Networking and the Mission of the Church, at Home and Abroad

Worldwide, people with disabilities, their families and supporters are all dealing with wider societies in which “the disabled” are often one of the most marginalized groups. The common goals and values of disability movements around the world, i.e., independence, productivity, inclusion, equal rights, dignity and self-determination, have been codified in national and global documents like the Americans with Disabilities Act and the UN Declaration of the Rights of People with Disabilities. In many countries, people with disabilities yearn for that kind of public and legal recognition.

Thus, people with disabilities, their families, supporters, and advocates often share common frustrations about social, legal, and economic barriers that cross boundaries of ethnicity, nationality and religion. That does not mean that the struggles are all the same. To use a parallel example, many of us involved in ministries with people with disabilities will recognize a moment when we or others say, “You know, we are all the same. We all have a disability.” That may be true at one level, but the desire to affirm connection may be done too quickly. It is first of all careless language, because it usually comes from people whom no one else would call “disabled.” The deeper bond is everyone’s vulnerability and limitation. Second, I may have a hidden disability, but the struggle in my life is not the same as someone with multiple disabilities who needs the help of others in dressing, eating, moving, speaking or getting to, much less into, church.

More accurately, the bond between people with and without obvious disability may be shared experiences of isolation or rejection and a yearning for inclusion and belonging. Context matters. Progress can be measured in many different ways. We may be, as genetic studies suggest, more than 99 percent the same around the world. We share common stories as humans, but each person is also unique. Some struggles and needs simply pale beside others. Our mission means thinking globally and acting that way through missions, but also acting locally, or even parochially, to minister to and with the disability
community and society in which we are planted. Together we can address needs right in front of us or hidden in plain sight.

**Challenges Facing Disability Ministries**

Enter then the Christian church and other religions, in all their diversity of forms and differences. In the wider world of the “disability community” and the private and public (sometimes called “secular”) world of supports and services, churches and faith communities have unique and powerful roles which, like other human “service” organizations, can be used either to help or to harm. This paper will explore three “worlds” in which disability ministries in the Christian church operate: (1) the wider world of churches and other religions; (2) the huge assortment of support networks and advocacy organizations in different areas of disability; and (3) the often confusing array of public and private service organizations. The church can play a pivotal role in clearing a path through the maze and bridging these worlds, so that together, we can all build societies in which people with disabilities and their families can participate as true citizens as well as members of the Body of Christ.

First, then, let’s explore some of the challenges in each world that may hinder partnership and collaboration.

**Barriers to Collaboration in Faith Communities**

Anyone involved in disability ministries knows that churches or other religious organizations can mirror the social attitudes of the community or society in which they live. Stigma, fear, prejudice, discrimination and/or patronizing attitudes do not stop at the door of the church. The church may not feel at all like a “sanctuary.”

Religious communities can make those attitudes even worse by using God’s name to justify them, such as through the common questions of “Why?” or “Who’s responsible?” Two scenarios embody these questions in multiple ways, either explicitly or implicitly. The first is when people with disabilities and/or their families are asked the same question that the disciples asked Jesus in John 9: “Tell me, who sinned, this man or his parents?” “What did you do that God sent you this disability?” The second reflects our inability to help or fix: “If you or we just prayed hard enough, or if your faith was strong enough, you could be healed.” Both questions are usually not asked of people with other physical maladies like cancer, for example. Both usually lead to feelings of being judged, cast out, and abused rather than welcomed and included. Variations of these stories happen in every Christian denomination.

Advocates for inclusive ministries often face the assumption, “We don’t have any here.” That may be true, but the next question is, “Why not?” Statistically, it is improbable that a congregation with 100 members would not have someone with a disability, or who has a family member with a disability. It becomes a vicious cycle, i.e., individuals or families have not felt welcomed, much less been invited or sought out, so they don’t come. “Shut-ins” may feel “shut out.” Too often they enter the growing ranks of the people who identify themselves as “nones” on surveys of religious affiliation.

The question for many clergy and congregations is about their lack of ability or capability, expressed by a lack of training, appropriate resources, and/or funds. (Note the irony—a feeling of “disability” about being able to deal with disabilities.) Ginny Thornburgh and Joni Eareckson Tada are leaders who have noted that accessibility and inclusion do not start with architecture and funding, but with changed hearts and attitudes. The Rev. Sue Montgomery, a Presbyterian pastor in Pennsylvania who uses a wheelchair, draws a parallel between “families.” A family impacted by disability rarely has any training
before encountering disability. They have to respond and learn as they go. Any church that describes or prides itself on being a family can do the same.

Barriers to Collaboration for People with Disabilities and their Families

The experience of disability, whether at birth or acquired, raises profound questions about faith, hope, and love. If you have not heard them directly, just ask any group of individuals or families, when you are trusted, to “tell you their faith story.” The response is usually one or more of the following three: (1) our pastor and church were just incredible; (2) God really helped us through and continues to do so, but God’s people never showed up, or (3) We reached out to our pastor and church, but the questions and attitudes drove us out, or worse, we were asked to leave.

At a recent small conference in Lancaster, Pennsylvania, the key speakers were individuals with disabilities and their family members. Two mothers of children with disabilities, one with autism and the other with psychiatric disabilities, relayed their faith journeys, which included being asked to leave a church—seven times for the first mom and thirteen times for the other. The first woman shared how she persevered until finding a welcoming congregation. In the second story, the grown son with mental illness got involved in a new church plant, and invited his parents back in. The obvious (albeit judgmental) question here is, “Who showed the greatest faith?”

Advocacy groups, parent networks and social service organizations may thus become the places where individuals and families believe the only real help can be found. To paraphrase a beloved psalm, “I lift my eyes unto the hills, from whence does my help come?” It comes from the Arc, Parent to Parent, People First, the state, you name it.” The underlying question is, “Who do people with disabilities feel like they belong to and with?” Those support and advocacy networks become, in essence, the community where their voices are heard, needs addressed, and gifts used. In other words, those networks effectively become their church.

Barriers in Social and Human Services

Far too often, people of faith take as gospel truth the stereotype that social service organizations, schools, and advocacy groups are “secular” institutions, with “godless” mindsets, maybe even hostile to faith. Truth be told, they are secular, in that they are funded by public supports, whether taxes or charities, with a mission to serve everyone, with or without faith. They understand that they cannot proselytize. But that does not mean that faith and religion do not play a huge role in the work they do.

First, there is no telling how many professionals or leaders in those arenas do their work because of their faith and sense of calling. Young people often find and live out their sense of calling to help others and/or make a difference in a helping profession or organization that is not, and cannot be, explicitly religious. There is a great void when it comes to opportunities for these professionals to explicitly share ways that their personal faith informs and supports their work or vice-versa. In my own work within a number of these professional networks, I have often found real appreciation for those who have worked to make explicit the often implicit issues of spirituality, faith, and religion. For example, the respect given to Jean Vanier, Henri Nouwen, and the L’Arche communities goes far beyond the Roman Catholic world and even religious world.

Second, the sense of professional vocation in human service may have been born from growing up in a faith community. Many young adults go through a stage of doubt; searching and/or wandering that is not received or welcomed by their childhood faith community, but rather leads to labels
as prodigal sons or daughters. The result is a conscious or unconscious decision, “If I am going to serve others, it will have to be through some other path than the church.” They move into professional disciplines where the language of helping is so different than that of ministry, especially when perception, truth, or practice is based on the foundations of scientific research and theory. Through their training and in early roles as helping professionals, they may also run across people with disabilities, family members, and other professionals who share similar stories, thus reinforcing feelings of disenfranchisement from faith.

Third, these professionals move into human service organizations where the walls between church and state are either misunderstood or, in fact, reinforced by oral tradition or practices that seek to protect people with disabilities from what can be deeply wounding experiences in church communities. If, for example, a social worker hears those “church stories,” he/she may have no framework, training, or policy for how to handle them. The convenient and often useful caution then becomes, “We are funded by the state and can’t deal with that.” This is akin to the common response of clergy who say, “I have no training in disability and so our church can’t deal with that.”

The Call to Collaboration

People with disabilities and their families need access to all three worlds: faith communities, support and advocacy networks, and public human service organizations and supports. They often yearn for the various sources of support in their lives to work together. The church, pastor and congregation, especially when allied with others, can help that happen.

Collaboration does not mean the “worlds” become the same. Rather, they overlap, with the individuals and families impacted by disability encircled by all three. Let’s spell out some attitudes that can help build collaboration and partnership.

- Secular and public services often have resources and skills that can help in ways church congregations cannot. Good public policy, laws, funding, and effective science all have crucial roles to play. For example, rights in a society that protect human dignity and ensure access can create a legitimate space for people, i.e., they have the right to be there (school, business, neighborhood, playground, etc.). However, it does not guarantee a sense of community and belonging, that new relationships happen, or that friends get made. It does mean there are more opportunities than in segregated settings.

- Congregations have unique power to nurture growth, a sense of identity, belonging, and purpose. Besides family, the most frequent answer to the question, “Who do you belong to?” is often a “church,” “synagogue” or “temple.” Congregations can be what their signs proclaim—places where people are welcome, known and loved just as they are, places with supports of all kinds, and an invitation to serve God and others out of a common recognition of strengths, gifts and calling. People want the same things: a place to belong and to give as well as receive. That’s why volunteer roles, jobs, and other helping roles within a congregation make such a difference for people with disabilities and their families. None of us like to be on the receiving end all the time.

- The core values of advocacy and service organizations are independence, productivity, inclusion and self-determination. At heart, those are public and civic values, which attempt to an-
swer fundamental human and spiritual questions of identity, purpose, belonging and choice. “Who am I?” “Why am I?” “Whose am I?” “What power do I have to make my own choices?”

The answers in the world of faith may be different—such as believing we are far more dependent on God and others than we are “independent and self-made”—but the questions and values are often very similar.

• Faith leaders thus need to understand the values and mission of any public organization in the same way that professionals in those organizations need to understand the ways those core values can be addressed by faith communities. For example, people with disabilities need more than the adjective “disabled” to answer the question of who they are. “Normal” people usually do not answer with something that may be publicly devalued. Instead, we use place, faith, job, and interests (e.g. Baptist from Atlanta who works at FedEx and loves the Braves). The key challenge is listening deeply, translating core values into different contexts, and working to find a common language. Recent tools in the human service world also being used in some faith communities, such as person-centered planning for people with disabilities and their families and circles of support, can do just that. Friends, families, members of one’s church, and service providers can come together to listen to and support someone’s needs and dreams, what’s important to them, as well as what’s important for them.

• When churches embody their own values about hospitality, identity, purpose and belonging, it becomes a powerful witness in the other worlds of advocacy and services. When congregations work with advocacy groups and services on those values, it is even better. The stories of inclusion and membership can ripple outward to those other worlds, just like stories of disinterest or alienation do.

• The same issues also face human service providers. An agency may have a mission statement that proclaims the value of community and rights, even the right to religious freedom, but often they do not know how to turn that mission into reality—for example, when consumers say in their individual growth or activity plans that they want to go to church. The church then needs to know enough about the “human services system” to work with them through the philosophical and practical issues. An agency can then understand that spiritual supports and congregational inclusion can put flesh (or, in human service language, be an outcome) of the agency values of choice, self-determination, community inclusion, and/or contribution.

You Are No Longer Strangers but Friends: the Power of Networking and Collaboration

Clergy and congregations have real power to build bridges between worlds once a commitment is made to doing so. The tools are networking and collaboration, built on the historic skills of faith communities to ask, initiate, advocate, and act.

With Public and Secular Agencies

Congregations networked with each other in a given community can share strategies for addressing the public sector and working with advocacy and support organizations. For far too long the “religious
“Community” has been known for its absence in the wider worlds of advocacy, support, and services. Together, congregations can point to a growing number of resources and key organizations to which people with disabilities, families, and professionals in the human service world can turn. An ecumenical and interfaith collaboration is a crucial shared witness in worlds of highly networked advocacy groups and human service organizations.

At the local level of individual congregations, the strategies for collaboration are traditional acts of outreach and mission into what may feel like a “foreign” mission field.

- **Invitation.** For example, a congregation has one or more children with autism or other disabilities who present issues in communication, teaching, and challenging behavior. Listen to the parents about what works, but don’t put all the responsibility on them. With their permission, invite the teachers from the child’s school to come give you pointers and/or train your church school personnel. The Archdiocese of Newark is utilizing the Psychology Department of Caldwell College and other experts in Applied Behavioral Analysis to teach children with autism how to attend mass, learn what is needed for First Communion, and more.⁸

- **Hospitality and Welcome.** Find out where the agencies and advocacy groups are, and invite them to do educational programs at your church. Open your building to them for meeting space. Do collaborative discussions on how your congregation might support the people served by their agency.⁹

- **Outreach.** Go meet them on their turf. Better yet, organize a group of congregations to meet with leaders of support agencies and advocacy groups. Listen, and explore ways of partnership.

- **Offering.** Offer to help agencies and advocacy groups learn more about your vision and ministries, those of other faith communities, and the growing number of resources related to spiritual and religious supports. Become involved in a community-wide disability awareness activity, such as Autism Awareness Month. Clergy can offer their skills in pastoral care to help residential service providers deal with grief, loss, and end of life issues with the people they serve, staff, and/or family members.¹⁰

- **Advocate.** Help individuals and families in your congregation search for appropriate services in their struggles with schools or service providers. After a presentation at a statewide Down Syndrome Association Conference, I invited families to “tell me your church stories.” One mother got up and said, “We took our minister with us to our daughter’s IEP (the interdisciplinary meeting at a school where a parent meets with numerous professionals to plan and/or review a child’s Individual Education Plan, meetings at which parents often feel frustrated and outnumbered). It was wonderful, we got everything we wanted... they thought he was our lawyer!”

That story often evokes deep feelings of empathy and laughter, but think of the possibilities. The offer to accompany a parent to the IEP meeting could be a support to a parent’s concerns, but also a demonstration of a desire to learn what the school is doing so that the church might adapt some of the same teaching strategies. The reverse is also true. During one IEP meeting attended by the religious education director, the IEP team, struggling with
speech and communication issues, was stunned to hear that the child had recently sung in the Christmas pageant. The same kind of offer could be made to adults with disabilities and/or families as they face annual planning and review meetings, usually called either an Individual Habilitation or Service Plan or a person-centered planning meeting.

• **Interpret.** A different communication issue is that the language and styles of communication in any of these worlds might seem like a maze of unfamiliar jargon to the other. The languages and practices of spirituality and spiritual supports are being explored by many professional disciplines. An agency may not feel able or capable to talk about religion, but it can often address spiritual needs and supports as one of the core person-centered and community-based supports. Spiritual assessments, personal choice, and appropriate ways for professionals to support spirituality as one part of holistic services are concepts and practices around which shared vision and collaboration can be built.

**With Advocacy and Support Networks**

Advocacy and support networks can be a huge resource and ally for congregations in inclusive ministries. Start with the individuals and parents you know, professional staff that provide services, and the internet. Parent to Parent, the Arc, SABE (Self Advocates Becoming Empowered), NAMI (National Alliance for the Mentally Ill), American Association for People with Disabilities, support and advocacy networks related to autism, deafness and hearing impairments, physical disabilities, blindness, traumatic brain injury... there are multitudes.

Many have some resources or projects focused on working with faith communities and networks, especially at a national level. As noted earlier, you may find an initial wariness based on negative past experiences. To build trust, be open to hearing the reasons for their skepticism. Go with the individuals with disabilities and/or their families you are supporting.

Collaboration can be both practical and public:

• Practical: Remember the examples of strategies under invitation, hospitality, and outreach. Simply hearing the “faith stories” is usually the most powerful way of educating, discovering practical needs and mobilizing collaborative vision and commitment.

• Public: Help with community, state or nationwide awareness activities. Add your voices, as appropriate, to advocacy initiatives regarding local, state or public policies. You will discover another multitude of issues involving social, economic and ethical injustice where the voice of faith may be needed. The challenge, as in any area of mission, is to think globally and act locally in concrete ways where many small hands, steps, and voices can make a huge impact.

**With Other Faith Communities: Seek and Ye Shall Find**

An individual congregation has any number of potential allies working at the intersection of disability and faith. They include:

• In the United States, *national offices* in almost every major religious organization and denomination. Check first with your own. They can offer support and connect you with others.
Many of those offices and programs are part-time, so your support of them is critical as you work together to infuse disability ministries into the life and mission of the wider church.

- **National networks** like Joni and Friends, the National Council of Churches Committee on Disabilities, the collaborative Lutheran networks like the Lutheran Developmental Disabilities Network, Friendship Ministries, and congregations that host national conferences such as McLean Bible Church.

- **Initiatives by service providers with congregations** such as Bethesda Lutheran Homes and Services, Volunteers of America in the Southeast, Hope Community Services in Anchorage, Alaska, and the initiatives by organizations like the National Association of Persons with Disabilities and University Centers of Excellence in Developmental Disabilities like The Boggs Center that have produced collaborative resources and projects.\(^\text{14}\)

- **Ecumenical and interfaith regional networks** that have begun in a number of cities and states, such as the Faith Inclusion Network in Virginia Beach/Norfolk, The Lancaster Christian Council on Disabilities, the Interfaith Disabilities Network of Atlanta, and the Coalition for Inclusive Ministries in New Jersey.

- **Professional associations and other state and national publicly-funded organizations** that are paths for dialogue between “secular” and “religious” arenas, such as:
  - The Religion and Spirituality Division of the interdisciplinary and international AAIDD (American Association of Intellectual and Developmental Disabilities) [www.aaiddreligion.org](http://www.aaiddreligion.org).
  - Statewide offices of federal programs such as the Developmental Disability Councils who have funded initiatives in developing inclusive congregational supports and training for clergy and faith community leadership. Examples include New Jersey, Pennsylvania, Texas and Wisconsin.\(^\text{15}\)
  - International, interfaith, and collaborative networks such as the l’Arche, the European Society for the Study of Theology and Disability, the Ecumenical Disability Advocates Network of the World Council of Churches and the Religion and Disability Studies Group of the American Academy of Religion. Exciting research and resources from the perspective of many different theological disciplines are coming out of their memberships.\(^\text{16}\)
  - The interfaith, interdisciplinary, and international Journal of Religion, Disability and Health. ([http://www.tandf.co.uk/journals/WRDH](http://www.tandf.co.uk/journals/WRDH)) Members of the Religion and Spirituality Division of the AAIDD now receive this journal as a membership benefit. With a subscription comes access to past issues. Or, check to see if your college or seminary has subscribed.
  - Almost every professional discipline and their related associations, conferences, and publications have had occasional presentations and articles exploring spiritual supports, including special education, social work, psychology, ethics, medicine, and more.

- Increasing numbers of books and manuals by both religious and professional publishers dealing with disability and religion. One example is Including People with Disabilities in Faith

- Amazing demonstrations of the gifts of people with disabilities in the worlds of art and theater, many of which would be delighted to do exhibits or performances at churches, colleges, seminaries, or conferences.

- Finally, the public arena of media and films. National documentaries such as Praying with Lior and A Place for All have been award-winning films. One major clearinghouse and distributor of documentaries, including the classic Ten Commandments for Communicating with People with Disabilities, is www.DisabilityTraining.com.18

This partial list will have expanded by the time this curriculum makes it to press. The point is clear—new initiatives and resources are sprouting up everywhere, providing new opportunities to learn from one another, and then to adapt and apply that learning to our own pastoral and congregational initiatives.

Conclusion: Embodying and Empowering a Broader Vision and Call

Participating in ecumenical, interfaith, and secular arenas not only gives people a chance to learn, but also a place to inform others of the creativity and commitment coming from their own ministries. Ecumenical and interfaith networking and collaboration can also provide a powerful witness to many in the public, secular, and professional arenas of disability. These professionals are only just beginning to see spirituality as a crucial dimension of support and quality of life. We can help them see that there is a world of faith communities and religious voices involved in the lives of people with disabilities and their families that is “deeper and wider” than they ever knew. Inclusive ministries, both within congregations and in collaboration with others in the wider public arena, can then focus on both practical needs and spiritual supports—both body and soul.

As faith communities move from intentional or unintentional exclusion of people with disabilities and their families to ministries alongside, to and by people with disabilities, they are living out the call to redemptive witness.19 When people move from outcast, exile and stranger to member and friend, from identification by their deficits to commonly recognized gifts, and from receivers of care to contributors to congregations and communities—that is a journey of redeeming those who were lost. Lost either because they had not heard or seen, but too often in the case of disability, it is because they had not been seen, listened to, invited, and/or welcomed by the Church.

NOTES
2. Winifred Anderson, Toby Gould, and James Paul, We Don’t Have Any Here: Planning for Ministries with People with Disabilities In Our Communities. Nashville: Discipleship Resources, 1986 (One of the earliest resources by a church publishing house.)
4. Psalm 121:1
Networking with Disability Ministries and Organizations, by Rev. William Gaventa


8. Archdiocese of Newark http://www.rcan.org/index.cfm?fuseaction=category.display&category_id=98 Persons Recognized Accepted Included Spirit-filled Education – The PRAISE Project is the work of talented professional educators with generous hearts in collaboration with the department for Pastoral Ministry with Persons with Disabilities. Contact Anne Masters masteran@rcan.org


11. For an example, The George Washington Institute on Spirituality and Health visit http://www.gwish.org/.


15. See files on the “Faith Community Leadership: A Collaborative Project between New Jersey and Pennsylvania” at http://rwjms.umdnj.edu/boggscenter/projects/Pennsylvania_Faith.html. Also, the Wisconsin DD Council produced an 11 minute DVD entitled Believing, Belonging, Becoming with four vignettes about congregational inclusion (two with children, two with adults). Available from The Elizabeth M. Boggs Center on Developmental Disabilities for $10.


17. Listing of recent resources is available at http://rwjms.umdnj.edu/boggscenter/projects/Pennsylvania_Faith.html.


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