A Rising Tide Lifts All the Boats: It is about All of Us

Bill Gaventa, M.Div.

Founder and Director Emeritus, Institute on Theology and Disability, Consultant, Trainer. Austin, Texas

Inclusive ministries coming of age

That is good for people living with disabilities is good for all of us, and a rising tide lifts all boats. In the past two decades, there has been a remarkable rising tide of people, faith communities, training opportunities, networks, and resources focused on building ministries with people with disabilities and their families. We are far from being able to say, "Every congregation is involved in some form of intentional, inclusive ministry," but we have come a long way from saying, "We don't know very many people in the congregation who have a disability." There are over fifty denominational and parachurch Christian organizations that focus on ministries with people with disabilities. Networks like the Institute on Theology and Disability, Key Ministries, and others, bring several thousand people together across denominational lines to share questions and resources, while learning from one another. The number of seminaries including disability concerns in their curriculum is rising, along with the number of seminary students who have disabilities. Multiple faith advocates have blogs addressing matters of disability and faith. Were one to type such words as, "disability," "faith," "church," "spirituality," or "theology" into most search engines, the result would be an array of practical, testimonial, and theological books and resources. This edition of Currents is one example of themed issues on disability, ministry, and theology that have been developed in the past decade.

Name some form of service or support with people who have disabilities, and after a bit of searching and networking, you can find a congregation providing such supports as a form of ministry; be it respite care, employment, inclusive preschools, inclusive schools, housing, advocacy, or others. All this has taken hard and dedicated work by faith leaders, lay leaders, families, academicians, and people with disabilities (who are also often part of the groups just named).

Multiple sources of motivation have fueled that work. Often, some form of relationship with people with disabilities has called forth a commitment to help change the ways that faith communities have too often colluded with cultural forces to erect barriers of attitudes, expectations, and architecture.

The temptation in practice at times has been merely to endorse the cultural model of advocacy for the rights of people with disabilities, to right the wrongs that people with disabilities In the past two decades, there has been a remarkable rising tide of people, faith communities, training opportunities, networks, and resources focused on building ministries with people with disabilities and their families.

have endured, and advocate for inclusion in faith communities. Multiple faith traditions have adopted policy and theological statements about disabilities, but those have not necessarily led to full-scale change at a personal or congregational level. Other faith traditions have focused less on policy and advocacy but have shown real strengths in reaching out to invite, welcome, and include people with disabilities and their families. As is the case societally, the challenge is to match church policy with individual and communal action, for structures and processes that disable others are usually changed by both. As African American theologian and civil rights activist Cornel West once said in a sermon, "Justice is what love looks like in public."

Can we, as faith communities, take a step back and ask what we are learning from all the progress that has been made, even in the face of miles to go? Can we reflect on what the implications of that learning are for the path ahead? One lesson learned is that when creatively committed people have worked hard to build specific accommodations and supports for full inclusion, we discovered that the underlying questions are not just about "them," (people with disabilities), but about all of us. Subsequently, the strategies and supports used help a much broader array of people, than merely those for whom they were developed. The answers are good for all of us.

How might these discoveries and revelations impact our motivation, calling, and strategies for the mountains of work that

^{1.} Cornel West, Sermon at Howard University, 2011. https://www.youtube.com/watch?v=nGqP7S_WO60

still need to be done? Not all "the mountains and hills have been made low," nor "crooked paths made straight." How might we both celebrate and use our experience in the work that lies ahead?

"Special" is about all of us

Doing what needs to be done through advocacy, systems changing learning strategies, and technology -- all of this results in solutions that not only help the intended audience (people with disabilities), but also many others without the label or stigma of disability. A major result is that it is not just about "them," but about human beings, all of us.

To illustrate this, let's start with some examples from public services, such as education, rehabilitation, personal support, and community living that have been or could be adapted to congregational settings. Readers of this article may be able to add some of their own examples to the list.

Architecture

The most common example may be architecture. While churches are not required to make buildings accessible under the Americans with Disabilities Act, many have. If parts of the building are rented out to other organizations, the requirements then apply. The serendipitous providence of doing accessibility well, is that it is appreciated by many others who may not have obvious physical disabilities or utilize wheelchairs.

Ramps, railings, and elevators are used by people who are elderly, who use walkers and canes, or who have physical problems such as heart conditions. Opening space up in the sanctuary to give people who use wheelchairs a choice about where they sit lets them participate on their own terms. Parents with children in strollers love ramps, as do delivery workers. Spacious accessible bathrooms are appreciated by many, beyond those in wheelchairs. Inclusive architecture raises the question of whether those we have called "shut-ins," in our congregational families are actually "shut out." This has also raised a broader realization that our architecture is an evangelical statement about who is welcome. One of the most humorous affirmations of this lesson came several decades ago from an Episcopal Diocese's work on accessibility and the importance of accessible bathrooms: "If they cannot go, they will not come."

Individual Education Plans (IEPs) and Person-Centered Planning

Despite much of the anxiety and frustration around IEPs for parents and school systems, when the team works and the plan is carried out, the child's learning is enhanced through shaping teaching around the child, the child's gifts, and needs—as opposed to shaping the student inside a "one size fits all" curriculum plan. In the world of adult services, concerning people with intellectual and developmental disabilities, person-centered planning has become the norm in a variety of forms.² The common factor is

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that the individuals supported, and those who know them best, are at the center of the plan, and supports and services are shaped around their dreams, hopes, and needs, rather than fitting them into "program slots" or predetermined "treatment plans." The very name, "person-centered planning," reflects the attempt to distinguish it from multidisciplinary professional team plans, in which people being supported often have little input.

No planning process is perfect. The quality of the plans and their outcomes, just like inclusive policy, depend heavily on the sensitivity, commitment, and follow-through of the individuals involved. In principle, the whole purpose is to hear and empower the voice and choice of individuals and families, around whom the supports are developed. Creativity is also required, such as inviting friends and allies in the community into the process in ways that recruit their support, input, and participation. In public education, the most obvious question is, "Wouldn't we like all schools to be more focused on children in ways that take into account their key interests, needs, and gifts?" This realization has helped shape the understanding that children and adults learn in different ways.

Congregations have developed a variety of ways to use the same approach in inclusive religious education. Some congregations have developed individual religious education plans for a child with a disability. Others simply make it a point to have detailed conversation with parents to learn how best to support their child in an inclusive environment. One of my favorite stories came from a mother at a Down Syndrome conference presentation who said, "We invited our minister to our daughter's IEP. It was wonderful. We got everything we wanted. They thought he was our lawyer!" That story always produces laughs and empathy from families. I have heard of a few other parents who have invited members of congregational staff or laity to come to their child's IEP at school. One purpose is to learn what the school is trying to do

^{2.} There are a variety of models for person-centered planning for individuals and for families, including MAPs, PATH, (www.inclusion.

com), and Essential Lifestyle Planning (https://tlcpcp.com). I have used the PATH process for groups in figuring out their strategic plan, as well as for students in a Clinical Pastoral Education Program to determine their learning goals in relationship to their career path. Essential Lifestyle Planning asks two key questions: "What is important for someone?" balanced with "What is important to someone?"

and see if teaching strategies at school may transfer to religious education. Conversely, the faith community may be able to tell the school team about strategies they have used which enhanced participation, learning, and socialization.

Adults who are supported by agencies also theoretically have the right to invite others to their annual planning meetings, which, if they invited staff or friends from their faith community, would highlight the importance of the spiritual dimensions in their lives. The presence of a congregational friend or advocate can be a huge source of support in meetings where individuals and families can feel outnumbered and overwhelmed by the number of professionals involved. If there is congregational frustration about whether a school or agency takes the spiritual lives of individuals seriously, could we then find ways to be invited, be present, and as appropriate, share the number of ways someone may be involved in religious education, worship, or other congregational activities?

One of the newer versions of this kind of planning for families is called Charting the Life Course.3 These are planning guides for families to think about what their son or daughter, and the family itself, might need at various stages in life. There are also growing models and resources for helping individuals and families plan for what happens after the parents are gone, 4 and, subsequently, resources for helping adults with intellectual disabilities plan what they would like and need toward the end of their own lives.⁵ This kind of person-centered planning for everyone facing the later stages of life is a huge need, as most doctors and healthcare professionals will tell us. Without those individualized plans, health providers and caregivers will not know how to individualize patient care, especially after someone's loss of the ability to communicate. Far too often, it could then become a battle between members of a family and health professionals or hospital policy. This kind of planning is good for all of us.

Assistive technology

The challenge of creating technological aids that may help individuals with their specific form of disability, whether in mobility, speech, fine motor skills, or others, often leads to technological breakthroughs that can help a much wider range of people. Examples might include puff-controlled wheelchairs, or computer-based communication languages using symbols and pictures that can speak someone's thoughts and feelings. Visual and hearing-assisted technology potentially can help everyone, such as through automatic captioning on movies or TV shows. The creative work done in technology to assist people with sensory, motor, and communication disabilities often produces new technological devices in everyday items, such as kitchen implements and household tools, which can be used more easily

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Understandings of behavior

In public schools that have worked intensively on inclusion, one of the biggest challenges faced is that of disruptive behavior. (All kinds of children could be disruptive at times.) Discipline has often been handled by a reward and punishment regimen (i.e., behavior modification), but often with limited effects for a wide range of "behaviors" Too often, medication becomes the option relied upon too quickly.

In the past twenty years, the promising field of "Positive Behavior Supports (PBS)" has emerged as an alternative to behavioral models that assume we can control someone else's behavior. In Positive Behavior Supports, all behavior is essentially viewed as communication. Behavior that falls outside of expected norms is perceived as an attempt by the individual to get something they want, something they are not getting, or to avoid something that is happening (i.e., to signal that "this is not working for me"). Thus, the task is to analyze the behavior very specifically, and then teach, model, and support behavioral options for the child or adult, for them to achieve their desired outcomes in more desirable ways. The approach, developed to include children with "challenging behaviors," has been generalized in many school systems to all students in the school, as a way of positively shaping behavior.

Think of the possibilities of Positive Behavior Supports for all children in inclusive religious education programs. Discipline is often the most frustrating task for volunteer Sunday school teachers. Helping teachers and aides to listen and observe more closely, and then guide a child with alternatives, is a much more humane, and dare I say Christian, process for addressing those kinds of issues, than getting into what can become an escalating

^{3.} http://www.lifecoursetools.com

^{4.} For one example, see The Arc's Center for Future Planning. https://futureplanning.thearc.org

^{5.} See a number of them in this resource list related to Grief, Loss, and End of Life Issues, https://faithanddisability.org/wp-content/uploads/2021/08/2021-Grief-Death-Dying-Resources.pdf

^{6.} For example, the Positive Behavior Supports in Schools in New Jersey: https://rwjms.rutgers.edu/boggscenter/projects/PBSIS.html

process of rewards or punishments, including exclusion. Those who use Positive Behavior Supports could teach congregational volunteers, as well, building another bridge for church/school collaboration. This is good for all of us.

Peer-mediated supports

Children learn from their peers, look to their peers, and imitate their peers. Peer mentor supports for children with disabilities are used in many schools to help with both learning and socialization.

Many congregations with inclusive religious education programs have done something similar by recruiting "buddies" from other students in the classes, or perhaps older students, to be a learning companion, aid, support, and model. There is a triple benefit here: it helps the teachers, it helps the child who needs more individualized support, and it is often a growth experience in faith for the buddies. I have heard congregations cite the impact on the "buddies" in helping to shape their thinking about vocation and call.

The same support could be used for adults with intellectual development disabilities, especially for people who may be new to a church, being brought by staff from residential programs. If a group comes together, and sits together, they may be arriving with little experience in attending services, a lack of knowledge of what the autism world calls "the hidden curriculum" of behavior and habits expected in any group setting, and inadequate support from a single staff person who has already worked hard to enable them to get there. It can be so beneficial to find others in the congregation with whom individuals can sit, apart from the group, and be guided by adult peers, as they learn what to do, how, and when during a worship service. It would be beneficial to recruit several volunteers to do so for each person, so volunteers could take turns, with the outcome potentially being the creation of a network of friendships enriching all involved. This is but another version of existing models in congregations, where long-term members are recruited to help orient new members.

Universal Design for Learning

Universal Design for Learning is: "a collection of best practices from education, special education, psychology, and neuropsychology that educators can use to design lessons and learning environments, so all learners have the opportunity to become purposeful, motivated, resourceful, knowledgeable, strategic, and goal-directed. Underneath all of that is a single driving factor: learner variability."

The primary premise of Universal Design is that those environments, including places like religious education classes and worship services, should be designed, from the beginning, to include a wide variety of people with varied learning styles and needs.

This body of theory and practice builds on realizations that people learn in all kinds of ways, and that good teaching and communication need to involve all the senses. The primary premise of Universal Design is that those environments, including places like religious education classes and worship services, should be designed, from the beginning, to include a wide variety of people with varied learning styles and needs. Faith communities are just beginning to become aware of the potential for creating inclusive environments. One of the pioneers was Barbara Newman, who worked for the organization now called All Belong. Her recorded talks for the Calvin Institutes of Christian Worship and her short book: *Accessible Gospel. Inclusive Worship* are wonderful introductions to the implications of universal design for faith communities.⁹

Community building and belonging

As people with disabilities and their allies have labored for more inclusive lives, a body of practice and resources has built up around the best skills and strategies to reach that goal. Just because someone lives in a community setting does not mean they are part of that community. Intentional and careful work is required by individuals, families, friends, and professionals to help build those personal relationships. ¹⁰

One of the core strategies in building relationships is through shared interests, rather than defined roles of volunteer and recipient. For example, if new individuals with disabilities are being welcomed into a congregation, inquire as to what passions, hobbies or interests they might have, and then introduce them

^{7.} See the second of the four vignettes in the 11-minute video, *Believing, Belonging, Becoming*, all different stories of inclusion in faith communities. https://faithanddisability.org/videos/

^{8.} https://theudlapproach.com/what-is-udl/. Lorie Lord Nelson is one of the pioneers and leaders in Universal Design. A more formal definition from a Center on Universal Design is: Universal Design is the design and composition of an environment so that it can be accessed, understood, and used to the greatest extent possible by all people regardless of their age, size, ability or disability. An environment (or any building, product, or service in that environment) should be

designed to meet the needs of all people who wish to use it. This is not a special requirement, for the benefit of only a minority of the population. It is a fundamental condition of good design. If an environment is accessible, usable, convenient, and a pleasure to use, everyone benefits. By considering the diverse needs and abilities of all throughout the design process, universal design creates products, services, and environments that meet people's needs. Simply put, universal design is good design. https://universaldesign.ie/what-is-universal-design/

^{9.} Barbara Newman, *All Belong: Inclusive Worship* (All Belong-Center for Inclusive Education, 2016). https://allbelong.org.

^{10.} Explore some of the ways I have appreciated and learned from their work in my own book: Bill Gaventa, *Spirituality and Disability: Recovering Wholeness* (Waco: Baylor University Press, 2018).

to people in the congregation who share those interests. This can help build pathways for people to talk to one another and connect, rather than having the single focus of a person's disability.

Erik Carter's research and writing on the spiritual needs and interests of people with disabilities and their families also illustrates that what we can learn about inclusive congregation's has wider applicability, in the wider world of public supports and services. As one way of reporting their results from interviewing over 500 families, Dr. Carter and his team shaped a model of the "Ten Dimensions of Belonging," as identified by the families as a whole:¹¹

One can immediately see its usefulness for any hospitality or evangelism committee in a congregation. This is not just about



people with disabilities and their families. Belonging is shaped through relationships of mutual giving and receiving, being present but also contributing, being welcomed but also being needed. Inclusion is not the same thing as belonging, rather one of the steps in that direction. It applies to everyone.

Inside communities of faith

These examples of strategies and learning that originated in supporting children and adults with disabilities have been adopted in congregations, to everyone's benefit. There are other accommodations and practices that deserve mention, which have arisen in the lives of congregations, but also have a wider impact. In preaching and teaching, for example, how might we discover ways to communicate and participate through multiple senses, which has long been a part of religious life in history, particularly before most people were able to read? Liturgy and ritual are important for many people with autism, for whom it provides a

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structure amid the sea of sounds and faces. Including people who have disabilities in traditional rites of passage has led to ways to provide individualized demonstrations of faith, which impact the whole faith community. Finding ways for everyone to use the gifts they have, in response to God's calling to support the life of the faith community, becomes a crucial step on the path to belonging. When we see one another giving of ourselves in ways we delight in doing, it is a witness to the importance of finding and using everyone's gifts in service and leadership. The key purpose of faith communities is supporting one another in times of need, but that support, and congregational life, is built on people's gifts, not their deficits. Working from people's interests, passions, and gifts, and using all the social capital available in congregations, can be a creative and transformative way to help people with disabilities (or anyone else) find jobs. 12

One of the lessons that has been learned from all the work of inclusive ministries is that congregations doing so "for the few" have discovered that the whole congregation has benefited in terms of spirit, hospitality, and, not infrequently, in increasing membership. Significant learning can happen whenever the question is asked, "How do we do that for a particular person or family?" then turning the question around, and asking, "How might we do it with everyone else?" Is applies to everyone.

^{11.} Erik Carter, "The absence of asterisks: The inclusive church and children with disabilities" *Journal of Catholic Education.* Fall 2020, Volume 23, Issue 2: 168-188. Two of his recorded lectures focusing on Belonging are online at Baylor University, https://www.baylor.edu/religion/index.php?id=936537 and the Calvin Institute for Christian Worship, https://youtu.be/sRZHwj6CarM

^{12.} The Putting Faith to Work Project. https://faithanddisability.org/projects/putting-faith-to-work/

^{13.} The Christian community sometimes bemoans the "unchurched," yet too often fails to realize that that population may include many whose presumed "differences" have not been welcomed. The tragedy there is that each person with a disability, or another kind of de-valued difference, is also connected to families, friends, and others. If a person with a disability or family finds unexpected welcome and inclusion in a congregation, others in their circles are going to hear about it, especially in these days of social media, and respond positively to it. The opposite is also true: if their experience is a negative one, either because of attitudes, lack of preparation, or outright rejection in too many instances, their network of family and friends are also going

Conclusion: What if we started at the end?

Universal Design has been noted as one of the culminations of many new understandings of how people can learn, be fully involved, and stay more focused on the tasks at hand. Its premise is the question: "Would it not be better if the program, classroom, or learning environment were designed, at the beginning, to be able to handle and include a wide variety of people with varying abilities, rather than constantly having to adapt or change structure, process, or practice that gets in the way?" How might that impact our planning and work together in faith communities?

A congregation in Canada was asked by someone who visited if they had any members with disabilities. The response was, "No, not really." Whereupon the visitor said, "What about that man in the wheelchair? What about that young woman in the choir?" The answer came from the congregation: "Oh, we don't think of them as individuals with disabilities. That's John. Her name is Sally," etc.

Forty-five years ago, there was a small Methodist booklet advocating for beginning an inclusive ministry that had the title: We Don't Have Any Here, an answer often given by congregations when asked about people with disabilities in their midst. To talk about a reversal, would it not be wonderful if congregations started with the vision of what it means for everyone to be welcomed and included, meaning, not seeing them first as individuals with disabilities, but as people who like to do this, sit there, help in this program, sometimes question the preacher during his sermon, and so on. We are all people with multiple stories that shape our identity. Seeing just one story (i.e., "Disability"), starts us off with a severely limited vision.

Whatever way a congregation might get to the point of Universal Design, it puts new meaning on our celebration of the "church universal." A church's light will then reflect that proclaimed whole, or as Jesus said, "The kingdom of God among us."

Dan Aleshire, former Executive Director of the Association of Theological Schools, once told me a personal story about his preaching at a church in Virginia, which long ago had worked on being inclusive, and had developed both residential and employment ministries with people with intellectual and developmental disabilities. When Dan stepped into the pulpit that morning, there was a visible and noticeable number of people with diverse abilities and disabilities in the congregation. Dan told me that he said to himself, "Well, all the people of God have finally shown up!"

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to hear about it, sometimes immediately in social media. The impact of including or excluding the "one" both make ripples in a community pond. The question for a congregation is what kind of ripple it wants to make.