

ELRENA EVANS

FOREWORD BY
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*Special
Grace*

PRAYERS *and*
REFLECTIONS
for FAMILIES
with
SPECIAL NEEDS



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BEGINNINGS

People were bringing little children to Jesus to have him touch them, but the disciples rebuked them. When Jesus saw this, he was indignant. He said to them, "Let the little children come to me, and do not hinder them, for the kingdom of God belongs to such as these. I tell you the truth, anyone who will not receive the kingdom of God like a little child will never enter it." And he took the children in his arms, put his hands on them and blessed them.

MARK 10:13-16

THE DIAGNOSIS

While trying to subdue one of my son's tantrums in the church hallway one Sunday, he knocked me to the ground. As I struggled to stand up without losing my hold on him, I turned away for a moment to try and explain his behavior to the growing crowd. As I did, he bit me, his teeth clamping into my skin until I had to wiggle his jaw to release them.

Weeks later, sitting in an empty classroom with my husband and the school psychologist for our first meeting, I looked at the sheaves of papers stacked high on the little desk beside me and thought, *Nothing in my life has prepared me for this moment.*

My son's first day at his new school was strictly choreographed: upon our arrival, five professionals separated him from me and walked him down the hall, name badges swinging from lanyards around their necks. It wasn't exactly the moment for a first-day-of-school photo opportunity, let alone any of the prettily worded prayers I'd seen on social media. Standing suddenly alone in the school office, I didn't have words.



The school psychologist who did my children's evaluations called me on the phone before our first official IEP meeting.

"I wanted to talk with you briefly before we meet," she said. She told me what a pleasure it was to work with my children, and what a remarkable family we have, before confirming that our middle son, then six, was indeed "different," in ways that would lead to a diagnosis and therapy and special education.

I balked. "Really? He has behavior problems, of course. Anyone can see that. And he's . . ." I paused before landing on my favorite go-to word for describing my children, ". . . quirky. He's quirky. But does that really mean he has 'special needs'?"

"I don't think you realize how atypical your son is," the school psychologist said gently, "because none of your children are typical. Your other children might just miss an actual diagnosis, but they clearly aren't what we would call typical."

I looked out the window to where my ten-year-old daughter was running in the backyard. She'd spent so much time running in the exact same circle that she'd worn down the grass to bare earth—we'd dubbed it "The Track." I watched her run, making odd little leaps into the air, her hands smacking against each other and occasionally reaching out to grasp things only she could see.

I looked over to my living room, where my eight-year-old son was also running, not in circles, but back and forth, back and forth. His fingers twisted into tumbling knots in front of his body as he ran, and when he stopped to jump, his upper torso knifed forward repeatedly. The tuneless hum filling the house was such a constant

in my life I didn't even hear it anymore . . . it was just my son, running and humming, always running and humming.

And these were the children who were *not* receiving a diagnosis.

The psychologist had gone quiet, giving me a moment to think. "You're right," I finally said. "I think I don't realize how different my middle son is, because I'm mostly comparing him to his siblings."

His siblings had always been able to pass for "normal." Or normal-ish. Maybe not for the middle of the bell curve, but they could rein in their odd behaviors just enough to get by. They were quirky, to be sure, but they were never completely out of control. They were never violent.

But my middle son had flipped the script on that one, and I didn't know how best to parent him. How do you pray for a child who is violent? What are the words?

Thus began our journey into special education.

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"This isn't my first rodeo," one of the many experts gathered around the table at our IEP meeting told me. "I've been working in special education for over a decade, and I have met a lot of special kids. But I have never seen anyone quite like your son."

I was exhausted from reading through stacks of papers, trying to understand my child in these new ways of charting and graphing, trying to process a world where learning the ABCs meant understanding Antecedents, Behaviors, and Consequences. I was still in the fog of alphabet soup acronyms ("Don't sign the NOREP until we figure out PCA or TSS!"), and my head was spinning as I watched the director of special education, the special education teacher, the

behavioral specialist, the occupational therapist, the psychologist, and the “gifted” teacher all bringing the very best of their professional expertise to try to understand my son. While I jotted down question after question after question in the margins of my son’s IEP, my husband drew increasingly complicated geometrical patterns all over his copy. We all cope in different ways.

At one point, I interrupted: “How do we know what part of my son’s behavior is because he has special needs, and how much of it is just because . . . I don’t know . . . he’s being a little stinker?” I tried to clarify my question. “Did he really upend the desk because he didn’t like the smell of the new markers? Or did he upend it just because he felt like it?”

The table grew quiet. My husband stopped doodling. The director of special education looked at me with a smile.

“*That* is the million-dollar question,” she replied.

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The lived reality of caring for my middle son’s needs on top of the regular demands of parenting four other quirky children threatened to consume me. I started to worry more and more about our younger daughter, sandwiched in between an inherently needy infant and an older brother who now had a diagnosis. I watched and marked the trajectory of her behaviors, wondering, as always, where the line was between an outsized personality and a child with special needs.

Our younger daughter has always been fierce. As a toddler, when she wasn’t pushing the furniture farther apart to see if she could still jump from one thing to another, she’d turn on the vacuum and

chase her older siblings around with the hose. “Help! She’s vacuuming me again!” was a cry we heard multiple times a day. When my aunt asked me what she wanted for her birthday the year she turned two, I said, “World domination. But she would probably settle for an armored tank.”

As other people’s children seemed to mellow during the preschool years, she only grew more intense. I brought up the question of her behavior with our family therapist: “What do I do with the fact that my kid *with* the diagnosis is currently doing better than the kid *without* the diagnosis? Does my daughter have special needs too?”

I paused, collecting my thoughts, and then continued. “How much of her behavior is inherently who she is, and how much of it is learned behavior from her older brother?”

“*That* is the million-dollar question,” our therapist replied.

Apparently I ask a lot of million-dollar questions.

I imagined a possible future for my daughter, filled with more IEP meetings, more special education, more therapy. I wasn’t sure how many more million-dollar questions I could handle.

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Not long ago my middle son announced, out of the blue, “I like my new school. Because if you’re a kid like me, and you need an aide, you can get one.”

It stopped me short. But my heart said, *yes*. This I have words for. And a prayer. A prayer that we can pray together.

PRAYERS

FOR AN INITIAL DIAGNOSIS

O God, the Creator of everything, we are scared. We cannot see your plan right now, but we trust in your Word to guide us. Thank you that we live in a time when people are starting to understand difference, and thank you that through knowing this diagnosis, we are better equipped to meet the needs of your precious child. Walk with us, Lord, every step of this journey. In Jesus' Name, *Amen*.

FOR DECISIONS

God of all knowledge, this path you have put us on requires so many decisions. We often feel insufficient to the task. Surround us with people who give wise counsel, not foolish; who care for our needs, not their own advancement. In this decision we are facing now, God, be our guide. Show us your wisdom and give us your peace. *Amen*.

FOR TESTING

Lord, as we look to begin the testing process with [Name], we ask for mercy. We pray that this testing process be fair and accurate, and if a diagnosis is given, that it is fair and accurate too. Help us to know that a diagnosis is not the sum of [Name's] identity, but merely a tool that allows us access to further supports. Help us use these tools wisely to better understand and care for the child you have given us. Be with us during this difficult time. *Amen.*

A PRAYER FOR A PRENATAL DIAGNOSIS

Heavenly Father, we are scared. We are grieving. The future we are being asked to prepare for is not the future we had dreamed of. We haven't even met this child yet, but we know that you have. As you knit our baby's inmost being together in the secret of the womb, be with us. Surround us with your hope and comfort. In the Name of your precious Son, *Amen.*

IN TIMES OF FEAR

O God, who calmed the turbulent seas, your words speak peace to trembling hearts. The future is so uncertain, and right now we can't even figure out the present. Fear finds us in the night and steals our breath; fear robs us of our joy. Be with us in this place, Lord. Hold our fear as you hold our hearts. *Amen.*

WHEN FRUSTRATED

Unknot our minds, O God of Peace, in this moment of frustration. Clear our souls of distress. When we feel like we can't bear it one

more second, remind us that you are the One who bears all things for us. Release us from annoyance and anger, and soothe us with your steadfast calm. *Amen.*

A PRAYER FOR EXHAUSTION

Lord, you promise rest for the weary—and we are weary. We are bone-tired, in ways we didn't even know were possible. The day-to-day realities of caring for our child have left us bereft. Trying to prepare for a future we never imagined has left us feeling hopeless, and fear steals our sleep and floods our dreams. Help us to trust that you are not only our rock, Lord, but our place of safety too—a place of gentleness where we can fall, knowing that you will catch us and hold us always in your arms. *Amen.*

FOR NEVER-ENDING MOUNTAINS OF PAPERWORK

God of all things, we can't imagine how many trees were felled in service to the paperwork we are asked to complete for our child. We are tired of medical histories, social histories, educational histories. We are tired of trying to reduce the complexity and wonder of our child to lines on paper. And we are tired simply from filling out all these forms. Give us grace to persevere through a flawed and frustrating system. Meet our needs here, Lord, as we bring them ever to you. *Amen.*

WHEN FACED WITH UNCERTAINTY

God, we really like the illusion that we are in control, but this situation has punctured that illusion. Teach us that even when we can't see the next step, you are beside us. Teach us that we can

trust you to stay with us. Teach us how to live with uncertainty. Give us wisdom and knowledge. As constant variables swirl around us, increase our assurance of your presence. In your changeless Name, *Amen*.

WHEN GOD DOESN'T HEAL

God of creation, you make all things beautiful in your perfect time. You are the God who walked the earth with us, bringing sight to the blind and sound to the deaf. We do not understand why you choose miraculous healing for some, but not for others. We remember your words to the blind man in the Gospel of John: "This happened so that the work of God might be displayed in his life." But sometimes we don't want to be your display, God. Sometimes we just want to be healed. Be with us in this pain. *Amen*.

FOR GRACE TO KEEP GOING

God of grace, be our grace.
God of the lost, find us.
God of grace, be our grace.
God of the broken, heal us.
God of grace, be our grace.
God of the suffering, succor us.
God of grace, be our grace.
Today, tomorrow, and evermore.
Amen.