

Boston College
SCHOOL OF THEOLOGY AND MINISTRY
Continuing Education Encore Events

**Transcript of "Families with Disabilities:
Recipients or Agents of the New Evangelization?", Part 2**

**Annual Pyne Presentation on Ministry with Persons with Disabilities
presented on April 11, 2014 by
Margaret E. Guider, O.S.F., and Maria Cataldo-Cunniff**

GUIDER: So Maria, are you ready?

CATALDO-CUNNIFF: I'm ready. OK, if you can't hear me or if I'm not clear, just give me a big wave, and hopefully I won't be too self-obsessed to notice you.

OK, so last week I took my kids to McDonald's for lunch. And after placing our order, I said to the woman very nicely, behind the counter, "Do you think you would mind having someone bring that tray over because it's a little much for me to handle the kids and the tray?" And she looked at me with this really blank look and went, "Uh, OK." And so I headed to the table.

And then a few minutes later, the woman that I recognized who had been standing behind me in line, walked over to me with these big rolled eyes and carrying my tray. And I said, "Well, thank you so much. I said that's so nice of you." She goes, "Well, like they weren't going to do it," and . . . But I said to my son Joseph, who's five, I said "Joseph, let's thank that nice lady for helping us out." And he said right there, he said, "Well, why did she help us, Mommy?" And the woman said, "Because I'm a nice lady." That's what she said. And she said, but this is important, she said, "And because now the next time you see somebody who needs help, you help them. That's how it goes." And I loved that. I mean I loved that.

And so she went over to her own table, and she had her lunch. And we didn't interact any more until she was leaving. And she walked back over to us. And she leans over, and she goes, "I got to tell you something." And I'm like, OK, here comes the story. "I had a cousin who had polio, and she had two beautiful, adorable little kids just like you. And when she couldn't catch her kids, she threw her crutch in front of them so they'd fall over." And I thought, no wonder I felt so at ease with this person who was helping me. I mean there was no judgment. She was not patronizing. She just did what had to be done. And that stuck with me.

So a few days ago, I was talking to my sister Lisa on the phone and telling her about this talk that I was going to give. And she goes, "Oh, good. I'm so glad. So often when people do topics about families with disabilities, they only talk about families with kids with disabilities." And I went, "Oh, yeah. I'm a member of two families with disabilities." I forgot, and so the family I grew up in, where I'm the youngest of seven children and the family where I'm the mama.

So one of my earliest memories from that first family is me about four years old, sitting in my parents' kitchen in this little kid-sized brown chair. I am surrounded by my six older brothers and sisters. It's loud. They're arguing. And this is sort of the only picture I have. But what I was told was, when I was little, I had to wear these, I do remember these . . . I had to wear these big, huge plaster casts every night when I went to bed. And my brothers and sisters used to argue about who got to help put them on and about who got to help me do my exercises at night.

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And there's another story of my mom asking my sister Lisa, older but then about 13, and I was about five, to go get my shoes for me in the other room. And Lisa looked at my mother, and she said, "She can go get her shoes by herself." And my mother said, "It's so much easier for you, Lisa. Why don't you do it?" And Lisa said, "Look, it's not going to help her at all if people start doing for her what she can do for herself, so"—and my mom still remembers that conversation, still remembers that that was a time that her perception of my disability changed, and not incidentally, her perception of my sister changed as well.

And then there was the time that, a few years later, my big brother Michael, then 15 years old and six feet tall, came to my school to put the fear of God, nonviolently of course, into a sixth grader who, up until that point, liked to make fun of me every day. It changed after that.

And these memories stand along with that of my dad, who bought me skis in the winter and a softball glove in the spring. He taught me how to throw and catch and hit in our backyard, just like he had with the other six children before me.

Now let me take you to that same backyard about two years ago. It's my mom's 80th birthday party, and I'm tromping across the grass chasing after one of my own kids and – boom – I hit the dirt. My sister Lisa calls from across the yard, "You OK?" I go, "Yeah." "Need any help?" Tried to get up on my own first for a minute, and I go, "Uh, yeah." OK. So she came over, gave me an arm. I got up. And I said to her, "God, I wish my husband would react like that when I fall down."

My dear husband—it wasn't his fault. We'd only been married for five years at that point, and he was still a novice at being a member of a family with disabilities. The conversation used to go something like this: "If you freak out every time I fall down, we're going to have a problem. It's not a big deal." "It's not a big deal? It's not a big deal? How could you say it's not a big deal? Of course it's a big deal. It's a big deal." "It's not a big deal."

How could I say it's not a big deal? Because it's not a big deal. Because a lot of things that seem like a big deal to others really aren't to families with disabilities. That's the Gospel that people with disabilities and their families preach. It's the Paschal Mystery. Compared to the joy of getting up, falling down is no big deal. Compared to the resurrection and eternal life, death is no big deal.

But wait a minute – when a kid gets made fun of every day at school, it's a big deal. When a teenager is sure he will never go out on a date, it's a big deal. When life has to be arranged around doctors' appointments, physical therapy, and paying for all these things, it's a big deal. And when a six-year-old girl sits at the kitchen table and asks, "Mom, why did God give me cerebral palsy," it's a big deal, both to the kid and to the mom, who is praying to get the answer right.

Miraculously, my mother did get it right. She said, "Maria, I don't know why you have CP, but I do know this: God gave you a great capacity to love." And that is what families with disabilities have—a great capacity to love—each other, certainly, but God's world as well. Families with disabilities have a more generous definition of what is beautiful, what is smart, and what is strong. This is how they will know that "you are my disciples," that you "love one another."

People with disabilities and those who love them also experience the Gospel from a privileged place in all Scripture. I remember the first time I heard these words from Isaiah: "How beautiful upon the mountains are the feet of the messenger who announces peace, who brings good news, who announces salvation, who says to Zion, your God reigns."

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I was an undergraduate at the Catholic University of America, sitting on the floor at a 10:00 p.m. campus ministry liturgy in the basement of Gibbons Hall. "How beautiful are the feet of the messenger who brings good news." I hated my feet. They were ugly, crooked, and generally annoying. I couldn't wear heels or sexy open-toed shoes or flip-flops or most sandals. But that night I got a new perspective on my feet. It wasn't metaphorical for me. These feet could be beautiful. God could use these feet.

And 20 years later, I was on a mountaintop; OK, not exactly. I was on the rim of a canyon called Hell's Gate in Kenya. My husband Gary and I traveled there about six months after we were married. We actually arrived at a time of great political unrest, so we had already been through a lot of scary situations by the time I was on the rim of this canyon looking down. And we were going to hike down there.

And I looked down and I said I'm sorry, honey. If I could get down there, I'd be OK once I got down there but I can't get down there. I felt terrible. I wanted to go. Gary really wanted to go. We tried all these, like, well, what if we did it like this and what if we . . . you guys all know the song . . . well, what if we tried it this way or what if we tried it that way? And there was just no trying it. It wasn't going to happen.

So I looked at Gary, and I said, "why don't you go without me?" "Go without you? You'll be sitting up here for like two hours all by yourself." "Yeah, but you really want to go." "Yeah, but honey, I don't want to go without you." Oh, my dear husband. I felt terrible.

Then our guide, Patrick, a tall, thin Kenyan man about 19, who did not outweigh me by very much, if at all, said "what if I carry you?" Gary and I looked at each other. We looked at Patrick. And we said, "you really think you can do it?" "Yes." OK. Patrick kicked off his flip-flops. Gary hoisted me onto Patrick's back. And I got my first piggyback ride in about 30 years. Now, if that is not the modern day version of the paralytic being lowered through the roof, I do not know what is. And let me tell you something: that canyon was beautiful.

Now, happily, obviously, I emerged from Hell's Gate as well. I came home to Boston. I got a job. I had a couple of kids. I quit my full time job. I became a stay-at-home mom and started spending most of my time doing laundry. It's true. Every once in a while, I'd get out of the house to do something really exciting, like go grocery shopping without children.

It was about three years ago I was in Stop & Shop in the checkout line behind a woman with two boys about ages four and two. Despite her best efforts, they were not following her instructions. Eventually she grabbed one and put him up on one hip. Then she scooped up the other one, who was screaming and lying on the floor, and put him on the other hip. She paid for her groceries, and off she went.

I saw this, and I thought, oh my God, when one of my kids won't get off the floor, I have to negotiate. Not fair. All of a sudden, I realized that my life with these kids would be a lot easier if I didn't have this stupid CP. I was really mad. I went home and I called my mother, relating the whole story. And as it has been for more than 40 years, she listened, waited for me to finish and said with so much love, "Yes, Maria, it would be much easier for you if you could juggle two kids on your hips. But do you know that that woman can't love her children the way that you love yours?" "Well, no, but what does that have to do with my CP?" Maybe everything. I thought of that talk at the kitchen table when I was six.

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Now, I don't know about you, but I've spent a lot of time fantasizing about what it would be like to not have a disability. People wouldn't stare at me all the time. I could walk up the stairs and not have to hold onto anything or anyone. I could pick up my kids and throw them around. But what else would change? There's no way of knowing for sure.

But about 13 years ago, someone shared a theory with me. It was my friend and classmate Greg O'Meara, now Jesuit provincial of, superior of whatever communities he's in, somewhere out in the Midwest. I don't know. I was bemoaning something about my CP. And he said, "You know, Maria, a bunch of us were talking about it, a bunch of us meaning my fellow graduate students at Weston Jesuit School of Theology. And we all decided it's a really good thing you have it." "What?" "Because, look, you're pretty and you're smart and you're funny. If you didn't have that, you'd be a jerk." Wow.

Now, I want you to know that five years ago I couldn't have given this talk. I already had two degrees in theology. I'd written plenty of papers on theology and disability, many read by Sister Margaret Guider. But I was so desperately ashamed of my CP that I rarely talked about my own experience. Every once in a while, I did open up to somebody else about the shame, about the pain of getting stared at, about wishing I could walk upstairs with a bag of groceries in each arm.

And I would get this response sometimes, often, "well, you know, everybody has a disability." Oh, I hate it, still hate it. I particularly hate it now when someone I love and respect says it to me, ooh, and especially when it's used to allay some kind of survivor's guilt or to minimize the value of another person's suffering. It's insensitive. And it hurts.

Recently, though, I'm coming to realize that "everybody has a disability" may have some value. At the very least, it provides another opportunity for evangelization. "Forgive them, Father, for they know not what they do." But in addition to this, "everybody has a disability" may even have some truth.

When I began today, I told you that I belong to two families with disabilities. But I really belong to three: my parents' family, my nuclear family, and the human family. You see, we're all members of this one big, crazy family. And every one of us has the exact same disability. Each of us and all of us are incomplete without God and without each other. We cannot survive on our own.

St. Paul, like me, and perhaps like you, prayed that God would take away the thorn in his flesh. This was God's response: "My grace is sufficient for you, for power is made perfect in weakness." And Paul continues, "So I will boast all the more gladly of my weaknesses, so that the power of Christ may dwell in me."

Families with disabilities already know this: complete independence is a pretention, and it comes at a cost. Pretending to be entirely self-sufficient, we limit our opportunities and the opportunities of others to serve us. On the other hand, pretending we're entirely powerless, we rob the world of our gifts and the witness of how powerful we really can be.

This is true for every person—able bodied or physically challenged, intellectually proficient or cognitively challenged. Families with disabilities, by letting God fill up what is lacking in us, by proclaiming what our disabilities have made possible, by being open to the courage God wants to give us, by not being afraid to ask for help or to give help to others—we stand or sit or lie down as witnesses to the truth that no one has to pretend she is something she is not. No one has to pretend to be anything but God's mirror, totally, completely and utterly loved by God.

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When the whole human family knows this, the Scripture will be fulfilled and the prophet's words will come to life. (singing) "We will run and not grow weary, for our God will be our strength. And we will fly like the eagle, we will rise again." (speaking) Do you want to sing it with me? (singing) "We will run and not grow weary, for our God will be our strength. And we will fly like the eagle, we will rise again. (speaking) Thank you. (applause)

GUIDER: Thank you so much, Maria. I just whispered in her ear she has to come back for a doctorate. We'll find childcare. Well, we've been through an initial presentation and a time of theological reflection and a very powerful witness from Maria. And I think now we need to answer our questions about the experiences of families with disabilities as recipients of the Church's ministries and the evangelizing role of families with disabilities as actual and potential agents of Gospel witness in the Church and in the world.

Some of my reflections on this, of course, are drawn out from my own experience as a sibling and as a daughter. And I realize that, looking back in time, as I was reviewing from basically my experience the way in which the Church has created spaces for persons with disabilities and families with disabilities, that we have not moved as quickly into, I would say, an integrated understanding within—and I'm speaking here of the Roman Catholic community in the context of the United States. I would have expected myself at 60 years old, for us to be in a radically different place as Church than we were when I was seven.

And as I experience the Church from Chicago, from Boston to Kenosha, Wisconsin, to New York City to Olean, New York, I'm not sure that people are able to transfer skills that they may have acquired in a very rudimentary way. And what I mean by that is, we're now, we should have been able to transfer the skills of being community, I think, as a Church.

And yet when I reflect on my own experience with bringing my mother with Alzheimer's to church, the impatience, the intolerance, yes, the pity at times, but the way in which the community was not really receptive to being inconvenienced, it was an experience of that déjà vu all over again that I recall with my sister Mary Ann when she was young. And the disabilities were quite different, but the degree of the communities' at times—I don't know how else to describe it but inconvenience—inconvenienced by a shout, inconvenienced by passing gas, inconvenienced by any number of things that can cause inconvenience.

And I really wonder what happens to a community of faith in a church environment, and I really wonder about do we need more pastoral leadership? Does this need to be talked about from the pulpit? When we talk about evangelization, is this now part of catechesis, because our horizon of disabilities is exponential at this point in time, from autism to dementia to illnesses that cause and create serious disabilities and limitations?

When I think of what we were talking about in the mid-1980s about accessibility, about ramps, about doors, in a way we are light years away from those conversations, and there are still places without ramps, without doors that open easily. I even realized today I should have had handouts. If anybody had come today with auditory difficulties or impairment, we did not have someone to sign. So even the best intentioned people drop the ball, and I count myself among them. So if the best intentioned and those who may consider themselves conscious to some degree are in this position, what can we expect from the larger Church?

But as recipients, it seems that persons with disabilities as well as their families . . . I really question the adequacy and the appropriateness in a broad-based kind of way of the evangelization processes

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that people are being invited to receive or are recipients of. It's not to say that there aren't those exceptional opportunities out there because of committed and insightful people who make a change in a situation. And that change is better than no change.

But my question really rests on the collective nature of our movement forward. And this is why I am so committed with regard to families with disabilities as well as persons with disabilities having voice and visibility as the Church reflects intentionally on families during these next two years. And if anything, my exhortation or my call to you today is, how can you be these agents of the local Church of Boston or Fall River or Manchester, wherever you've come from. How can we be agents of raising the bar with regard to the consciousness of the place of families?

And I think we're in another social space, socially and politically, and someone gave voice to it earlier this afternoon. Because of our social, political reality, are families with disabilities and persons with disabilities more accepted, or is something else happening within our culture that is leading more to a culture of privatization? So needs are met in terms of concrete needs, like sort of first-order needs, we might say, but the relational hopes, not needs, but the relational hopes and desires as Christian faith communities, are we fulfilling those? And what do we need to do as agents collectively, as families working together to build up this awareness?

And it seems that the awareness really needs to perhaps begin . . . and this is why the legacy of Margaret Pyne, Professor Peg Pyne, is so important, because it really needs to begin with people preparing for ministry, for people who are in ministry, because someone has to be the interlocutor, someone has to be the interpreter, someone has to be the person who invites, so that we can hear and listen to the experiences of one another and move in the way that God's grace is moving us.

So what I'd like to now is . . . What's the time, Kevin?

Kevin: (inaudible).

GUIDER: 2:47? So we have –

PARTICIPANTS: 3:47.

GUIDER: 3:47? 3:47. Yeah. We have about 13 minutes, so I'd invite right now any comments, reflections that people would like to make. And we have a couple hands up, so if we can just sort of . . . We have 13 minutes, so just keep the comments brief. That would be great. So we have one up here.

PARTICIPANT: I'm 64, and when I went to public schools, if a child could not climb steps and move around independently, they didn't have a right to attend. And this segregation taught those of us who were able bodied and had no substantial cognitive problems, that we did not have any obligation to make any accommodations for people who did have those problems. And that attitude—that if we make some accommodation, we're going out of our way and it may be commendable but it is not an obligation—was widespread, and of course it's still widespread in our society, though not as widespread.

And the attitude was also that, if we made some accommodation, while it was commendable, the person who was the recipient should grovel with gratitude. I call it the "grovel with gratitude attitude." And it's very much still present in the Church, though, as I say, I think it's less, but it's still very much present.

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GUIDER: Thank you. Anyone else—thoughts from the earlier conversation on John’s chapter nine? And then also . . . In the back? It’s all yours.

PARTICIPANT: Yeah. Just some of my thoughts. I think it’s very important just in these discussions about people with disabilities, and I know the Proposition 32 thing as well, I know it sort of conflated the sick with the disabled and crossed that boundary a little bit. I think my takeaway just from today really is just that it’s most important to remember that, no matter what your situation, your circumstances or your scenario, there are always people who would rather be in your shoes.

And just to give, I guess, some extremely provocative examples, one of my friends that I became friends with in the hospital, he was paralyzed from the neck down, and he was a quadriplegic, and so he literally had no use of his hands. So even though I’m a paraplegic and I can’t use my legs, I’m very grateful that I could use my arms. And because I’m living in this time of 2014, it’s not like 1950, where I’d need to work in a steel mill and lift heavy weights and whatnot. I can do plenty of stuff on a computer or write or whatever. There’s all sorts of technological advancements that facilitate my paraplegia.

And so I think the other thing as well is, especially for all of us in here specifically, none of us are blind, and we all look up and see the evangelizing role of families with disabilities, etc., etc. But there are people who don’t even have the gift of sight, and so no matter what your circumstances are, there are always things to be happy about, there are always blessings that other people don’t have. And if you really, really, really can’t think of a blessing, if you’re really struggling, just you’re in the physical boundaries of the United States of America, so, yeah, thanks.

GUIDER: Thank you so much. We have three hands up.

PARTICIPANT: Thank you. I think one of the things that I will probably take away with me, being the parent of a child who is profoundly disabled and the daughter-in-law of somebody who is blind; what we typically experience when we go to church—there are eight of us—and as I was sharing at our table, we have to sit in the front row because we have to secure a particular seat for my father-in-law, who also has another physical disability.

And many, many times, people will come up to me and say, “I just want to say you have such a beautiful family” or “you touch me in some way.” And I think from now on, instead of just saying thank you, I’m going to say, “Can you share with me why you feel that way?” And maybe that will give me a little bit more insight. Do they see us as recipients or agents of the evangelization? I’ve sort of just taken it, you know, “Gee, thank you and I’m flattered and that’s very nice.” And I usually come out with a comment like, “You should have seen us about an hour ago trying to get everybody out the door.” It wouldn’t be as graceful. So that’s what I hope to take away with me.

GUIDER: Thank you.

AGNES: Right. I’m called Agnes, and I’m a student at Boston College School of Theology and Ministry, and I’m from Uganda. And from my socio-cultural context, we don’t have most of these resources for people with disabilities. So one thing I’ve realized is that it’s important to look for resources within our faith communities to help people with disabilities, because at times we don’t help them because we don’t have these resources.

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We have cases where these people have cases in court, and courts have dismissed these cases because they don't have, for instance, people that are blind. In most cases the courts don't have people to help them with the interpretation so, as a result, those cases are dismissed. In cases of child abuse, they're like, "Well, we can't help you." So I think there are people within our communities, and we can invite them to help us with such services in our ministry so that we can serve people in our communities very well. Thank you.

GUIDER: Thank you, Agnes.

PARTICIPANT: I guess I come here as a parent of an adult-age-now daughter with multiple disabilities, cognitive and intense chronic medical conditions and such. And I'll just, I'll say a quick sentence. Basically, I changed parishes so that my daughter could receive sacraments. But with that, I guess what I want to say is that I've been reflecting as an adult. And kind of at this point, God has blessed me in any ways, and we've done well. So I would like to kind of give it back.

And reading the pope's *Joy of the Gospel*, the biggest thing I can say is that, when I hear all of this and everything that's been said, I see two things: Those pamphlets that she had and was showing us from the sixties, the basic message of those is still needed today. We have made progress. We've come in with programs, and programs are good, OK? But I do think that what's happened is kind of like the Pharisees and the programs and everything in John 9. I think there's been so much emphasis on the program that we've almost lost the sight of compassion.

And having been through very intense experiences as a parent with a child going through this over the years, I would have much rather had a far less structured program, if there was a structured program, and had more of the joy. Like I said, I have switched parishes because I needed a strong support. When your faith is something you want to hang onto and you need to receive sacraments, I'm not going to a parish that doesn't accept my daughter. It takes a strong parish. We have good parishes that are very supportive, and we have other parishes that are so caught up on the programs that they just turn you away.

And I guess my last comment would be, one of the biggest things is religious ed. The programs are wonderful. But if I'm in—and my experience was Virginia, I was in Falls Church, Virginia. About 20 minutes away is Leesburg, Virginia. The parish was five minutes from home. But they were starting this program. In order to get religious education, we had to go out to Leesburg, out in the next county, to be able to get a formal program for my daughter.

No coordination of parish activities. We were expected to give our envelopes to our own parish. But we had to go to Mass out in the other parish. We'd never know what was going on in our own parish because there was no coordination. They sent us off to another island, if you will, had no idea that, when they were having spaghetti suppers and community activities or liturgical or social, that we were out there just in our own turf. How could we possibly participate in our own parish? OK?

So again, I think that the pope's articles 198 to 200 in his *Joy of the Gospel* ask for more of a balance between programs and compassion.

GUIDER: Thank you so much. One last comment, and then I'll close. Yes?

PARTICIPANT: May I say briefly, this question of resources as a Church is very important to me. I said earlier how I'm from a parish with a lot of immigrants. The way I've looked at it, is the Catholic schools are the key to seeing the problem, because we've moved so far away from the poor generally

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in Catholic education that it originally was set up for immigrants and the poor. Today it's so far, so expensive that the poor are getting poorer, you might say; the rich are getting richer. It's a gap.

So if you can solve the problem of the Catholic schools, a lot of these other things can be solved. And the way I think we got to solve it is Catholic education cannot continue going more for the middle class and rich. And if necessary, we've got to give up generally, general education as a Church in the rich countries and shift those resources to the poor, maybe Confraternity of Christian Doctrine and handicapped things, but we can't keep going with this Catholic education the way it's going. And there's the resources. Take it away from general education and focus those resources on the poor—preferential option for the poor.

GUIDER: Thank you. Well, and with that final comment in terms of the preferential option for the poor, I think it's an appropriate way for us to conclude this day. As we begin our journey into the Holy Week, that we somehow identify ourselves with those followers of Jesus that remained committed as recipients of the message, as receptive to the message but also as agents of Gospel witness in the Church and in the world.

And as a way of concluding, I just want to thank Melinda—there she is—for all of her efforts in pulling this together. And a thank you to all of you for making time to be present here at this afternoon of reflection and sharing. And a special thanks to Maria for a marvelous presentation. And thank you, thank you so much, so thank you. (applause)