Belonging: From Strangers to Friends and Partners

All of you who are here today no doubt come from a variety of backgrounds, faith groups, agencies, forms of disability and ability, and roles. You are advocates, families, professionals, friends, people with disabilities, members of faith communities. You are part of the community and you represent, for many people, pathways into community. You are connected to each other in ways you both see and don't yet see. You may have heard about each other from the people you support but have never met. You are a living example of the paradox noted by John McKnight and others, in that while it is hugely important that all people with disabilities have an opportunity to be included and to belong in communities in the ways they choose, it is often people with disabilities and their families who draw people together in ways that forms community. For here, the American love of independence faces the reality of universal dependence, and the only real way forward is interdependence on one another.

But families, support services and agencies, and faith communities too often feel like they are living in separate worlds, or, to use an illustration from childhood, playing in separate sandboxes. Or worse yet, all in the same sandbox but not playing with one another. Erik Carter documented some of this with his Tennessee study of around 500 families, asking about the importance of spirituality and faith in their lives. A huge majority of the families reported that spirituality was important in their lives and homes, something like 75%. But when asked who had supported them in living out the importance of that dimension of life, both public systems (meaning schools, agencies, and others) and congregations got pretty low marks. Public services never even asked about that dimension of life. Faith communities too often failed to respond when families sought the kind of supports needed for them to participate as a whole family. The irony, of course, is that both the public and religious worlds profess that we are person and family centered, seeking to help people live lives of participation and connection.

So why, we would might ask? There are some good historical reasons:

1. These are different world of helping, with different languages, different understandings of caring, different policies, different concerns about credentials. Put people of faith in the world of agencies and systems who do not work there, and it is a world of acronyms, attitudes, and processes much different than how a faith community might respond to a person or family. Put a really good social worker or direct support professional in the world of religious congregations, and you have another confusing set of acronyms, attitudes, a huge diversity of styles, and customs much different than a school or agency. "We never got any training in this" is a common refrain from professionals in both faith communities and service/education systems. Thankfully, the language of spirituality is becoming one way for talk about the same thing.

2. There are misconceptions about the separation of church and state in disability services and healthcare. Some in the service world believe you can't talk about religion with individuals and families because they get public funding. That's wrong. You can. You

cannot and should not proselytize, but you can talk about it. Holistic, person centered, and family centered care almost demands that you do.

3. But both also lead to suspicion between the worlds at times. Both might hear about an individual's or family's problem with the other. Educators, human service professionals and advocates have heard the stories of neglect or outright rejection that individuals with disabilities and their families have sometimes faced in faith communities. So they are leery, not wanting to do anything that might exacerbate that…but which also concedes the power of the spiritual dimension of life to both harm and to heal. Pastors and others in faith communities may hear desperate searches for services or supports, dissatisfaction with teacher or service provider, and often, be stymied, because they do not know what to do in the face of bureaucracies, systems of eligibility, and boundaries placed by agencies and funding sources on what they can provide. And, like many in the general public, they have heard for years that it takes "special training and expertise" of one kind or another to realty be of help. Thus avoidance and inaction, i.e., disempowering, takes over.

I bet you all have your stories about this, on all sides of helping and support. When talking with individuals and families, we need to be prepared to hear them and take them seriously. Truly listening without defensiveness is the first real step of any helper. And we need to be wise, because collaboration between different organizations and kinds of helping is never as easy as we think it should be or could be. One of my favorite definitions of "collaboration" is that of "an unnatural act by frequently un-consenting partners." Too often, people feel "collaborated," i.e., told by one side or another what they should do to make everything all right. People get stuck in their roles, like a choir unable to sing together, with verses that sound like this:

Family
Professional in Agency or Congregation
Individual.

Remember, partnerships and collaboration take time. Miroslav Volf talks about a dance of embrace in his book entitled Exclusion and Embrace, a book that is not about disability at all. As strangers to many others, he asks if we are called to "Embrace the other." His answer is "No." We are called to have the will to embrace them. And that happens by lowering our guard, moving towards another, seeing their response, and, before any embrace happens, stepping back a little, and make sure what needs to be said in that space is said. Kind of like a dance. A too quick embrace, as we all know, can feel false and, for many, invasive.

But, on the other side of the barriers, there are all kinds of values, resources, policies and trends that speak to the potential and value of effective partnership between individuals, families, agencies, schools, and faith communities. Some are:

1. The values and methods of person centered planning and self-determination speak clearly to listening carefully to what is important to individuals and families, not just what is important for them, and respecting/supporting their interests, choices, and dreams, not ours for them.

2. Helping agencies are supposed to be “culturally competent.” One cannot address that without addressing the ways that faith shapes the traditions and practices of different cultures, and how that is reflected by an individual or family.

3. Helping congregations live up to their signs that say “Everyone’s Welcome.”

4. Faith communities are the biggest example of “natural, generic support organizations,” a mainstay of what disability systems say individuals and families need. What’s more, they are treasure chests of potential connections and relationships, as well as many different kinds of activities. In other words, social capital.

5. The power of spirituality and spiritual supports in multiple areas of health care, human service, and quality of life is being demonstrated by vast amounts of research. Not much of that has taken place in the IDD world, but that is changing.

6. People are more than single stories defined by one characteristic. There are multiple stories that make up all of us, and we need multiple ways to connect and belong to and with others who share those interests and values. And, ideally, people need multiple organizations and networks who claim them as members. We all need “our people.”

7. No expert, of whatever kind, knows everything. No one place can meet all the needs and wishes that a person might have. As professionals, the real skill is not what we know, but whether or not we know what we don’t know, so we are willing to ask, listen, learn, and partner. People who are clients, patients, asking for help in any way, can spot pretense pretty quickly. I, for one, am more willing to trust someone who says, “I don’t know, but I can find out.”

But now…the resources are out there. Look and ask. The models are there. Tell me any service or support for a person with a disability and/or a family, and I would wager there is a congregation somewhere who has worked on making that happen. Ask about an agency or provider who has both seen the potential and realized the power of spiritual supports and inclusion, and I can give you some examples, including larger provider agencies who have developed roles for “Coordinators of Spiritual Supports” to help train staff, consult with faith communities, guide planning and practices.

You have in your packet a listing of possible things that provider agencies and services can do in this mission, and another list on the flip side of what faith communities can do. Read them carefully, and you will see some as the same thing in their respective organizations. They are processes of inward learning and training, and outward invitation and requests for partnership and collaboration. If you want specific resources for many of these, ask around today for who has done something like that, or send me an email. Or search online. Who do you know who might know, and who might they know. Believe in the gospel of Kevin Bacon and six degrees of separation as the pathways to connection.

We could talk about all of these, but I know something about my limits and yours! But let me share a couple of examples:

1. Partnering through involvement in planning processes.
   Every person or family has the right to invite others to be part of planning processes, such as a person-centered planning meeting, or an IEP. More than a quarter century ago, I spoke at a Down Syndrome Conference in South Carolina and invited, after my talk, for people to share their "church stories." One mom talked about how they had realized they were being too protective, and the youth group and young adult group, planned well, became a pathway for more independence. A second mom stood up and said, "We took our minister with us to our IEP. It was wonderful. We got everything we wanted. … They thought he was our lawyer. It always gets a laugh…but think about it. Having a faith community representative there also says, "This child and family are part of our people too. We want to help. We want to know what you are doing, and how that might help us." And the reverse is true: they might information that would help the school team. But the key is the power of presence, and the re-balancing of power.

2. Helping people with disabilities get jobs. Unemployment remains one of the greatest needs for adults with disabilities. Period. How do lots of people get jobs? Through connections. In the Putting Faith to Work project, Erik Carter and I and four University Centers of Excellence in Developmental Disabilities hypothesized that a faith community has two key sources of power here: First, the capacity for a small group to organize around an individual with some kind of need. Second, the social capital of the congregation, made up of members who are employees and employers, who could be tapped to help find possibilities and job trials, not for a supported employment client, but for someone whose name they know and who people in their congregation are rooting for. It works. It is not rocket science, but sweat, heart and head equity.

3. Special Olympics: There are congregations for who a mission event for the whole congregation is to sign up to help at the annual Special Olympics meet in town. It is, one might say, witness.

4. Parent support and individual support. Some congregations have parent groups, ways for parents to support one another. And others have used the "circle of support" model from the disability world to help people be included. See the 11 minute video, *"Believing, Belonging, Becoming"* with four vignettes of faith community inclusion.

5. Addressing Grief and Loss. Grief and loss permeates the lives of many people with disabilities and the environment of support agencies. Staff changes, moving, loss of

friends or family members. There are many more resources now for addressing that grief, including a new national website on AutismandGrief, but agencies could work with local chaplains or pastors to help form a support team that could help individuals, families and staff in those times of crisis.

And the list could go on. You could help me add to it.

Suffice it to say, both faith communities and agencies have a choice to make around inclusive faith supports that has to do with what the commercial world calls branding and what the Christian world calls witness and evangelism. A faith community who works hard at inclusion of one or more people with disabilities and their families…it is like dropping a stone in a pond. The ripple effects go out. Others will hear about it. Relatives, teachers, agency staff, families, and more. The opposite is also true. A negative experience can wound individuals and families deeply, as many of you know, but it also can be spread like wildfire.

An agency that pays attention to this…well, you stand the chance of more satisfied and grateful customers and families, and some excellent PR, plus, as some congregations with active inclusion programs have found, providing a new and enticing vocational avenue for young people thinking about where God is calling them.

So kudos to Highland Park and the rest of you who have planned and attended this event today. Let's hope it opens doors to new ideas, resources, relationships, and allies…just as it invites each of you on an even deeper spiritual journey yourself. May God, Yahweh, Elohim, Allah or however you name your creator, go with you as well…which he, she, or they have already promised they would do.

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