

Signs of the Times: Theological Themes in the Changing Forms of Ministries and Spiritual Supports with People with Disabilities

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If you ask a family with a disabled child or member, or an adult with a disability, to “tell me your church stories,” and if you are trusted, the response is rarely lukewarm. Some will talk about how important their faith or congregation has been to them. Others will tell you how painful and wounding their experience was. That’s why trust is important, because responding truthfully about an issue around which there are powerful feelings, beliefs, and experiences is not an easy thing to do. You may be walking on holy or hellish ground.

In listening to those stories in the past few years, I think we are at a new point in the development of inclusive congregational and religious supports. The new era has many promising signs and some dangerous ones. It also is a time when families, people with disabilities and leaders in congregations are beginning to interpret their experience through the sacred scriptures, symbols, and traditions of their respective faiths. That’s a crucial step, for it means that people who are advocating and working for more inclusive congregations can understand their experience as living out ancient understandings of faith. Including, accepting, and celebrating the gifts of everyone and the diversity of humankind is thus not something new, but rather a response that represents the best of religious traditions and beliefs and illustrates the heart of key theological issues.

Signs of a New Era

Here are a number of word snapshots of experiences and stories:

- Many services for children with disabilities started in church basements. Most have moved up and out, and in congregations there is a new focus on accessible spaces, altars, even pulpits that change their height to fit the person behind it.
- More than 2100 congregations have signed up to be part of the Accessible Congregations campaign, coordinated by the National Organization on Disability and its Religion and Disability office led by Ginny Thornburgh. They have distributed more than 70,000 of their excellent introductory guide for congregations, *That All May Worship*, and helped sponsor several hundred conferences around the country.

- The written resources for congregational ministries have multiplied many times over, with good resources for religious education, outreach and worship, and new ones in theology, pastoral care, and seminary education. (See the 180 page resource guide, Dimensions of Faith, http://rwjms.umdj.edu/boggscenter/products/prod_info.htm#dimensions.)
- Some congregations are attributing their growth to their outreach to, and inclusion of, people with disabilities and their families, while they even more quickly celebrate the renewal of spirit that it has brought to their life together.
- Congregations and religious services are making the connection between supports for people with disabilities and people who are elderly, and supports for family members who are 24/7 caregivers. Faith in Action grants through the Robert Wood Johnson Foundation have helped start hundreds of interfaith volunteer caregiver programs. Respite care is no longer a foreign word.
- In some new churches, rooms off of sanctuaries are being utilized, not to take people out of the sanctuary, but to bring them as close as possible, while also taking care of other needs, like having a nurse with them, going to the bathroom more frequently, or addressing other needs.
- When a diocesan task force on accessibility brings a resolution to an annual conference that by a certain date, every congregation should be accessible, or if not, then take down the “Everyone’s Welcome” on their front sign, you know that a new era is happening. (P.S. It did not pass, but it got people talking, thinking, and working. A subsequent resolution did pass, one that committed the Diocese to holding Diocesan meetings only in buildings that are accessible.)
- A parent leads a presentation to future priests and clergy about the importance of inclusion of children with disabilities in parochial schools, and says that if they are not prepared to support the inclusion of their child in the parochial school, at all levels, that is a violation of a baptismal promise. Or, stated more forcefully, “if you are not prepared to support the inclusion, then don’t baptize them.”
- Other parents of children with disabilities report stories of moving to a new community and church shopping, or doing so as they decide to try again within their own community, and they find a congregation where the welcome mat is out, the supports in place, and/or simply asks, “What do you need and want?” Some parents are so used to having to fight for inclusion, they are not sure what to do.
- Policies and statements about faith communities and people with disabilities have been passed by many individual denominations, but also by the National Council of Churches, ecumenical organizations like the Rhode Island and Massachusetts Council of Churches, and the US Catholic Bishops. Others about the about the right to religious expression and spiritual supports have also been developed by national advocacy and professional organizations such as The Arc and the AAMR.

- A variety of networks around religious supports for and with people with disabilities and their families are growing, both in North American and internationally. (See histories of major networks in Herzog, 2006).
- Faith supports and religious inclusion is beginning to attract researchers from both within faith traditions and from the perspectives of social and health sciences. One sterling project (pun intended) is a national project called “A Space to Listen” in the United Kingdom, funded and led by the Foundation for Learning Disabilities, and focused on what people with learning disabilities (UK word for intellectual disabilities) think about their own spirituality and faith, and what support agencies can do to help support them (Swinton, 2002).

Caution and Warning Signs

But the signs are not all good. Neither are the stories. Some continue to haunt me. A parent responded to one of my “Spiritual Journeys” columns in the national Arc newsletter, *Insight*. She had worked hard to involve her son with autism in the worship life of the congregation, practicing at home, and then taking him to church. His noises became problematic, and she moved with him to the rear of the church, then into the lobby. There, she noticed that while his speech and sounds were not intelligible, they were mimicking the pattern and cadence of the litany and liturgy. It was then that a deacon came up and asked them to leave because of the ongoing disturbance. The irony was that the scripture reading for the morning was about welcoming the stranger and those who are different.

Many congregations have not yet begun to address the possibilities of inclusive ministries and faith supports. Nor have professionals and service organizations. That inertia or reluctance is shaped by a number of issues and barriers:

- The equation of faith with reason. We know that the capacity to love does not depend on reason, neither does hope. But sometimes faith still gets linked to intelligence and the capacity to understand the more abstract parts of faith and religious tradition.
- The use of church/state separation to justify avoidance of spiritual issues by “secular” service and support organizations.
- The polarization of science and religion that leads to powerlessness by health and human service professionals in their capacity to handle matters of spirituality and faith, even if they know those are a major resource for an individual or family, and a refusal by some in the faith community to see God at work in the gifts of scientific understanding.
- More ominously, the ways in which children and adults with disabilities become the “canary birds” of ethical dilemmas, the people around whom ethical issues of treatment and resources are raised because of assumptions and judgments about their quality of life. (“Canary birds” were often sent into a mine before people, to see if the atmosphere was clear of poisonous gases.)

Those issues and barriers, and the negative stories that many individuals and families may still have as they search for a congregational home, should not keep us from celebrating the good that is happening. To use Biblical imagery that is familiar to both Christians and Jews (in what one could call the first sermon on accessibility in the Bible), there are indeed “ways being made straight in places that have been deserts, valleys being exalted, mountains and hills being made low, crooked ways straight, and the rough plains smooth.”

Reframing the Journey

There are at least three implications of this growing shift. First, it is crucial that the new examples and stories be told and celebrated, for they inspire others to action and help inclusive ministries to become the norm rather than the exception. Second, the next significant wave of inclusive ministries and supports will come when individuals and families (including many who have been excluded in the past) have the courage, forgiveness, and chutzpah to try again, and do so with a commitment that they should not have to justify inclusion, but rather, have a right to belong as much as anyone else. Third, a new era of worship opportunities for and with people with disabilities highlights issues and themes that are not just about “them,” but about us, all of us, everyone.

As more and more people of faith come to understand the implications of inclusive ministries and congregational supports, there are deepening ways of understanding the spiritual and theological significance of this frontier. It happens when people begin to connect new ministries with ancient themes and images of scripture and faith, and begin to understand that faith communities may not be doing something new as much as they are recovering age old traditions. They are discovering that sacred beliefs are understood yet anew by being the people of God, at whatever level of ability or disability, in prayer, praise, and play together. Different traditions and faith communities will have different images, but let me share six that have been important to me as I seek to understand the impact and meaning of inclusive faith supports. To reemphasize, these are themes and images that are not just about people with disabilities, but about all of us.

Hospitality to the Stranger

Congregations have begun to move beyond “special ministries to special people” to recovering the ancient call for hospitality to the stranger as a foundation for accessible, inclusive, and welcoming communities of faith. In a so-called “normal” world, people with disabilities are often the prototypical “stranger,” even beyond the “strangers” of race, creed, and nationality. Children and adults with disabilities often feel like “strangers” within their own communities, even where all other traits are shared. Faith communities are recovering the call to welcome the stranger as a core tradition of Jewish, Islamic, and Christian faiths. In the Bible,

that call ultimately is not about what the host does for the stranger, but how the stranger, over and over again, brings the presence and spirit of God to the host.

Parker Palmer (1986), an author and teacher, with a number of books about spirituality, education, and community, cited this call to hospitality as a fundamental building block of community in a conference entitled *Merging Two Worlds* in Rochester. He noted that there are several reasons why a Biblical faith calls us to welcome the stranger in addition to the awareness that the stranger often bore gifts from God:

- If the world (or my congregation) is not safe for strangers, it is not safe for me. For I am always a stranger or could be, to someone (s) else.
- Strangers save us from a fundamental danger of modern life, boredom. Being all the same is often boring. (Conversely, an assumed homogeneity often hides real differences.)
- A recognition that there is both diversity and unity at the heart of creation, a “hidden wholeness,” as Parker Palmer cited Thomas Merton.

The question now is often not how congregations are welcoming to people with disabilities, but how they are welcoming to anyone who is a stranger.

Re-Membering the Body

When people who have been excluded are now included, what faith communities are doing are doing is “re-membering them,” helping them become members again. A young teenager at a synagogue in New Jersey gave a Youth Day sermon the same day that several adults with multiple disabilities from a nearby developmental center were celebrating their bar and bat mitzvahs. His task was to speak from the readings for the day, the very boring parts of Numbers that recite the census of the various tribes of Israel. Then he made the wonderful connection, that what the synagogue was doing that day was making the point that these adults with disabilities were being counted again as “one of us.” Jason Kingsley and Mitchell Levitz (1994) two young adults with Down Syndrome, made the same point with the title of their book, *Count Us In: Growing Up with Down Syndrome*.

When a child or adult with a disability participates like any other in the rites and rituals of transition and membership, such as baptism, confirmation, First Eucharist, bar and bat mitzvah’s, they are being “re-membered.” When people with disabilities are invited to join as full members, not just attend, they are being “re-membered” as part of the body of the people of faith.

There are powerful stories in the New Testament, for example, of the power of doing that for one person, such as the shepherd going in search of the one, leaving the ninety and nine. It is a move from a person being “apart from” to being “a part of” a community of faith.

In theological terms, when a person or people are saved from isolation, from being oppressed or enchained by stigma or environment, from being seen as a person with no gifts or rights (outcast) to being a contributor, then there is an ancient word for that kind of re-membering...redemption. If it is about moving past wounding experiences that a person or family might have had in the past with their clergy or congregation, to a new effort to include, a move beyond experiences of either neglect, or in some cases, spiritual abuse, then there is another ancient name for that kind of re-membering that includes forgiveness and reconnection...reconciliation.

Restoring the Sanctuary

Inclusive and accessible congregations often focus on architectural accommodations. Those are important, but not nearly as important as the attitudinal accessibility and welcome. Where, for a child or adult with a disability, and their family, or for anyone, is their safe place? The place where you can be just who you are? Where is the place for you to come with all of your gifts and needs, strengths and weaknesses, abilities and vulnerabilities, and be known and loved “Just As I Am,” an experience that for many is “Amazing Grace” and acceptance, to be valued for what you bring.

A father of a young man with Down Syndrome tells me about his son and the role he plays in their church and the religious life of their family. He notes, “Our sanctuary would not be the same without him.”

For most children and adults with disabilities and their families, that place has not been their church, temple, or synagogue. A place is not safe if you can't get into it, but more importantly, it is not safe if the stigma, attitudes, prejudices or fears about you follow you from the “world out there” into the religious sanctuary. When those stigmas or fears are given divine power, or a disability is seen as a lack of faith, then it is even less safe.

A young man with Down Syndrome seeks to be baptized in his congregation. The pastor misunderstands his desire, and thwarts it with a statement that “he doesn't need to be baptized, he is already there,” meaning he is not really responsible and would not understand. He and his mom do not give up, and after some re-education, another pastor on staff holds a baptismal ceremony for him, but a private one only with family and friends. When he comes out of the baptism immersion, someone notes the ring around the baptismal pool, whereupon the young man notes, “That's my sin.” He got baptized, but the whole congregation lost out on being part of a sacred moment that would have renewed everyone's understanding of baptism.

In the books of the Torah and Biblical tradition, claiming sanctuary was a freedom available in seven towns to those who felt that they were being unjustly

accused. As congregations learn to help their worship space become safe as well as welcoming and accessible, perhaps the role of a sanctuary is being restored for everyone! At a conference in New Jersey several years ago, I heard George Gallup, the pollster, comment on the huge number of support groups of various kinds who met in church basements. The challenge, though, was for the “church upstairs to include the church downstairs,” i.e., to help make the faith community a real sanctuary for everyone.

Recovering the Gifts

When the sanctuary is there, a person or family knows it and feels it. It is like the words of the song written by Tom Hunter in his album of songs written in collaboration with The Beach Center for people with disabilities and their families called *Connections*: “It is awesome to be surrounded by people who are not sorry, by people who are not sorry, for what you cannot do.” Moving beyond pity is the first step. Looking for what someone can do, and celebrating that, is the second.

When people begin to look at children and adults on the basis of the gifts and strengths they bring, not just on their needs, then a congregation is beginning to practice what is the best of person centered planning, and what John McKnight and John Kretzmann (1993) would call “capacity vision.”¹ It is really the shared interests, abilities, skills, and strengths that connect us.

Congregations who have been welcoming and inclusive often come to the point of saying, “We are not doing so much for them, but rather, they are doing a whole lot for us.” Part of the transition here to a new era is then focusing more on gifts and interests. The pathways for connections and relationships are not built on the paradigm of disability/ability but on shared values, visions, interests and gifts. One of the simple yet profound ways that some Catholic families have told me they have been included is to be able, as a family, to “bring down the gifts,” i.e., carry the bread and wine to the altar for the Eucharist. When we see gifts in everyone, whatever the size (think of the story of the widow’s mite), then there is no gift that a congregation really does not need, or should not be able to find a place to use, if it puts its creative imagination to work.

Reversing the Call

The importance of capacity vision, and celebration of gifts, is because the real question for people of faith is not how so called “typical” congregations are called to welcome and include people with disabilities, but how all of us, people with disabilities included, are to respond to our understanding of God’s call in our own lives as a individual and as member of a people of faith. How does each person respond to the obligations of mitzvah, the call to discipleship, the practice of the five laws, or however “call” is understood in a particular religious tradition that one embraces?

A woman named Cathy MacDonald was my first teacher on this, many years ago, at one of the first-ever conferences on inclusive congregations which I helped organize. As she told her story about being sent to a large old state institution because of her cerebral palsy, her move out through group homes and then to her own apartment, she ended with the call to all of the audience “You know, it is really important for you to be nice to handicapped people, but it is more important for you to let them be nice to you.”

In the Christian tradition, a statement is often made that it is “more blessed to give than receive.” If most people are honest, it is also easier. People of faith are taught to be givers, to be helpers, contributors, stewards, committee members, followers, and disciples. It is harder for everyone to admit wants, or reveal needs, places where one would like to receive. When children or adults with disabilities are seen as the “designated receivers,” the ones who only need, without gifts to give, then congregations fail to allow everyone the dignity, right, and responsibility to give to others out of their own sense of call. In recent years, there has also been a renewed focus in some seminaries not just on how issues related to disability are included in the curriculum, but also on how people with disabilities may also be called to roles of ministry and service.

Think of the loss, to everyone involved, if the following had not happened. A young man with Down Syndrome is invited and trained to be a church usher in his Catholic parish on the Jersey shore. Who comes to church on one of his first Sundays of service? A man and woman, new grandparents, coming to the church for the first time in a long time, just after the birth of their grandson with Down Syndrome, coming to seek sanctuary, solace, and understanding for the questions that were reverberating in their lives and souls. Think of what it meant to be a greeter, and be greeted, on that morning. (And not only greeted, but talked with, for a long time, after the service.)

Recovering Our Senses

As congregations practice inclusion with people with many forms for sensory and motor impairments or disabilities, then what happens? Congregations learn new forms of communication and connection that help everyone to move beyond the spoken, heard, and read word which literally helps everyone recover our senses of feeling, sounds, movement, taste, and touch.

As people with intellectual disabilities are included, worship sometimes has to become more spontaneous, with places for simplicity and spontaneity. Who enjoys that? Usually everyone. A rhetorical question asked by a clergy person in a sermon may get an answer, and one many wish they had given!

As congregations make their sanctuaries accessible and welcoming, who comes back? Sometimes it is the older people or others that have been called “shut-ins”

but may have been “shut-out” by barriers of attitude and architecture. Rabbi Dan Grossman, of Temple Adath Israel in Lawrenceville, New Jersey, tells the story of how their new building, built to be as accessible as possible, enabled a 90+ years member to come back to services at least once a month. She could not get into the old building. When she died, the family was able to have the funeral at the new sanctuary. And it turned that that woman, and her husband, had kept the synagogue alive during the depression by paying the mortgage. It was indeed a “re-membering.”

When a congregation uses a sign language interpreter, for many it seems like a form of liturgical dance that “typical” people enjoy watching just as much. A simple movement version of The Lord’s Prayer which I used for years in services with people with intellectual disabilities is even more profound for those who have said the words for decades, and now learn it in a new way. In a new era of technology, a phone line can be built right into a pulpit, so that someone who is truly shut in by illness or disability can hear, and share their voice, in the service.

As congregations learn to include people with visual impairments, people often are challenged to recover their use of touch, and the simple power of a guiding hand or elbow.

As readers you can cite more examples out of your own experience. The possibility is that the use of color, taste, touch, sights, sounds, symbols and actions that speak beyond words helps communal worship and life to become more alive. When a sanctuary is really safe, then all feelings are welcome, and even the scars and stigma of emotional and psychological illness can be addressed and soothed. The growth that occurs may be the community’s confidence that it can indeed embrace and sustain people with many forms of disability, both visible and invisible.

Rekindling the Spirit

In the last decade or more, there has been a growing awareness of the importance of the role of spirituality in health, health care, and human services (see, for instance, Weaver & Koenig, 2006). A wide variety of “spiritual assessment” tools have emerged in different areas of health and human services to understand and utilize the role that a person’s spirituality may play in their care and recovery (Hodge, 2005). That trend, along with the movement away from a “medical model” of disability to models of diversity, empowerment, person-centered planning, and inclusion, leads to a gradual emergence of a language that enables “secular” services and supports to pay closer attention to the role of spirituality in the lives of the people they support. Indeed, it also leads to a greater awareness of the role of spirituality in the lives of professionals and caregivers, as well as the people supported and served (Gaventa, 2005).

It's About All of Us

From hospitality to remembering to restoring sanctuary to celebration to reversing the call to recovering the senses, a new era of worship opportunities made possible by inclusive and accessible congregations is not thus just about children and adults with disabilities and their families, but about all of us. The stories are not just about disability, but in fact become modern parables for the faith traditions and communities in which everyone lives.

If congregations truly are becoming communities of faith and worship where everyone's presence is welcome and wanted, where pain is received and relieved, strengths sustained, gifts called forth and used, and vulnerabilities are seen not as a sign of sin, but as a reminder of the gift of grace that can work through all of God's people, then there really is a new era to celebrate...for all of us.

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Published in on-line journal, Fall 2006 Disability Studies Quarterly Fall 2006, Volume 26, No. 4