Out of the Shadows
Making room in your parish for people with disabilities
BY KEVIN CLARKE

Continuing what has been a series of powerful gestures to quite literally embrace people with physical or intellectual disabilities, Pope Francis celebrated Mass during the jubilee of the sick and persons with disabilities on June 12. He was accompanied by altar servers with Down syndrome and persons with disabilities proclaimed the first two Scripture readings, including one in Braille. “The world does not become better because only apparently perfect—not to mention fake—people live there,” he said, “but when human solidarity, mutual acceptance and respect increase.”

In an age when many seem to believe “anything imperfect has to be hidden away,” the pope said that limitations are part of being human. “Each of us, sooner or later, is called to face—at times painfully—frailty and illness, both our own and those of others.” The day before the Mass, answering questions from participants at a conference on catechesis for persons with disabilities, Pope Francis said a pastor who declines to provide special religious education classes “must convert.”

“Think of a priest who does not welcome everyone. What advice would the pope give him?” Pope Francis asked. “Close the doors of the church! Either everyone or no one” should enter.

With one in five Americans—over 55 million, according to the U.S. Census Bureau—growing up with some form of physical, intellectual or neurological challenge, it is unlikely that there is a single parish in the country that is not touched by the issue of access and programming for parishioners with disabilities. Yet when you look around your church on Sunday, are people with developmental or physical challenges evident? Is your parish encouraging them to be present?

It is more likely that “you don’t see them because they don’t come,” says Stephen Riley. “And why don’t they come? Because they don’t get invited or they’re forced to the quiet room or discouraged from attending sacramental preparation.” It is a self-reinforcing cycle that in the end can mean further isolation from parish life for members with disabilities. Their families, perhaps infuriated or just hurt by the sense of exclusion they feel, will also disappear from parish pews, “living in the shadows” of parish life.

Pulling people out of those shadows has been the work of a lifetime for Mr. Riley. He is the father of a young woman with Down syndrome and the executive director of Maryland’s Potomac Community Resources, Inc., a nonprofit that promotes the full inclusion of teens and adults with developmental differences into community life. In recent years, P.C.R. has worked closely with the Archdiocese of Washington to build unique parish-based programs for youth and adults with physical and intellectual disabilities.

Until now, aside from scattered anecdotes generated from dioceses across the country, how well—or how poorly—the church is serving physically or intellectually challenged people and their families has been one of the “unknown, unknowns,” Mr. Riley says. But this month, the Center for Applied Research in the Apostolate released a first-of-its-kind study of Catholic parishes in the United States that documents how well they have been responding to calls for inclusion and accommodation. The study was commissioned by P.C.R., the National Catholic Partnership on Disability, the Department of Special Needs of the Archdiocese of Washington and Catholic Charities of the Archdiocese of Washington. Explaining the rationale for the survey, Mr. Riley says, “We’re just trying to stir the pot and get this conversation...[and] new thinking going.” He hopes the analysis will further promote the inclusion of persons with developmental and physical challenges and “allow the parish to be in their lives and for them to be in the life of the parish.”

Accommodating Parishes
The CARA study offers generally good news on physical accommodations for people with disabilities. The vast majority of churches were either designed from the ground up to include access (42 percent), especially following the passage of the Americans with Disabilities Act in 1990, or retrofitted to create it (71 percent). But ramps into a church do not help people with physical challenges get to the altar to act as lectors or eucharistic ministers or give them ready access to a choir loft or even a bathroom. And extending access beyond church doors and into other parish properties remains a problem: Just over 50 percent of parish halls were deemed accessible.

All the same, Janice Benton, Executive Director of the National Catholic Partnership on Disability, saw progress over “where we were five or 10 years ago” in CARA’s num-

Kevin Clarke is a senior editor and America’s chief correspondent.
bers, especially the 51 percent of parishes that reported wheelchair access to church sanctuaries. Going forward, she thinks the new data will allow her group and others working for access for people with disabilities to establish a comprehensive baseline for measuring future successes.

CARA reports 87 percent of all responding parishes at least “somewhat” make accommodations for persons with disabilities for sacramental preparation such as the Rite of Christian Initiation of Adults, reconciliation, first Communion and confirmation; and over three-quarters “somewhat” offer accommodations to allow those with disabilities to participate in parish youth ministry programs. Ms. Benton acknowledges these positive notes. Still she believes “building awareness” of access and participation issues “is still huge,” pointing out that even pastors who acknowledged the need for access and accommodation often did not know how to utilize diocesan resources that would help them toward those goals.

“We need to be well past asking, ‘Should a child with disabilities be prepared for sacramental life?’ or ‘Should a child be accommodated?’ That should be a given. What we should be asking is how.” She adds, “If there’s an understanding that everyone belongs in the first place, and there is, then how do you accommodate that in a way that really engages people?” Even small efforts to that end can have a multiplier effect, according to Ms. Benton, as families who are experiencing a structurally welcoming parish get the word about it out to other families who may have dropped out of parish life.

Obviously the level of response on access and participation varies from parish to parish. Some are providing exemplary services. The study describes one parish that offers an Open Hearts Program that is “staffed by volunteers who have training with people with disabilities,” meeting “monthly for meal, prayer, music and fellowship.” This same parish also has a group that offers a caregivers support group and offers resources for respite services. Other parishes report struggling to pay for a wheelchair access ramp or a car service to bring to Mass the elderly or people with physical disabilities to Mass.

Seven in 10 parishes do not have anyone on staff who is responsible for coordinating efforts to include people with disabilities. In those parishes without paid or volunteer staff to confront the challenges of accessibility and participation, a pastor’s general awareness of the pertinent issues is
key. According to the study, nine in 10 pastors were aware of someone with an age, intellectual, neurological or other disability in their parish, but only 48 percent of those pastors knew of opportunities in their diocese for parish staff to access training to accommodate people with disabilities. The report notes, “Even fewer pastors [three in ten] reported that members of their staff had actually attended such trainings regardless of whether it was offered by the (arch) diocese or another organization.”

The Large and Small of It

According to CARA researchers, there are two primary factors that contribute to the extent to which parishes respond to the needs of people with disabilities: size/location and participation. Larger, suburban parishes are more likely than smaller parishes in urban or rural settings to have the financial and personnel resources “to make the kinds of accommodations needed in order to include people with disabilities on committees or in ministry roles.” It should not come as a surprise that parishes with higher levels of participation of parishioners with disabilities in ministerial roles or on committees are more likely to offer the services and access accommodations that people with disabilities need.

Survey authors call that an “intersecting spiral of inclusion.” Ms. Benton likewise noted the clear “synergy” that emerges when parishes make even small efforts to include people with disabilities in ministries and parish councils. Not only does their participation lead to more inclusive outcomes in terms of parish policies, priorities and design, the enhanced visibility, she believes, allows more people with disabilities to recognize themselves in parish life and get involved. Deciding which comes first, the presence of people with disabilities on parish committees or the physical accommodations for them, is a problem that Thomas Gaunt, S.J., CARA’s executive director, says will be the focus of further study.

“What’s often impressive is just how creative parishes are in trying to address these pastoral needs,” he says. He explains small parishes may not have the resources to create a “program” for catechetical instruction for children with autism, but they may reach out to a local special education teacher to help tutor the one or two children with autism in the parish. “People are earnest and creative in trying to address these pastoral needs and in a [broad] survey like this we may not be capturing that.”

And parishes seem to be responding to the growing number of children diagnosed with autism and other developmental challenges. Eight in 10 pastors say their parish at least “somewhat” offers a

Find Help for Your Parish

The National Catholic Partnership on Disability: www.ncpd.org
Potomac Community Resources Inc. promotes the full inclusion into community life of teens and adults: www.pcr-inc.org
Ministry with Persons with Disabilities for the Archdiocese of Washington: www.adw.org/disabilities/
International Catholic Deaf Association: www.icda-us.org
Cusa is an apostolate for persons with chronic illness or disability: www.cusan.org
For more references, consult with your diocese or parish.
way to include students with disabilities in religious education (85 percent). About four in 10 responding parishes use one-to-one aides (43 percent), a modified curriculum (38 percent) and/or small group learning (37 percent) to accommodate children and youth with developmental or neurological disabilities such as Down syndrome or autism.

Beyond helping them through the sacraments, parishes that welcome and integrate young people with developmental disabilities can fill a yawning gap that opens up just as these vulnerable teens teeter on adulthood, P.C.R.’s Stephen Riley says. Schools often provide developmentally or physically challenged youth opportunities to interact with the world outside their homes and families. But when those young people graduate from high school, those opportunities can evaporate.

Mr. Riley learned that the hard way. It was precisely the experience his daughter had upon her graduation. Developing community capacity to address that looming deficit is why he first became involved at Potomac.

**Beyond Access**

Much work remains to physically prepare parishes spaces to accept people with disabilities, and more outreach and programming can help include these parishioners fully in church life. But even more work lies ahead, one parent of a Down syndrome teenager argues. Yes, families that deal each day with the myriad challenges of physical or developmental disabilities need the church’s spiritual help, but they also desperately need the church to offer practical support.

Joe McGrath of Lafayette Hill, Pa., is generally satisfied and grateful for everything his parish has done to keep his daughter Maura engaged. But he is asking for more. At 17 his daughter is non-verbal and requires total care. The financial and physical challenges of parenting a child such as Maura can feel overwhelming at times, he allows. He knows people and marriages that have broken under the strain. He also knows there are many public resources available to help people with children with special needs—if they were aware of them. And that is where the church can be a big help, he thinks. “Special needs fairs are something every diocese should do,” Mr. McGrath says.

He put one together for his parish, bringing materials and social service representatives together representing a gamut of physical and developmental needs, including resources for the elderly, veterans, the hard-pressed parents of children with autism. Thirteen families that day signed up for services they did not know existed for them, Mr. McGrath says, including an 80-year-old woman who was able to qualify for home care for her husband, a veteran with disabilities she had been caring for on her own. “The church can’t help everybody, and I understand that, but it can do more,” he says. Noting the high suicide and divorce rates within the
growing number of U.S. families with autistic children, he warns; “Families are sinking.”

Though the majority of parishes reported maintaining a list of resources to refer people with disabilities for professional help, only 20 percent of large parishes said that they regularly hosted a support group for families with members who have disabilities, and only 23 percent of them reported the same on support groups for the people with disabilities themselves. Smaller parishes fared even worse.

Ms. Benton agrees that parishes are still learning how to better “walk with and support families” beyond the church or parish social hall. “Minimally [parishes] should be aware of what these families’ needs are. Is there a way for the parish to help? And what would be helpful?” Respite services for often overwhelmed caregivers is an area parishes might explore, she suggests. Other parishes have created parish nurse programs; some have even sponsored housing programs for families and individuals with special needs.

Some Next Steps

Though Ms. Benton was pleased to see that 27 percent of parishes reported services in Spanish for people with special needs, she thinks even more has to be done to produce and share bilingual resources for the inclusion of people with disabilities; her office is in the process of translating all of its material. Ms. Benton also highlighted outreach and service to people in the nation with hearing loss as a continuing deficit, with only three percent of survey respondents reporting services for persons with disabilities and their families in American Sign Language. Fewer than one in 20 (four percent) of parish websites were designed to be accessible to parishioners with sight or hearing loss. Ms. Benton urged anyone producing catechetical or other parish video resources to especially remember to caption their content for the hearing impaired.

The new report is just the beginning of CARA’s efforts to capture the experience of people with disabilities in the church. Future analysis will further hone the depiction of that experience and suggest new areas that will require attention. What this effort does not tease out is what the church loses, according to Father Gaunt, when it does not find a meaningful way to involve brothers and sisters who have disabilities.

A common starting point of the spirituality Father Gaunt has learned through participation with the L’Arche community in Washington, D.C., where differently abled people create a home together, is that “those who are disabled, brothers and sisters so often excluded and ignored, are the source of God’s grace; they are our closest encounter with Jesus.” For all the talk of what the church can do for its brothers and sisters who are disabled, Father Gaunt points out, it is the rest of the church community that is diminished by their absence.