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Sacraments for Every Child

How parishes can welcome children with disabilities

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When Jimmy was baptized as an infant, he had no apparent physical problems. But as a young boy, he began to experience difficulty walking and running. Eventually he was diagnosed with Duchene muscular dystrophy. In order to receive the physical and occupational therapy he needed, as well as other mobility supports, Jimmy's parents moved him from the parish school to a local public school. As a result of this switch and his parents' later divorce, the boy never received the sacraments of Eucharist and confirmation. Then Jimmy's mother unexpectedly died when he was an adolescent, and his grandmother became his guardian. She realized that the boy had missed the final two rites of initiation and approached the pastor about

administering them in their large, inner-city parish. By this time, though, Jimmy's condition had grown worse; he regularly used a wheelchair. The pastor was unsure how to include Jimmy because the church building contained a large number of physical barriers.

I heard about the request from Jimmy's grandmother and called the pastor, who had never thought about the physical obstacles involved for such a child. The pastor told me he had met with the grandmother and worked out the situation, which started a whole process of changes, including the construction of a graded plane or ramp for one entryway. The family still attends Mass regularly at the parish.

Such stories are not uncommon. How can parishes welcome children with disabilities and ensure that they receive the sacraments and become active Christians to the fullest extent they can? Since most families do not want to stand out or make demands, the parish staff and parish leaders must anticipate the needs of children (and others) with disabilities and initiate changes. That means holding a meeting focused on welcoming those with disabilities and inviting parents so they can help make the list of potential problems or obstacles before their children reach the age for reception of the sacraments. Then the parish should address the issues raised.

Sacraments, according to St. Augustine, are "a visible sign of an invisible reality." Since they lead us into a deeper relationship with God, the sacraments are vital to all. The U.S. Catholic bishops expressed this sentiment in their 1978 pastoral statement on persons with disabilities: "Just as the church must do all in its power to help ensure people with disabilities a secure place in the human community, so it must reach out to welcome gratefully those who seek to participate in the ecclesial community."

To "reach out" to people with disabilities most Catholic parishes need to use inclusive language; learn the different types of disability and respond appropriately in reshaping the physical parish environment and the educational preparation for the sacraments; and allow a spirit of welcome to overcome any misconceptions, inertia and bias toward persons with disabilities, including children.

Careful Language and Distinctions

Much progress has been made in the area of language. Today, parishioners typically understand that many formerly acceptable terms (crippled, Mongoloid, handicapped, even "the disabled") are no longer acceptable. It is better to use precise and accurate terms like a "child with cerebral palsy" or to speak of a "person with a disability," which communicates that one sees the person first and the disability second. If needed, parish leaders can invite experts to instruct parishioners on such changes in a workshop format.

Parishioners and parish leaders must also learn to recognize distinctions within disabilities and the different patterns of disability. Those who plan the parish initiation rites may have already begun to account for them. The most obvious examples relate to physical spaces, the very issues that stumped the pastor in Jimmy's case. Other examples include children with hearing or visual impairments; they can be seated close to the action and/or be given amplification (earphones) and other assistance, like signing or someone to accompany them throughout the rite. Children with motor impairments may need a wider pew, an aisle seat, a walker, wheelchair or other seating supports. Good resources are easily available to help guide parish leaders (see <http://www.ncpd.org/ministries-programs/catechesis>).

More subtly, impairments and disabilities may require parishioners to revise their general understanding of the sacraments and what sacramental preparation entails. Religion teachers and parish staff in particular should be schooled in such matters. For example, certain conditions of childhood lead to a shortened lifespan, which necessitates an accelerated pace in receiving the sacraments. Does this apply to someone in your parish? Or consider: What is the role of the anointing of the sick with regard to childhood impairments and disabilities? It is not always clear. But for a young man with Duchene muscular dystrophy, like Jimmy, which tends to cause increasing breathing difficulties, ritual anointing may be appropriate, particularly when or if he and his family decide to forgo a tracheotomy and permanent mechanical ventilation. Or consider an adult sacrament: it is now quite common for individuals with Down syndrome to date and marry. If this is the case in your parish, how does the pre-Cana program take it into account?

When working with people with disabilities, parish leaders should emphasize unity rather than difference. This is not only the Christian thing to do but has also become the basic principle of "universal design," a new standard in commercial architecture.

Leaders should also be prepared for surprises, like the unintended benefits that will probably emerge for the parish at large. One of the most beautiful liturgies I ever attended took place at the Rochester Institute of Technology, which has a large community of individuals who have significant hearing impairments. By sheer chance, during a visit I witnessed an entire liturgy that was seamlessly bilingual: both spoken aloud and through American Sign Language. I found it moving and powerful to see literally embodied the prayers I thought I knew so well but only heard or thought of in the abstract before this. There are practical benefits, too. When a parish builds accommodations for wheelchair use, it eases the transportation of children in strollers and helps all who use canes or walkers or have joint problems. In creating large-print resources for children with visual impairments, a parish assists many other individuals, too.

Of course, building a ramp or buying large-print music materials may not address the most significant needs of parishioners with disabilities. Nothing takes the place of asking the people affected what would help them. In the case of children, the parish must work closely with their parents or guardians and teachers. It also helps when parish leaders become acquainted with the communities and agencies nearby that work with persons who have disabilities. In turn, the parish can help families connect with these agencies. All children with disabilities are entitled to therapies through early intervention programs (from birth through their third birthday) and through the public school system (from age 3 to 22). Those who attend public schools will have tailored support detailed in an individualized education plan, called an I.E.P. The plan may also be helpful in making accommodations for children to receive the sacraments.

Whereas Jimmy dealt with physical disability, Xavier must cope with a developmental disability. (Xavier is a composite character—not a single individual—whose story includes features from several real-life people.) Xavier was diagnosed with autism at two. He currently attends a full-day, year-round therapeutic school with a one-on-one aide in the classroom with him. Now age 12 and in seventh grade, he is able to converse with the other children, though he is better with adults. Xavier's parents would like him to participate in the sacrament of reconciliation, either in a private meeting or within a larger community celebration during Lent. The deacon who coordinates this program told them this would not be possible. They complained to the pastor, saying of Xavier: "He keeps more detailed track of his sins than anyone else we know!"

In such a case, the pastor or deacon or other appropriate member of the parish team should meet with Xavier and see what he actually understands about reconciliation and how he can engage with the sacrament. Since the case shows that Xavier has reached seventh grade and is good with adults, it is likely in this example that the deacon sees the boy's disability as a stigma; that is something the deacon and the parish (not the boy) should overcome.

The biggest distinction between physical and developmental disabilities is that the latter are more often

misunderstood or even missed. The similarities are even more important than distinctions. The parish must see each individual as unique instead of dividing people into classes or classifications.

A Welcoming Spirit

Sometimes a change in practice can lead a community to a change of attitude. At other times, the change of attitude precedes the change in practice. Compare the real-life cases of Nancy and Angie, born 30 years apart.

In the late 1950s Nancy (not her real name) was born, the third child of devout parents. She was diagnosed with Down syndrome. In the hospital run by a Catholic order of women and staffed by Catholic doctors, her parents were told that Nancy would be better cared for and her two brothers would be less negatively affected if Nancy were placed in a local institution for children like her. Her parents agreed, as did most families at that time. Nancy was never baptized, never received a full educational experience and died young (as did many persons with Down syndrome who were sent away from their families).

In the late 1980s, Angie was born, the third child of devout parents, and was diagnosed with Down syndrome. But Angie lived at home with her two brothers, was baptized, attended public school with an I.E.P., received first Communion with her classmates, was confirmed with them, finished high school, learned to drive (better than her brothers, according to her parents) and is now dating and considering marriage.

What is different? Certainly it's not Down syndrome. What changed was the attitude (and knowledge) of the community. The United States has a long history of housing "undesirables" outside the home and local community. But it has gradually become clear that separate means unequal, that is, less than equal, which is detrimental not only for the individuals who are separated but for the larger community, too.

My own children benefit from sharing classes and parish activities with other children who are different from them. They instantly recognize difference, and they have learned that I welcome a discussion about it. Such conversations allow them to be comfortable with their own uniqueness and with what is different about others.

Any discussion of individuals with "disabilities" contains irony, but that is especially true for Christians, who embrace a host of unexpected exceptions to the norm: a king born in a manger, redemption won on a cross, life found in a tomb. For Christians, no barrier in attitude or thought or practice should prevent us from extending a hearty welcome to all parish children and inviting them to the sacraments. All of us are "individuals with disabilities." All of us need the healing power that comes from "the water flowing out from beneath the threshold of the temple." And none of us will achieve self-actualization outside union with Christ.

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