

# Contents

Preface	ix
1 Meet the God of the Mountain	1
2 Who Is God?	11
3 Our Children Go to Church	23
4 Sacraments for Children with Special Needs	41
5 Living a Sacramental Life	53
6 Cultivating Compassion, Empathy, and Social Responsibility	67
7 Building Strength and Perseverance	79
8 Developing a Prayer Life	91
9 Miracles, Meaning, and Healing	105
10 Concluding Remarks	115
Resources	121
References	127

## 4

# Sacraments for Children with Special Needs

The sacraments are at the heart of Catholic Christianity, including not only our Roman Catholic tradition but also Eastern Orthodox, high Anglican, and Lutheran traditions. Yet many parents of special-needs children wonder whether their child should receive the sacraments at all. They may ask “Does he really *need* the sacraments?” Often this question is gently dropped in the ear of parents by well-meaning family members and friends who reason that since many children who are cognitively disabled are incapable of committing a mortal sin, they don’t *need* the sacraments.

This can seem like a powerful argument, because it taps into parents’ fears. “What if my child is turned away?” “Will he be able to sit still in a CCD class?” “Will she understand that the bread is Jesus?” No wonder some feel relieved when someone they love and trust tells them, “Relax. Your child is already holy in God’s sight; she doesn’t need the sacraments.”

Mercedes and I heard this from more than one well-meaning family member. Yet we knew that the sacraments are not just a ticket into heaven. Danielle’s autism was severe enough that she is incapable of the conscious rejection of God that is mortal sin, but we wanted her to receive the sacraments anyway. The sacraments lie at the very center of our relationships with God and neighbor.

## Why the sacraments are important

The sacraments are a visible sign of the invisible God. This gets at something fundamentally important. We are a curious mix of matter and spirit. They cannot be separated without doing violence to our nature as human persons made in the image and likeness of God. Further, God's incarnation in Jesus means that Jesus is our central sacrament. Our God is invisible. We who live in the world of matter need visible, material signs of his presence. The sacraments are these signs.

Bread, wine, water, and chrism are tangible realities. The smell of fresh bread baking is delightful, but preceding it is a lot of physical work by the farmer who harvested the wheat, the laborer who threshed it, and the miller who ground it into flour. To make bread, you must mix flour with water and yeast, work it into dough with your fingers, knead it with your knuckles and the heels of your hands. It's work! Bread is tangible; it's something you can bless and break, something you can raise to heaven saying, "Take this all of you and eat of it. This is my body, which will be given up for you." It is something you can feel as it is laid in your palm, something you reach for with your fingers and raise to your mouth. It is something you savor as you chew and become one with as you swallow.

This tangible experiential understanding of the sacred in our everyday lives is what the sacraments are all about. They connect us to the invisible God. We *need* the sacraments, and so do our children.

Children with autism are well-equipped to experience sacraments. They rely more on posterior and right-brain circuits to compensate for impairment in the anterior and left brain. These circuits tend to involve sensory processing, especially visual feature analysis. They mediate senses such as touch, hearing, and body awareness. They are more imagistic and associational. This

sort of sensory, visual, and experiential processing matches the spiritual understanding that comes from participation in the sacraments. The sacraments are one of the best ways to engage such children in religious and spiritual learning. They *need* the sacraments.

### The church's sacramental imagination

One of the most interesting tensions in the history of the church has been between iconographer and iconoclast, picture maker and picture destroyer. At times iconoclasts got the upper hand and destroyed priceless images. People with disabilities would surely side with the iconographers. Vivid visual images adorn our churches. Statues, stained-glass windows, and paintings are more than mere decoration. They teach the faith—something especially important in a world where very few people could read.

People with language problems use icons too. They may use pictures instead of words to communicate. The word used to describe these pictures is *icon*. How marvelous! The word itself associates picture language with the rich iconographic tradition of the church. Just as illiterate peoples in traditional societies relied on visual icons to better grasp God and his relationship with humanity, children with developmental impairments rely on picture icons to discover their own spirituality.

The church's sacramental imagination has flourished in many ways at different times in its history. One traditional activity that has seen a recent revival is the May Crowning, in which children process to the statue of Mary and place a crown of flowers on her head. This honors the Blessed Mother as Queen of Heaven. Processions of all sorts were popular at various times. Medieval mystery plays were performed first in the church, with clerics playing the parts, and later on village greens, with actors. Liturgy and theater have always seemed to me to tap into something ancient

and authentic in the experience. They hearken back to cave and hearth, where shamans acted out stories of their travels into the other world and back again.

Even clowns were used in theatrical productions during the Middle Ages to capture the imagination and convey important information about the faith. They established rapport with audiences who responded to the physical humor. Also, clowns could step outside of the action and speak directly to the audience. These traditions intersect with the way many in the developmentally disabled community have learned to forge meaning in their lives.

### Sacraments are everywhere

The church's sacramental imagination extends to all of life. Life itself can be sacramental. One's ordinary experiences can become visible signs of the sacred, and living in awareness of such signs can enrich our lives not only as Catholic Christians but also as fathers and mothers of children with special needs.

What do I mean exactly? I mean seeing our children, disabilities and all, as signs of the sacred present among us. It begins with a conscious decision to see your son or daughter as "a finger pointing toward the moon" to use a familiar Zen image. It is even more powerful when you choose an obvious feature of your child's disability itself to be this sign.

For Mercedes and me, this meant seeing Danielle's silence, her inability to speak, as a profound sign of God's silence.

Herman Melville once said, "Silence is the only Voice of our God." We come to feel God in our lives precisely in situations when we are brought to silence, devoid of clear and explicit answers. We may go away unsatisfied, holding our hands up to the sky and voicelessly pleading, but silence speaks. It gives us time to feel, and it changes us. When we recognize the silence as

God's voice, we recognize that time will lead to acceptance. Reality will be what it is, whether we wish it to be or not. God's silence gives us time to appreciate that reality, and in silence embrace it.

Seeing life as sacramental means that we see God in the world around us. Nothing is too small or mundane; in fact, the smaller and more mundane, the better! Even one's breath can be sacramental. Let's recall that our word *spirit* comes from the word for *breath* in Latin. When one is *inspired*, one is filled with *spirit*. Breathing consists of *inspirations* and *expirations*. At the end of life, one *expires*, or *breathes out* one's last *breath*. God breathed his spirit (Hebrew = *ruah* = *breath* = *spirit*) into the first man and woman to give them living souls. An awareness of the energy-carrying capacity of breath puts us directly in touch with spirit. This enlivens us.

Here's another example. I love to walk with my daughters, Shannon and Danielle. On nice evenings at twilight we go to the playground in our neighborhood. When it has been rainy, the large detention basin fills with water like a pond, and we often see Canada geese, mallard ducks, and other waterbirds. Every once in a while a great blue heron lands at the water's edge. He will stand on one leg and gracefully bow to drink of the water. Waterbirds are a powerful sign to me because they bridge the worlds of water, land, and sky the way our lives bridge the worlds of matter and spirit, and the way God bridges the heavens and the earth. They remind us that God is both transcendent and immanent, and that the kingdom of God is both already and not yet.

Jesus taught us to make our neighbors sacraments. We are instructed to see our neighbors, especially those whom we ordinarily think of as the *least* of our brothers, as *identical with Jesus himself*.

Then the king will say to those at his right hand, "Come, you that are blessed by my Father, inherit the kingdom prepared for you from the foundation of the world; for I was hungry and you gave me food, I was thirsty and you gave me something to drink, I was a stranger and you welcomed me, I was naked and you gave me clothing, I was sick and you took care of me, I was in prison and you visited me."

Then the righteous will answer him, "Lord, when was it that we saw you hungry and gave you food, or thirsty and gave you something to drink? And when was it that we saw you a stranger and welcomed you, or naked and gave you clothing? And when was it that we saw you sick or in prison and visited you?" And the king will answer them, "Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me."

—Matthew 25:34–40

### What are we waiting for?

For parents of special-needs children, much time is spent waiting. We wait for the child to be born. We wait for him or her to meet developmental milestones such as rolling over, sitting up, and walking. Parents of children with physical disabilities may wait far longer than other parents for these events to occur. Parents of children with cognitive disabilities wait for their child to begin to talk, to put two or more words together, even to say "I love you, Mommy and Daddy." If the disability is severe enough, these things may never happen. So we wait. The waiting continues as the child grows older. At family gatherings we wait for our child to notice that it is her cousin's birthday party and that a woman dressed like a princess is twisting balloons into animals

and other figures. We wait for our child to join the group of children in the living room who are telling the woman, "I want my balloon to be a dog" or "Can you make mine a hockey player?" We wait as our child sits alone, watching videos of twirling toys and classical music for the hundredth time, uninterested in the other children or the balloons.

Later we wait to see if the parish director of religious education will accept our child into the program or say he must prepare in another parish fifteen miles away. We wait to see if she will be ready to receive first communion at seven years old, or eight years old, or eighteen years old. We wait for our lives to return to normal, for the anger and resentment to pass away. We wait to see if God will answer our prayers. The spirituality of special-needs parents is a spirituality of waiting.

While waiting, I have learned that the only moment you have is the present moment and that you will miss it if you don't pay attention to it. Being comfortable in the present moment is one of the most important things you will ever learn as the parent of a special-needs child.

So how does one embrace the present moment and transform waiting into living?

First and foremost, you must pay attention to breathing. Without changing anything about how you breathe, pay attention to your in-breaths and out-breaths, your inspirations and expirations. Simply feel the rising and falling of your diaphragm while breathing naturally. Every time you breathe in, know that you are breathing in. Every time you breathe out, know that you are breathing out. When a thought arises, turn your attention to the thought and maintain bare attention, becoming aware of the thought as it arises, exists, and falls away. Then return attention to your breath.



This exercise is one of the most powerful tools I know to calm the mind and put myself into the present moment. It is part of a Buddhist practice known as Insight Meditation, a highly effective way to simply watch the mind and body without judging or getting wrapped up or involved in the often destructive self-talk that accounts for much of our thinking. Instead of distancing yourself from life by thinking the same program loop of thoughts over and over again, you just watch the thoughts arise, exist, and disappear. Eventually you see that these thoughts are simply a process that has no real substance. Without suppressing or forcing it, you find yourself able to detach from the thoughts as they lose the power they once had over you.

You don't need to set aside any special time or place to pay attention to the present moment. You can practice it while waiting or while engaged in activity. For instance, if you need to clean up a mess your child has made, turn toward awareness of your breathing. As you reach for a towel, feel yourself reaching for it. As you blot the spill with the towel, become aware of the movement your arm makes and whatever sensations arise during it. If the thought arises, *How could this happen to me?* simply turn full attention to the thought, neither rejecting it nor accepting it; rather, just be aware of it and know when it disappears. You will soon rediscover the present moments in life instead of just waiting for them to be over. Once you rediscover the present moment, you can rediscover God there.

### Bridges between the visible and the invisible

The sacraments build bridges from the visible world to the invisible world of spirit. We live in a sensual, tangible, and visible realm, but there's also a hidden world of silence and love, where meaning and belonging are found. This is the sacred world where God dwells. Jesus, in his life, death, and resurrection, is the

quintessential bridge between these worlds. The sacraments, and the sacramental view of the world, are the means by which we can fully access the abundance to which Jesus calls us.

The image of a bridge spanning the gulf between visible and invisible, sense and meaning, is the haunting metaphor used by Hart Crane in his great collection of poems entitled *The Bridge*. The final stanza of "To Brooklyn Bridge" is a magnificent expression of the sacramental character of our visible world.

O Sleepless as the river under thee,  
Vaulting the sea, the prairies' dreaming sod,  
Unto us lowliest sometime sweep, descend  
And of the curveship lend a myth to God.

### Your special needs child can be a sign to others

I am constantly amazed how my daughter Danielle touches so many lives without saying a word. When Danielle was about eight, my wife and I were struggling with the question of why God would allow Danielle to remain nonverbal. One day I learned that the state developmental center where I work as a physical therapist was looking into the Picture Exchange Communication System (PECS), a way for nonverbal people to communicate using picture icons. The system is widely used by children with autism, and our speech therapists were hoping to use it with adults. We used PECS with Danielle.

I casually mentioned this to my friend Dino, a speech therapist, and before I knew it, we had arranged to have Danielle demonstrate the system to the entire speech department. I was nervous when Mercedes brought Danielle into the physical therapy gym where we were holding the meeting. I was afraid that she might behave poorly and not be able to show the speech therapists how PECS worked. However, she took one look at the

parallel bars in the gym and immediately placed some icons on the sentence strip and gave it to me. The pictures made the sentence *I want sensory play*. The icon for sensory play was parallel bars. Danielle had nailed it. The speech therapists, many of whom had doubted PECS would work, started to talk about trying it.

Dino leaned over to Mercedes and said, "Do you see what just happened? Danielle has just taught us how to help many people at this developmental center and maybe even all the centers in the state." Without saying a word, she had become a sign to others. I remembered two sayings of St. Francis of Assisi: "Preach the gospel always; use words if necessary," and "You may be the only gospel your neighbor ever reads." Surely at this time and place Danielle had become a worthy gospel and a worthy sign of God's love.

---

### **A Family Activity**

#### Attend Perpetual Adoration of the Eucharist

One of the most beautiful activities our family does together is to sit before the Eucharist. I recommend it to others.

A parish near ours sponsors perpetual adoration of the Eucharist, during which visitors can drop in and pray before Jesus. I remember how my sons Brendan and Colin would walk along the curb in the parking lot with arms out to the side as if they were on a balance beam. I would carry Shannon in a car seat while a very rambunctious Danielle would run away from Mercedes and me. In summer this took place in the shadow of giant yellow sunflowers that grew in a narrow strip at the edge

of the pavement. Somehow we always managed to get ourselves together and enter the small chapel in reverent fashion.

Inside, a large consecrated Host was displayed in a monstrance shaped like the Blessed Mother. The most beautiful thing was that the Host was embedded in the sculpture's frame in such a way as to form a curve of Mary's pregnant belly. One couldn't help but associate this poignant icon with the beautiful words of the Hail Mary: "Blessed are you among women and blessed is the fruit of your womb Jesus." Here we would sit silently for several minutes in prayer and adoration. We sat rapt in the sacred mystery and the beauty of the moment. I felt confident in that moment that we were fed by the mystery and the beauty of the experience, each in his or her own way.