

**Transcript of**  
**“Hidden in Plain Sight - Spirituality,  
Disability, and Wholeness”**

**presented on November 8, 2019 by**

**Rev. Bill Gaventa**

**Dean Thomas Stegman, S.J.:**

Good morning, everyone-- lovely, lovely day. I was in charge of everything except the wind, so you can blame somebody else. So welcome to today's presentation. I do want to reaffirm what Meghan said. Pyne Lecture is really a big thing for us at the STM. And we brought it from Weston, and we're very proud and grateful to be able to have a wonderful presentation like we do today. And we have a great history of this.

Today's presentation, "Hidden in Plain Sight: Spirituality, Disability, and Wholeness"-- it's my pleasure to introduce our speaker. Now, you always got to be careful, when you say things. And I remember speaking, I said, wait a minute, I know your wife. Now, that can be a little bit of a dicey thing. But as I'll point out, his wife is a distinguished New Testament scholar, from whom I've learned much.

Bill Gaventa is the founder of the Summer Institute on Theology and Disability. He's now the Director Emeritus. He's the co-ordinator of the Collaborative on Faith and Disability, linking a number of University Centers of Excellence in developmental disabilities, who are addressing spirituality through initiatives in training, technical assistance, research, and dissemination. He was formerly director of community and congregational supports at the Elizabeth M. Boggs Center on Developmental Disabilities in New Jersey.

Bill's primary areas of expertise and experience are spiritual and faith-based supports with peoples with disabilities, training for clergy, seminarians, and community services staff, aging and end-of-life grief issues, and intellectual and developmental disabilities, cultural competence, and community building. He has served as the president of the American Association of Intellectual and Developmental Disabilities 2016, 2017. As a writer and editor, he's edited newsletters and several books. He's written articles and chapters, and served as the editor of the *Journal of Religion, Disability, and Health* for 14 years, now serving as an associate editor.

His book, *Spirituality and Disability: Recovering Wholeness*, was published by Baylor University Press in the spring of 2018. And as Meghan just mentioned, that book is available to purchase-- I think, a very good price-- at the back of this room. Bill and his wife, Beverly Roberts Gaventa, moved in 2013 to

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Waco, Texas, where she serves as Professor of New Testament interpretation at Baylor University-- then on to Austin in 2018, where their son Matthew, daughter-in-law Sarah, and grandson Charlie are living.

His career has been dedicated to supporting the ministerial-- I'm sorry-- the ministry of pastoral care among persons with developmental and intellectual disabilities and their families. We are so honored to have him join us today at Boston College. Please join me in giving a very warm welcome to Reverend Bill Gaventa.

[APPLAUSE]

## **Reverend Bill Gaventa:**

Well, it's a delight to be here. I hope you folks in Boston will understand my accent. And it used to be for a long time, when I'd be up in the north, people would say, you're not from here. Then I'd go back to somewhere down in the south, and people would say, you're not from here. And finally, what I realized-- and what's a guy in the Army once told me-- he says, you're borderline south. That's your accent. So you're kind of in between.

And that's where I've been-- in between, all my life, which is part of what this lecture is about, in terms of trying to be bridging between the worlds-- the secular world of services and supports with people with disabilities and faith communities, religion, theology, and ministry. In 1995, I had an unexpected experiential exercise in disability that I would not recommend. Although, it's much more common now than is commonly believed.

I ended up in a unit in a private psychiatric hospital due to the first onset of a major clinical depression. I didn't recognize this unwanted visitor in my life. It took the form of major anxiety attacks, the inability to sleep, and ruminating so much in my head and soul that I had little energy left to interact with anybody around me in any kind of typical way.

Once there in the hospital, the rumination changed to try to figure out what in God's name had just happened. What had I done? What kind of secrets needed to be uncovered? What was the thing there that, somehow, if I got a hold of, I could fix it, or somebody could help me fix it? My favorite staff person was a psychiatric aide in that unit. His name was Conrad, and I did a fair amount of talking with him.

During one conversation to me, as I was talking about trying to figure all this out, he said, Bill, you know, what you're looking for may be hidden in plain sight-- may be hidden in plain sight. And that became one of the phrases around which my psyche began eventually to reorganize, as I got not out of the depression-- Parker Palmer says, you don't get out of the depression-- you get through it and come out the other side.

But it became one of those key things that I thought about a lot, in relation to that. It became a phrase that I used to describe the importance of spirituality, including spiritual assessments, histories, needs, gifts, and community participation, and the need in the lives of people with intellectual and developmental disabilities and their families. Let me explain. In the Western world, in particular, the models and theories that drive services and supports with people-- oh, I forgot about my slides.

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Sorry. How many of you were here last year for Erik Carter? Erik Carter is a PowerPoint master, per se, and so it's really risky for me to follow him. But this point was also one of the things that grabbed my experience. And I don't know if you know Michael Leunig, and it says something, and this relates to our Western world and Western cultures. Michael Leunig had-- in Australia, had his own experience of depression.

And he wrote, "God bless this tiny little boat and he who travels in it. It floats and floats for years and years, and sinks within a minute. And so the soul on which we sail, unknown by years of thinking, is deeply felt and understood the minute that it's sinking"-- the minute that it's sinking-- the thinking, the sinking, and the soul. So in our Western world, understanding disability has come from the medical models and social models of disability.

Scientific perspectives and research have definitely shaped the medical model. The social model of disability has taken on increased importance, as people have talked about disability from a variety of other disciplines and perspectives, and especially interdisciplinary world of disability studies and advocacy by people with disabilities themselves, who say, the medical model does not work for us. But neither theoretical model pays much attention to spirituality or theology, for sure, or the religious dimensions of disability and inclusive community supports.

I spent a huge number of years reading articles in the professional journals around disability, looking for any words that I could link in to the whole concept of spirituality. And if you know those journals, they are mostly graphs, and charts, and research studies, and quantified and so on and so on. And unless you get to the abstract and maybe the discussion at the end, you can begin to think about, what are the implications of this for people's everyday lives? I'm just not the research scientist that, that Erik was.

And one of the great ironies is that, in the world of health care services-- acute health and psychiatric services-- spirituality has been a huge topic of research and of interest, and about its role in helping people to cope, and resilience, and the kinds of meaning that it enables people to find in their lives. In terms of what we do in the IDD world, we talk about the huge importance of natural and generic supports.

How many of you know that term, if you're coming from the DD world? We really hope for natural and generic supports. But we don't often include spiritual communities as one of those natural and generic community supports. If I came to an agency and said, let me tell you about a community support organization of which there are about 350,000 of them around the country, including a whole lot in this community, they would say, what?

Those are congregations and faith communities. And the cultural model of disability-- it's a variation on the model-- social model-- is much more conducive to explorations of the ways in which disability is shaped by identity, and culture, and context. But the result of not taking spirituality seriously, not unlike the-- in other areas of health and human services, is a fracturing of theory, and of research, and services into two separate worlds-- one, almost disability here, and over here, religion and spirituality.

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Two separate worlds with two different languages often, in the past-- a splitting that does no service to people with intellectual and developmental disabilities and their families who are trying to lead holistic lives as part of inclusive and whole communities. Let me share some examples of that. Ellen Cook, a Roman Catholic parent, long time ago, wrote one of the first books on faith, and churches, and people with intellectual and developmental disabilities-- had this wonderful quote.

It said, "Parenting a disabled child is forces living one day at a time. It places a family in the middle of a measured scientific/ educational/ medical model"-- hear that measured medical scientific educational model-- "while confronting it with all the chaos that real life has to offer." We go into service systems, where things are planned, and there are processes and assessments and all these kinds of things.

And a plan may look great on paper, or an IEP, or whatever, but people's lives often don't follow those plans. At least mine doesn't follow mine. And I don't know about yours. But that really struck me early on. Early on in my career at the Boggs Center in New Jersey, I met a woman with psychiatric disorders-- borderline personalities-- who was also studying in seminary and wanted to be a chaplain.

And she said, when I go to the psychiatric world and work in the psychiatric world, my interest in spirituality and faith is seen as a symptom, rather than as an asset. And when I go to the faith communities, my experience with mental illness is seen as a symptom and a disability as well. So there she was, kind of stuck between those two worlds that didn't allow her to claim her own identity.

Erik Carter and his colleagues, in a more recent research about-- with 500 families in Tennessee, found that families said that spirituality is a dimension of life for them, an important dimension of life was incredibly important to them in their families and at their home. But that dimension of life was never addressed by service or educational agencies as a resource, and neither was it really recognized as important by their religious communities, given the kind of barriers that many people faced in trying to become more included and participating members of congregations.

So families live in that world, but people for some-- it's just taken-- the religious community is just beginning to recognize, in many ways, and embrace the spiritual needs of people with intellectual and development abilities and their families-- and their gifts, not just their needs. We still got a ways to do before most service systems begin to see that as a huge asset and a part of people's lives.

With little imagination-- there's not a lot of imagination about how to do that out there-- much less the capacity for those two systems to collaborate with one another. So what we need is-- you could say would be a tikkun olam, to use the Jewish expression. We need a repairing of the breach, a coming together, a making whole again.

Our Jewish friends would call it or some people might call-- I love this word "re-membering." Think about re-hyphen-membering, when we are helping people to become members again. We are reconnecting people into the wider sense of the body. It's not just an intellectual remembering, but helping people to be connected. When I was a chaplain in Rochester years ago, and worked with faith communities on helping people from our center and in group homes to become members of their congregations, I sometimes facetiously wanted to-- somebody said, well, what do you do?

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I wanted to call myself an orthopedic surgeon on the body of Christ. What I meant by that was you hear all these stories in those days about somebody's toe or finger being chopped off in an accident, putting it in ice, and they go to the hospital, and an orthopedic surgeon connects that toe or that finger back to the body. And that-- how do we then get those connections back to the wider body of the community and practice?

Well, before I talk about doing the bridging, let's look at some of the-- one of the premises-- let me say this-- and one of the premises of the lecture and of the book is that-- and I'll come back to this, but to tease your mind a bit-- if you start off trying to understand disability and what it really is, my premise is that you end up in the world of spirituality. And I'll explain that a little bit.

And if you start off trying to understand what spirituality is, you end up in the world of disability, or you end up in the world of limitation and vulnerability. And so the question is, how come these folks-- how come these two systems are not more integrated? But why the separation? You know some of the reasons. You may have your own.

First, disability came to be defined and understood through medical and scientific models, and all the factors that separate religion and science came into play. John Swinton-- I hope you've read some of his work and seen some of his work, because he's one of the best pastoral theologians in this area-- notes that, in the world of science, what is good is what's observable, what's true is what's measurable, and what's beautiful is what's replicable.

Think about that. In the world of science-- whereas in the world of spirituality and faith in human life, we have many other standards for what's good, and what's true, and what's beautiful-- ways of looking at what those dimensions of people's lives. Our processes in the faith world for understanding what's good, and true, and beautiful are much different. Perhaps the ultimate expression of this rupture here is when people go into science trying to prove the existence of God by those objective or measurable kinds of things.

Second, I might add to the trio of what's good, true, and beautiful is a different perspective on power-- is a different perspective on power. And science, a goal in research has been able to expand knowledge, and therefore, enhance, and shape, and help future treatments and help people. Arthur Frank, in his wonderful book called *The Wounded Storyteller*, says that we have three narratives for illness in our society, or disease or something. One of them is that I'm going along, I get cancer, I have depression or whatever, fall into the pit, and the by the miracles of modern medicine, I'm pulled out of that pit and set back on my path on a-- through being healed, and on my way back as if nothing had happened.

And we celebrate the miracles of modern medicine and the latest cure for that. The other model is you're going along and fall into the pit, and you can't get out, and it blows your life to hell. It's full of chaos, and you start testing and start thinking about, what maybe everything I believed in wasn't true. And so you wonder where my life is going to go from there. And that's what sometimes people often not in the world of disability or psychiatric illness would think about disability. How could I live like that?

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But Arthur Frank says the third one is that the metaphor of journey-- that you go along, you fall into something, you climbed back out, and then you-- or part way out-- and then continue on another journey, on what becomes for you the new normal, or a way of restructuring, and reclaiming, and reframing your life, and finding hope, and meaning, and love, and purpose in other kinds of ways than you did in the past.

Many of you in this room are here because you found that. You found how to do that in the world of disability. You found how to do that. In the world of spirituality and faith, there have also been efforts to control and to fix what people believe in practice. And obviously, equating cure with one's faith-- with one's level of faith is one of those. Scientific processes can lead to caregiving processes that are, in fact, sometimes called technologies of caring and helping, which sends a shiver up my spine, as if this was a process, and one, two, three, four, and you'll get here-- and if you just do that process right.

Which ends up separating people from the real heart of care, and we end up with a system that doesn't know how to enhance caregiving capacity. Or as a chaplain and quality care person once said to me, we end up with a system that knows how-- doesn't know how to enhance commitment and relationship, and therefore, relies upon compliance with processes and regulations. Third, we've all seen and heard the effects of bad religion and bad science on people.

That's probably the part of the problem why spirituality is not embraced by many people in the disability world-- because of the oral tradition of all the stories that have really wounded people with disabilities and their families-- people passing on experiences and being asked to leave this church, or asked to leave that church, or the pastor never coming to see me. I've got a ton of those stories. I wish we had time for them.

You've probably got your own. But those are still out there, even though that's begun to change in many ways. And churches are, for the most part, really beginning to move towards more hospitality-- not always, but it's beginning to change. Both are areas in bad science and bad religion where families can end up feeling victimized and judged.

Historically, that happens in the world of faith, like we said, when the lack of a cure is being then blamed on that person's lack of faith, in terms of being able to do that. And Harold Wilke and others long ago said Jesus separated that link in John 9, and that that was not a question of that person's sin or the family's sin. It just separated that from any concept of sin.

It happens in human services, when one of the latest techniques will come along in the arena of human services and people say, oh, that's the answer-- finally. Go back to the 1990s, when the whole methodology of patterning came along, and people worked with kids with multiple disabilities and patterning. And you had 60 or 70 volunteers who had to be with a family and the kid, with the premise that, if you moved all the arms, and the muscles, and the legs, and everything, that those patterns would be rebuilt in somebody's brain.

And if it didn't work, the patterning folks said, well, you didn't do it right-- which is the same thing as saying, you didn't have enough faith, or you didn't do it right in a different kind of way. And then you

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also then get people in the service system saying, we don't know how to deal with spirituality, or we're afraid of it. And if they say that, that is, ironically, kind of an acknowledgment of its power.

And they may have seen the power to hurt people, but they may have not had much experience with sensing its power to be able to help people as well. Bad science happened with eugenics, which, of course, came out of a world that was incredibly scared of immigrants and all those others who threatened a pure ethnic identity. Both science and spirituality are arenas that can hurt people by over-promising the success of particular actions or treatments.

And both the arenas of science and spirituality have their own dogmas and their own zealots. In the midst of battles, and theory, and dogma, the real stories of individuals and families often get missed, and they're not heard, or honored, and often completely ignored or lost. Fourth, one result has been a great reluctance by anyone in humane sciences to do anything that looks like proselytizing, with good historical reasons for that.

But it also makes people working in the arena of intellectual and developmental disabilities leery of doing anything that someone then might accuse them of violating church-state boundaries. We can't do that, because we're funded by the state or by taxes, which is not true. You can pay attention to spirituality. You just can't proselytize. And while at the same time, they're saying, we are working towards holistic services and supports to families and individuals.

There's been little opportunity for training and spirituality for professionals in multiple kinds of disciplines in the arena of intellectual and developmental disabilities. Spirituality has not often been included in any part of professional formation and development. In fact, the prevalent model still of being professional means you've got to separate your professional practice from your personal beliefs and values.

Most families and people that I know are not looking-- they don't want people to be proselytizing, but they sure want to know what the value base is of the professionals who are working with them. What people want is a value-clear professionals. They don't want value-free professionals. They want to professionals are people who are committed to them in multiple kinds of ways. And those are the people we say, just like with teachers, are the good doctors, or the good social workers, or the good psychologists, or clergy-- people who they know have got a heart and are committed to them.

Parker Palmer got at that with his wonderful book on the courage to teach. And fifth, in the arena of intellectual developmental disabilities, one of the barriers to honoring spiritual needs, interests, and supports is the equation with faith with reason-- the equation of faith with reason. Religion too often gets seen as something you have to be able to understand intellectually. Therefore, how could people with intellectual and developmental disabilities understand anything related as part of that, so what do they know about spirituality and faith?

A similar question often gets asked about their capacity to understand death. Oh, we shouldn't tell them about the death of their sister, or brother, or mother, or let them participate in the service, because

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how could they understand? It might be upsetting to them. I would like people to ask, how many people at that service understand what death is, and how many people are there who are upset?

That's exactly what grief is about. It's not an intellectual activity. If you go trying to say, I understand death or understand why somebody died in a tragic car accident, you're going to have a hard time coming up with an answer right away or for you in that. It's an experiential exercise, and which people then-- as some of the writing I and others have done around grief and loss-- all of us quote, "act out" our grief and loss through socially acceptable processes of going to wakes, writing cards, going to services, having services, going to the cemetery-- all of those kinds of things by which we act out, in appropriate ways, our loss and our attempt to comfort other people.

And for us not to give people with intellectual and developmental disabilities or people on the spectrum the opportunity to do that, it's not an intellectual exercise. It's an emotional exercise, an experiential exercise, and an experiential understanding. Religious leaders in the past sometimes used this as an intellectual barrier as well, with the classic question that some Christian communities have asked about the intellectual capacity to understand the sacrament of communion-- or in Jewish tradition, being able to understand the teachings of the Torah.

How can they really understand the Torah lesson for today, and can they really say something about that in a bar or bat mitzvah. Let me tell you one of my favorite stories about this-- comes out of the UK. A young guy with autism was in the process of getting ready-- being trained for his first communion, and he just really wanted to do that. I want to be part of that communion. I want to receive can. Everybody else does.

And think about it. It's tactile. It's a thing where you move. It's a symbol. You're doing something. It's not an intellectual exercise at all. It's about being part of what everybody else is doing. So before he went through the ceremony, to allow that, the bishop came to visit the church one day, and as people were invited up for-- to receive communion-- as you know what happens in many Catholic Churches-- if you're not yet confirmed or whatever, or if you're not-- if you're Baptist like me, you can go through the line, but you then are asked to cross your hands like this and get a blessing, and then return.

This young guy gets up to the bishop like this, and then he looks at the bishop and says, you know, you're really greedy. You've got all those Jesuses in you, and you won't give me one. In a month or so later, when he then was allowed and did what he did to need to do to receive communion, of course, that was just a huge day of celebration. And all of you in this room probably got your communion stories coming out of this arena, about what it means-- like the young woman in the reformed church, who came up with her mother to the pastor to be part of the church.

And the pastor did the usual questions and-- not quite the usual questions, but the pastor says, so do you love Jesus? And she said, yes. And he says, do you know Jesus loves you? She said yes. And do you know you want to be part of this church? And he said yes, and then she turns to her mom-- she's a young woman with Down syndrome-- and says, do I have to get a physical for this too? That that's where people are used to asking questions-- are people taking people really seriously.



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So finally, as I've worked with people with intellectual and development disabilities and their families, I've seen and heard them express great appreciation for the new ways that understanding disability as causes and ways of supporting and treating other people, like positive behavior supports, self-determination, new technologies, person-centered and family-centered planning-- a real appreciation, finally, for some things that are helping taking people more seriously, and doing what essential lifestyle planning does, which is asking people what's important to them, not just what's important for them. What's important to you, but what's not just what's important for you.

Those origins of those new kinds of strategies for helping are primarily in the worlds of human sciences and secular policy development, but many of those ways of understanding service and support still have a hard time getting at the depth of love, and hope, and despair, and meaning, and core values, and motivation, and yearning for relationship and community, or sense of purpose or commitment that I hear, when you get to know and sit with people with disabilities and their families-- that they hear what they yearn for at the level of their soul, so to speak.

The concepts and definitions of disability and spirituality have both evolved over time, and they're-- think about it-- they're both constructs. They're both ways for trying to understand something. We have a constructive disability that tries to say, this is what-- a way to understand limitation or vulnerability. And so is spirituality. It's not something I can grab a hold of. It's a construct, a way of understanding parts of our human experience. Both are hard to do that in any real objective sense.

The search has been for definitions and models that function effectively to understand and address human needs and experiences. And I'll go back and say, each one is incomplete, I think, without the other. That unity hidden in plain sight has profound implications for more holistic supports. So let's get into that a bit.

That's further beyond. Look at your PowerPoint-- or your slides. I'm not going to try to keep on doing this. I'll try to catch up. So after the Enlightenment, how did we begin to understand disability? Disability became perceived as a defect and as a medical problem. There were huge advances in health, scientific tangents and fads, such as eugenics, that led to tragic consequences and isolated immoral treatment based in institutions that became warehouses, and sometimes killing fields.

The first job I had-- real job I had-- was as a Protestant chaplain in one of the old hellhole institutions that had 1,500 people in the same space. There had once been 4,000 people. When the combined advocacy of families, wounded veterans, people with disabilities, and professionals and human rights advocates led to increased community-based supports and quote, "normalization," the definition of disability and medical deficit began to change.

Yeah, there it is. OK. Now if I can go back. OK. We all have our needs. In 1980, the World-- I remember this, when I was a chaplain, and the World Health Organization came out with this new model of disability in which disability or disorder could be seen as happening here, that led to some kind of impairment, that led to then a lack of ability to do something that normal typical people can. And what we thought about it-- using the words of those days-- became the handicap, the social determinants of-- the implications of having those kinds of impairments.

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Now, people with disabilities and advocates, especially in the UK, said, wait a minute. That doesn't work. It's not a one, two, three, four, linear progression, just like a grieving process is not a one, two, three, four, linear progression. In about 2000, the World Health Organization came up with this model of understanding disability. And take a look at this, and take a look at it carefully. So one's disorder, or disease, or one's health-- put yourself in this position, not just a person with a disability.

We all have body structures and functions. We all may have some kind of health condition that's visible or not visible. That health condition may impact our activity and our daily lives. And then that limitation in activity and the body function health may impact then our participation in community life, and is called typical life. And that activity and doing all that is also impacted by environmental factors, which are, for people with disabilities, barriers, stereotypes, policies-- all those kinds of barriers that get in people's way.

But it also is environment in terms of culture, and beliefs, and attitudes, and stigma. And personal factors are what do I think about my health condition? What do I think about my disability? How do I think about that, and how do I work with all this so that I move towards then more holistic participation in community life? And in the World Health Organization thing, the real disability these days is what limits your participation-- what limits your participation, whatever it is, in community, or we could say congregational life.

Legal rights, and scientific theory, and research have also gotten at the importance of meaning. Through the disability rights, human rights come along with these new definitions that have been [INAUDIBLE] but we also don't recognize that human rights have foundations and theological concepts, like the value of each person, the Imago Dei justice, and the Golden Rule. There are two or three other models of disability. Two of the three leading models of disability in the world, both of them include spirituality-- or models of the quality of life include spirituality-- unfortunately, not the one that's most used here in the United States, which is kind of ironic.

So an amazing amount of progress has been made toward inclusion, since I started in the 1970s, through channels of disability rights and justice. But we've not paid as much attention to relationships and belonging. Hear that carefully. We've not paid as much attention to relationships and belonging. In the world of deinstitutionalization and community services, we have said, what's important? What's the important question is real estate-- where?

Where do people live? Do they live in the community? What kind of setting? Does it foster inclusion? It's the "where" question. It's the "where" question. It's the "where" question. And the real question-- and we'll get to this in a minute-- is the "who" question. Who are people connected to? Where are the relationships? Because you can live in a community and be just as isolated as you might have been in an institution. Or you can maybe have never gotten into a community, and then-- and still be isolated in a community.

Simply put, rights helps people get through doors, into community, and maybe into congregations, and many parts of the community. But rights don't get you relationships and a sense of belonging. Rights don't get you relationships and friendships. You get relationships with other advocates, and they're--

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profound relationships have been built between advocates and others working on inclusion. But rights don't lead necessarily to friendships and a real sense of belonging.

You might also say that concepts and practices like person-centered planning, and self-determination, and cultural competence all lead logically to taking seriously the spirituality of the people we serve. But in other words, the search to understand disability ends up in the world of what people think about disability-- what their attitudes are, what their values are-- both in the environment, and the individual, and in the community.

And that's where I would say then disability ends up trying to understand-- disability ends up into the spirituality, and what we think and belief from various ways about what it means to be disabled. Now, take going in the different direction-- spirituality. Understanding and definitions of spirituality have been around for centuries, closely tied to religious life and practices-- with a huge tradition of that, as you know, in the Roman Catholic community.

In the past decades there have been increasing interest in research in health and human services and the importance of spirituality, as we've said before. And there's a woman who's been a champion of this in the medical world and secular world of human sciences, Dr. Christina Puchalski at the George Washington Institute on Spirituality and Health. If you don't know it, it's got a great website.

But she defines spirituality as "the dimension of a person that seeks to find meaning in his or her life. It is also the quality that supports connection to and relationship with the sacred, as well as with each other." A variety of strategies have come out for doing spiritual assessments and supports by health care professionals, and chaplains, and other religious professionals.

Most of them come from the arena of acute care health services, but both traditional writings on spirituality and this modern research most often come out of people become aware of those intense spiritual issues-- out of times of crisis, or out of times of feelings or situations of extreme vulnerability, of illness, or end-of-life issues, or out of the kinds of intense isolation and loneliness of people. At times where those liminal places between the Earth and whatever is beyond the Earth and the Heavens, in which we can no longer avoid the questions of human limitation.

My own definition has evolved in conversation with those theories, but primarily by my experiences working with clergy, as a clergy person in the world of people with intellectual and developmental disabilities, on both the religious and the secular sides. My first full-time job in this area, like I told you-- at this large, old institution called Newark State School in upstate New York, which was once called the Newark State School for Feeble-Minded Young Women of Childbearing Age, coming out of the '20s, when they tried to get any woman who was seen to be promiscuous off the streets.

So like the Buck versus Bell decision came. Three generations is enough-- all that kind of stuff. They would be put into institutional settings. As I worked there, it became clear to me very quickly that the greatest spiritual needs in that place whereas the need of celebration and belonging. Where does somebody celebrate somebody's lives, rather than be sent away or seen as deficit? And where do people have a sense of belonging other than to say, I belong here at Newark, or I belong to Newark?

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There was just no good answer for that there in that facility. One of my pastoral care strategies, which I learned from another chaplain early on, was I started trying to meet the Protestants in that institution by taking around birthday cards for people. And it felt like a kind of act of protest against the institution, because I'd sometimes go into wards where people were severely disabled and say, where so-and-so? And they'd say, over there.

And they'd say, why? And I said, it's their birthday today. And this amazement would come over the face of the staff. Nobody had recognized that. And if it was somebody who was in a couch or a bed, I tried-- always tried to find birthday cards that had color. And in those first years when birthday cards came out that played "Happy Birthday," boy, I was really popular. You know, but I'd tape them to a bed or to a wall, and-- just as ways of saying, on this day, this person was born all a long time ago. And how do we celebrate that person?

One of my most profound experiences came out of that-- was one day going to a guy and saying, where's Charlie? And Charlie was sitting in a wheelchair over by the window. And I went over to the window and knelt-- kind of squatted down-- I could do it easier in those days-- and said, Charlie-- and Charlie was one of these older people who just had 1,000 wrinkles, and they all kind of went like this.

This was a unit where nobody talked, as far as I knew. And I handed out-- reached out the card and said, Charlie, I'm Bill. I'm from church. Happy birthday. Today is your birthday. And all of a sudden, he started to reach out, and he smiles. These frowns started to gradually go up like this. Then he pulled his hand back and he said, but I don't have anything to pay you for it.

If that's not a symbolic story about living in a world where we think we have to earn grace and have to earn some kind of love, or that we have to do that to earn. I can think of most of us-- most of you have friends that, if they didn't give you a birthday card, they'd be in real trouble in your family-- or if we forgot somebody's birthday. But that was one of those profound moments that each of you in this room have had of other kinds, where you see the core of what grace, or value, or individuality, or connection means in people's lives.

And as I worked toward moving to build bridges of inclusion with faith communities, I began to see that the spiritual questions-- and you all know this-- it's preaching to the choir-- the spiritual questions about what it means to be human are at the heart of the values that drive public services and intellectual-- around intellectual and developmental disabilities in the United States, codified in the Developmental Disabilities Act.

Oh, it got there by magic. Sorry-- so the DD Act and almost every agency has these values in their mission statement. We're here to help the independence, productivity, inclusion, and self-determination of people with intellectual and developmental disabilities. And they will also say, we try to serve with cultural competence. All of those are the big five. They're in the DD Act.

And what are those? Those are American and Western answers to the questions of identity. Who am I? In America, what are we supposed to be? Independent. And of course, it was progress to say and believe

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that people who are seen as dependent and not able to be independent at all could become more independent. That was a huge step in the right direction.

But if that's the be all and end all of things, sometimes-- and I think we're trying to help people be just as lonely and isolated as everybody else is in the world, because we don't know how to deal with-- we don't know how to deal with dependence, so we assert our independence. And we really need to work out our interdependence, which is the lesson that we-- is all over the map in this country at this time, in this day and age. So independence-- what's our core values, meaning what what's an identity? What's sacred to you? What are the things you most believe and value?

Productivity-- we say, can we get people jobs? Employment becomes the answer to that. But the productivity is the American answer to the question of, why? Why is your life? What's your purpose of your life? What am I supposed to do? What kind of difference do I want to make? Where do I make a contribution in my life? Where can I do that? And we answer that with employment, because by golly, we live in a capitalist system, and that's what you're supposed to do is be productive, and be useful, and be a useful part of that system.

But we haven't really asked people with intellectual and developmental disabilities, yet it's changing-- thank God-- it's finally changing around person-centered planning and employment-- what do you really want to do? What do you like to do? And can we find a way for you to do that in a way that's going to get you a job, or a way that you can do something in the community, where you're contributing and doing something for people-- to use the words of call and vocation in a religious way?

And not that it's just your and mine vocation to serve them. There's a sense, what is their vocation, their sense about how-- what they want to do with their lives in the world? And their vocation, I think, is beyond just helping us so-called typical people teach us something about what it means to be alive. They've got a bigger vocation than that. A person with a disability once said to me, my job is not to help you get over your crap.

I've got other ideas about a job. You may need to do that, but I prefer you not do it around me. Now, some people with disabilities, of course, don't have any control about what we think or what we do around that, but we never give them a chance to say, what do you really want to do, and how can we help you do that? And the inclusion question-- as my wife, the biblical scholar, would say, the question in the Bible is not who are you, but whose are you? Whose are you? Who do you belong to? Who are you connected to? Whose are you?

Connections and friendships with self, with the sacred, with time, with place-- we are pretty much people of the present, but other cultures are much more connected to a sense of ancestry or to future. If I ask you the question, what's the sacred place for you in your life, or the sacred places, you could probably name some things that-- where you go. Where are those places for you? Who are the people? And we'll come back to that in a minute.

And self-determination is really what kind of power or ability. Who's going to listen to my voice? What kind of agency do I have as a person to help, who will honor my decisions and who will honor my

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preferences in the world? And we're beginning in the system to learn a lot about that-- about just because you can't legally make a decision doesn't mean we can't honor preferences, and wishes, and things that people like to do.

And then cultural competence-- will my personal uniqueness and cultural heritage be respected? I'm going to go back to that self-determination for a bit-- no, the productivity of the "why" question. Most people who see somebody with a disability or intellectual disability, what's the first question they ask? What's wrong, or why did it happen? It's the "why" question. People are trying to figure out why.

How did this happen? What happened? Any time some crisis happens in our family, that's part of the process. Somebody dies, has an accident, we start saying why right away. And it either goes in to it's somebody else's fault or it's my fault. It's anger or guilt often, in relation to that-- but that why question. And I think people get so caught up trying to figure out why people with disabilities are in the world in their lives that they forget about that their question is a different kind of why.

Most people with disabilities are not sitting around trying to figure out why I have a disability. They, in fact, are figuring out how to have a better life, and how to get more connected, and how to do things and so on. And so that's where the so-called typical "why" gets in the way of people and our helping people ask a "why" for them. So it should come as no surprise that the core spiritual questions about personhood, community, and purpose, and the divine are raised in the context of disability.

Why? Although, more typical and traditional explorations of spirituality have rarely focused on disability, they have experience. They are experienced and expressed most clearly in human situations of vulnerability and limitation, or times of great celebration, or dealing with death, and suffering, and disease, dealing with the unusual. The same questions of identity, purpose, and connections, and control, and respect for cultural identity are raised by those experiences of being on the margins of life-- those liminal moments, times and places where the present and the eternal seemed to collapse to that moment and crystallize questions and answers for meaning, and what do we make of this in our lives.

Or said another way, leading-- seeking to understand spirituality leads to a place where many people with disabilities and their families would say, welcome to our world. Welcome to our world, trying to figure all of this out. So there are two ways to think about looking at this, a model of this. We often see Venn diagrams something like this, where you've got families, faith communities, service systems all impacting people with disabilities-- individuals with disabilities.

And then maybe, right in the middle there, people from all of those dimensions pay attention to spiritual needs, and gifts, and supports. It's still not honored by lots of faith communities and services. I'd propose a little bit different kind of a model that looks a little bit like this-- that spirituality is really at the heart of who we are as people, whether you're a client, consumer, family, person with a disability, professor, social worker, whoever-- that we all have at the core of however we define our spirituality for us.

And that's part of who we are and our families, and that we are parts of wider systems-- faith communities, services, supports, government systems, civic systems. And then we're all part of that

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wider community as a whole-- that somewhere at the heart of all of that is something about what it means to be individual, what it means to be human, connected to one another, to belong-- all those kinds of things.

And how can we get to the point where then spirituality are seen as some of the questions that need to drive what we try to do and how we try to help from multiple kinds of sides, and from multiple kinds of perspectives? So start off looking at trying to define spirituality-- disability, you end up looking at all the beliefs, and practices, and images, and values, and so on that we have about what it means to be human.

And you start off trying to define spirituality, and you end up looking at-- end up in the world of where vulnerability and limitations-- it's no surprise that most-- many of the Catholic Saints, who are known for being spiritual masters-- either women or men-- were people who dealt with some kind of chronic illness or some kind of limitation in other ways. If you're a veteran, you know the old expression that says there's no atheist in foxholes.

And I think many families and people with disabilities kind of find themselves in perpetual foxholes-- or at least one could say perpetual potholes-- on the journey, as we try to go through a more-- try to find a more meaningful part of what it means to be part of community, and to be recognized as valued and worthy. So I'm going to stop right here with enough theory for a minute. And I could tell stories some more, but what we're going to do in just a moment is take a break, and then we're going to come back and say, all right-- and answer the question that may be in some of your heads.

Oh, Bill, this is really nice and I like that model, but what do we do with it? How do we make this work? So we're going to do that, but for right now, any questions before we break? Susan. You've got a mic coming.

## **Participant:**

Thank you. Welcome, Bill. Here's my question. You talked earlier about the professional and the personal, and bringing-- I heard you say about bringing our full selves into our relationships. But as people who serve, perhaps, as chaplains, or ministers, or professors, or whatever, how do we do that? In my ministry with folks with disabilities, how do I bring my whole self into that relationship without crossing any—

## **Rev. Gaventa:**

Boundary.

## **Participant:**

--boundaries, right. Thank you.

## **Rev. Gaventa:**

That's an area that I'm fascinated with lately-- and let me tell you how I got there. It came out of dealing with issues of grief, and loss, and end-of-life issues for people with intellectual and developmental

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disabilities. Some of the stuff that's in the book that is-- my book is partly classic Stan Hauerwas. You're creative by stealing stuff from other people and forgetting where you got it.

There's a model on aging, about the six-- five or six tasks of aging. And one of the tasks of aging-- one of them is an interfaith model that came out of Chicago. And it's in the chapter on end-of-life issues there, but one of the values of aging and task of aging is getting reconnected to community, because you've been working so much.

How do you get reconnected to community? That was at the Nancy Lurie Marks Foundation yesterday. And one of the head staff used to work in lawyer, accounting, financial world, and he said, I got a second vocation now. And that's my new life-- a different kind of life and a way of contributing to the community.

Another one of the challenges is the challenge of keeping one's faith in times of crisis. Another one is being able to say goodbye to people, as you get older. But one of the challenges that fascinated me was the challenge of blessing-- the task of blessing. Where do we, as people, allow older people to give their blessing to the younger generations, or to receive a blessing, as an elder, for who they are and what they have given to other people?

In the Bible, that was a part of-- natural part of human life. Think about the Jacob story and the power of that blessing, in many ways. So as I began to ask questions about-- so when people with intellectual development disabilities, who've been served by an agency for years-- and hopefully, some of the staff has been with-- in their lives for a long time-- and they move towards the end of their life, who in their life is going to say to them-- if they don't have multiple other friends, and many don't, who's going to say to them, you have really given-- taught me a lot, by virtue of being your pastor, your chaplain, your social worker?

We put people with disabilities in the position of saying thank you to us, the helpers, all the time. Especially towards the end of life, where do we turn around and say, thank you for what you've taught us over time? That's only professionally honest, because most of us who've worked in this field derive our own sense of vocation and meaning out of what we've found there.

There's a wonderful article by Samuel Wells in the Christian Century this week, that essentially says, what use are boundaries, when a friend of yours is dying? Now, the question about friendship raises those questions of boundaries in the world of disabilities. If you've worked with people and they've been-- you've been part of their lives for a long time, I'm not going to call that person a client, or a consumer, or whatever.

And there are boundaries. There are surely professional boundaries. I should never abuse somebody, in terms of intimacy, or some kind of other-- there are ways that I can observe those boundaries. But if I, as a professional, take the power and say, no, I can't be your friend, then it's kind of ironic, in an age of self-determination and speaking for yourself, that then we've taken the power to define what that relationship means to the other person.



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So there are clearly people who I would say are my friends now, even though they would also see me as their pastor for a long time. Now, it doesn't mean you take away the boundaries. Trace Haythorn dealt with this at an AAIDD Conference on a panel in Atlanta a few years ago. The question came up, and he said, what a professional should be able to do? A professional is somebody who knows how to navigate boundaries-- not just to hold them like their walls, but to be able to navigate.

And you know when there are times that-- just throw out your professional stuff and sit with somebody. They don't need you fixing or trying to do your stuff. They need you to fix and listen. So it's navigating that and getting some skills in that. There's a new kind of ethics called for professionals. If people are living in our communities now, they may-- the people we support may be going to our church, going to our grocery store, maybe living next to us on the street.

Then wait a minute-- that's a different kind of relationship than just being the patient who comes to the office, or somebody going for therapy somewhere. What is this community all about? In the back.

**Participant:**

Hi, Bill. My name is Dennis Heathey. We've communicated a few times.

**Rev. Gaventa:**

Yeah.

**Participant:**

How are you?

**Rev. Gaventa:**

Good.

**Participant:**

I've got a question about several things. One is when you look around this room, most folks are 50-plus. And we're living in a post-Christian era, and we're looking at things-- how do you justify chaplaincy, in terms of return on investment? What does a chaplain provide, beyond relationship, that a social worker, or a nurse, or someone else can provide? How do you actually put, in a quantifiable way medicalizing what chaplains provide in a manner that makes it actually sellable to-- actually sellable's not the right word-- make it something that's of value to the medical insurance industry or the hospital industry?

**Rev. Gaventa:**

Behind that is the question of, how do you evaluate spirituality? How do you see that as important and put some money behind it, so to speak? And there certainly are people who work in acute care chaplaincy who've-- there's a lot of writing on that, because you can use Medicare funds and other kinds of funds to help pay for pastoral services. And we've, in our correspondence-- I know of three, or four, five, six-- growing numbers now a secular-based agencies who've decided to put together a role of what they would call a coordinator of spiritual supports.

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And what those folks do is really get to use-- as a friend of mine said, person-centered planning that doesn't include spirituality is not good person-centered planning. So if you really take-- pay attention to what people's culture is, what their dreams, and desires, or hopes, or connections might have been, and then that person not only helps the staff and the agency to listen to that part of somebody's life, but then helps to build connections where they-- with other people who share that, then it becomes ways of community connection, of belonging in the community.

It comes ways of acting out cultural competence as an agency. It becomes ways of living out self-determination. Whatever I think about spirituality, if it's your choice that you want to go to church, well, by golly, I'm supposed to help you do that, if that's self-determination. And I know those agencies are-- begun to look at quantifying that, and they will say. But then it gets hard, because a lot of that's around quality of life kinds of measurements, and quality of life measurements that we have in this country look for objective stuff, which are really hard to find in areas such as identity, and a sense of belonging, and a sense of purpose in one's life.

You can say whether somebody got a job, but you may not be able to talk about whether they like that job or whether it's their sense of vocation. Now, the HSRI here in Boston and their national core indicators research that they've done with all the states, there is a higher correlation, just between the data, on people who go to a faith community at least once a month and employment.

I'm not sure what that means. It may mean that those are people who we would call people with less significant disabilities, and they have an easier time getting a job or whatever. But we'll come back to looking at that whole issue of employment afterwards. I think we need to look out of the acute care and see how people have tried to quantify it. We had a CPE program in New Jersey, and we put clinical pastoral education students at a Kessler Rehab from September to May.

Every time we put a student there, their patient satisfaction scales went up on leaving. When the students left, they went back down. And we kept on using that to say, you should get a chaplain. You're big enough. You say you're a model rehab center. The other model rehab centers have got pastoral care departments. Get a chaplain. But they couldn't figure a way to fund it, supposedly. But patient satisfaction is one of the ways that people do that.

But it's not easy, in terms of that, and in community services. One of the people who's here-- you might want to talk to Frank. Talk to Dennis during the break. Frank works for an ARC where that's a large part of his role, an ARC in New York State. And that's one of the agencies where they've begun to do that, and I've shared with you some others. Heritage Christian Homes in Rochester area really does that well, and they've got a department of three or four people.

Because what they know is that, by getting connected-- people connected to faith communities, if that's what they want to do, it opens all kinds of other doors to friendships, to ways to serve, to fun stuff, to recreation things, to other-- so it's like a study done a long time ago in Ohio about older people coming out of institutions back into the community, and they called congregations ports of entry into the community.

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That's what it is for a lot of us. If we go to a new town, and if you're a person of faith, you start church shopping or synagogue shopping-- not just because you're-- that's part of who you are, but you know there's possibilities of finding community there. But it's a great question, and I look forward to talking to you some more. Dennis has worked with the Department of Health here, public health here, and I know a lot of people who-- your ears should have been ringing the last couple of days.

**Participant:**

How much is the book on the table?

**Rev. Gaventa:**

How much is that child in the window? You'll have to ask them. I think they got a good discount, and cheaper than you can get it online. I'm not selling it. The BC College Bookstore is.

**Participant:**

OK, thank you.

**Rev. Gaventa:**

But it's going to be cheaper here than if you order it online. It is available electronically a bit cheaper through Amazon, but I don't like to order anything through Amazon these days. They're the devil. Any other questions? One of the questions raised one of my stories that many of you have heard, and I'll just tell it. I went to speak with the two group of families with Down syndrome in South Carolina-- the Down Syndrome Association once.

And I did my talk, and afterwards, I said-- we had time. I said, OK, tell me your church stories. This is South Carolina. There are not many synagogues, or mosques. And all the families started getting up, and every one of them had some kind of story about how they're related with their faith communities. One mom got up and said-- this is one of my favorite stories. Two favorite stories out of this-- one good and one hard.

One mom got up and said, my minister went with us to our IEP. It was wonderful. We got everything we wanted. They thought he was our lawyer. And it always gets a laugh, especially from many family group or professional group. But think about it more carefully. If families knew that they could ask their-- or churches knew enough to say, could we go with you to your IEP-- and if you want to talk about a situation a power imbalance, for most families, to go with them, sit with them, help to articulate issues or just listen in-- and people from the school might say, why are you here?

Well, we want to know what you're doing, so we can know what we might do back in church school or whatever. But just think about the difference it would change the balance of what happens, and the communication that could happen in that room. And there was a story about-- another story that related to that. I said that-- told that story once. And so we started doing that, and we went to IEP of a young man with autism. And the big question in the IEP was why he wasn't talking in school.

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And yet, they knew he could talk, but he wasn't talking at school. And the people from the congregation were able to say, well, that's really interesting, because he just sang in our Christmas pageant. So the question becomes, then how does-- why does he feel safe enough to use his voice there in the faith community, but not at school? And what's going on beyond that?

The other story was a mom came up to me at the break, like we're going to do right now, and said, I couldn't get up and tell you this because it's still too raw. They had moved from Pennsylvania to South Carolina. Their daughter was "microcephalic," quote, unquote-- had been in supported employment at McDonald's in Pennsylvania, had a uniform, went to work, pride of employee.

Got to South Carolina, and no supported employment program in that part of the state-- she ended back up in a sheltered workshop with 70 other people. And then, of course, she began to act like the people around you, begin to act-- sometimes catch behaviors or habits that are not so good. And they started church shopping, I guess because they had been part of something in Pennsylvania.

And they kept looking, because they didn't really have any good experiences. And there wasn't, in those days, the kind of resources or whatever that would kind of pave the way-- or faith communities knowing enough to say, you're welcome here. They went to one where they tried to get her involved with some kind of young adult group, and it just didn't work. And they got home that night, and the young girl-- the young woman said, no more church. No church, mom. No church.

And the mom got into being a mom and said, well, we've got to go to church. We're part of God's family. It's God's house. We need to find a place where we can be part of God's family. And this young microcephalic, moderately disabled young woman said, well, it may be God's house, but He's not home. It's one of those stories that goes right through you, and keeps on going right through me, and one of the things that fuels-- that's fueled my work for years.

But the struggle and the blessings of working in this area, because there are just so many way-- things that we have been taught in unexpected and moments of revelation-- and some hellish moments, but that's the way it is. All right, let's take a break, and we'll come back and put some of this to practice. All right, so let's try to put some of this into action a little bit, and to think about how we might do that. How do you operationalize this?

Again, my premise is twofold. Faith communities can use these core dimensions of spirituality to help understand somebody. And it's non-sectarian, so you could use this in a way that put into any kind of faith tradition-- about my identities, and sense of purpose, or community. How do you do that? How might you do that within your own community, if you did it on yourself?

And then secondly, hopefully, it's a model that secular services and agencies can use to explore those core dimensions of spirituality and practices for doing so. So the spirituality language, I think-- not just in this arena, but another arenas-- provides a language that enables people coming out of the scientifically-based, supposedly secular services, and religious communities to talk to each other-- to talk to each other in ways that maybe they can begin to understand each other around the people they support.

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So the first part of this, identity-- who are you? Who am I? Who am I? It involves asking about people's values, their religious and cultural identities, what brings meaning to somebody's life, their preferences and passions. It's more than what do you believe. It's more, what's most important to me? What are the most important things to me in my life? Another lens might be, what's most central or most sacred to somebody's identity?

Core values-- sense of who I am, including the sacred-- so let's set this up with a simple exercise, and we'll go from here and start this. I'd like you all to take the backside of one of those pieces of paper or something you brought, and I want you to write "I am" on it, and put 10 blanks-- in a line, column, or row-- your choice-- 10 blanks. And I want you to say-- use words that you might use to say who you are, and you cannot use your job.

You cannot use your job, the way so many of us define our worth. You can use roles, affiliations, relationships, passions, hobbies, memberships, qualities, things you love, anything like that, but you can't use your job. And just fill in those blanks. Fill in those 10 blanks. I'll tell you another favorite one of my stories from Garrison Keillor, who said-- because I hate to interrupt the energetic talking-- Garrison Keillor once spoke to a group of young clergy or seminarians and said to them, remember, when you get up on Sunday morning, be very, very careful, because you're interrupting why people came to church.

The whole meeting with friends, connecting, talking-- that that's so often what we're doing. Alright, what did you notice by sharing this? What happened? If we had time, we'd get everybody to tell their 10, but we don't. What did you notice?

**Participant:**

Lot of relationships.

**Rev. Gaventa:**

Lot of relationships, great.

**Participant:**

I just noticed that every person who was a parent, that was the first thing.

**Rev. Gaventa:**

Every person was a parent?

**Participant:**

Parent is the first thing on the list--

**Rev. Gaventa:**

First thing-- all right. Were there other common denominators?

**Participant:**

Shared interests [INAUDIBLE]

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**Rev. Gaventa:**

Like?

**Participant:**

Reader, blogger, mother, church-goer.

**Rev. Gaventa:**

OK. OK.

**Participant:**

A sense of community.

**Rev. Gaventa:**

Sense of community. Any other kinds of things? But it became a way for people to start connecting with-- the questions we usually get to after the conversation on the plane that says, who are you, where are you from, and what do you do-- when you begin to start looking for those points of connection with people. All right, one of the things, when you do this with a group of people-- and we're going to use it for some other stuff-- is that you notice-- that I notice is very, very rarely does anybody, in doing this kind of thing quickly, say anything about any part of their lives that they would consider a deficit. Think about it.

**Participant:**

I said challenged.

**Rev. Gaventa:**

Challenged-- OK, great. I was talking to Dennis earlier, because he was talking about appreciating my saying something about my depression. I don't go around sort of broadcasting-- I'd worked in this field too long before it happened that, once I got through it, I had to say, if I want to hide this, that's crazy. That's what I've been fighting against all my life. And then secondly, it was-- but I don't want people, when I say-- if I say something like that, to interpret it as meaning, oh, wow, see Gaventa, he got-- he really conquered that depression-- which is a bunch of baloney.

That's usually the kind of story-- the kind of faith story that people would say, because of my strong faith or something, I conquered that. That was not the case at all. I'm totally lucky and grateful, since, to be alive. But usually, we don't say those kinds of things to begin with. I wanted to because that's the origin of hidden in plain sight, that phrase, for me this morning. And there may be important parts of people's identities-- cancer survivor, maybe recovery-- in recovery.

There are just multiple kinds of things like that. Now, how many of you have had the experience of having others define you through one of those characteristics only? Such as—

**Participant:**

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When you're a mother, when you're an at-home mother, particularly, people don't give you credit for much else.

**Rev. Gaventa:**

Right, OK. One-- others? There were some other hands. Where'd they go?

**Participant:**

As a person who has birth defects and can speak and think why people on principle think that I am imperfect and stupid [INAUDIBLE]

**Rev. Gaventa:**

I've forgotten his name, but you know the guy who-- one of the great guys who's also an advocate and humorist with facial difficulty? He's got a little wonderful little book called *The Church of 99% Sincerity*-- or something like insincerity is just kind of play with some of the ways people use attitudes. Any other ones?

**Participant:**

You're religious.

**Rev. Gaventa:**

You're religious, yeah-- in this society sometimes, yep-- even though we're not persecuted for it, though people would say we are-- sometimes are. Yes?

**Participant:**

Gender.

**Rev. Gaventa:**

Gender? Yeah, told our gender. Yep. OK, in the back?

**Participant:**

People told me that I'm not a believer in Christ, and I am. I gave my life to Christ a very long time ago.

**Rev. Gaventa:**

Well, let me quickly tell you all, because it's one of my other favorite stories-- it doesn't quite deal with this, but goes back to the healing stuff. There was a guy with a disability in New York who got really tired of people coming up to him and saying, can I pray over you? And if your faith was strong enough, you could be healed. And somebody did that to him once unsuspecting, and the guy shot right back to him and said, well, if your faith was strong enough, you could cure me-- which is, in fact, more biblically accurate than the other.

All right, so all of us have had that experience of that one part of our identity that carries negative assumptions or connotations-- assumptions about what it means to be man, woman, stay-at-home

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mom, minister, priest, Southern Baptist. If I told you Southern Baptist background, you'd all of a sudden start thinking, oh my god, one of those? You know, or could.

I would too, given the way some of our Baptist friends have gone. I've got that old high school friend of mine who's here-- but Roman Catholic, pastor, professor, student-- we make all kinds of things. The key lesson here is that we are more than one story or thing. We like to think in our country that we're the masters of our own stories, but no. So many of our stories depend upon what you all said over here-- relationships.

So much of our identity is tied up not just by me being me, but my identities comes from multiple kinds of relationships. Are we still there? Oh, this is moving along by magic. I don't know how it's happening. But I don't know if you know the quote or have heard this TED Talk. If not, go look it up. It's short-- less than 20 minutes. Chimamanda Ngozi Adichie from Nigeria. Just the the danger of a single story-- the danger of a single story.

"All of these stories make me who I am, but to insist on only one of those negative stories is to flatten my experience and to overlook my many other stories that form me. The single story creates stereotypes, and the problem with stereotypes is not that they're not true, but that they are incomplete. They make one story become the only story. Hear this-- power is the ability to not just to tell the story of the other person, but to make that the definitive story."

Something like this ought to be the jumping off places for both faith communities and agencies. Good person-centered processes can get it at least 10 qualities about somebody-- anybody-- roles, relationships, preferences, or whatever. But it could be done in a planning meeting, but it can also be done over coffee, and meals, and simply a shared conversation. Why? You know the answer to this. Too often, the identity of people with intellectual and developmental disabilities is determined by one story and by one label.

Too often, they are seen as only part of the disability story, whether we think-- whatever we think that is. So not only is it wrong-- we are also taking the power to define-- say who somebody is, rather than using our ability to find out who somebody really is, and the multiple dimensions of their lives. So once we do that, the possibilities for honoring multiple dimensions of identity are endless. First, a common task is helping people with disabilities or people who've been labeled with a single story to tell their own story.

You want to do something effective in a congregation for education? Get people with disabilities or their family just to tell the story. They don't have to do a lecture. Just tell their story or their faith journey. Tell their story, and all of a sudden, this person-- people become alive in multiple dimensions there's nothing more powerful than that. This is who I am. This is not who I think I'm supposed to be or who you think I am.

It begins when congregations in the public square with a simple question-- not just, what's your name-- or to a parent of a child with disabilities, to say, tell me about your child. We got in a discussion earlier at



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our institute this year that was a discussion that became a podcast from the Mormons. And one of the theologians, who's also a parent, talked about various things people had said to her as a parent.

And somebody said, what's the question that you want people to ask you? And the question was, tell me about your child, or tell me about your son or daughter. Don't put any kind of meaning on that. It's practicing the most ancient form of assessment. The word assessment in Latin means "to sit next to." We use assessment as a way of objectifying and moving apart from, but assessment at its root means to sit next to-- over a cup of coffee, over-- everybody ended up with the same table out of Boston College Continuing Ed event-- whatever.

You begin to know each other. So in terms of faith identity, think of how this reinforces the importance of-- think about how this reinforces the importance of growing up in a faith community and absorbing a sense of identity through doing so-- not just through the official rites of passage, like first communion, or multiple forms of worship or ritual, or education, or recreation, or service, or experience of learning.

Think of the stories you've heard and the experiences you've had about the transforming quality of those rites of passage for people, children and adults, with intellectual and developmental disabilities-- how that inclusive rite becomes something that is not only meaningful to the individual, but transforms a whole community. How many of you have seen the movie *Praying with Lior*?

Yeah. Look it up sometime. Find it somewhere-- 25 minutes, 30 minutes. It's about Lior Liebling, who's a young Jewish man with Down syndrome in Philadelphia, who grew up in a congregation. His mom was rabbi. She died-- dad got remarried. But Lior has-- his gift is davening, the capacity to lead in prayer, and to pray with ways of moving in others. It's an incredible film. You really see the power of that kind of community.

And then think of what people then have the chance to experience and grow up in a faith community. Then they've got the chance to practice all this stuff. So often, people with-- people say to people with intellectual development abilities-- they go to a congregation for the first time and they don't know what we in the autism world call the hidden curriculum that's part of every congregation. Each one of your congregations has a hidden curriculum, and you don't know what that is until you do something that steps over the line, right?

And that's what families are so afraid of. It's the hidden curriculum. And we need to make that hidden curriculum explicit. But the way you learn a hidden curriculum is not through intellect, but practice, practice, practice. Jenny and I grew up as Southern Baptists. We had multiple opportunities to practice-- going to church, I say, as a missionary kid, more times a week than I ate. You learn that through osmosis, and you knew what to do when.

Think about when you go to a faith community that's radically different than something you've grown up to. When I first went to a Catholic Mass or an Episcopal service, I was what I would label liturgical challenged, because of not knowing what to do, and when, and looking desperately for the guide to do that. But think about also the way that somebody begins to be able to say, I am John, or I am Mary, and

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by golly, I am Catholic. And I go to this parish, and Father Tom is my priest, and sister so-and-so. I'm an acolyte, and then all these other parts of things start adding to people's identities.

So our challenge these days is, how do we create and help people have multiple stories, starting from the things where they already are, and going from that. So give people more than one story. So secondly, think about who are you, the question. We've answered that for people with disabilities and ourselves through the single channel of employment-- or not who are you, but why are you-- sorry.

But the deeper question is, what do you really like to do? What do you want to be? What do you want to do in the world? What do you think your purpose is? What's your sense of vocation or calling? What are your gifts? What kind of difference would you like to make in the world? So starting from passions, and experiences, and interests, and then moving into roles where you can share those passions and interests, that is the beginning of helping people find a sense of purpose.

And that sense of purpose can be lived out through employment. How many of you know people with intellectual developmental disabilities who, like some restaurant owners, have probably got their first paycheck nailed to the wall? They're so proud to have earned that money. But there are also so many other ways that we express our sense of purpose and can make a difference.

How do we find-- the question is-- for people to have opportunities to give as well as receive? For service agencies, and transition planners, and employment programs, how do we give chances for people to test out their interests to do something meaningful, and in spite of the tons of money poured into employment for people with IDD?

And there are lots of creative things are going on, but the rate is still pretty terrible-- the unemployment rate. But you know the stories. Bill Kiernan, I think, told me about the story about young woman with Down syndrome who started the cookie company in Boston.

[INAUDIBLE]

Yeah. And that's happening in baking. You see all these things on Facebook about coffee shops being run by people that are shaping employment opportunities around what people like to do, or finding something like to do. And for faith communities, how do we help people with intellectual and developmental disabilities, or any kind of stigmatized identity, have a sense of identity, have a sense of doing something in the faith community that they are giving as well as receiving-- that they are being disciples, that they are doing mitzvah, that they are following the laws, if you're coming out of the Islamic tradition?

We say, in our Christian tradition, that it's more blessed to give than receive. It's also a whole lot easier. None of us are very good receivers at asking for help. That quandary of most pastors is that people come to church hurting, but most people have got on their Sunday best, and the pastor never gets told what's going on somebody's life. And therefore, they-- because we're all supposed to be showing our Sunday best and our strength.

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Our identity is so wrapped up in our sense of independence and of not needing others, that we often ache for support. And in that capacity, and the irony is, that we think people with autism are socially inept. Hear that carefully. We think people with autism are socially-- if we can't figure out ways to say something about places where we need some help or support, then we're not-- we're kind of socially inept as well, if you want to talk about that in a different way.

How many of us sing, as Christians, "Just As I Am," but nope, we don't really want to show people just who I am? so the danger of people with disabilities in the terms is the danger of being seen as a single story. And we make them the designated receivers in our congregation, and being like a designated driver. Or to use the lingo of a service system that once meant equality-- the word that I hate-- that people we serve our consumers, that that's our only role is to consume.

The reason I hate that term is because it makes it-- it portrays an image of people with disabilities as being people who consume what society gives without any production or sense of giving coming back out of that. So in a congregation, the quickest path to inclusive supports in a congregation for a person with intellectual and developmental disabilities is for the church, or parish, or synagogue is to find somebody a job in the congregation.

Find a way that they can make a contribution-- to be an acolyte, to be an usher, to be-- put up the chairs, to help with coffee hour, to clean, dust something, to be part of work days, to do this, to be a teacher's aide. If we can't find somebody with an intellectual disability something to do in the congregation, it says more about our lack of imagination and creativity than it does about their ability.

They may need to do it with somebody else, do it together, but let people see people acting out their faith as believers and as parts of this congregation, that they're not just there to receive-- they're also actively doing something and giving. I got a bunch of favorite stories about that. I'll tell my Roman Catholic story. It was about the young man with Down syndrome down at the Jersey Shore who became an acolyte.

And his mom took him to mass so he could be an acolyte one day, and after Mass, a young man-- the mother couldn't find him. Mom goes to temple, can't find young son. There's some kind of story here. And she finally did find him, and he was talking with an older couple. And it turned out that older couple had come to parish, the church that day full of questions, and uncertainty, and kind of hurt in their heart because their first grandchild had just been born, and the grandchild had Down syndrome.

And think of what it meant for them to walk into that parish and see this young man in a socially-valued role in that parish, who took pride in what he was doing. It's no wonder they wanted to talk to him about, so who are you? And think about the power of that-- not just for the individual, but for others.

And think about trying to marry the potential of employers and faith communities to one another. It's one of the projects that Erik Carter, and I, and some others did about six years ago, and the model is out there. We did a project called Putting Faith to Work based on a simple idea from the Old Testament, that your farmer was not supposed to harvest all of the crops, but to leave 1/10 of the field so that the

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widows and the orphans could pick their own food and have the dignity of work, and thereby, not just have it given to them.

So the idea in our project was the one magical component of most congregations is the capacity of a congregation to get a group of people around somebody who has a need and a group of people to support. It can happen for a short time. It can happen for a longer time. Could happen through a committee, or it could be kind of a flash mob of help, to help somebody do that.

But what we did was get a group of people together, person with a disability who wants a job, have a chance to get to know that person with a disability-- part of their congregation. And then figure out what they need might need to help get them better prepared for the job, but then use the social capital the rest of the congregation to find-- to say, Ralph, this guy we're trying to help find a job-- you all know him. He's grown up here.

This is what he loves to do, and we're trying to find a place for him to have a job-- get a job. Tell the whole congregation that. Think of all of the roles that they have out in the community in contacts. Think about all the potential places. Oh, I know somebody who might be interested. Oh, we could think about that. Think about that.

And that's how most of us get our own jobs anyhow is through contacts and networking. It's not through bulletin boards and through-- use the power of that networking. And then, if it's somebody who has grown up in a congregation, it's about getting Ralph a job. It's not but it's not about starting to support an employment ministry-- although, that's what they're doing.

So the power of to think about having to do something, or if not a job, somewhere where they can use their interests, and their gifts, and passions in volunteer ways, or others as well. Putting Faith to Work-- it's online. You can download the manual. It's non-sectarian. You can adapt it to any of your theologies. I think there's some really powerful stuff about what it means to work.

Third, the value of inclusion-- and the question is around connection and belonging-- not who am I, but whose am I? That's the major identity question in the Bible, and the Quran, and the Torah. In some parts of the country, we might say, who are your people? Who are your people who are? Family, home is the place you go where they got to take you in-- or the Friends song, why so many of us know it-- where everybody knows my name.

Not just where do you come from or where do you come from multiple forms of connection. You think about connection, those connections can be-- sorry-- to the natural world, connect around nature, around pets. Walking a dog is one of the most socially connecting activities for anybody in a neighborhood, because people want-- come together around pets and animals, and start conversations.

Connections to time, connections to places, connections to ourselves, to others, and to whatever it is we define as sacred-- and through those connections, we gradually build a sense of belonging. Those of you who were here last year, I hope heard Erik Carter, but what he's done now, out of talking to families and individuals with developmental-- intellectual and developmental disabilities, is come up with a model of what it means to belong, as spoken by families and individuals.

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And if you haven't seen the model, this is not just a spiritual or religious model. It is-- kind of goes everywhere. 10 aspects of belonging-- to belong, you've got to be present. You may need to be invited. You want to be welcomed. You want to be known. Robert Raines had this wonderful quote which said, we all think we want to be well-known, when what we really want to be is known well-- that we really want to be is known well.

To be accepted, to be supported, to be cared for-- congregations do that with each other-- to be befriended, to be needed-- people need me here to do something-- and to be loved. And that is not just faith communities, but faith-- that's what faith communities can do par excellence, that many other places cannot do. But that's why congregations are so important in this.

So there are lots of resources out there for faith communities and community building resources. I'm not going to try to list them all. And I'd also want to say before we get away that there are people in Boston beginning to do more on interfaith connection around building inclusive congregations. Some of that's coming out of the Jewish Federation. Molly Silver runs one of those. There's a conference in December that they're going to invite people to, and there's going to be a bigger one next spring funded by the Ruderman Foundation.

But it's becoming not just Jewish, but becoming gradually more interfaith. And Molly was supposed to be here this morning, but part of the value in this-- I'm a firm believer in connecting with people who are doing this, because you get to see other people and what they're doing. Yes?

**Participant:**

I just want to invite anybody who wants to come visit a 37 year old community for people of all abilities in west Concord. You're totally welcome to come visit some day. Fellowship, it's Christian perspective and it's Sunday afternoons. And if you want to visit and see how it works itself out, there are some folks who also identify with the church in close ministry, so they're inclusive and some disability community specifically. If you want to check that out, please let me know.

**Rev. Gaventa:**

Are you a L'Arche community?

**Participant:**

No.

**Rev. Gaventa:**

You're not.

**Participant:**

We're just a UCC Church.

**Rev. Gaventa:**

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Oh, OK, cool.

## **Participant:**

A group home started opening up in the '80s—

## **Rev. Gaventa:**

Well, that's the connection and people building this kind of interfaith coalition, because it's happening in different parts of the country. And you begin to say, wait a minute, that's what we'd like to do, and you go do it from other people. And that's the value. It's one of the skills and community building, which is that little skill that we say never happens in churches, but it happens in human services, which is the value of friendly competition.

Well, if our UCC can do it, how come First Methodists can't do it? We do that in all kinds of other ways, and let's see how to do that. But let's go back a minute and start say something about expanding this from those dimensions of who you said you are-- I am. For years, literally 25 years working on connecting people with disabilities with others, I worked on this kind of model.

How do I connect people with disabilities with somebody who's not disabled? Through churches, through friendships, or volunteers-- whatever. And you know in that one-to-one connection like that, and you're inviting people to come to your community. And people who've never had an experience in disability might have all kinds of questions and uncertainties, and all kinds of stuff going on. And sometimes the people with-- then with disabilities have also got all kinds of questions going on, like is this person going to really talk to me, or they're going to just pat me on the head?

Or are they going to talk to the parent or somebody else, and not to me? There are all these kinds of questions, all these spiritual and psychological things swirling around in that. And then, with the best of community building theories and practices, I finally got it. It looks like this-- that what you do-- think about the 10 things you listed-- is we start connecting people through common passions, or interests, or roles, or things that you do, or relationships, and start working through there and finding out what people like to do together so that then, you can--

If you know a person with an intellectual disability who loves to do something, you go looking not just-- you go looking for somebody who loves to do that thing too, even if they don't know anything about disability. You go looking for another person who shares that passion, and invite them into a relationship where-- to come meet somebody who shares that passion, but never has a chance to express that in community, or talk with other people about it, or other kinds of friendships.

Let me tell you one story Erik Carter tells in Madison, Wisconsin. He was part of a church. Think about this-- Madison, Wisconsin. A group home opened near them, and they found that out, and they decided, let's try to get some men in the church-- it was men in the group home-- let's try to get some men to go over and meet these guys, and get to know them and befriend them.

So they put a notice in the bulletin. They advertised for a couple of weeks for a meeting after church. How many people showed up on that meeting? Zero. So they say, well, that didn't work, and so they

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thought some more about it, and thought. And about a month later, they put together a bulletin that said, we're thinking about starting that event on Sunday afternoon so all the men who are Packer fans can get together and watch Packer games, and drink some beer, and have a good time as part of church fellowship.

How many showed up? 50. Yeah, 50 people. And then they said, and by the way, we've got some guys up the street who live in a home who've got some disabilities. We could help you with that, but they're all Packer fans and they never get a chance to be with other Packer fans, or go to a bar, or watch a game, or have a beer or anything. And for genuine Packer fans, what's the bigger tragedy-- the disability or the lack of being able to do that with Packer fans?

The tragedy is they can't get to live out that kind of interest in their life. And so they got that going, and the guy, the connector could say, I'll teach you about the disability stuff, but I don't know the Packer stuff. You guys are the experts on the Packer stuff. Out of that shared interest, then people got connected. And people were beginning to do that in a variety of ways.

Young guy with-- severe on the autism spectrum who loved to break glass and New Jersey, he finally got a job at a recycling center. He could break all the glass he wanted. And there's a story in the book, and I'm not going to give it away. You got to read the book from Australia that's even better. But it may not be quite proper for a religious setting to tell it.

I say facetiously sometimes, the question about the challenge here is, quote, "reversing the tragedy"-- what people think is a tragedy. People think disability sometimes is that. Bob Persky had a wonderful quote from a husband-- a father who said to another father, can't you see it's we who tell other people they're a tragedy? It's we who tell other people they're a tragedy by the way we relate or don't relate?

And to change the need or the deficit from anything having to do with an impairment to the deficit of experience. Chaplain student of mine went to a group home near Atlantic City was trying to figure out what religious connections there were. The staff people said, oh, they're all Christian. We love to watch the church on TV on Sunday morning, and everybody joins in. And the chaplain said, well, wait a minute. One of these guy's name sounds awfully Jewish. You sure he's not Jewish?

And she said, no, he's not Jewish. He loves to be-- watch that service. And so she went up to the guy and said-- Scott, I think his name was-- Shabbat, and he said, shalom. And all of a sudden, of course, that came right out of this tradition. There was something there, and they found out that that was his tradition. And lo and behold, as grace would have it, there was a synagogue about a half a mile away that was just starting to work on inclusion, and a match got made in relationship to that.

The tragedy is the lack of experience in the things or opportunity to express the things that are most important to you. And the most important question is the "why"-- why we do all this. And you've got your own answers for that. The why question may be because we're all created in God's image, that we all belong to God's family, to the people of God, to the ummah, the people of-- the body of Christ. We all believe in some of the core things that have come up to me.

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And bubbling up and all this is what's talked a lot about these days is hospitality to the stranger, and people with disabilities are the quintessential strangers in our communities. The irony is a lot of congregations who work very hard on diversity don't include disability in that diversity, and haven't caught yet that the definition of disability is evolving from a disability issue to a diversity issue.

People with disabilities are going to be with us and part of us, and some people are beginning to say from the very-- theologically, to think about how people with disabilities were there, in a sense, at creation, or things with disabilities were there-- that disability is not a sign of the brokenness. And that's one of the things that gets me really up the wall when, people say disability is evidence of our brokenness of the human kind.

Well, you may believe that Adam and Eve, by their disobedience, broke something, but don't put that on somebody else. If you want to talk about evidence of brokenness, let's talk about me or you in relationship to that. Then also, the ways to begin to do this-- think about what doing spiritual-- oh, so anyway, again, you connect through the "who." Who are the people? What is the thing that connects people? Where does that happen? Where does that happen?

Think about where those people gather. When do they happen? How do you get to be there? Who gets invited? How could you come to get to know some people there? And then the why question about why this is so important to people in people's lives-- you can also begin in secular services. Talk about spiritual assessments and helping to capture through person-centered planning.

And this whole thing about connection goes back to the sense of the third thing. What's the third thing that connects us? And the third places-- there's a concept in sociology about the third places where we gather. And my experience this week in Boston for the last few days is that the third place where I have had the most interesting conversations with people is with my Lyft drivers, taxi drivers.

I have connected with people who I never would have connected with because we were in the same place, and they happened to be friendly people, and we had marvelous stories together, and then shared commonalities. But third places are congregations, saloons, farmers markets, schools, educational places. Where are those third places where we-- besides work and home-- where we can connect to each other?

And how do we make sure that people are visible there, especially when there's something around a shared passion? The other piece about the spirituality piece is that this is a thing that's across the lifespan. It's not just for adults. There are spiritual dimensions and experiences at birth, at the onset of diagnosis, in early years. Think about the power of faith-based early intervention, getting kids involved in nurseries and Sunday schools early on.

Inclusion in a religious education, walking with people through the journey of adolescence-- I had a Methodist guy say at a church where their youth group had really worked on being inclusive, and he was beginning to get kickback, blowback from some parents saying, my kid-- who didn't have a disability-- I'm not sure my kid can handle that. And you want to say, well, they're going to need to be able to handle stuff like this in the future.



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And what would be a better place in the world than for a youth group, where you learn how to connect with people around differences and to see one another? And if you want a ministry by youth groups, it's to be inclusive of people who, at their schools, get bullied, and stigmatized, and teased during that time of life when all of us are trying to figure out who's the "in" group, and what do you have to do to be cool, and all those kinds of things that are going on.

With adults, with getting to transition to adulthood and work, adult relationships, grief, loss, and end-of-life issues-- all of these involve spirituality and spiritual dimensions in our lives. So my hope is that this understanding that spirituality is hidden in plain sight can help faith communities and support agencies, that collaborative efforts can begin to work with each other across those areas of service-- that people, instead of having their lives dissected into different sectors, that we can begin to surround people and more holistic ways, and that for professionals in the world of disability, we could begin to pay more attention to the role and power of spirituality, as well as paying attention to professionals-- our own spirituality, and what drives our commitment to be professional.

You know where the word professional came from? Professing vows to a religious order. You professed your vows. And I say to people sometimes facetiously these days, The professed vows in a religious order and made vows of poverty, chastity, and obedience. In these time and days, most professionals would not make vows of chastity and poverty.

They may make values to obedience, because too often, most of our human service systems are run on fear, and on doing the right thing, and making sure you don't make any mistakes. But can we make other kinds of vows, like the vow to be more mutual in our relationships, and share power, rather than holding all the power, and to be able to walk with people through people's lives? And for spiritual leaders, can we begin to see that the core spiritual values are at the heart of good practices?

And together, if we can get systems of support around people to unite and work together, then perhaps people can begin to feel like there's a uniting center, and you repair that breach and help people to have more holistic lives, with people around them who will talk to each other, and work with each other, and then keep on learning together. That's what I have to say, and there's a lot more about it in the book, if you want to.

[APPLAUSE]

Let me say to you-- We copied this thing about being interested in keeping in touch with what's going on, there's a bunch of websites, and listservs, and things to do. We've got this Institute on Theology and Disability that'll go into its 11th year next summer in June and May. It's great community. I am-- finally learned how to let go of something, and there's a new group of people taking it over.

Old dogs can learn new tricks. But there's interfaith effort beginning to happen here in Boston, like around the country. So there's a question or comment. Yes?

**Participant:**

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I'm going to try and make this make sense. I was lucky to get to meet Judith Heumann, a great advocate and leader in the disability rights movement, this week. And I was so excited to meet her. The congregation where I work, we've been trying to learn about the disability rights movement and its heroes, and where we're teaching that is through the concept of saints. Now, I know Judith Heumann is not part of a church, and so it's a very loose definition. And we're not the only church that has—

**Rev. Gaventa:**

But she is Jewish.

**Participant:**

Yes, I know. So we're not the only church-- well, I don't know. I'm going to try to not ADD this question. So I realize how, when I shared with her excited I was to meet her, what that must have sounded like. I shared a little bit about our community, and that we call it a community of friendship and worship for people of all abilities.

Well, my question is around this idea of identity. It was very important to her, and I can understand why, that-- to define disability community, and that disability, not ability, it needs to be the defining word. So I guess it felt like she and I, in particular, had a disconnect, and there's maybe some-- perhaps a disconnect between when we are, as a religious community, trying to form inclusive community, and we don't want to talk about broken-- we talk about common brokenness.

But we don't want to talk about needing to change, and that we are whole as we are-- that can feel erasing for some folks with disability, and I think that's how she was-- the point she was trying to make. And so I just wondered if you have any comments on that, rethinking professional ethics and thinking about how these questions around identity work themselves out in the progression of the movement and change in society. Could you say anything about that?

**Rev. Gaventa:**

Sure. As you know, there are just all kinds of issues around labels and things like that. And there's a new sense of people in the disability advocacy community that say to claim disabled not because they're sick and tired of equally challenged, or equally able, or are challenged-- ability challenged, or those kind of euphemisms. They say, no, this is what I am. This is what it is.

And there's a parallel in the same way with people-- other groups and movements who've been on the margins, who take the very identity that's been used to exclude or minimize, and turn that into a notion of power. Black power, women's power-- you get that same kind of thing that begins to happen. And so you get that thing. The key thing, I think, when a community is then begin to say to the people who are involved is, how do you want me to refer to this? And let them tell you, rather than our telling that.

At one of our institutes, a pastoral counselor said he works with people with psychiatric illnesses and other things. And he starts off the sessions by saying, you know I've got to put down something for the insurance, and I've got to use a label. But in our sessions together, what do you want me to use? And

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give people then the power to name that part of themselves that-- in a way that they can begin to use that.

Now, it also used to be that there's a little Methodist book from 30 years ago that is entitled-- about the early ministries-- it was entitled *We Don't Have Any Here*, dealing with, I think, you ask a congregation, do you have any people with disability? No, we don't have any here. And they were trying to say-- refute that and show some creative ways of doing it.

I'm waiting for the we don't have any here to be the sign that we've almost reached the kingdom in this kind of way. And I've heard this from a parent in Canada, where some-- where they had a congregation that was very inclusive. Somebody asked them about disabilities, and the person in that congregation said, oh, we don't have any here.

And the person said, well, wait a minute. No, there is people-- there's a guy over there in a wheelchair. There's this young man with Down syndrome. There's this other older person who uses a cane. Oh, that's just Jim. And that's just Jane. And that's Bill. I don't know think about them as a disability. I think about them from their name, and that they're part of this congregation.

So one of my versions of reaching the kingdom is that we don't have any here, because we are all known in ways that are important to us. But it's a very loaded area. It's a loaded area in lots of other areas of life too. It talks about the power of language, just like the old Down syndrome thing about sticks and stones can break my bones, but names can really hurt me. Any other questions or comments?

## **Participant:**

Thank you so much. My name is Sheila, and I am a chaplain at the Dana-Farber Institute for Cancer in Boston. And I wanted to respond to the gentleman's comment earlier on how chaplaincy can be measured or valued. So in my role, I participate in a lot of stem cell blessings. So stem cells come from either the patient or a donor, and they are often the last resort for people in treatment for cancer.

And so it's a long process to both donate and to receive stem cells. And these cells can come from all over the world, and they have to be injected almost immediately into the patient. And so we bless the stem cells before they're put into the patient. And I've been told by the clinical staff that stem cells are more readily accepted into the body-- they can be rejected, which is devastating-- if they've been blessed. They've actually measured this and done studies on it. And so this actually affirms the chaplains in the hospital, because we spend a lot of time blessing both the patient and the cells.

## **Rev. Gaventa:**

Well, that says something to me about the attitude of the center towards all of that, and that they-- all of them recognize we're walking in holy ground. And that, I imagine, would feel very healing to people. Any other questions? Back in the back.

## **Participant:**

It's a pleasure being here today, and thank you. I could feel the higher realm all around me, and I'm sure I was not the only one. I'm looking for more of a feedback from you. I'm a special mom. My daughter has

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special needs. And often, in talking to other parents, they do feel that their children come from a higher ground a realm of spirituality. And somebody who is not spiritual may think this is crazy, but I know mine come from there.

So for someone like you, and so many of us that are here, can you give us some feedback? I know it's not from the mind, and I know it's there, because it's connecting me and her and so higher up. Anything you can add to that, please?

## **Rev. Gaventa:**

Well, here's a way I would respond to that. I would say there's all kinds of layers in response to that. I could say that it's through people-- friends of mine and people I've worked with that I've certainly become more aware of higher realms myself. I'm very careful about making a designation about saying God sent-- or some higher realm sent this child to be, because there was-- once upon a time, there was a terrible poem that used to float around called something like a meeting-- started off like, "A meeting was held quite far from the Earth. It's time again for another birth."

And God and His angels are figuring out, who can we send this child to? Because they're special parents. And most parents would say, when somebody says, oh, you're so special, their first response, if they're honest, is to gag. Now, their child may feel it's special to come from another realm, and what I would mostly say to that is then you, as a family-- and thank God, about 30 years ago, people began to talk about the sense of-- Ann and Rud Turnbull began to talk about and research the positive contributions that children with disabilities made to families and people with disability.

Because before that, of course, that professional assumption was a family had a child-- send him away-- going to be a complete burden. And it took heroic people to stand up against that. What I would say is you, and you found other parents, for whom that sense or that belief has been a core meaning-- come to be a core meaning for you at the core of all those questions about being parent, and about what all this means for you, and so on.

And I may not be able to prove that in any kind of scientific way, because they won't ask the questions. But by golly, I'm not going to come in and take that foundation out from underneath you unless I think there's something better to take its place. The beliefs that we have around core things in our lives, we so too quickly say, oh, that can't be true. You can't really believe that. The importance is, how does that belief function in your life, and how does that function?

And the way it functions is for the good, as best I can see it. Some of you who are old enough, like me, did you ever see the little 12-minute movie called *Mother Tiger, Mother Tiger*? I've got it on tape. I'd be glad to put it on Dropbox and let you-- I could do it illegally. I can't find the people who own the copyright. But it was done by the same guy who did the movie called *The Parable*, Forsberg, a long time ago.

I'm really dating myself. But it's a 12-minute story about the birth of a child with multiple disabilities to a particular family. And it starts off with the husband and a very pregnant wife playing around in the

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nursery, which they are decorating. And she's on our knees and says, I can't get up. And husband comes over to help her get up, and she looks playfully and said, God, why'd you do this to me?

And her husband, or somebody, said, no, He didn't do it to you. He did it for you. Then the child is born, and very dramatically, in five minutes, they go through all these horrible things about diagnoses, and getting diagnoses on paper, and nobody around to support them, and ending up with her older, multiply disabled mom at home, child in a crib crying, and a lot of noise, and the mother at the end of her wits.

And she goes over to the crib and yells, and just say, why all this? Why it happened-- and then she goes downstairs-- this is very dramatic-- very dramatic, maybe overly-- goes to their safe and pulls out a pistol, comes back upstairs, and for a moment, pulls a blanket over the daughter's head. And for a minute, you think she's-- oh my god, this mom's going to kill her child-- which has happened before, and sometimes has happened in the past.

But that's not what happened. She does fire after she's said some things, and she hits three things. She hits a mirror, she hits a picture of a parent with a child, and she hits this doll that's in a Russian doll kind of form up on a shelf-- and falls into a swoon. Now, the symbolic piece of that, what she's hitting is this clown up on the shelf-- a la my image of God-- this picture in the mirror-- I am not who I think I am, but different-- and this other picture of a family with a child-- this is going to be different.

She falls into a swoon, and her waking up from that, she remembers that experience in the nursery before the child was born, where she said-- they said playfully, oh, He didn't do this to you, He did it for you. And that became her rallying cry, and the brick on which she began to rebuild her life-- and then became an advocate. And then all of these-- some pictures about all the things that have flown out-- come grown out of that.

As a pastor, I would never walk into a situation like that and say, oh, God did it for you, not to you. That's not for me to say. That's not for me to say, but if a family comes to-- usually, the long time in that crucible to figure out what the meaning of this for them is, and that's what it is, as part of their spiritual or faith tradition, then by golly, I'm going to support that and say, I'm so delighted that that's-- and that means something to me.

And tell me more about it, so I can learn from you. Then I'm going to be on holy ground with you, because you'll be telling me about what means the most to you. Think we better stop or it.

[APPLAUSE]

[MUSIC PLAYING]