

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

presented on November 8, 2019 by

Rev. Bill Gaventa

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

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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:

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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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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

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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 exr e wh- ei0uot ebthnt yxrg1 6tg to htouxrg1 6xrg11ri2uo

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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

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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 year

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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 2.2 (6)6.6 (e)0.7 (f)0.7 (g)hic9 (P(0.7 (Q)1.7 (b)0.7 22(4 7 6.3 (s)4.3 (t)0.8 (u)4.3 (v)TJ23.7y)7.5 (w)inw

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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.

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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.

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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 betwe

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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.

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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?

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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 the-

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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

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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

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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

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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 chairs, tebo9.6-0.7 02 j-9.6 03.4boc -0.000 Td(-)8(-0.2 6 r).1 6946 0 Td(w)6.4 0 6.4 0.8

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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.

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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--

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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

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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 can w 53 (s) 6.3 (ab) 2.2 62.0.6 (1 02 (TJ05) 9.6 (v) 5.4 (e) 3 (y) 6 theny86th

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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--

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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 hap-0.7 (0)3.2 (0)0.00m, ant10 us(0)0.7 \$ 0.8 (0.7 8