

Us, Not Them: The Project of Life
Keynote Address: *Us, Not Them: The Project of Life Conference*
Rome, Italy. June 2, 2023

First, let me say thank you to all of you here, and to Sister Veronica and others who have organized this 2nd National Congress. It is an honor to be here, and I have watched with excitement from afar as I saw some of the precursors to the Congress and its growth.

Grazie mille.

Us, Not Them, the Project of Life. A provocative title. Let me give you my take on its meaning by starting off with a story of my friend Florence, from the 1980's, when I was the Chaplain and Coordinator of Religious Services at a state-run institution in Rochester, New York.

Florence was a short, round woman who went with 30 to 40 other Catholic residents of that Center to mass every Sunday at one of three Catholic churches. I sometimes went as well, celebrating the fact that this was one significant form of inclusion in the wider faith community after years of institutionalization. The fact that this was a large group of people going in mass to mass, in ways that never really facilitated interaction with the other parishioners, was a lesson yet to be learned.

One Sunday, I sat right behind Florence. The priest, of Austrian German background, was usually strait-laced, controlled, and not very effusive. But this Sunday, after his short homily, he then led the congregation in the recitation of the Creed. From my experience in Catholic masses, and in Protestant services where a creed is recited, it is usually something done somewhat on autopilot, cited from memory, not requiring a lot of thought. But this Sunday, he threw himself into leading it, like a solo singer. One could sense the congregation gradually responding more actively, perhaps out of curiosity about what had gotten into Father this morning. As he finished with a flourish, Florence, all five feet of her, stood up in front of me and started clapping.

I, of course, wanted to slink under the pew, alarmed that this action might cause a scene, and threaten their, or our, or my acceptance there. But three weeks later, I, a Protestant clergyman, got invited to give the homily at that church. I started off by sharing my reflections on Florence's "behavior." What had come to me was that if we all said the profession of faith as a Christian community with enthusiastic hearts, minds, bodies, and souls, and it was indeed a reflection of the active belief and actions of our community, well, then, we all ought to applaud and celebrate that kind of faith that leads to embodied Christian action.

I would wager that something like that has happened to you time and time again in your work with people with disabilities, times when someone says or does something out of the ordinary, which is completely unexpected, and, on examination, more of a revelation than a problem, a speaking of the Holy Spirit that says that you, or I, were just the receivers here. I thought I was the giver, but I just learned something in a holy, unexpected way. They, "them," gave to me, or,

depending on where it happened, to the us who were there. Those stories and experiences are, for me, what drives my commitment and vision. We could spend the rest of this conference sharing them. Think of them as “parables,” short stories that grab one’s attention, and often turn our thinking upside down.

I began as a clergyperson working in this area in a time where everyone thought you had to do something different, something “special,” to reach and help “special people.” Religious education had to follow special education techniques. Leading worship with people with intellectual disabilities required “special skills.” But I soon realized, that as I and others asked, “How do we do this, or that, with a person with an intellectual disability?” that the first thing we should do is reverse the question: “How do we do that for anyone else?” Or, in other words, not how we do it for them, but how do we do it for us? And then start there, with adaptations as needed.

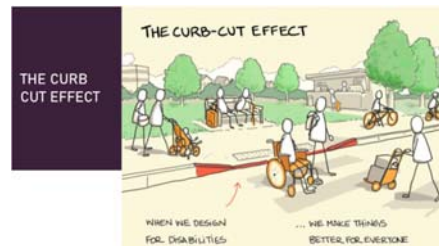
For example, the old question used to be in Protestant circles, “How can THEY receive communion if they do not understand communion?” Reversing the question, “How do we know anyone really understands communion?” If we prevented people from receiving communion based on accurate theological knowledge, many people would be excluded. That’s why the Catholic Bishops’ Conference of the United States has a new national project to remind believers about the holiness of communion.

Or, another example, how do people with disabilities grow in faith? Especially if they have an intellectual disability. Reverse the question. How does any child grow in faith? They start by getting included in the community of faith early on, hopefully experiencing it as the expression of a joyful, loving God. Then they start to learn the habits of going to mass, what to do when. They don’t get it all at once. They have lots of practice. Then they get to the age when they can be assisted to make a decision, at their own level of ability, about their choosing that church or faith tradition as their own. Thus, the importance of being included from the very beginning, rather than being sent off into special religious education programs with people “like them,” perhaps after they have not been included in their early years, and then being expected to know what to do when they come back into the whole church.

But, over and over again, as helped by my friend Florence, I grew in my faith by something that “they” said or did, which was in fact good for me, and on thinking about it, could also be good for the whole body of Christ. If people with disabilities are culturally seen as the smallest or most hidden parts of the body of Christ, then, according to Paul, those parts of the body are essential to the whole, even if the whole does not yet know it.

There is a corollary to the strategy of “Reversing the Question.” Reverse the Answers. When we find strategies or methods that are truly effective in working with and including people with disabilities, then, lo and behold, they often turn out to be good for everyone else. One example is working to make worship more participatory, by appealing to more of the senses, doing different things in the service, moving, and interacting. Roman Catholics have always been better at that than many of us Protestants, who think that the service is the heard and spoken

word, sometimes sung. Only recently have we gotten better at liturgy that involves all the senses, using symbols, movement, and other interactions. You need that to keep people whose cognitive abilities or short attentions spans makes it hard for them to sit and be still. And what happens? Most everyone else likes it better too.



It turns out there is a name for this. In the 1980's or so, the University of Minnesota put in curb cuts throughout their urban university campus because of new federal laws about accommodating people with disabilities. Then they asked the students, faculty, and staff why they did that. You know what the people in wheelchairs said. But the bicyclists said it was for me. The young families with strollers said it was for them. The workers who filled the vending machines said it was for them. It is now called "The Curb Cut Effect." When we do something for those people, the "them," with disabilities, it ends up being used by many of us.

Other examples include kitchen tools once designed by Occupational Therapists that now have much better handles and ease of use, technology advances like voice to text apps on our computers, and emojis and communication by symbols on our phones. Many of us now use, and count on, captioning that started because of deaf people. But it is larger things as well. From architecture came universal design, making spaces better for everyone. In education, we now have special education strategies maturing into universal design for learning, designing learning environments that are organized to accommodate different styles of learning from the very beginning. In behavior, we have Positive Behavioral Supports, a more ethical way to help "those people" with "challenging behavior issues" learn behavior that is more effective at meeting the unspoken needs under their problematic behavior. Positive Behavior Supports are being applied in the States to whole schools, not just to specialized classrooms or individuals with conditions like autism.

But I would like to look at some examples that involve matters of the spirit and faith, lessons learned in areas of disability and faith that end up being about US. And our Project in Life as God's people.

First, for me, was coming to understand a different way of understanding spirituality as something that included everyone, regardless of intellectual or physical abilities. While its importance was not and still is not frequently recognized in services to and with people with disabilities, it is implicit throughout our models of service and support. Our Western values that shape services are independence, productivity, inclusion, self-determination, and cultural competence. They are secular ways of answering questions that are at the heart of spirituality:

- ▶ **Independence** (Who am I?), i.e., a person's core values, meaning, and identity, including what is sacred.
- ▶ **Productivity** (Why am I?), i.e., a sense of purpose, call, vocation, or obligation, being able to contribute.
- ▶ **Inclusion** (Whose am I?), i.e., connections and relationships, to self, others, the sacred, time, and place.
- ▶ **Self-determination**: "What kind of control or power do I have over what happens to me?"
- ▶ **Cultural competence**: "Will my personal uniqueness and cultural heritage be respected?" At the heart of self-determination is the question of preferences, choices, power, and control.

But really, I learned, those questions are universal. You can easily see how connections and inclusion in the people of faith, and a sense of being connected to the sacred, however experienced, is not an intellectual exercise. We are learning from people with disabilities that one of their greatest desires in their participation in churches is a wish to serve as well as receive. "They" feel that God is calling them to serve in their faith. "We" say everyone has gifts. But people do not know they have gifts unless someone receives them. And they, like we, all have our quest to learn and act on how we are called to make a difference in the world, i.e., our vocation.

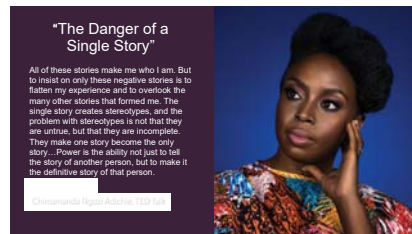
But it may be in "Who am I?" question of identity that it is most profound, which also fits the project of this Congress, defining the "US." Let me quickly teach you a simple exercise to do with a group of people sometime. We don't have time to do it right now.

Everyone takes a piece of paper and writes "I am..." followed by ten blank spaces or numbers. Then everyone fills those ten with parts of their identity: relationships, hobbies, interests, passions, characteristics, etc. The only rule is you cannot use your job. I, for example, would be husband, father, grandfather, gardener, football (soccer) lover, reader, fan of several different sports teams, sometimes fisherman, Christian (specifically Baptist but not so much that anymore) Bruce Springsteen fan, etc.

Then you get everyone to share their ten out loud. Two things will happen. Even if you know people, you will find out important things about their identity that you may not have known. People will start wanting to talk with each other about shared interests, like being a gardener, or a grandparent, or a soccer fanatic. Second, I have never had someone use a devaluing label in their top ten. They may say "cancer survivor," or recovering addict, with pride. Or claim a label that once devalued but is now worn as a badge of pride, like woman, or black, or deaf, or even now, autistic. But what is most important to them are things they see as gifts, as bringing meaning and purpose to their lives.

So, it becomes a powerful exercise in what makes for a holistic identity, and why labels that make others into a "them" are so destructive. Nigerian novelist Chimamanda Adichie calls this

the *Danger of a Single Story* in a wonderful TED TALK, one that has nothing to do with disability on the surface. that has nothing on the surface to do with disability:



All these stories make me who I am. But to insist on only these negative stories is to flatten my experience and to overlook the many other stories that formed me. The single story creates stereotypes, and the problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story...Power is the ability not just to tell the story of another person, but to make it the definitive story of that person.

Thus, one might say, part of our call as people of faith is to help others have as many positive stories as possible, including any that will help them claim being a child of God, created in the image of God, a member of this parish, or more. A spirituality that includes everyone.

Another example is what I am going to talk about tomorrow in my workshops: helping people with intellectual disabilities cope with aging, end of life, grief, and loss. As a chaplain, I had numerous pastoral experiences in this area, then provided trainings for direct care staff for about ten years in New Jersey. in the last five years, I helped the Hospice Foundation of America to create a website on grief for autistic adults and their families, friends, and caregivers, including clergy. As I and others worked to learn how to best help people with those disabilities cope, what was staring me in the face were attitudes and strategies that were good for everyone. Just for a quick example, worrying about how someone with autism might behave at a funeral mass or wake makes you realize, "We all act out our grief" through cultural traditions and habits that have developed over the centuries. So our job is to help people participate in the community of mourning, and learn the habits, behaviors, and ways that we all use to share our grief and comfort others: cards, flowers, visits to the grave, and more. Mourning is a full body exercise, not an intellectual, act of understanding.

Finally, let me use an example that has come out of the work of Erik Carter, someone whose work you need to know. He and others did a research project asking 500 families and people with disabilities about their interest and involvement in spirituality. They learned a lot, but out of the responses, Erik also put together a model diagram that described what the individuals and families said would help them feel like they belonged in the community of faith, to the US. Here it is:



I would simply ask you. Is that not a visual model of what belonging means for all of us. And not just belonging to a parish or a congregation, but to a community, a group, an organization.

My closing theological thoughts would simply be that this is why, I think, God calls people of faith to the margins, and to people on the margins, because at those margins, wherever there is a "them." We are called there because that is where God is, where Jesus lives, and where we see God more clearly than we do at the center. We learn, there, lessons and revelations that need to be at the heart of who we are as a people, because people on the margins, really are at the heart of who we are as human beings. In the Bible, we find a Jesus and a God who are always reversing expectations.

Perhaps WH Auden said it the best in his long poem, *For the Time Being*, about what we as God's people are to do between Jesus's time and the time when He comes again:

He is the way,
Seek him in the land of unlikeness
And you will find strange beasts and unique adventures.

He is the truth,
Seek him in the kingdom of anxiety
And you will come to a city that has expected your return for years

He is the Life,
Seek him in the world of the flesh
And at your marriage, all its occasions shall dance for joy.ⁱ

May your project in life, your vocation, and your life as a child of God, always come back to the US, and may you dance for joy.

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