

## **A PERFECT GIFT .... A Child with a personal handicap.**

*Soon after the birth of my son Charlie\*, who has Down syndrome, a visitor asked whether he was "mild, moderate, or severe"—referring to his level of cognitive impairment. I knew the 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.*

**Relationship Changes Everything**

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 honored 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."

Charlie does well because we love him and attend to him out of that love. We make accommodations to compensate for the challenges that arise, and 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 to notice and offer comfort when we are hurt.

People often say, "I could never handle a child with a disability." But the beauty of parenting 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 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. The challenges that come with his diagnosis make up only a small part of life with our wonderful little boy.

## **Stained Glass**

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

***Our love for our children has nothing to do with their abilities. We love them simply because of who they are.***

This hit home for me. We weaned Charlie off a feeding tube when he was seven, spoon-feeding him and often wiping his face afterwards. I wonder how many people saw us and decided a life like his isn't worth living. Had anyone asked, I would have said, ***"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 worked hard to gain basic feeding skills that most people take for granted, and we are so proud of his valiant efforts.

## **Perfection**

Many parents want perfect children, and our culture is obsessed with superficial perfection. Photos are airbrushed, and social media depicts seemingly perfect lives. However, God calls us to seek perfection not in appearance or abilities, but 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.

## **A Fundamental Truth**

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 fundamental truth that 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 our children has nothing to do with their abilities. We love them simply because of who they are, and understanding this teaches us how to truly love everyone. We also begin to understand our own worth, which depends not on our skills or appearance, but solely on the fact that we are created in the image and likeness of God and loved by Him. Our lives—all our lives—are worth living.