

Boston College
SCHOOL OF THEOLOGY AND MINISTRY
Continuing Education Encore Events

**Transcript of “Families with Disabilities:
Recipients or Agents of the New Evangelization?”, Part 1**

**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**

Dr. Jane Regan:

Today it’s my honor to introduce our presenter, Sister Margaret Guider, who is one of our own.

Sister Meg holds a doctor of theology degree from Harvard University, and she currently serves in the Boston College School of Theology and Ministry as associate professor of missiology, a position she’s held since 1990. Sister Guider is a popular teacher here at the STM, and her teaching interests include world Christianity and mission studies, contextual theology, Mariology, discipleship and contemporary issues in religion, culture, and society.

Her current research focuses—if that doesn’t keep her all busy enough—her current research focus is on the Church in Brazil, the contemporary relevance of the Franciscan theological tradition for Christian life and practice, and the consecrated life in the twenty-first century.

Sister Meg is the author of *Daughters of Rehab: Prostitution and the Church of Liberation in Brazil* and the editor of *Doing What Is Ours to Do: A Clarean Theology of Life*, as well as numerous chapters and scholarly articles. She is past president of the American Society of Missiology and has served as an advisor to missionary societies, religious congregations, and Catholic institutions. Sister Guider is a member of the Sisters of St. Francis of Mary Immaculate out of Joliet, Illinois and recently served as the congregation’s vice president and counsel for mission from 2008 to 2012.

Lastly, Sister Guider comes to this topic from a perspective that is informed by being a member of a family with disabilities, as well as her experience in leadership with Franciscan sisters in her own community, a number of whom live with various late-onset disabilities.

Please join me in welcoming, Sister Meg Guider.

Sister Margaret Guider:

Good afternoon, everyone. It’s a pleasure to see you all here, and thank you to Jane for your introduction. I appreciate it greatly.

Before I begin, I’d like to say that I’m actually making this presentation today in partnership with a friend and a former student, Maria Cataldo-Cunniff. Maria is a person with a disability. She holds a master’s degree in theology from the University of Notre Dame and from Weston Jesuit School of Theology, and she’s a board-certified chaplain.

While she now spends most of her time being a mom to Joseph, age five, and Margaret, almost four—my namesake, actually—Maria occasionally preaches and leads retreats as well. She serves as an on-call chaplain at Children’s Hospital in Boston, where she has been part of the spiritual care team for 10

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years. Through working with the Gospel Healing Narratives, Maria makes meaning out of her own experience of disability and illness and hopes to help others do the same. So I ask you to welcome Maria as well. Thank you, Maria.

Well, we have an afternoon together, and I'd like to begin with a lecture format, and then we're going to move into a discussion of John chapter nine, the story of the Man Born Blind. And I'm going to invite you into a theological reflection process, because it is one of the Gospel narratives that I think enables us to really engage this question of families with disabilities.

So after that, we'll have a little feedback from the tables. And then I'm going to invite Maria to offer her presentation. And then we'll take a break. And then we'll come back. I'm going to make some further comments. And then we'll open it up into more of a plenary question and answer. Does that sound like a good way to go? All right, well, it's the only way we're going to go, so (laughter) I guess it's at least a good way.

All right. So let us begin. Families with disabilities—recipients or agents of evangelization? In my lecture this afternoon, I want to examine two generative questions that are critical and consequential for families with disabilities as we engage and are engaged by communities of faith.

And the two questions that I have on the screen—the first, when it comes to the evangelizing mission of the Church, is there anything genuinely new that families with disabilities are receiving? Is there anything genuinely new that families with disabilities are receiving? And number two—when it comes to Christian witness, in what ways do these families serve as agents of evangelization in the Church as well as in the broader society?

So those are the two generative questions that are in the background as I make this presentation. And they're questions you may leave here today and say, "Gee, I'm not sure she answered those questions as I expected." But, as I said, these are generative questions. They're questions that cause us to keep on thinking, so hopefully there'll be some answer, but many of the answers you are also bringing to these questions. And indeed they're questions that we live with.

So in this presentation, I want to invite each of you to consider the ways in which families with disabilities are not only recipients of the Church's ministries—and I want to be clear here, because in some cases, because of, first of all, inadequate theologies of families and, second of all, even more inadequate theologies of disability at times, there are also ways in which we need to understand how families are both actual and potential agents of Gospel witness in the Church and in the world—actual and potential.

From the outset, I want to state clearly that, in focusing on families with disabilities, it is not—is not—my intention to prioritize the experience of families with disabilities over the experiences of persons with disabilities. And I want to be very clear about that. Rather, my intention is to guarantee that families with disabilities are on the Church's radar screen these next two years, visibly and vocally giving voice and vision to what it means to be a family in the best of times and in the most difficult of times, but mostly in ordinary times.

As I begin, my hope is that I can contribute in some small way to the process of helping to raise the Church's consciousness. And I know that you share this goal with me. And I mean the Church in the broadest sense of the term—about the ways in which families with disabilities face more and less successfully the daily challenges, the daily challenges of life that involve recognizing the weight of reality, shouldering the weight of reality and carrying the weight of reality.

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This three-part way of analysis or of reflection comes out of the writings of Kevin Burke, a member of the Society of Jesus, who has written a great deal on the Spanish theologian from El Salvador, Ignacio Ellacuría. And Ellacuría's thought was dependent on a Spanish philosopher named Zubiri. And this way of understanding reality, I think, allows us to get a perspective on the way that not everybody is recognizing, shouldering and carrying the weight of reality, but we are in different places on that trajectory. And how is it that we understand the place where families are on that trajectory?

I also hope that, as a consequence of such consciousness raising, Church leaders, ordained and lay, as well as families with disabilities, will find the means of inspiring and building up communities of faith in ways that are purposefully inclusive, intentionally accessible and passionately committed to experiencing the presence of the living Christ who dwells among us and within each of us.

I've just put on the screen a quotation from Jodi Picoult from her book or novel *My Sister's Keeper*, and this is the quote: "Maybe who we are isn't so much about what we do, but rather what we're capable of when we least expect it." Similar to other recipients and agents of evangelization, families with disabilities, whose number I include myself, are no strangers to the dynamics of resiliency as well as fragility and vulnerability. We know from the inside out how some families or family members pull together with incredible strength and hope, while others are completely torn apart, broken and burdened by despair and dysfunction.

Like other families, we find ourselves at different points on this continuum of life, often in paradoxical ways, being strong, resilient, and dysfunctional at the same time. We share a realism, I think, about the here and now as well as a memory and a vision of past and future that serves to orient us on our journey of composing faith, losing faith, and recomposing faith, hope, and love. We are not particularly special, but I think we are particularly conscious; conscious of the grace-filled intuition that maybe who we are isn't so much about what we do but rather what we're capable of when we least expect it.

So my objectives—and I'm speaking them and they're on the screen as well—first, to provide a working definition of the terms I'll be using: families with disabilities, evangelization, recipients and agents, to explain the context for my interest in the topic, to review the Church's current interest in evangelization and families, especially as they pertain to families with disabilities, to reflect on John 9, a Gospel point of reference, to consider the experiences of families with disabilities as recipients of the Church's ministries, and to explore the evangelizing role of families as actual and potential agents of Gospel witness in the Church and the world.

So some terms and working definitions. As a teacher who is now quite a bit older than many of her students, I have grown more aware of how important it is to define with some clarity and precision the term that one uses, and not to presume that everyone has the same operating definition. There's lots of generational differences present. So here are my definitions for the key terms. And I'm open to discussion and debate and disagreement about this definition that I've given. I'm sure it's incomplete, and it is need of perhaps more than tinkering, but perhaps a complete revision. But that's what we're here for this afternoon—for discussion and debate.

Families with disabilities, here's my definition, are constituted by individual persons. And I was sharing this with somebody who said, "What about animals?" so I put animals in, OK. And after she made that comment, I thought you're absolutely right—that are bonded together by blood and/or affection, whose lives are informed and influenced to greater and lesser degrees in distinct and complex ways by the phenomenon of one or more disabilities: cognitive, physical, sensory, emotional,

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and the list goes on, be they permanent or temporary, lifelong or late onset, that require of them a heightened consciousness and a sensitivity to both the limits and the possibilities of the human condition as well as the interactive dynamics of being in relationship in radically interdependent ways.

It's quite a mouthful. It's not going to make its way into Merriam Webster. But we have a few microphones around. Where are the microphones? OK. We have a few microphones around. We can do this a little more interactively. We've got the time, so we might as well do that. As you consider this definition, what do you affirm and what do you think is missing? Right over here and back there?

PARTICIPANT: Having been a foster parent of 20 kids, I would say that the legal option, which would cover adoption and foster care, is missing.

GUIDER: OK. Great. Thank you. So how would you add that, because where I have "there by blood and/or affection". . .

PARTICIPANT: And/or legal action.

GUIDER: Action? OK, great. Thank you. I will add that. Over here, please?

PARTICIPANT: I think what is missing, what I see missing, is the social component. And by that I mean, what does it mean for families with disabilities to live in a society that is hostile? That it's prejudiced, that has bias, that celebrates able bodies, so on and so forth.

GUIDER: OK. Great. Thank you. Over here, please, and in the back then? If you want to say your name and where you're from, that's good too.

BRIAN: Hi. I'm Brian Devin. I'm from the Mass. Hospital School. And one of the things I see missing is the caregivers, whether they're therapists or other type of other professional people that become part of the family as a result of the disabilities.

GUIDER: And you'd want more clarity—the bonds of affection aren't . . . That's not complete enough?

BRIAN: They're not limited just to the family and the dog.

GUIDER: No, OK. This helps me with clarity, because I understand that bonds of affection as extending the circle of the family, but that clearly needs to be more expanded. Yes? Oh, I'm sorry, yeah? We have one in the back.

DARYL: Hi. My name's Daryl. I'm from Boston. And I think the elephant in the room, so to speak, for this definition is the term "challenges." And I think another way to think about it is really just, when you have a disability, there are challenges that have not been, that you did not choose. I mean you don't actively decide to have a disability, and so it's a challenge that's sort of, I guess, been presented to you as opposed to, I don't know, a challenge like, if you're like Michael Jordan or Kobe Bryant, you play basketball because you like to challenge yourself, but you don't choose to challenge yourself with disabilities, so that's all.

GUIDER: OK, good. Thank you for that. And there was one over here and another over here. Yes?

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PARTICIPANT: I was just going to add . . . build on Devin's thought that the bond is professional. It's not only affective. It can become affective, and it's wonderful when it does, but it's also professional, which brings in whole questions of commitment and ethics and stuff like that.

GUIDER: OK. Great. That's a good qualifier. I appreciate that. Yes?

PARTICIPANT: Hi. I just wanted to say that I really like the phrase that says "require of them a heightened consciousness and sensitivity, limits and possibilities," because I think that's the dual side of the issue, of the human condition. (inaudible) tie his shoes – but he just spoke at the United Nations, so (inaudible).

GUIDER: Yeah, the paradox. And right here and then back to Mary Jo.

PARTICIPANT: Thank you. What I like about that last whole piece of it, that require of them a heightened consciousness and sensitivity to the limits and possibilities, as well as the interactive dynamics of being in relationship in radically interdependent ways—to me that's a very positive statement. And to me it says "this is what people with disabilities and their families have to offer the world and the Church, who sort of miss those points all together." So I love that part. Thank you.

GUIDER: Thank you. Let's see, Mary Jo?

MARY JO: Yes. Thanks, Meg. It is a mouthful. But it's required for the subject matter, so thank you very much. I wonder if you would consider adding psychosocial to the kinds of disabilities.

GUIDER: Sure.

MARY JO: Because that doesn't really fit as neatly as we might think in sensory or emotional. And I would drop the parentheses around the "sometimes animals."

GUIDER: Oh, OK. Very good. Let me just read the definition again: Are constituted by individual persons, and sometimes animals, are bonded together by blood and/or affection, whose lives are informed and influenced to greater and lesser degrees in distinct and complex ways by the phenomenon of one or more disabilities—permanent or temporary, lifelong or late onset—that require of them a heightened consciousness and a sensitivity to the limits and the possibilities of the human condition as well as the interactive dynamics of being in relationship in radically interdependent ways. Any, yes—we have here and here?

PARTICIPANT: I would just like to make a technical suggestion. I'm visually impaired, and I can read the white background but I'm not able to read the shaded. And just for future reference.

GUIDER: All right. Thank you.

PARTICIPANT: Thank you.

GUIDER: Thank you for that.

PARTICIPANT: What struck me was "seen or unseen." To me, it's some disabilities, you know, if you have a crutch or, that's, you can see there's a disability. But I've often had the experience of, if someone, if you can't see it, people don't give you any leeway because they figure you're perfectly normal.

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GUIDER: So the visible and the invisible, yeah, OK. Thank you for that. And another over here?

PARTICIPANT: I also noted the mention of the word temporary. In many cases, people who have a temporary or limited disability for a certain timeframe – by the time they figure out where they need to go or what is available to them, sometimes that disability has already cleared itself up, for lack of a better term. People who are in serious surgeries or cancer victims, things like that. It is a disability that needs some attention, but it's temporary, so sometimes they don't get any attention at all.

GUIDER: Thank you. Over here?

GERALDO: Good afternoon. My name is Geraldo. I'm here with my wife. We come from Randolph. And sorry for being late. It was quite a challenge—the traffic and the logistics. It's a mouthful, but I understand, you're trying to be comprehensive. The one thing that struck me, and perhaps you already talked about this, and if you did—is the term “radically.” When you say “radically interdependent ways,” I'm definitely in agreement that it has to be “relationship” (inaudible) but I don't quite get why “radically.” Could you please expand a little bit on that?

GUIDER: I think that sense of, that why I include “radically” is that it really goes to the core, to the root of who we are as persons in relationship. That it can't be—there's a way of being interdependent superficially, radically there is the alternative to superficial. OK? Yes, in the back there?

PARTICIPANT: Yeah. One thing (inaudible) and, I don't know, I guess I'm kind of just being annoying right now, but I guess, for me, when I hear things like “families with disabilities,” of course Americans with Disabilities Act, 1990, that's a big law. I think saying that in that phrase, sort of like families with disability, I feel like it kind of just gives almost too much agency to people who are surrounding you. And of course that is, it's always a blessing to have people who are going to help you out and be with you and connect with you and whatnot but, at the end of the day, though, it's like the family doesn't have the disability. It's the persons who have the disabilities. And I feel like, I don't know, never mind, I was just getting annoying. Sorry.

GUIDER: No, that's OK. Finish your thought. Please.

PARTICIPANT: OK. Well, I feel like, when we say things like “families with disabilities,” it suggests that we're all in it together. And of course you are to some extent, like you are all supportive, you all want the same things, you all want positive things to happen in your life. But there's really no way for people who don't have the disability to understand what it's like really, or even think about it. It's like, I have a physical handicap, of course. I use a wheelchair. So it's like there's no way that people who are close to me can really know what it's like not to walk. They can lay in bed the whole day and not walk, but they're not going to know what it's like. But of course that's just . . . I don't know. I'm done. Thank you.

GUIDER: Thank you. One over here and a couple over there.

PARTICIPANT: Hi. Thanks for sharing this, and especially after some of the comments, clarity—a little ambiguous to me in the sense of are informed and influenced. I guess I'm trying to kind of understand what you mean by that in the sense of . . . like for example, my family growing up had, my sister was disabled. And we had cousins at a distance. There wasn't much interaction. Now, they were definitely informed and influenced. So is it, so I'm wondering, in my head, do you mean my whole extended family as well or?

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GUIDER: Yeah, I do.

PARTICIPANT: You know what I . . . OK. So that's kind of not clear to me.

GUIDER: OK. Yeah, I'm looking for the broadest definition of family, because this has been one of the contentious issues in the Church: how do we define family? And if it gets too narrowly defined in terms of a nuclear family, a father, a mother, and children, I have real concerns that that is not taking us in the right direction with regard to a theology of family. That's my take on it. I know that we need sometimes more restrictive definitions, but I also think, for us to understand family in a multiplicity of cultures—and we do belong to a world Church—that nuclear family scenario cannot be the one that defines the discourse. It can be a part of the discourse but it can't be the definition that informs all of the discourse.

When I use the language of informed and influenced, once again what I'm trying to avoid there is that people are defined and determined by the disability. So we're informed and influenced but we're not defined and determined by the disability. So similar to the question about why did I use the language of radically—it's an alternative to superficiality—informed and influenced is an alternative to defined and determined. Does that . . .

PARTICIPANT: Yeah, in some ways. I'm just offering . . . It might be a little unclear in terms of kind of where the definition of families with disabilities begins and ends.

GUIDER: So you're looking for a boundary?

PARTICIPANT: Yeah, as a kind of definition.

GUIDER: No, thank you for that comment, because this issue of boundaries—where are the boundaries of the family? And as I think about my own family background, my mother's whole family was in Wisconsin. My father's family was kind of scattered. It was just myself and my sister Mary Ann with Down syndrome. And somehow along the way, my parents picked up these friends and acquaintances—people my father met on the train that suddenly became intimate members of our family. And they themselves didn't have family, and so they became part of our family and incredible supports to my parents. And we called them Aunt Etta and Uncle Jack.

And that's why, in my definition, I'm trying to include those people in the family as well, as well as aunts and uncles and cousins, but I understand that there may be also a need to put some limits and boundaries on exactly who constitutes the family. But I'm clearly taking an option here to leave the definition wide open, only sort of constrained by people being bonded together by blood and/or affection or professional relationships. That one really does become a part of the family, even though it's in the context of a professional relationship.

So I realize that that might not be a definition that would be ecclesially accepted if we wanted to really engage this question of families with disabilities. So for those purposes, I may need to put more contours on it. Yes? Oh, OK, one more?

HOLLY: Hi. I'm Holly Clark from the Cranberry Catholic Collaborative in (inaudible), Massachusetts. And I am an individual with a permanent birth defect growing up, and I'm very grateful for this workshop. But my main comment is I know how to turn (inaudible).

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GUIDER: Oh, good. That's what I was trying to do as subtly as possible. Please come and help. See, we can do more together than we can separately. Now you have my full and complete attention. Yes? Oh, I'm sorry.

KATHY: Hi. I'm Kathy Ryan from the Carter School in Boston, and what strikes me about this definition, (inaudible) definition of family with or without disabilities, because I don't know any family anytime ever who hasn't been challenged temporarily by something up on that list. So I feel like it's a really good definition of what a family is, and I like the broadness of the definition.

GUIDER: Thank you. Yes?

PARTICIPANT: Yeah. Forgive me. I think I've overdone my comment (inaudible).

GUIDER: No, you haven't.

PARTICIPANT: OK. But I was just thinking as well about this definition in the context of perspectives, and I think that that may be a simpler. I think you maybe said ecclesiastic or whatever way to think of it, because for people, for persons with disabilities, you are forced to take a different perspective on life, interactions, whatever, whether it's physical, mental or cognitive, yada-yada-ya, emotional, oh, sorry, I didn't mean yada-yada-ya as in like the rest of them are not valid. Sorry.

But you're forced—the individuals with disabilities—we're forced to take different perspectives, whereas families or people, friends, whatever it is—they choose to take a perspective that, sort of that you have, like to really just empathize with you and understand where you are and where you're coming from. And I think maybe that might be a more useful way to think about it as well, because no matter what, whether it's families, your mom, dad, brother, sister, uncles, whatever—they're not forced to assist you.

Just because you're bonded by blood and affection, it's not . . . I think talking about perspectives would allow the agency of the people who are helping the person with a disability to really shine through, like they choose to help, they want to help. It's not like . . . I'm sure we could all imagine that some members of our families may not be as helpful as others. You know what I mean? OK.

GUIDER: Sure.

PARTICIPANT: I'm done. Thank you.

GUIDER: Thank you. And I will take one last comment here, and then I'll move on. We have a couple more terms.

Two things. One, I don't know if this is a definition or a description or both. And second, families with disabilities doesn't, is a shorthand. It doesn't seem quite right. I think it's really more families with members with disabilities. I think that's more accurate. And I think this sounds very nice, yet, and it often is, yet we also know that many family members aren't always very nice. Maybe all of us aren't always very nice, to speak for myself. And there's not just sibling rivalry where that can be expressed. There's also parental frustration when there aren't enough supports, parental feelings of guilt, as if they're responsible for the disability, which in some cases is literally true. And in other cases, parents feel guilt as if they somehow have failed to produce a healthy child and therefore it's their fault.

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And this all gets mixed up and combined. I can only sit about 20 minutes a day. And I was lying in a booth in a restaurant. And I had my shoes off and so on. And a woman saw this and started making very loud remarks about people with stinky feet and so on. And my brother-in-law, who was there, got very protective and defensive of me and really told her off. We hadn't been able to bring my chair because it wouldn't fit in the car with all the people. And I can walk some.

So it was really fascinating. We hadn't had situations where he could be protective before. But he said, when you leave, you use that crutch. He said, "I want her to see that." And so he was expressing his family feeling there in a way that I hadn't seen before, and it was fascinating. Meanwhile, his wife, my sister, doesn't want to admit that she probably has the same genetic disorder. It's fascinating.

GUIDER: Thank you. Thank you. Well, I think just our sort of wrestling with this definition and trying to add to it and put more contour helps us to see, in a way, the difficulty of even talking about this topic. And yet my reason for wanting to engage it, is I don't want to not talk about it because there are ambiguities. I still think it's important to try and wrestle the topic in a way that it can go forward.

So let's move on to the next definition; and once again I'll read this. And this is the definition of evangelization. Remember, this whole presentation is driving in the direction of what is new about the New Evangelization for families with disabilities?

So evangelization "emerges from the encounter between the Christian message and the challenges of reality." That's a definition, an active definition that Leonardo Boff gave to evangelization in the 1990s. And in a way his perspective, his point of reference on that, was coming out of the final document of Puebla, which was a gathering of bishops in Latin America in 1978; 1979 actually is the accurate date.

The Church has been acquiring an increasingly clear and deep realization that evangelization is its fundamental mission and that it cannot possibly carry out this mission without an ongoing effort to know the real situation, taking us back to those threefold ways of understanding reality, and to adapt the Gospel message to today's human beings in a dynamic, attractive, and convincing way.

So there's probably more that we could add to this definition of evangelization. There has been so much since the synod in 2012. We've sort of been bombarded with texts and reflections on evangelization. My question is, what is genuinely new about the New Evangelization? And does this definition in terms of that final part—dynamic, attractive, and convincing—what does that mean for families, both as agents and as recipients of this evangelization?

The next term is "recipients of evangelization," which I will simply define as those who receive or are receptive to the Gospel of Jesus Christ and the evangelizing mission of the Church. It's simple. It's not complex, but to put the emphasis sort of in two ways: those who receive as well as those who are receptive in terms of being open.

And then "agents of evangelization," those who take on an active role in promoting the Gospel of Jesus Christ, or bringing about a specific effect of evangelization as well as those empowered and authorized to act on behalf of the Gospel as witnesses to the Reign of God. Once again, this is a broad definition. But I want it to be as broad as possible so that it extends beyond the boundaries of the Church.

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Let me read it one more time: those who take on an active role in promoting the Gospel of Jesus Christ or bringing about a specific effect of evangelization, those empowered and authorized to act on behalf of the Gospel as witnesses to the Reign of God.

We have a question. Oh, wait for the microphone because they're recording everything.

PARTICIPANT: Thank you. Those empowered and authorized to act on behalf of the Gospel . . . empowered and authorized by whom?

GUIDER: By baptism.

PARTICIPANT: Ah. Thank you. That would be good. Yeah. Thank you. I can live with that.

GUIDER: OK. And probably I should add that. I probably should add that. Yes, OK, good. All right. So there are our definitions. So let's move forward here.

My context in terms of interest in the topic. Personally, I speak from a family perspective that is informed by being a sister to my sister with Down syndrome, almost 60 years now, and the daughter of a mother who lived with Alzheimer's related dementia for 13 years, and a faith-filled Irish father who pretty much made lemonade out of lemons his entire life. My perspective also is informed as a niece, a cousin, and as a friend who became family, of relatives and close family friends, what one might call extended families with disabilities.

I also am mindful of the ways in which my perspective is informed by my relationship with my own religious sisters, my religious family, a number of whom live with late-onset disabilities of various kinds.

Let me put a footnote here. I don't know if anybody was here—a couple people were here. About a month and a half ago, I gave a presentation to consecrated men and women in the Archdiocese of Boston. And it was entitled "We are Family," because once again, in all of this discourse on family and preparation for the extraordinary synod and for the general synod that will be happening in 2015, religious families aren't included at all in the discourse. And this is one of my reasons for saying, what is the definition of family? If it's too narrow, I'm not sure how our evangelizing message is going to move forward in productive and collaborative ways.

Now, professionally speaking, I speak from my past life training and experience in the field of special education and my subsequent training in theological studies and 25 years of experience in theological education. Religiously, I speak as a Franciscan sister, deeply committed to the Gospel way of life and inspired by the Gospel of Francis and Clare, both of whom gave expression not only to the joy of the Gospel but also to its nonnegotiable demands of encounter and embrace, encounter and embrace.

And as I have displayed up here, Pope Francis greeting children, two little boys with Down syndrome, a man with, it looks like, multiple physical disabilities, and another young woman with disabilities, I want to call your attention to this word *haecceitas*, a Latin word, because this encounter and embrace of the other is a recognition, ideally, of the Other who is uniquely created in the image and likeness of God.

This unique creation would be described later by the Franciscan theologian John Duns Scotus with this Latin word *haecceitas*, which is rendered as this-ness. And I would once again add that qualifier of radical this-ness, meaning "there is no other you." Whether cloning can happen or it doesn't happen

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or whatever, this understanding of *haecceitas* is about a radical this-ness and uniqueness of every person signaling their irreplaceability, their particularity, and their uniqueness as a person. If you want to see the recognition of *haecceitas* in action, I think these few photographs of Pope Francis capture that.

So the New Evangelization and families with disabilities. Acknowledging that every view is a view from a point, my converging interests caused me to pay attention, when in October of 2012, bishops and representatives of the people of God from around the world convened at the Vatican for a special synod on the New Evangelization. How many were familiar with that synod? Did you follow it at all in the news or did you hear about it or read about it?

Well, the thing is, is that, in some circles it was very popular and many people were talking about it. And in other circles, it just sort of wasn't of interest, which I think itself may be instructive. For 12 days, they considered the strengths and weaknesses, opportunities and limitations of evangelizing efforts currently in place throughout the world. Many observers and commentators had a difficult time trying to discern what was truly new about this New Evangelization of Pope Benedict XVI and the ways in which it was similar to or distinct from those proposals by his predecessors, Pope Paul VI and John Paul II, all of whom had new evangelization projects in different times.

The three tasks of mission, to those who have not yet experienced the Good News of Jesus Christ, those who have experienced it but seek to understand it more deeply, and those who have experienced it but who have grown indifferent, hostile, or disillusioned, were sort of in the three frameworks for this New Evangelization. However, in the estimation of many, that which was truly new was the novelty of the times in which we live more than the evangelizing mission of the Church itself.

As for the distinctiveness of this current papal vision for the New Evangelization, there is a broadly held conviction that it is best understood with regard to particular emphases, attitudinal tone and characteristic zeal rather than any particular innovations in catechetical content.

Let me repeat that. It's about particular emphases: where will our gaze go? What will we be paying attention to, our attitudinal tone. It's not about necessarily immediately changing rules and regulations and traditions, but what is the attitudinal tone that we take when we speak about them? And then a characteristic zeal, somehow a zeal that communicates a passion for the Gospel message more than any particular innovations.

Now when, at the conclusion of the synod, 58 propositions for the New Evangelization for the transmission of the Christian faith were shared with the world Church, what happened? I was struck by their relevance for families and persons with disabilities but sorely disappointed to find the only explicit mention of persons with disabilities in proposition 32. There were 58 propositions. Proposition 32 is entitled "The Sick."

And here we go, and I will read what is on the screen: The New Evangelization must be ever aware of the Paschal Mystery of the death and resurrection of Jesus Christ. This mystery sheds light on the suffering of people, who can find in the Cross of Christ understanding and acceptance of the mystery of suffering that gives them hope in the life to come. What is the theological construction that we are being given here? OK?

Second point: In the sick, the suffering, persons with disabilities, and those with special needs, Christ's suffering is present and has a missionary force. For Christians, there must always be a place

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for the suffering and the sick. They need our care, but we receive even more from their faith. What is this proposition saying about recipients and agents? What kind of theologies are undergirding this proposition?

Through the sick, Christ enlightens his Church so that everyone who enters into contact with them will find reflected the Light of Christ. This is why the sick are very important participants in the New Evangelization. Is there a difference between being a participant and being an agent? That's my question. All those in contact with the sick need to be aware of their mission. We cannot forget, when we build new hospitals, to pay attention, so that we do not lack a consoling and supportive environment and a place for prayer.

All right. Now I'm going to ask you just to turn to one another at your tables and unpack your feelings hearing this proposition. OK? We'll take about maybe five minutes. I know there's a lot of energy in the room. Maybe we can pull out a few more microphones and get maybe five impressions. OK? Don't everybody raise their hands at once. And if you've spoken before, maybe we'll try and give people who haven't spoken before a chance. Yes?

BILL: I'm Bill Horan from Manchester, New Hampshire. We have a large group of immigrants in our parish, so . . . but this phrase, "we receive even more from their faith." They need our care, but we receive even more from their faith. It implies that term that Mother Teresa used, "Christ in a distressing disguise." These people have problems. Oftentimes, if you look at them, you can find Christ there. We receive even more than their faith. So without the immigrants, we wouldn't be there as a parish. And they've helped to inspire us a little. If they could have it so tough, why can't we do it? Why can't we get along? So I think it's true: receive even more from their faith.

GUIDER: Yeah? Up here and then . . .

PARTICIPANT: So I think we pretty much figure that it's missing the agency piece. And we pretty much figure that it's . . . sickness and sick itself is not enough to adequately describe the physical reality and the giftedness of disabled people experiencing disability. And also though, since we're moving into mission field and evangelization, it's probably a good starting place for us to realize that the primary mission field, of course, is first ourselves.

We need to teach Church and Church insiders what it is because we cannot presume faith among disabled people—people experiencing disabilities—any more than we can presume it among people not experiencing disabilities. And we cannot presume that we come with any answers at all, absent asking for the agency of the people who live with disability.

GUIDER: Yes. Absolutely. I present this to you because actually this is available on the Internet under the Vatican Website, all 58 propositions. And the thing is, is these are the kinds of documents that are not received. And because they're not received in the sense of being received by the whole Church – they may be received by bishops and they may be received by a few people in my classes, they may be received at a level of Church leadership, but these were propositions put out to the whole Church. And my concern is, where is not the pushback but where is the feedback? Where is the feedback? If we're unaware of the documents, where is the feedback?

And I think actually those who constructed these propositions thought that they were informed and influenced by things like the U.N. Convention on Persons with Disabilities. That's why it even got in there. But as we look at it with the level of consciousness that exists in this room, we realize this is like something they were saying in, you know, Christ renews his parish in 1968, that there's a time

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warp here. And how is it that it's still being constructed in this way when one would expect that we have so much more at our disposal, especially after the year 2000, during the Millennium, when Pope John Paul II was repeatedly issuing letters and exhortations, not big exhortations but small, about persons with disabilities?

So it's not as though the Church has not, on the part of its leadership, been made aware, but there's something that's not filtering in. Yes? That's you. Oh, we need a . . . oh, I'm sorry. Go on.

PARTICIPANT: First of all, a question, all right. Is it the idea of the New Evangelization . . . Did that come out of this 2012 . . .

GUIDER: Yeah, that language of the New Evangelization, everybody thought it was new. But as I said earlier . . .

PARTICIPANT: I know. It has a history.

GUIDER: Pope Paul VI had a new evangelization, Pope John Paul II had a new evangelization, Benedict had a new evangelization.

PARTICIPANT: Right. It's all kind of relatively new. All right. Just in the circles in which I work and move, I am a board-certified chaplain, and I don't see . . . I know from what I hear from my peers and also from what I'm feeling from our institutional Church is, the New Evangelization is something really new, when actually what I'm hearing is it's a renewed evangelization. And that makes more sense, at least from my perspective, to make it new again. I mean this is Vatican II in a way—to make new the message of Jesus. That's why I feel people that are hearing this, say for the first time, are seeing it as Pope John Paul II, John, not John but . . .

GUIDER: Paul VI.

PARTICIPANT: Pope Benedict.

GUIDER: Oh, yeah, Benedict.

PARTICIPANT: Yeah, Paul VI or whoever else was using this new evangelization. But it just, it doesn't sit well. And it's disturbing.

GUIDER: Yes. Thank you for that. And as I said earlier, I think one of the key things to remember about the quality of new is not so much about the Gospel message. I mean the Gospel message is always new. But the thing is, is that we are living in new times. And how the Gospel message is communicated in these new times, how we attend to the spirit of the times I think is critical. And as I read this, I don't say this for the purposes of criticism, for the sake of criticism, but this hardly seems to be a statement that fits 2012. The problem is that it's not a timely statement. Yeah. So can we have one more comment over here?

PARTICIPANT: I work with families who have kids profoundly disabled. And some of them are Catholics. And they have shared with me statements like the one I think is coming from paragraph number three. And one of the statements that they have shared with me is that their children are angels. So I see on that third paragraph a particular vision of being sick and being a person with a sickness or an illness. And I wonder, how do you explain that? Or do you have any comments about that?

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GUIDER: Well, I do have a comment. I'm going to advance my lecture here, because what I want to say I'm going to say later, but I might as well say it now since you raised what you did, and said. In preparation for this lecture, I happened to be at my parents' home. They are both deceased, but actually one of my colleagues in the STM—his daughter is making her First Communion—and I had a recollection. My mother was a seamstress, and she preserved everything perfectly. And I thought, I think we have, there's Communion dresses in the basement. As my recollection was, they're beautiful.

So sure enough, I go down into the basement, and I find these two Communion dresses—my Communion dress and my sister Mary Ann's Communion dress—in separate boxes, perfectly put together, saved for . . . I don't know for who, exactly. But anyhow, I was going to pull them out for this colleague's little girl and see if they would fit. I opened up the boxes. They're in pristine condition.

And then I found in another box material from my father that he had saved. And I want to share with you some of the things that I unearthed in that box. All right. This certainly, by Charles Bauer, *Retarded Children Are People*. OK? The date on that is, let's see, 1964. OK? The publisher is the Bruce Publishing Company in Milwaukee. Charles Bauer was the Catholic chaplain at the Newark State School.

Now the title, in a way, for our purposes now, is somewhat . . . not something that we might put on the front of a book right now. But actually, what I was amazed at is, getting into this, how people were trying to make meaning for parents at a time when consciousness about disabilities was now something that we could speak about publicly in society but also in the Church. So I don't want to make light of it, but I want to . . . And then the next thing was *For Parents of Retarded Children* by a Redemptorist priest who was an ethicist, whose name was Monsignor Breitenbeck.

And I, when I found this, I remember my father talking about this Monsignor Breitenbeck. And it's like we knew Monsignor Breitenbeck. I never met him. But the thing is, is whatever Monsignor Breitenbeck had said to parents and families, it gave them a new understanding of who their children were in terms of the faith community and what the parents needed to do in order to be agents in their faith communities.

Now the next thing I found was this: *May the Retarded Receive Communion*. Now this may seem like a question, but what Monsignor, his name is Gerard Breitenbeck, what he does is an incredible, fascinating moral argument for children with cognitive disabilities receiving First Communion, just slicing through the tradition in such a masterful way.

And then I found my father's letter to the Daughters of St. Mary of Providence. They had a school on the north side of Chicago. It was a residential school where children would go during the week and then back to their homes on weekends. This is before any of the public schools have classes for special needs children. And in that letter, my father—there's questions—"Why do you want your daughter to come?" And my father writes, "Because I want her to receive her First Holy Communion." And then in that same box of things, I found this. It's a Sacred Heart with a little girl receiving her Communion.

And what I was so conscious of as I read that letter, how important it was for my father, and for my mother too, but my father is the one whose letter I had, it was that Mary Ann be part of the sacramental life of the Church. And so I think, as we talk about recipients or agents of evangelization,

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we have to take the long view in terms of the history of where we have come from and a measuring stick: have we gone as far as we would have hoped by now? I think, for some people, the answer to that question is we haven't gone as far as we had the resources and the abilities to go. But we have made movement and strides.

But when you think, for example, of the debates that have gone on in the Southwest about the little girl who's gluten intolerant and the arguments and the disagreements, one wonders, how far have we come? How far have we come? So anyway, I'll stop there. I don't know.

So let's move on. All right. I'm looking at the clock here, and I'd like to finish up this part and then we'll move on to a break, and then we'll come back for some table discussion of John 9.

So in addition to being recipients of the Church's care and concern, what is then truly new about this new evangelizing process, as someone has raised the question? On October 8th, Pope Francis announced an Extraordinary General Assembly of the Synod of Bishops focusing on the pastoral challenges to the family in the context of evangelization. He reconfirmed the anticipated Ordinary Assembly of the Synod of Bishops to be held in the fall of 2015 along with the World Meeting of Families scheduled to take place in Philadelphia in September 2015.

Now you can go online and you can begin to already get materials with regard to that family assembly in Philadelphia in 2015. But the question I'm asking is, where are the families and the persons with disabilities in this celebration of families? And right now do we need to begin to figure out strategies for occupying space at that gathering?

Never before has proclaiming the Gospel on the family in this context been more urgent and necessary. This is from the pope. The importance of the subject is reflected in the fact that the Holy Father has decided to call for a Synod of Bishops which is to have a two-staged itinerary, as I've said already. Then in February, Pope Francis writes a letter to families asking prayers for these three intentions: the two synods and this gathering in Philadelphia. It's sort of like a World Youth Day for families, that's the best sense that I can get of it.

Would there be a time and place for families with disabilities and persons with disabilities to have voice and visibility, voice and visibility? Now the answer to my question came yesterday, just in time for this presentation, when the Vatican announced that Pope Francis will wash the feet of a group of disabled and elderly people, two different groups, as part of an Easter ritual imitating Jesus Christ's humility on April 17th during a visit to a hospice in Rome.

The pontiff will visit the Centro Santa Maria della Provvidenza Fondazione Don Carlo Gnocchi home on the city's northwestern outskirts on Thursday, which commemorates Christ's Last Supper with the apostles. Pope Francis has often shown particular attention to disabled persons and the elderly, condemning a hidden euthanasia in modern societies against the old.

Clearly, from the perspective of the pope, persons with disabilities and their families are on the pope's radar screen, up front and center, but what about the rest of the church? When the pope visited Assisi in October, there were very, very powerful experiences – and this also in part when Melinda (sp?) and I were working on this lecture, I was actually inspired by that trip to Assisi because you saw the pope engaging with persons with disabilities and their families.

There was a particularly touching scene where there was a young boy with a disability with a brother who was close to his own age. And the pope reached out to the young boy with a disability, gave him

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the usual big embrace, but then he also did the same thing to the brother, and then he put his arms around the whole family.

And for me, that was an iconic moment – to see that – so often when we see him going through the crowds in St. Peter’s Square, you know, he’s extending himself to different people, but this really communicated – his first gaze was on the young boy with the disability but the second gaze went to his brother and the third gaze went to the embrace of the whole family. So I think there’s a way in which the pope experientially engages with the people of God. But are the people of God internalizing this message? You have a question. We need a microphone.

PARTICIPANT: I actually have a comment. And I love that story of the pope and that image of the two boys. Going back to what he’s going to do on Holy Thursday, if he goes to a hospital, I think you said it was a hospital . . .

GUIDER: It’s a hospice. I think it’s a residence. This was rapidly translated from the Italian. So I think it’s what we would call a residence. I don’t think it’s a hospital.

GUIDER: OK, because my concern was, if it’s a hospital or perhaps even a hospice, the image that he’s really portraying is reinforcing the sick.

PARTICIPANT: Exactly.

GUIDER: Yeah.

PARTICIPANT: And we know that he does far more than that in his public appearances.

GUIDER: And I really wondered to what extent (I think the pope is getting more cautious), a friar friend of mine . . . about not having his encounters, you know, because he’s so much about this experience of encounter, to not turn into media circuses. And so he is out and about visiting people many people in many human conditions that we are not seeing because it goes unannounced, and he purposefully does not make his intentions or whereabouts known, so as it not to turn into a paparazzi event of a papal sort.

But it will be interesting to see, based on what happened last year in the youth jail, and to see now what happens this year, how is that going to be socially constructed in the context of the media?

All right. Well, I think everybody may have a few calluses on their bottom side now. We’ve been sitting for a while. There are some snacks and coffee and things back at the table. Why don’t we take about a 10-minute break? We’re going to circulate John Chapter 9 at the tables. I’d like you to read through it and then, on the second side of the sheet, there are some questions. So why don’t we just take a 10-minute break, and then I’ll introduce the table exercise when we get back.

What I’d like you to do at your tables is perhaps just a quiet reading of this Gospel passage from chapter 9 of John’s Gospel. And perhaps before you start reading, it might be a good idea to look at the questions that are on the reverse side. And I’ll give you some quiet time of about five minutes to just go over that passage and underline what you’d like in light of those questions, trying to make some connections between this passage and its relevance. How might this particular passage serve as a biblical foundation for moving forward this discussion on persons with disabilities and families with disabilities in a way that could be productive; or should we look elsewhere? OK?

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Great. If I could draw your attention back . . . this isn't an exercise in biblical exegesis. OK? This is basically an exercise in theological reflection. How does this scriptural passage get our thoughts stirring and moving and reflecting in ways that enable us to think critically about how we engage life as we know it with what this Gospel passage suggests to us? And then we'll talk a little bit later on, some movements toward action as a result of the answers and reflections that you give.

So what I'd like to do is take about 20 minutes for this discussion at the tables. And you can proceed as you would like. I have those questions ordered, but you don't need to follow that order, so no need for a secretary at the table. I know we thinned out a little because people had other commitments moving toward 3:00, 3:30, so people might want to move to another table to fill out the tables, but not necessary, just a suggestion.

And so we'll take 20 minutes, and then we'll bring those conversations to a close, and then Maria is going to make her presentation. And then we'll open it up for a bit of a plenary discussion, and I will give some further thoughts on the nature of being recipients and agents. OK? So that's where we're going until 4:00. So we have 20 minutes right now for the table reflection.