

Introduction

If Only Children Came with Instructions



If only children came with instructions
Then parenting wouldn't be so much trial and error,
and error and trial,
and more error.

Did I do the right thing?
Handling that problem, I mean, not about having children (Well . . .
maybe that too . . .)
Responding to her meltdown?
Addressing my concerns with the school?
Challenging him to do more?

When I look back on my days as a parent, none are error free.
Some days are good.
Some are a mixture of good and bad.
Some are just bad days.

If children did come with instructions would I be a better parent?
Or would I be more concerned about following the instructions
than loving my child?
Getting to know her smile.
Watching actions and reactions.
Reading his facial cues.

Would I have let my child
teach me,
lead me,
help me,
to make things up as we went along?

Would I have learned

to love, deeply love, my child for who she is?
to find joy, in things big or small?
to feel pain, in ways I never thought possible, for him?
to hope for things yet unseen?
to be challenged beyond belief?
to still be standing through it all?

Maybe, but maybe not.

Yet, this is my story now,

still unfolding,

still progressing,

I find my way

as a parent

without instructions.

—HHW

I OFTEN wished for an instruction book for parenting a child with developmental challenges. I thought it would make the journey easier. When I was pregnant with my oldest son in 1992, my husband and I bought the book *What to Expect When You Are Expecting*. I liked reading it and learning about what was going on in my womb. I read how the baby was developing week by week. I eagerly followed it until my son was born at twenty-five weeks gestation—forty weeks is full term—weighing two pounds, two and a half ounces.¹ I was not expecting that! That edition of the book only had a small section on what could go wrong. We had to put the book aside and make it up as we went along. We had to learn a new vocabulary and figure out what parenting looks like when you are not expecting to be a parent so soon.

Suddenly, we were thrown into the new world of the Neonatal Intensive Care Unit (NICU). What role does the parent play when it takes many doctors, nurses, and support staff to do what would have been done in your womb? We felt like bystanders. We didn't get a chance to hold him until he was two weeks old. After that, we

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were sometimes told “he is too sick to hold,” which goes against a parent’s natural instinct when a child is sick. Our baby was in the hospital, and we were commuter parents. I carried a picture of my son in my pocket so I could take him home with me. It was a long 114-day journey of joys, challenges, pain, faith, and hope. When we got him home, we could almost use regular parenting books again.

Two years later, almost to the day, we were back in the same NICU with our youngest son, who was born at twenty-four weeks gestation, weighing a pound and a half, and sicker than our oldest son. That journey was even longer and more extreme than the first. The instruction book we could have written about our first experience was put aside, and once again, we had to make it up as we went.

Our second journey in the NICU lasted 151 days, with one complication after another and seven surgeries. After he came home, the complexities built—failure to thrive—and built—profound hearing loss—and built—autism diagnosis. It was many years before the challenges slowed down and we felt like we got to be “normal” parents again. He is now twenty-three years old. Challenges still exist, but he is further along than we expected or even dared to hope in those early years. No instruction manual could have prepared us.

I have learned over the years that experience is a great teacher. Some of the experiences can be written down. Some cannot. Wisdom and understanding do not come from books alone but from engaging with life and with people. Parenting is a journey of ups and downs, ins and outs. Even if you are prepared in theory, nothing can prepare you for the reality. Parenting is the greatest and most challenging thing most of us do. As parents, we thrive when we embrace the whole parenting journey: the joys, challenges, pain, faith, and hopes.

Parenting is not for the faint of heart. The child’s need for food, sleep, attention, safety, health, and love are always foremost in the parent’s mind. Decisions need to be made about bedtime, discipline,

and education. Factors of each child's temperament, skills, and abilities are to be considered in those decisions. If two parents are raising the same children, then the factors are complicated. How are decisions made? Do we have different roles? What if we do not agree with each other? Another factor that affects parents is the judgment of other people.

Parents are bombarded with judgmental messages from parenting experts about how we are doing too much or not enough for our child. We are judged on how we discipline (or do not discipline), how we support (or do not support), or how we interact (or do not interact) with our children. Parents judge other parents based on our style of parenting, decisions, tone of voice, or choice of clothing. We compare ourselves to other parents, sometimes to make ourselves feel better, "at least I am not like that parent," or to put ourselves down, "I will never be as successful as that parent."

When children have Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), and/or Fetal Alcohol Spectrum Disorder (FASD), the task for the parent becomes even more complex. Often, the developmental challenges of these disorders create additional stress for parents. Judgments from others and from oneself are harsher, comparisons to parents of neurotypical children increase, feelings of frustration and inadequacy heighten, and a search for help or answers often falls short of expectations. How do we live with both the pain and the joy of raising children with developmental challenges? Like most parents, we deeply love our children and seek to do our best to raise them, but raising children with these challenges is different. It can seem exponentially more difficult. Often, parents feel stretched beyond our abilities.

As a parent who sometimes—no, often—feels stretched, here's something I have noticed that has both an upside and a downside: everyone seems to have advice for parents who are struggling. Even people who have never parented a child will freely offer advice. Sometimes advice is welcome. There is a time and place for advice. But there is also a time and place for simply listening to the parents.

How do we live with both the pain and the joy of raising children with developmental challenges?

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Sometimes parents need emotional support, reassurance we are not alone, and a listening, nonjudgmental ear, rather than advice. Parents must continually work on our own emotions and reactions, so we do not place undue burden or strain on the child. We must monitor our own feelings, frustrations, and experiences, so we are able to tend and care for our child. This is tough and lonely work. Sometimes the difficulties get better and sometimes they don't, but most parents get better at handling them.

Listening to Parents

Over the years, I have met and listened to numerous parents who have children with developmental challenges. As a pastor, part of my role is to listen to the experiences of the people I serve, listening for their struggles and joys, listening for how they sense God is present or how they feel God has abandoned them, and listening for how God's word may comfort or challenge them. As a professor of pastoral care, I have listened to people who live with mental illness and developmental challenges—and their families—and I have taught seminary students to care for all God's children and to foster caring Christian communities. As a parent, I have more than twenty years of lived experience raising my two sons. My youngest son lives with autism and a profound hearing loss. I have listened to parents I have met in support groups, education events, and at school functions.

Throughout this book, my reflections are joined with the cries, wisdom, and hopes of other parents whose children have developmental challenges. Since I have learned and grown from the stories of other parents and value the wisdom and power of personal stories, I designed a survey to invite parents to share their stories and experiences for this book. The survey was sent via a link through personal connections and social media, and encouraged to be shared widely. Fifty-nine parents took considerable time and effort to respond to the survey.

Many of these parents are raising their biological child, some are raising their adoptive child, and a few are raising their grandchild. Some are new to this journey with their young children—some recently diagnosed—and others have seen their children grow into adulthood. All of us deeply love our children *and* struggle with our children’s developmental challenges. We want other people to hear our stories, to listen without judging, and to care without fear or pity.

My intent is not to write a “how to” book on parenting. This book does not offer tips or techniques. This is a book about the experience and the complex internal emotions of being a parent of a child with developmental challenges. My goal is to let other parents of children with developmental challenges know they are not alone, give voice to the often-unexpressed experiences of parents of children with developmental challenges, and offer reflections and insights as a parent, professor, and pastor for parents, family, friends, and members of faith communities.

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What Are Developmental Challenges?

For the purposes of this book, developmental challenges refer to challenges affecting a child’s development—cognitive, social, emotional, or physical—caused by Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), and/or Fetal Alcohol Spectrum Disorder (FASD). While there are many issues or disorders that may cause developmental challenges, these three disorders currently are the most common—ASD, ADHD—or particularly challenging—FASD. Because there are many organizations and resources that focus on each one and can help parents with the details, this book moves beyond the details of childhood disorders and focuses on the experiences of parents.

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder is a neurodevelopmental disorder, meaning that it is a disorder that affects the development of the

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brain. It is called “a spectrum” because it includes a wide range of symptoms, skills, and levels of disability from mild to severe. The broad spectrum of autism makes it difficult for parents, and many other people, to understand the challenges of autism. For example, an individual with mild autism (one end of the spectrum) may be one who would have been formerly identified as having Asperger's syndrome.² This person may need a few supports to help them interact socially with others, but they have a normal to high intellect, their traits can help them secure a good job, and they are able to become a self-supporting adult. Individuals with mild to moderate autism (midrange on the spectrum) need social supports and may also have intellectual deficits, requiring lifelong support. While they may never be able to become self-supporting adults, some independence may be achievable. Individuals with severe autism (another end of the spectrum) may have little to no ability to care for themselves or to communicate verbally,³ and they will always need supportive assistance. For many, their parents are their caregivers.

Attention-Deficit/Hyperactivity Disorder (ADHD)

Attention-Deficit/Hyperactivity Disorder is also a neurodevelopmental disorder. It is marked by an ongoing pattern of inattention, hyperactivity, and/or impulsivity that interferes with functioning or development. It includes Attention-Deficit Disorder (ADD). Individuals with ADHD often do well as they age and become self-supporting adults. A variety of medications, treatments, and education techniques are available to manage the symptoms. The school years, however, are the most challenging for parents. The heightened levels of activity and the child's difficulty paying attention can interfere with education and relationships.

Fetal Alcohol Spectrum Disorder (FASD)

Fetal Alcohol Spectrum Disorder “is an umbrella term describing the range of effects that can occur in an individual who is exposed to alcohol during the nine month prenatal period. . . . These effects may include physical, mental, behavioral, and/or learning

disabilities with possible lifelong implications.”⁴ The most severe form is Fetal Alcohol Syndrome (FAS). The range of disorders includes Partial Fetal Alcohol Syndrome (PFAS), Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE), and Alcohol-Related Neurodevelopmental Disorder (ARND).

Fetal Alcohol Spectrum Disorders are not as common as either Autism Spectrum Disorders or Attention-Deficit/Hyperactivity Disorder. Yet, FASD profoundly affects all aspects of a child’s development. Often, an individual with this disorder is unable to gain insight or learn from experience. This creates a perpetual challenge for parents and, depending upon where the individual is on the spectrum, may require a lifetime of support.

A Word about Diagnoses

Diagnoses are technical descriptions to organize, categorize, and provide consistency. They assist in getting an individual support or access to services or programs, and insurance coverage. Diagnoses ought to be limited to care and treatment, not used to define children. A child is never a diagnosis; they are a living, breathing mystery of life with quirks and a personality, joys and challenges. Outside of medicine and insurance coverage, the diagnosis ought only to be used as a framework for understanding the challenges affecting an individual person. How does ASD, ADHD, or FASD affect them? For instance, if a person has ASD, do they have a preferred way of communication or interaction? Or are there certain situations that increase stress? Getting to know the whole person—the gifts, the personality, the joys, as well as the challenges—ought to be the focus of parents, family members, friends, and members of faith communities.

Who Is This Book For?

This book is for parents of children with developmental challenges who are seeking encouragement, wisdom, or support. It is also for

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family, friends, and members of faith communities who want to support children with developmental challenges and their parents.

For Parents

If you are reading this book as a parent of a child or children with developmental challenges, you may or may not find your experience in these pages. Depending on where you are in your journey, you may find it valuable to jump around to different chapters or specific sections.

- If you are new to this experience, you may want to jump right to the chapter on hope (chapter 8), or you may want to read the reactions of other parents when they received the diagnosis for their child (chapter 1).
- If you have been at this for a while, maybe a certain topic appeals to you, or maybe you are curious to find out if there are other parents who share your experience.

Be kind to yourself as you engage this book. If a section is difficult for you, leave it. If it doesn't apply, let it go. If it touches you deeply, sit with it.

Just as children with developmental challenges differ from one another, so do the experiences of parents. You may find some experiences or feelings or thoughts are familiar to you. On the other hand, you may find some challenges or joys are unlike your own. You may also find yourself surprised as to how the stories affect you. Whatever the case, be kind to yourself as you engage this book. If a section is difficult for you, leave it. If it doesn't apply, let it go. If it touches you deeply, sit with it. My hope is that you will find support and encouragement in these pages. May you know you are not alone. It is a long and varied journey, and somehow, you will get through it.

For Family and Friends

If you are reading this book as a friend or family member of someone who has a child with developmental challenges, you will receive a glimpse into raw emotions and seldom-expressed experiences of parents as well as insight on ways to be helpful. Not all people experience the same event the same way. But I hope this

book will give you an idea of what your friend or family member may be going through and guide you to offer care and support. What you learn may open an opportunity for a deeper conversation with your friend or family member. For example, if you are wondering about the experience of your friend or family member, you might say, “I read a story about a parent who described their parenting joys, or challenges, as _____. What is it like for you?” Or, simply, “What are the joys or pains you experience as you parent your child with developmental challenges?” If you ask these questions, be prepared to listen and be prepared for raw emotion. Refrain from offering advice or judging. Listening and caring are two important things you can do. If you are interested in helping or supporting, a good follow up question is “How may I help?”

If you think this book might be helpful for your family member or friend to read, be aware that they may or may not be interested. Some parents will welcome the book, read it, and be glad to know they are not alone. Others do not have the time to read a book. Some parents feel the stories of other parents may be more than they can handle at this point in their life. Other parents are tired of hearing other people’s stories, because the stories they have heard were not helpful. A mother of child with ADHD, responding to the survey, offered her observation about the value of other people’s stories,

Half the moms on the planet have some horror story about how their son was almost diagnosed with ADHD, but it’s just because he was an energetic boy and his teachers didn’t know how to handle him, and they were going to put him on medication and screw up his brain, but now he’s a rocket scientist/brain surgeon/whatever. Good for that parent’s kid! It has nothing to do with your kid, though.

As parents, we never know how our children are going to turn out. It is good to hear stories of hope, but the story may not consider our child and our child’s gifts, interests, or abilities. I have noticed that people use these stories to try to make me feel better about my son’s future. The truth is I feel a lot better about his future if they get to know my son, care about him, and love him as he is.

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For Members of Faith Communities

If you are reading this book as a member of faith community, I hope you will learn ways for your faith community to support parents of children with developmental challenges. Many parents of children with ASD and ADHD stop attending worship or do not attend community or social events sponsored by their faith community. The sensory issues, especially sounds, in a faith-community setting can be challenging, not to mention that many community events expect children to sit still and not make any noise. In addition, the parent and the child's week is filled with work, school, homework—which may take many hours—doctor appointments, therapy sessions, and chores around the house, so both parents and children need a break. Sometimes it takes too much effort for a parent to educate a faith community on how to work best with their child. Other books have been written on how to include children with different needs in a faith community and are included in the resource list at the end of this book. My hope is that the stories in this book will move you to listen to the parents in your faith community and help you find ways to embrace, support, welcome, utilize a variety of resources, and engage with parents and their children in a way that will be meaningful for all involved.

Structure of the Book

This book follows the structure of the online survey I designed for parents of children with developmental challenges.⁵ I wanted the questions to cover various aspects of the parenting experience—from their early experience to their joys, challenges, pain, and hopes, to resources and faith, to wisdom they would share with others.

The participants were asked the questions below. The chapter corresponding to each question is noted in parenthesis.

- What did you think and feel when you knew something wasn't quite right with your child but didn't yet have a diagnosis? (chapter 1)

- What did you think and feel when you received the news of your child’s diagnosis? (chapter 1)
- What are your joys as you parent a child with Autism Spectrum Disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD), and/or Fetal Alcohol Spectrum Disorder (FASD)? (chapter 2)
- What are your challenges? (chapter 3)
- What causes you pain? (chapter 4)
- What faith resources, if any, have you found helpful? (chapter 5)
- What do you do to take care of yourself? (chapter 6)
- If you were to write an instruction book for family, friends, or faith communities about parenting a child with ASD, ADHD, FASD, what would you include? What do you want them to know? What are ways they might help you? (chapter 7)
- What gives you hope? (chapter 8)

The parents who responded to the survey do not speak for all parents of children with developmental challenges. Nor are the answers from the participants I’ve included in this book the only answers to these questions. In fact, even the parents who responded may answer the same questions differently at different times in their life—or even different times of the day. The questions in this book are intended to begin a conversation with parents, which I hope can be ongoing, dynamic, and helpful for parents, family, friends, and members of faith communities.

Experience can be a great teacher. May the cries, wisdom, and hope from the parents in this book—and your own experiences—guide you, teach you, offer you hope, and help you to become a better parent, family member, friend, and member of a faith community.