some, the residents are able to lead the blessings by themselves, and in others the direct care staff recite them from translations or transliterations. Over 90 percent of the direct care staff in the JFGH residential settings are not Jewish, which makes it necessary for nearly all of them to be educated in various aspects of Jewish living. The Jewish Living Coordinator and Committee of JFGH provide a bridge between the staff and Jewish traditions through required staff training, and members of the committee serve as mentors to each home, providing an ongoing personal contact and guidance. In addition, recognizing that staff cannot do it all, JFGH relies heavily on ongoing support from volunteers and congregations, and has a full-time volunteer director. Holiday celebrations are a particularly busy time. Volunteers come to the homes to help prepare special foods connected with the holiday, or the residents go to a synagogue to work with the members. For example, every group home has a sukkah (booth for the Feast of Tabernacles) built by residents with the help of volunteers.

Residents are also actively involved in the larger Jewish community. They are recognized and greeted at community gatherings and at the Jewish Community Center by the volunteers they’ve met in their homes. Each year residents volunteer alongside staff at the Jewish Federation of Greater Washington Super Sunday Dial-a-thon fundraiser, helping to support the larger community. Group home residents have gone on missions to Israel sponsored by the Jewish Federation; they are full participants in the tour, returning home with a greater appreciation of Israel and, at the same time, giving the other participants a chance to know them as persons first. And residents of several homes regularly attend synagogue services where they participate fully in the services.

One congregation especially involved in facilitating the inclusion of people with disabilities in the larger Jewish community is Shaare Tefila in Silver Spring. The religious school and synagogue have an emphasis on being part of a community within Judaism, and express that in a variety of ways. Within its own religious school, it serves a number of students with disabilities who are integrated into the regular education setting. The school’s post-confirmation class (11th–12 grade) has been particularly involved with JFGH residents, spending time in the homes at holidays talking with them about Hanukkah and the idea of religious freedom, and about Purim and the importance of standing up for what you believe. Several times a year group home residents share Shabbat dinner with the congregation, giving residents and staff the opportunity to experience the meal in a larger community context. The congregation also set aside a regular morning service to focus especially on the participation of persons with disabilities, inviting the president and executive director of JFGH to speak, and involving residents in the reading of the Haftorah (selection from the prophets chanted in Hebrew) and the leading of Hebrew and English prayers and other honors. And when a new group home opened nearby, the congregation raised funds to purchase equipment for its kosher kitchen, as well as Judaica, and welcomed residents to the community and to participation in all congregational activities.

Shaare Tefila is one of many congregations in the Greater Washington area that involves adults with developmental disabilities in all aspects of their programming. With increased contact comes increased comfort as people get to know each other as individuals. A number of the JFGH residents have become formal members of congregations of their choice and speak proudly of their rabbi and cantor. During the annual Mitzvah (performing good deeds) Community Service days held by congregations, the residents of the group homes perform community service along with everyone else, contributing to making the community a better place.

Marcia F. Goldberg is Jewish Living Coordinator with the Jewish Foundation for Group Homes, Rockville, Maryland. She may be reached at 301/984-3839 or by e-mail at mgoldberg@jfgh.org.
Aaron, a six-year-old boy with Down syndrome, and David, a nine-year-old boy who has multiple disabilities, attend regular Sunday school classes (though on different campuses) at North Heights Lutheran Church in suburban St. Paul, Minnesota. In spite of having substantial communicative and intellectual limitations, which sometimes present socialization challenges in the inclusive (mainstreamed) setting, the boys and their classmates benefit from inclusion, growing in the ability to maintain friendships with others and in their Christian faith.

North Heights Lutheran Church, a two-campus church of approximately 8,000 members, believes every person is created by God and has a unique purpose for his or her life. The church, ministering to about 2000 children and youth each week, has a calling to introduce Jesus to children at a young age so that they eventually make a life-long commitment to Him. Every opportunity is taken to minister the love of Christ to every child who walks through the church doors. There are ministries and activities for children of all levels of ability and diverse backgrounds nearly every day of the week.

The value placed on inclusion of persons with disabilities by North Heights can be traced to a conversation that occurred about 20 years ago between a mother in the congregation and the senior pastor. The mother, whose young adult son with severe mental retardation was residing in a county residential facility located near the church, asked the pastor why the church hadn’t reached out to provide religious education for her son. The pastor immediately put together a task force, charging it to do all that it could to provide this outreach. Task force members rapidly reached a consensus that North Heights should indeed reach out, not by taking a program to the man at this residential facility, but by creating a Sunday school program at the church tailored to his needs. Today, around 150 young adults and adults with disabilities, primarily with mental retardation, are transported to North Heights by area group homes. In addition, children and adults with disabilities who live with their families, such as Aaron and David, make up a growing part of the congregation.

For Aaron and David, the typical one-hour inclusive Sunday school class period generally looks like this: The first half features small group and individual activities such as listening to Bible stories, prayer, and arts and crafts activities. The second half is a large group comprised of several regular classes meeting together, where group prayer, singing, and listening to a storyteller occur. These are enriched through the use of flannel boards, puppets or other audio-visual materials. During the activities, accommodations are made for both boys. For example, Aaron is “action-oriented” and enjoys coloring, handling clay, painting, and singing, but isn’t too keen on sitting and listening for extended periods of time. Hence, when Aaron loses interest, perhaps wandering away from the group activity, a volunteer takes him aside for an alternative activity or sits with him in her lap to help focus his attention on the activity.

While church staff and volunteers in the congregation are constantly looking for ways to provide inclusive activities to persons with special needs of all ages and ability levels, at this point there is more inclusive programming available for children than for youth and adults. Many of the older youth and adults attend the Special Needs Sunday School, a non-inclusive program, and also attend an evening program at the church called the I Am His Club that offers prayer, music, snacks, and crafts to participants with disabilities. This existence of both specialized as well as inclusive options in the church is due partly to the long-standing history of providing specialized programming to adults from the county residential setting. But, in addition, it stems from the fact that finding same-age nondisabled peers to provide needed supports for adults with disabilities in inclusive activities is more difficult. Hence, there are more inclusive opportunities for children, such as David and Aaron. For example, both boys, in addition to having a mainstream Sunday school program, attend an inclusive program each Wednesday evening called Kingdom Kids Pioneers, a club that offers Bible stories and activities, crafts, and recreation, and worship opportunities. Moreover, they both attend an inclusive summer Sunday school and vacation Bible school each year.

The North Heights motto, “To Know Christ and To Make Him Known” has sparked the development of a vital social network that undergirds the inclusive religious education effort. Glimpses

Christ Himself demonstrated the highest possible form of inclusiveness.

- “He is a very smart child and enjoys the class. I think this shows in his interactions with his friends and classmates. He has never been disruptive to the class” (Aaron’s teacher).

  Asked to reflect on the reactions of nondisabled classmates to the boys, here is what parents had to say:

  - “They like having him around and are helpful when needed” (David’s parent).
  - “In general, people seem to enjoy Aaron, including his peers in Sunday school. Many will talk to him by name. He likes to play chase games, duck duck gray duck, etc. and other children will join him for that at times. Because he is difficult to understand, they are sometimes confused by him. At this age, some seem to go out of their way to be compassionate and pleasant, as if they understand he is somehow special, but others seem to be oblivious to any differences” (Aaron’s parent).

  Teachers and teacher aides, when asked to capture nondisabled classmates’ reactions to David and Aaron, wrote the following:

  - “Acceptance, usually – especially with the adult in charge helping other children who are not familiar with David to understand and help him participate. Ignoring, especially in more active activities” (David’s teacher).
  - “Eager to help with him. Curious and interested in him. Show concern for him” (Aaron’s teacher).
  - “Aaron is not identified as any different than they are. They show concern and give support when needed. They enjoy his company and playing with him” (Aaron’s teacher aide).

  While overall a positive experience with inclusion is reflected in these comments, inclusion is not challenge-free. The presence of challenge becomes clearer when parents, teachers, and aides were asked specifically to talk about things they would like to see improved in the inclusive program and challenges they discern about inclusion in general. Here is what they said:

  - “The hardest thing is to find people willing to be with David. He doesn’t need one-on-one as much anymore, but I always make sure the teacher or helper is comfortable with him. I think church leadership could do more to help find partners for those with special needs. I know it is scary to get to know them, but usually once you do you will find a side of God’s love you didn’t even know was there…” (David’s parent).
  - “We think it is very important that the teachers and department heads know specific needs and information about disabled students. Like for Aaron, his family let us know of his needs and what helps with his specific responses” (Aaron’s teacher).
  - “There is little I would change, but I would make sure the right people, properly trained, were immediately available to support the teacher when a disabled child needed help. This additional help provides proper support for the teacher and maintains control of the situation while focusing proper attention on the needs of both the disabled child and their classmates” (Aaron’s teacher aide).

While this questionnaire focused on the inclusion of David and Aaron, the responses are guiding a broader effort to enhance the inclusion of all children with disabilities at North Heights. Plans include the following:

- Recruit volunteers who are interested and willing to be trained in ministering to and promoting the learning of students with special needs.
- Train all educational personnel in the use of instructional strategies in inclusive classrooms.
- Create a set of policies and procedures that guide inclusion in religious education and reflect Jesus’ love for children.

Christ Himself demonstrated the highest possible form of inclusiveness with everyone He encountered, even those who rejected Him. In this, He set the standard for Christians to follow, and it is that standard that North Heights seeks to embrace.

John Rynders is a Professor Emeritus in Special Education Programs at the University of Minnesota, and a member of North Heights Lutheran Church. Noreen Rickenbach is Director of Children’s Ministries at both campuses of North Heights Lutheran Church, Arden Hills and Roseville, Minnesota. She may be reached at 651/631-2299.
A Gift of Faith, Family, and Community

by Mary Brosseau

The Hispanic community in Orange County, California, is rich in faith, in a sense of extended family ties, and in cultural diversity drawing, as it does, from a number of Latin American countries. It also comprises a slight majority of the Catholic population of the Diocese of Orange. Supported by diocesan offices, the parishes in the diocese are involved in ongoing efforts to improve their ability to include Hispanic children with developmental disabilities in religious education and other aspects of church life.

For Hispanic parents of children with developmental or other disabilities, there is a deep desire to be included in the life of the church. “Parents come to me very hungry to get some experience of God for their child,” says Luis Ramirez, Associate Director for Elementary Religious Education for St. Joseph Parish in Santa Ana. “For Hispanic families, the communal dimension of life is so important,” notes Fr. Christopher Smith, pastor at St. Joseph’s. For these reasons, any signs of rejection or exclusion on the part of the church community are devastating.

When parents come to me having had such experiences with religious education classes or staff, to calm the storm I ask parents to think back to a time before their child was born, when they did not know much about children with disabilities and were afraid of the unknown territory they were entering. And I point out that this is how the church staff often feel. Staff may simply not know what to do. We have found the solution is a partnership between church staff who have a knowledge of religious education, and parents, who know their child’s special needs. They must all work together in finding ways to support the religious development of children with disabilities.

When parent advocates, Hispanic religious educators, special educators, and community representatives work together in parish and diocesan teams, they open doors for inclusion. When I came to the diocese 19 years ago as Director of Special Religious Education, we had no Spanish-language religious education materials for persons with developmental disabilities and their families. Since that time, the diocese has worked with families, the Hispanic community, and special educators to remove barriers to participation of Hispanic children with disabilities. Today, we have religious education materials in Spanish for children with special needs and their parents, options for individual assistance and special classes in religious education, guidelines for parish staff that focus on identifying ways to help Hispanic children with disabilities learn about God, and resources for parish leaders.

Ministry Developments

God has blessed the development of this ministry, inspiring parents to advocate, church leaders to respond, community agencies to assist, new resources to be developed, funding to be made available, and good people to volunteer:

- In 1993, Bishop Jaime Soto, then Director of the Office of Hispanic Ministry, introduced me to three parent advocates who worked for different community agencies serving persons with developmental disabilities. They had formed El Consorcio de Grupos Latinos del Condado de Orange (The Hispanic Consortium of Orange County). They requested a religious celebration that would support the faith of families of children with developmental disabilities and raise awareness of their needs within the church community. Thanks to this collaboration between parent advocates and the diocese, we have now had eight annual celebrations with as many as 400 in attendance.

- In 1996, a new special religious education curriculum for use in Catholic churches nationwide was published in memory of Rose Fitzgerald Kennedy. With the support of the editor, Grace Harding of the Diocese of Pittsburgh, and Nuria Chekouras, then Associate Director for Family and Child Religious Education for the Diocese of Orange, we developed the Spanish language edition with funding from the Kennedy Foundation, and also produced a parent manual with input from diocesan families.

- In 1999, the diocese hosted a Spanish language conference for El Programa Rose Fitzgerald Kennedy para Mejorar la Educación Religiosa Católica en Niños y Adultos con Necesidades Especiales (The Rose Fitzgerald Kennedy Program to Improve Catholic Religious Education for Children and Adults with Special Needs). The conference, funded by the Kennedy Foundation, was designed to give participants the understanding needed to foster and support the faith life of persons with developmental disabilities. Follow-up workshops have been presented at the annual Religious Education Conference of the Diocese of Orange.

- Diocesan and parish staff work with parents to develop participant profiles, asking families, “How can we help your child learn about God?” “Parents need to be able to say who their child is,” says Olivia Cornejo, Associate Director for Family and Child Religious Education. “They need to be able to say what the child is capable of in terms of understanding and behavior.” One strategy being used is to develop a statement asking parents, “Does your child attend special education classes? Do you have a copy of the IEP that we can use?” This opens the door to addressing the particular needs of each child.

• Teachers and aides are being taught concrete methods and behavioral strategies for teaching Hispanic children with special needs. It reduces anxiety when they can see that they only need to know how to help this one child, not have expertise in all aspects of special education. Persons with a professional background in special education serve as consultants to the church program in order to develop learning and behavioral strategies and train volunteers. Stan Martin, Coordinator for the Special Religious Education Program at St. Joseph’s, obtains written permission to look at the student’s IEP and talk to his or her teacher. The question he asks is: “How can we tailor our teaching methods for this student’s needs so that he or she will be successful?” Teachers are amazed that there is something else out there for their children and are more than willing to help. Because of the support of Hispanic members of the staff of the diocese, and the volunteer work of Hispanic special educators, the diocese is moving forward in training religion teachers and aides.

As a result, nine parishes now provide religious education in Spanish to children with developmental disabilities. In one of the first, St. Joseph’s Church, it has become a tradition for the students from the program to lead the procession into church on the day they first receive Holy Eucharist. According to Luis Ramirez, “The other parents are amazed by the presence of children with disabilities. When they see how happy they are to receive Communion, they hold them up as an example to their own children.”

Ongoing Advocacy

There is always a need for ongoing advocacy. Fr. Christopher Smith has raised the level of consciousness of his parishioners by references in his sermons to persons with disabilities. Now members of the congregation inform him when someone has a special need. “We have a responsibility,” he says, “to serve all the members of our church, no matter what their language, economic or cultural background, because they are part of the family.” He has observed that some Hispanic parents tend to have a sense of personal responsibility for whatever misfortune befalls anyone in the family. They may believe that God is punishing them for their sins even though they are not sure of what they did to deserve it. When you instruct the parents that this is not how we believe God acts, there is a tremendous sense of relief.”

Statements such as the following from the United States Catholic Conference of Bishops’ Guidelines for the Celebration of the Sacraments with Persons with Disabilities give parish staff and parents support and guidance in the inclusion of the children with disabilities in the life of the church:

Pastors are responsible to be as inclusive as possible in providing evangelization, catechetical formation and sacramental preparation for parishioners with disabilities. Persons with disabilities, their advocates and families, as well as those knowledgeable in serving disabled persons can make a most valuable contribution to these programs. Parish catechetical and sacramental preparation programs may need to be adapted for some parishioners with disabilities.

“Parents can use these supports to become strong enough to knock on church doors,” according to Olivia Cornejo. It is through the advocacy and support of parents and professionals and their willingness to partner with diocesan and parish staff and volunteers that Hispanic ministry on behalf of persons with developmental disabilities is moving forward in the Diocese of Orange.

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Miriam and Her Family

Jesus Piceno is one of the Hispanic youth ministry leaders at Blessed Sacrament Church in Westminster, California. His wife, Imelda, is a lector, reading from Scripture at Sunday Mass. Their daughter, Miriam, has Down syndrome and participates with her parents in church programs for the extended family. The couple is active in helping parents, especially recent immigrants, to access community services for children with special needs. “What a difference it makes to have a sense of belonging to a community of faith,” says Jesus. “At church Miriam is part of the community. She doesn’t appear different from the other children and is referred to as ‘Miriam,’ not ‘the child with Down syndrome,’” according to Imelda. Imelda also notes that the most important thing the church has done to help Miriam’s spiritual development is to offer this acceptance. “She has been part of this church since she was two, has learned about her faith here, and now knows a number of the prayers and hymns by heart.”

Through their involvement in the Jovenes Para Cristo (Youth for Christ) ministry, Jesus, Imelda, and Miriam have paved the way for the participation of other families who have children with disabilities. They are now looking forward to the day when Miriam receives First Holy Communion.

Contributed by Jesus and Imelda Piceno, Blessed Sacrament Church, Westminster, and by Mary Brosseau, Director for Special Religious Education, Diocese of Orange.
I talked with a father last week about his son, Brian. Brian just turned nine and is enjoying the new school year. The father was excited because this is the first year that Brian is in a class with other students who do not have a developmental disability. Brian is one of three kids with a developmental disability in the class, and he seems to enjoy school more since he has experienced a fuller amount of inclusion in his classroom. The father expressed feelings of relief, excitement, and encouragement – finally his son had a place at the table. He then paused, thought for a moment, and said, “I wish it was the same at our church.”

Brian’s dad expressed a sentiment shared by many people with disabilities and by their family members. This generation of people with disabilities has experienced a higher level of societal inclusion in schools, jobs, services, etc. We definitely have not arrived, but past legislation has helped to break down some barriers. Yet many of these barriers still exist in our faith communities. Religious communities, not required to meet the standards of the ADA unless accepting federal monies, have often lagged behind in their intent and ability to include people with disabilities. Brian’s church is one of these communities. His dad explains that their church does not discourage Brian’s participation in activities, yet they also do not encourage his inclusion into the full life of the community. It is for people like Brian and his dad, and for the congregations they attend, that the Interfaith Disabilities Network (IDN) exists.

The Network’s History

The Interfaith Disabilities Network was born out of a history of religion and disability work in the metropolitan Atlanta area. Beginning in 1985 the Commission on Disability Concerns of the Christian Council of Metropolitan Atlanta (CCMA) worked to help local congregations become accessible to persons with disabilities. The CCMA is a nonprofit dedicated to helping local Christian congregations become involved in serving the larger community. The Commission on Disability Concerns worked during its existence to help local Christian congregations increase their inclusion of people with disabilities. This committee, comprised of volunteers, held a major conference, published brochures on hospitality and accessibility, and helped educate local congregations in their efforts to become accessible.

Also in the Atlanta area since 1990, the Coordinated Network for Persons with Disabilities (comprised of Jewish Family and Career Services, Jewish Educational Services, and the Atlanta Marcus Jewish Community Center) in the Atlanta Jewish community has been working to help local synagogues welcome persons with disabilities. They offer disability awareness training, architectural accessibility information, and respite services to local synagogues to assist them in becoming accessible. In 1995, Jewish Educational Services began offering educational consulting services. In its 1999-2000 strategic planning process, the CCMA dissolved the Commission on Disability Concerns. Around the same time the Atlanta Alliance on Developmental Disabilities (AADD), in consultation with the Coordinated Network of Services for Persons with Disabilities, the Shepherd Center (a spinal cord and brain injury specialty hospital), and other local leaders in religion and disability communities began a strategic planning effort to start an interfaith collaborative that would spearhead religion and disability work in Atlanta. In March, 2000, the CCMA “passed the torch” to AADD to not only continue the work of the Commission on Disability Concerns, but to expand this work to include the larger faith community. In July, 2000, AADD began the Interfaith Disabilities Network.

Mission/Vision

The IDN has a stated mission to advocate for the inclusion of people with disabilities in their faith communities. It is based on the premises that: 1) people with and without disabilities are valuable members of their faith communities; 2) faith communities benefit by removing architectural, attitudinal, and programmatic barriers; and 3) inclusion allows people with and without disabilities to practice their faith and use their gifts in worship, service, study, and leadership. The IDN includes self-advocates, parents, caregivers, professionals, and other interested parties from various disability and faith communities. It is open to the participation of anyone interested in helping advocate for inclusive faith communities. While working with people with developmental disabilities and their families, the IDN is intentional about including and working in various disability communities. This commitment is born of the belief that removing barriers to one disability often dovetails with the steps needed to welcome people with any disability.

The IDN is currently involved in three main areas of activity: collaboration, information-sharing, and community service. In the area of collaboration, the IDN seeks to bring together indi-
individually and faith backgrounds who have experience helping to increase inclusion among faith communities. These individuals, with their wisdom on congregational inclusion, function as a network that is then able to assist other individuals and congregations who are beginning the journey to fully including people with disabilities.

The IDN also is building a database of congregations who state that they “welcome people with disabilities.” Although these congregations are at various stages of accessibility and full inclusion, they all seek to include people with disabilities and are committed to increasing their accessibility. Currently, 60 congregations in the Atlanta area have indicated their commitment to welcome people with disabilities. Information on these congregations is being shared with the community through a collaborative effort of the IDN and Parent to Parent of Georgia. (Visit the website http://www.parenttoparentofga.org/ and search the Special Needs Database for “Religious Services”).

The IDN is also intimately involved in helping to educate congregations and the larger community about inclusion. It provides education to local congregations on the why, what, and how of including people with disabilities. In addition, it works to offer education for local theological schools and for the larger community. An example of this education is a recent forum sponsored by the IDN that featured religious leaders from local Christian, Jewish, and Muslim communities as well as a sociology of religion professor from Emory University. Each presenter dealt with the topic of the religious leadership of people with disabilities, and time was allotted at the close of the forum for group discussion.

Community Service

Key to the IDN mission and future success is a commitment to community service. In addition to its collaborative efforts, information-sharing, and education, the IDN endeavors to help congregations in the concrete activities of welcoming and including people with disabilities. The Inclusive Congregations Project is helping to further this aim. Members of the IDN realize that congregations often mean different things when they state they are “inclusive” or “accessible.” For one congregation this might mean they have a ramp and accessible bathroom, whereas another congregation might mean that their facility is fully architecturally accessible and they include people with disabilities in all aspects of their community. Facing this disparity of meaning, the IDN is seeking to help congregations set a standard for being inclusive.

Through grants from the Robert Wood Johnson Foundation’s Faith in Action Program, and the Georgia Governor’s Council on Developmental Disabilities, the IDN is working to help four local congregations become fully accessible and inclusive of people with disabilities. Through this project, the IDN will be able to detail working models of inclusion among Christian, Jewish, Muslim, and Unitarian Universalist faith communities. Congregations from each of these communities have committed to working with the IDN over an 18-month period to: 1) document their history and current accessibility/inclusion status; 2) address any areas needed to increase accessibility/inclusion; and 3) begin a respite program to serve people with disabilities and families.

The IDN is in the initial stages of this project. Each congregation is starting the process within their community of forming the committees/taskforces necessary to implement these activities. Each congregation has also informally identified specific needs that respite related services could address. The Unitarian-Universalist congregation has 8-10 children attending their regular religious education classes whose parents have expressed interest in further support. They are brainstorming ways to offer respite not only to these parents but also to the larger community.

A local Jewish synogogue involved in the Inclusive Congregations Project is already involved in respite-related activities through the local Jewish services agencies. Yet they are talking with their youth group about volunteering monthly to help staff a respite home in the community. A local Muslim congregation is attended by 20+ adults with developmental and/or physical disabilities. They are planning to form a local support group that will allow them to encourage each other as well as provide their caregivers time for respite. Finally, a local Baptist congregation that sponsors a group home is looking to further their outreach by partnering with a masjid and synagogue, and jointly offering a community-wide respite program.

Obviously, respite is not the only service that congregations can offer people with disabilities and their families. It is the current focus of the IDN with these four congregations because of related grant stipulations. However these examples illustrate a point repeatedly learned by members of the IDN – inclusion of people with disabilities in faith communities is similar whether one is working with a church, synagogue, masjid, or other religious group. We all have different beliefs and ways of worshipping and serving. Yet, in each of these faith groups there exists a core commitment to allow all seekers to participate in the community and its search for meaning. Once this commitment to inclusion is recognized, congregations within all faith groups can grow in their ability to welcome and include individuals with disabilities. And through the work of the Interfaith Disabilities Network, Brian, his dad, and any other people with and without disabilities can have a place at the table of our faith communities.

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Incorporating Spiritual Supports Into Residential Services: The PSCH Model

by Terry Gleson

Years ago, a colleague of mine wondered aloud how many of the people with disabilities whom our agency serves attended religious services regularly when they lived at home with their parents, but stopped after they moved into “the system.” PSCH, Inc. operates more than 20 residences for persons with developmental disabilities, as well as day treatment centers, a clinic, and service coordination in New York state. The question remained in the back of my mind. I was reminded of it whenever I read reports in studies and magazines about the beneficial effects of faith on people’s physical and psychological health, and when I saw a documentary on the low incidence of dementia symptoms among some groups of nuns. In recent years, an enormous amount of research seems to indicate that people live longer, deal with stress and crises better, and experience a greater sense of meaning and purpose in their lives when they have some degree of religious faith, and belong to some sort of religious community. If faith and worship could enhance quality of life, shouldn’t it be part of our delivery of quality services?

At first glance, the idea seemed ridiculous: How could a secular, nonprofit organization get involved in such a deeply personal and private part of people’s lives? How could my quality assurance department rationalize this form of advocacy? How could I, as a quality assurance director, justify to the board of directors and the executive director this use of resources? I knew that whatever the answers, they would have to be grounded in the language and principles of the field of developmental disabilities: I couldn’t talk theology, only philosophy. I had to avoid the subjective and anecdotal, and concentrate on the objective and empirical. Surprisingly, the answers were not difficult to find, and emerged from three main sources.

Firstly, in New York state we are very familiar with the principles known as the 3I’s&P – that is, we strive to enhance people’s Inclusion, Individualization, Independence, and Productivity. As an agency, we teach these principles at staff orientation, we include them in our policies and procedures and our staff evaluations, and we particularly train our clinical staff to incorporate these principles in their work. It occurred to me that probably there was no better instance of inclusion and individualization than connecting a person to a worshipping community in that most faith communities are committed not only to welcoming strangers and newcomers, but also to seeing beyond those characteristics that tend to stigmatize people with disabilities in broader society. Individuals with disabilities might experience a much higher level of acceptance and integration in a worshipping community than elsewhere. Further, if faith is such a personal, individual phenomenon, then the expression of that faith could be seen as a radical form of individualization: when people choose to participate in a worshipping community, they make a public statement about their deepest selves.

Secondly, the process of person-centered planning not only pursues the same goals of inclusion and individualization, but it envisages creating quality relationships between persons with disabilities and people in the broader community. Ideally, these circles of support not only enrich people’s lives, but may also provide another layer of protection and advocacy. Once again, it seemed worshipping communities might reasonably be expected to provide possibilities for trusting friendship and advocacy.

Thirdly, our agency was vigorously pursuing self-advocacy programs for the individuals we served and training for staff, and even the briefest exposure to a self-advocacy program sensitizes people to the broad issue of consumer rights. Now on the list of rights that we hand to every person at admission, and to all staff during their orientation, it states that every person has the right to “observe and participate in the religion of their choice.” Surely, as service providers, our responsibility did not end with simply informing people of their rights, but had to extend to protecting and promoting those rights, and facilitating their exercise.

When I absorbed all these fragments of information, it seemed to me that if we are genuinely working for an optimal lifestyle for people with disabilities, then we should be doing everything we can to facilitate their inclusion in worshipping communities, and that certainly we could no longer pretend that this was not important. The strategies that we adopted subsequently changed the face of our agency. Five years ago, a handful of those we served attended worship services, and only then because they were taken by family members; currently, more than half attend worship services with some regularity, and most of them are taken by staff.

In analyzing how this was accomplished, I think that one of the most important elements was that the agency’s
administration communicated with one another and trusted one another. We could have achieved very little, if anything, if senior management was not a well-functioning team who listened to each other, and respected and supported each other. One of the significant features of this transformation was that it was accomplished by a relatively small group of people.

Nowhere was the power of this small group more apparent than in the area of staff training. The first area that we looked at was staff orientation, where staff were first introduced to the 3I’s & P and the concept of normalization; consequently, training materials were rewritten and trainers instructed to use participation in worshipping communities as an excellent example of inclusion and individualization. Similarly, self-advocacy training for individuals with disabilities and staff focused on the right to worship, and our internal auditors were instructed to inquire specifically of staff and those we serve about how this right was being protected. Residence managers were briefed at meetings, not only on the need to offer the option of attending worship, but also on ensuring that staff and transportation were available where required. The effect of this focused training was rapidly apparent: New staff arriving at their first assignment began asking why those they were serving were not going to church or synagogue. New managers just presumed it was normal to take people to worship and did so. Experienced staff who had wanted to take individuals to worship in the past, but did not feel that was permissible, now felt able to assert themselves. And, individuals with disabilities, returning from worship, began telling others about their experiences, sometimes even playing tapes and teaching them hymns. Within months, the number of individuals we serve who were participating in worship rose dramatically.

However, one of the difficulties of this initial success was translating it into more or less permanent structures. How could we sustain this phenomenon when management changed, staff were transferred or moved on to other jobs, or service recipients moved on to less restrictive environments? A number of tasks recommended themselves:

- It is a simple assignment to establish, in the admission package, not only what an individual’s religion is, but also their current pattern of worship. We found that prior to their admission, a number of people were accustomed to weekly, even daily, services of some kind, and no continuity had been established. This not only deprived them of their customary spiritual supports, but also the support of the communities in which they had participated.

- An agency’s policies and procedures can be rewritten to acknowledge the importance of each person’s spiritual life and to provide continuity in each individual’s pattern of religious worship, consistent with their right to choose. Further, the policies can remind staff of each individual’s human and civil rights to worship in the religion of their choice.

- An agency’s database can be developed to identify those individuals who are particularly vulnerable to being excluded from worship opportunities, a sort of spiritual risk assessment tool. Our experience revealed that those least likely to participate in worship communities were those with infrequent family contact, limited ability to communicate and to ambulate, and greater support needs.

The response from clergy and congregations has ranged from unremarkable to excellent. Prior planning and discussion has eliminated some problems with wheelchair accessibility, special arrangements, and participation. However, one dimension of this initiative remains problematic: How much of a church’s or synagogue’s instruction and worship are truly accessible to persons with intellectual disabilities? Mary Therese Harrington, in A Place for All: Mental Retardation, Catechesis & Liturgy, comments “Catechesis [religious instruction] without liturgy [worship] is dry and suffocating. Liturgy without catechesis is asked to carry more than it can bear.” Agencies can strive to deliver people to the door of the church or synagogue, but they cannot form and educate people in their faith; they cannot design developmentally appropriate services; they cannot ensure that people’s experiences are reflected upon and then connected to the lessons of Scripture, the cycle of the seasons, the lives of holy men and women, and the dynamics of the liturgy. It is precisely in this problematic area that worship emerges as a community responsibility in which everyone has to play their part. Agencies have to learn to value and promote the spiritual well-being of individuals who use their services, they have to pursue inclusion and individualization, and facilitate genuine relationships between people with disabilities and the broader community. However, there must also be people and places to welcome the vulnerable when they arrive, to greet them with respect and lead them by the hand to a place of honor, and to genuinely minister to their needs.

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Including All God’s Children: Rock Bridge Christian Church

by Rev. Maureen A. Dickmann

Woodhaven Learning Center was founded in 1964 to serve children with developmental disabilities. In a wooded setting on the outskirts of a university town, the campus provided residential care for an average of 100 children at a time. Many of the original residents grew to adulthood at Woodhaven. They acquired the skills necessary to maintain employment, some in a sheltered workshop setting and others in the wider community, returning “home” to the campus each evening. Their spiritual needs were attended to by Woodhaven’s chaplain, and Protestant worship services were held each Sunday morning.

By the early 1990’s trends in caring for persons with developmental disabilities had taken a decided shift away from segregated care facilities and toward integrating individuals into a more normal community life. The Woodhaven board of directors decided that moving from campus-centered care to decentralized housing with staff support would be in the best interests of the residents. Apartments, duplexes, and houses were secured and over a five-year period most of the residents moved into individualized living situations with staff support and supervision provided by Woodhaven. Campus chapel services were discontinued during this process, and some residents who had been faithful participants in the services were keen to continue Sunday morning worship elsewhere. The executive director invited them to attend her church, Rock Bridge Christian Church (Disciples of Christ), with her. Several eagerly accepted her invitation.

Rock Bridge, founded in 1981, is a small-membership church with a strong commitment to outreach (“serving the least of these, Christ’s sisters and brothers” — Matthew 25) and inclusivity (welcoming all of God’s children regardless of race, class, age, ability, etc.). When the first Woodhaven clients attended worship, they were warmly welcomed (as every visitor is) and urged to return again soon. They did. They also told their friends about the warm reception they had experienced and invited them to come, too.

As pastor, I visited with each one after repeated attendance indicated their interest in our church. I explored with them their faith journey (most had been baptized as infants or children at their parents’ home church) and whether they would like to become members of our church. Many were eager to claim Rock Bridge as their church home. As is customary in most Disciples churches, we offer an invitation to membership every week during worship. Individuals or families indicate their decision to join by simply coming forward while we sing our hymn of commitment. At the conclusion of the hymn, either they transfer their membership from another church or profess their faith in Christ as the Son of the living God. I welcome them into membership, the congregation reads a confirmation and support from their teammates, each team requires a little extra attention, and, for the most part, compliance – for a few weeks anyway.

Disciples celebrate communion every week. Deacons have responsibility for preparing and serving communion as well as collecting the offering. In a 1995 meeting with our nominating committee, I suggested that a particular Woodhaven resident would be capable of serving as a deacon. The committee responded with enthusiasm, knowing how honored this individual would feel and what an important statement her service as a deacon would make about the full inclusion of persons with developmental disabilities in the life of our church. She was overjoyed to become a deacon and will start her third term next January. In each of the subsequent two years, another Woodhaven resident has been added to the rota of deacons so that there is one on each team (a team is comprised of four individuals who serve a total of four months throughout the year). Having a Woodhaven resident on each team requires a little extra attention and support from their teammates, who have been glad to offer that because of how much being a deacon means to each of the Woodhaven folks and to our worshiping community.

In addition to serving as deacons and participating so broadly in the opening of worship, Woodhaven members are also active in other ways. One serves regularly at the local soup kitchen. He cooks and serves dinner to 50 homeless people with the help of a friend who was formerly one of the support staff at his home but who now works at another Woodhaven residence. Their friendship...
continues to grow through serving others. In fact, this Woodhaven resident was very instrumental in his friend's choosing to join our church, too, and he is now an elder and board member. He has spoken of how the loving embrace of Woodhaven residents in our faith community is what made him want to give "organized religion" another try. He's not the only Woodhaven staff person who has been persuaded to join our congregation due to the heartfelt invitations of our members from Woodhaven. Their unbridled enthusiasm, devoid of the self-consciousness that inhibits some of us, makes them the best evangelism activists a church can have.

Their participation across the life of the church, from bringing food to share in our fellowship potluck dinners to helping with annual church clean-up days, to all the other ways they take part has had a transformative effect on our congregation. I won’t say there haven’t been occasions when my patience has been tried and we've had to confront challenges but, on balance, we’ve been blessed by the gifts they bring: simplicity, enthusiasm, faithfulness, genuine compassion, openness and warmth – these are qualities any faith community gives thanks for in its membership. Welcoming Woodhaven residents into the full life of our faith community has helped Rock Bridge Christian Church discover the kingdom of God in our midst.

Robert's Story

My name is Robert Morrow and I have been a member of Rock Bridge Christian Church since 1995. I like the people there because they are happy and I am, too. Every Sunday I greet people there. Now I know everyone's names and they know me, too. Sometimes I take care of people's dogs when they go out of town. I've been a deacon for four years. I help pass the offering plates and bring them to the communion table. Then we serve communion to all the people. One month out of the year I get to prepare communion: I put grape juice in little cups and put them in trays. After worship, I wash the cups. It's fun to wash the cups and it helps our church. Sandi is my deacon partner. We help each other.

Our church cooks and serves dinner to 50 people at a soup kitchen two times every month. Over two years ago, I started helping cook and serve with my friend Bill. He used to be the staff person at my house and now he goes to my church, too. We fix noodles and salmon and jello and put them on plates for the people who come to the soup kitchen. They thank me. Then I wipe the tables and sweep the floors, which I learned how to do at work. (Note: Robert is employed by Alternative Community Training, a nonprofit organization that provides supported employment).

I like being a member of Rock Bridge Christian Church because I have many friends there and because I like to help other people. I get to do that when I'm acting as deacon and working at the soup kitchen. I also love to sing at church and enjoy refreshments with my friends at coffee time after worship.

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AAMR Statement on Spirituality and Religious Freedom

The following policy statement was adopted by the American Association on Mental Retardation (AAMR) in 2001. It is excerpted here with permission:

Spirituality is an important part of human experience that may be expressed both through religious practice and through expressions of personal meaning and values. Spirituality and religious preference should be part of any holistic, interdisciplinary assessment of individual and family needs, interests, and strengths.

Spirituality, spiritual growth, and religious expression are rights that should be honored by supports from service systems and religious communities that respect a person's history, tradition, and current preference or choice.

Faith communities and other community expressions of spirituality may also need support and assistance to build their capacity to welcome and include people with disabilities and their families.

The need for meaningful supports that respect and honor spiritual needs and religious preferences in both service systems and faith communities represents an important opportunity for partnership and shared responsibility between provider agencies, advocacy organizations, and religious communities.

Training and education regarding spiritual supports for people with mental retardation and their families should be provided within both public agencies and spiritual communities.

The complete text of the policy statement can be found on the AAMR Web site at www.aamr.org.
gave a good deal of thought to attending a Lutheran college like Capital University and majoring in religion, but at the time the school was not accessible and so I decided on Ohio State. Ordained ministry remained in the back of my mind, but it just didn’t seem like a good choice because women were only beginning to be ordained, and most church buildings I knew of were not anywhere near being physically accessible.

At Ohio State I majored in English Education. The university is totally accessible and I literally encountered no barriers in my four years. The one life-changing thing that did happen during that period of my life was the death of my father. It was one of those moments that made me even more determined to do the best I could for myself “in spite of my disability.” When I graduated from college I began to look for a job in teaching, naively assuming that I wouldn’t have any problems related to being differently-abled. Wrong! I went to the first several interviews without telling them I am differently-abled, and the reaction was “Well, we didn’t know you were handicapped” as if that were the end of any possibility of my being a good teacher. Eventually I began to sub for a school system close to where I was living and then became a permanent part of the staff.

I taught for about three years then went to graduate school for a Masters in Rehabilitation Counseling. Upon graduation I was hired as a counselor at a large hospital in Columbus, Ohio, where I worked for the next couple of years. In 1989, I reached a crossroads in my career. Due to budget cuts people were being laid off. I was one of the chosen and found myself either needing to find a new position in the same field or look for something new. I began the interview process, but there was always some reason I didn’t get the position. Was God trying to tell me something? One day I went to talk with my pastor and he asked me a question that was hard to ignore: “Is it possible God is calling you to something else?” It was the first time I allowed myself to think of being a minister. Could I do it? One day, on the spur of the moment, I went to Trinity Lutheran Seminary in Columbus, Ohio, and talked with the admissions officer. I had a tour, looked over the courses, talked about financial aid, and before I knew it I was enrolled as a student in the summer Greek program. Looking back on that period of time I realize God wasn’t just calling, God was pushing!

The four years of my seminary education were the happiest and most fulfilling I had known to that point. I made dear friends, received affirmation of my call to the ordained ministry, and best of all learned to see myself as a gifted person “because of my disability.” I can’t say that I was totally supported by everyone I knew in my decision to go into the ministry. Some of my friends and even some of my family thought I was crazy to do this. How do you explain to someone “I just know this is what I am supposed to do”? It is a very personal experience and almost impossible to convey in words.

In my senior year, I encountered my only true moment of opposition. Each of us had to have a final interview with our candidacy committee which would determine if we were approved for ministry. When I went through my interview I was told they were going to delay my approval because one member of the committee didn’t feel I was “Lutheran” enough in my theology. For once my radar was up and I suspected that the delay had more to do with my disability than anything else. Well, when you give me a challenge I will meet it head on, so I did all the extra work I was asked to do and was eventually approved for graduation and ordination.

I waited about 14 months before I received a call to serve as the pastor of a small town congregation in northwestern Ohio. I served there for nearly five years. It was a time of great growth for everyone involved. For me it was a time to deepen my spiritual life and my dependence on God. It was also a time in which I grew and became more self-confident as a person. There were of course difficult times, but with the help of God we were able to accomplish a great deal.

In 1999, I received and accepted a call from the Evangelical Lutheran Church in America (ELCA) church-wide offices to serve as its Director for Disability Ministries. It was overwhelming and a little frightening at first, but I eventually began to feel comfortable in this work I had been called to. In my position, I work with all aspects of the ELCA in helping them to understand how to effectively reach out to persons with disabilities. In the three years I have been in this position, I have seen great strides made by the ELCA in including persons with disabilities in all aspects of the church. There is still a long way to go in creating a totally inclusive church for all people with disabilities, but the work towards that goal continues every day.

I am very fulfilled in the work I do. It is an exciting thing to know you are changing the lives of people, including people you will never meet. Most important to me, though, is that I am sure the Holy Spirit is at work in my life. I believe that God called me to this place, and with God’s help I will continue to do effective work until I am called to another place.

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doing, this disabled God is also the revealer of a new humanity. The disabled God is not only the One from heaven, but the revelation of true personhood, underscoring the reality that full personhood is compatible with the experience of disability. This disabled God understood the experience of those in my Shepherd Center Bible study as well as my own, and called for justice not from the distant reaches of principle, but by virtue of God’s incarnation and ultimate knowledge of the uncertainties and accidents of human existence.

This encounter with the disabled God was the source of the liberatory theology of disability that I have written about in the book, *The Disabled God*, which calls both for justice and for the recovery of vital Christian symbols and rituals (Eiesland, 1994). This theology is now increasingly read by liberation and feminist theologians as well as growing numbers of ministers and lay persons who have disabilities or are temporarily able-bodied. It identifies that although sometimes Christianity continues to buttress prejudice and exclusion, it can also foster vision and commitment to change toward a better society, a more adequate theology of humanity, and a model of the church in which all participate fully. In promoting this vision, we also counter the prevailing sentiment that the religious practices and history of the able-bodied constitute the only relevant spiritual pulse and narrative, and that whatever is outside this ambit is of little, if any, significance.

A liberatory theology must support reflection and action to promote justice for people with disabilities and the temporarily able-bodied. What is justice? While we may all have definitions, I contend that justice and just action are primarily virtues and practices of full participation, of persons deliberating about particular visions of human flourishing (fullness of life) and working together to remove barriers in their institutions and relations so that they embody reciprocity and mutual appreciation of difference. Thus justice is first about just listening. Not simply listening, but listening for the claims for justice made in the process of everyday life.

Just listening means attending to the ways in which everyday talk (and sometimes commonly accepted silence) makes claims about justice. They are not theories to be explicated or fully developed agendas to be followed, they are instead calls, pleas, claims upon some people by others. Personal and social reflection on the demands of justice begins in hearing, in heeding a call rather than in asserting and mastering a state of affairs. The call to be just is always situated in concrete social and political practices. Too often temporarily able-bodied people have been eager to devise strategies of response to what they deem as the unhealthy lives of persons with disabilities, before they have just listened. They have attempted to speak for us, deciding how and where we can best serve God, before they have just listened. They have pronounced us sacra-ments of grace, without listening to our fierce passion to be participants not sac-raments. The process of examination of church and society must begin with listen-ning, hearing the calls for justice ex-pressed by people with disabilities who are among us.


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