

A PERFECT GIFT

Our son Charlie* was born with Down syndrome in 2007. My training as a developmental psychologist had focused on the deficits faced by people with disabilities and how to deal with those challenges. But I soon found that it was of limited use for understanding my own son. He certainly has challenges that come with his diagnosis, but they make up only a small part of life with our wonderful little boy.

Soon after Charlie's birth, a visitor to our home asked, "So, is he mild, moderate, or severe?" She was referring to his level of cognitive impairment. I was very familiar with her terminology, but the question shocked me. In my arms, I held my beautiful baby boy, who defied easy categorization. Clinical labels may describe some aspects of an individual's "functioning," but they don't tell the whole story. Labels could not describe how Charlie's smile lit up a room or how the sweetness of his soul had captured our hearts so completely.

I have since come to understand that clinical categories also miss another important dimension of personhood: we are created to be in relationship with others. As Pope Saint John Paul II said in his encyclical *Evangelium Vitae (The Gospel of Life)*, "Within the family each member is accepted, respected and honoured precisely because he or she is a person; and if any family member is in greater need, the care which he or she receives is all the more intense and attentive."¹ Seen through this more complete lens, Charlie is very "high functioning" within our family.

He does well because we love him and attend to him out of that love. We make accommodations to compensate for the challenges that arise, with the result that his strengths become more apparent. He plays an integral role in our family's happiness. For example, he is our most empathetic child—the first one to notice when we are hurt and the first to offer comfort.

People often say, "I could never handle a child with a disability." The beauty of parenting, I tell them, is that you aren't given a child with a disability. You are given your child with a disability. Your child enters the world in a relationship with you, and that relationship changes everything. You are not called to "handle" a disability. You are called to love a particular person, and caring for him or her grows out of that love.

I once read an article in which a woman discussed the reasons for aborting her child with Down syndrome. The deal-breaker for her was watching a boy with Down syndrome at a restaurant with his mother and father. They had to hand-feed him a slice of pizza, she said, and wipe his face with a napkin.

This hit home for me. We are now weaning my seven-year-old Charlie off a feeding tube. Although he's making progress, we still spoon-feed him and often wipe his face afterwards. I wonder how many people have watched us feeding him in public and decided a life like his isn't worth living. But if anyone were to ask, I would say, "It might look a little crazy from the outside, but he's an amazing little boy, and it's a good life."

It's like looking at a stained-glass window from the outside: The colors look dark, and you can't quite make out the figures. From the inside, however, with the sun shining through it, the effect can be brilliant.



From inside our family, love illuminates our life with Charlie. What may seem dreary to others, perhaps even unbearable, is actually filled with beauty and color. We know, for instance, that Charlie has worked hard to gain basic feeding skills that most people take for granted, and we are so proud of his valiant efforts.

Many parents want perfect children. Our culture is obsessed with perfection—a superficial perfection. Photos are airbrushed, and social media sites depict seemingly perfect lives. God calls us to seek perfection, too. He does not call us, however, to perfection of appearance or abilities, but to perfection in love.

Christians know what perfect love looks like—Jesus offering himself on the Cross. Love in a family where one member has a serious disability may look unappealing from the outside. Indeed, love in any family is messy; there are faces to wipe and sacrifices to make. It's natural to fear that such sacrifices will require too much. But this is where the deep mystery of sacrificial love becomes apparent.

In our family we have found that our hearts, rather than being weighed down, have become larger. Caring for Charlie has given us more patience, more compassion, and more love for others—especially those on the outskirts of society, whom Pope Francis so often calls us to care for.

Perhaps this is why so many families of children with disabilities, despite difficulties, often radiate joy. When I meet another parent of a child with Down syndrome, there is usually a moment of instant recognition and understanding. Our eyes meet, and we smile conspiratorially, as if we're in on the same secret.

The secret we share is the fundamental truth of our existence: every life is a good and perfect gift. Many know this on an intellectual level, but those who love someone with a disability see it in their loved one's face in a particular way. Our love for them has nothing to do with what they can or can't do. We love them simply because of who they are. Understanding this teaches us how to truly love everyone, whether they have a disability or not. We also begin to understand our own worth, which depends not on our skills or appearance, but solely on the fact that we are persons created in the image and likeness of God. Our lives—all our lives—are worth living.

The author has a Ph.D. in developmental psychology and has been advocating since the birth of her son Charlie for children who are prenatally diagnosed with disabilities. She and her husband are the proud parents of five children.*

*Name changed for privacy.

1 John Paul II, *Evangelium Vitae (The Gospel of Life)* (Washington, DC: United States Catholic Conference, 1995; reprint, Washington, DC: United States Conference of Catholic Bishops, 2008), no. 92.

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