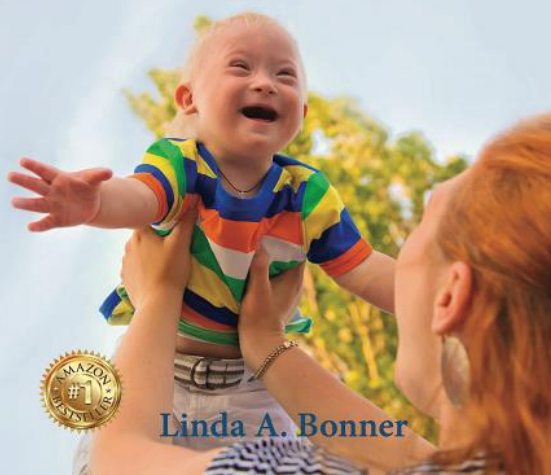


Blessed with Extraordinary

-Revised Edition-

*Empowering Families and Advancing
a More Inclusive World*



An encouraging guide for families of children with disabilities focused on practical support, meaningful action, dignity, belonging, and creating inclusive communities.

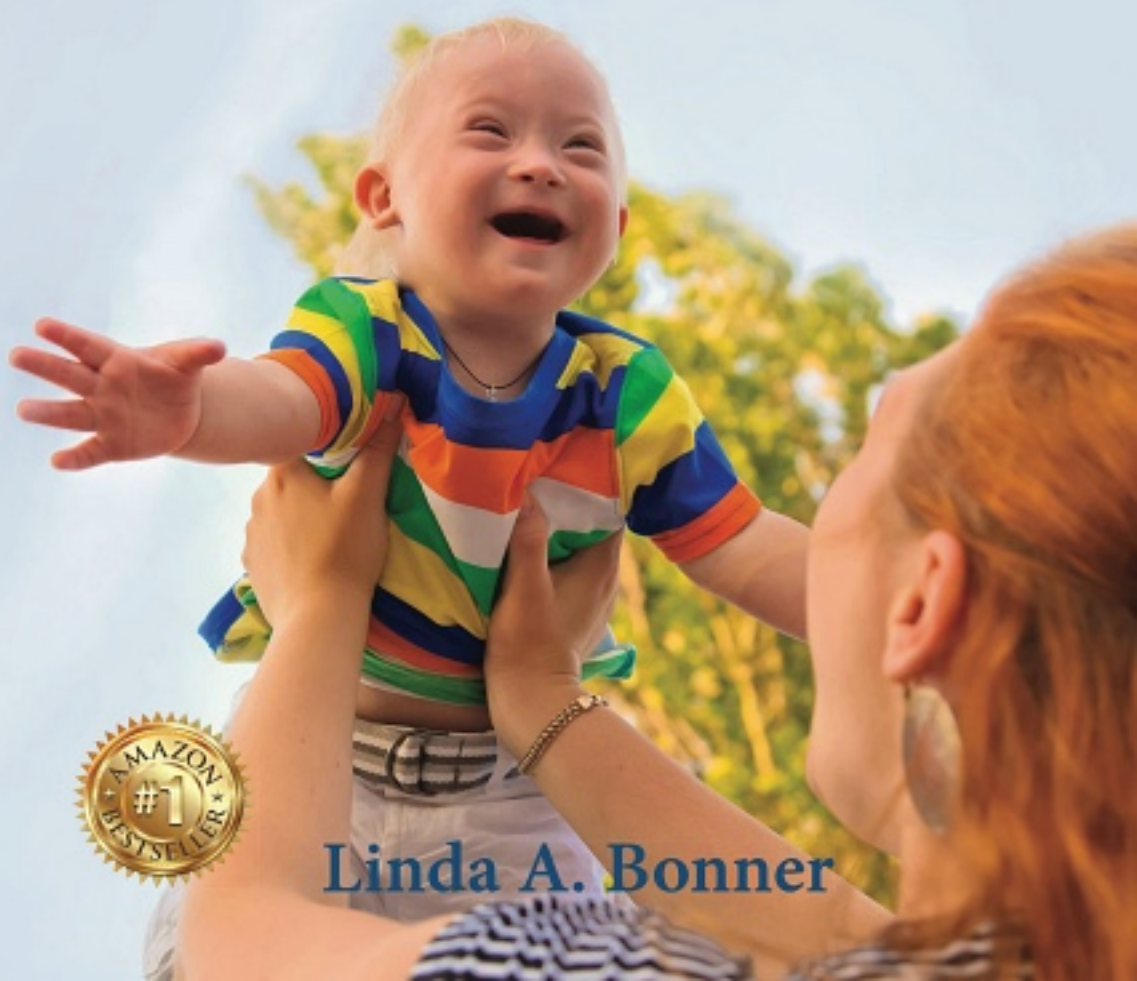
Blessed with Extraordinary: Empowering Families and Advancing a More Inclusive World By Linda A. Bonner

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Linda A. Bonner

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Table of Contents

Acknowledgments	v
Introduction	1
Disability Language: Why Words Matter	5
Chapter One Off to a Good Start	9
Chapter Two Pre-School	14
Chapter Three Elementary & Middle School	17
Chapter Four Outside Activities	23
Chapter Five High School	26
Chapter Six Post High School	29
Chapter Seven Independent Living Skills	38
Chapter Eight Faith & Gratitude	45
Chapter Nine Self-Care & Caregiver Bill Of Rights	52
Chapter Ten Finding Support	63
Chapter Eleven The Small Things Are Worth Celebrating	75
Chapter Twelve Life Care Planning & Legal Needs	80
Resource Library	93
About the Author	103

Introduction

This is my personal account, from a mother's perspective, of my journey to raise my son, Kevin, who has Down syndrome. What I share in this book are my own personal feelings, emotions, and experiences. When Kevin was born, I was overwhelmed with first becoming a parent and second being the parent of a child who needed specific medical attention and therapies to meet his daily needs.

Blessed With Extraordinary is designed for parents and caregivers of children with Down syndrome and other forms of intellectual and developmental disabilities (IDD).

I wrote this book to share the encouragement I received while raising my son. In my desperate search for information to be the best possible mom for Kevin, I met with and talked to anyone who could expand my base of knowledge.

I found that there was so much to learn about my child and his needs! I must admit I was very impatient. Finding and accessing the resources I needed took a lot of work. It is my privilege to share what I've experienced and learned in an effort to help others on this incredible journey. I've been where you are, struggling with uncertainty.

Think of this book as a "toolbox" with resources you can pick up as you need them. Not all of these resources may pertain to your situation or your child. My hope is that I can bring some light to your days by sharing my story.

In these chapters, you'll learn about:

- The importance of self-care, including “50 ways to take a break” and other tips
- Finding support and reaching out for help using your current network
- How a foundation of faith can help with healing and acceptance
- The power of gratitude
- Celebrating the small moments and milestones
- Building and expanding a personal network
- Life Care Planning for your child – financial and legal processes
- Vital Resources for education, personal support, and disability services

I'll share personal stories of our journey and include ideas and resources from other parents and caregivers. At the end of each chapter, you'll find questions to consider, a space for journaling and reflection, and a place to build your own list of resources and support options.

The following pages are intended to teach, inspire, connect, empower, and serve the caregiving community for children with Down syndrome. I want you to remain hopeful yet realistic. By doing so, you'll create a more rewarding life for yourself and your child.

When you become a new parent to a child with an IDD, you have much to learn about this new little one. They may have different medical needs, therapies, different feeding needs, appointments to schedule, and much more. What should I do first, second? Where can I get the information I need? Who's the best specialist for my child? These questions can become all-consuming!

That was my experience when my son was born with Down

syndrome. Over time, I lost my identity and only became a mom, all day and all night. I put self-care on the back burner and put every ounce of energy I had into my child. Based on discussions with other parents, this is a common dilemma. It took me several years to realize I was doing myself and my child a disservice by ignoring my own needs.

Your story might be similar, or it may be very different. In preparing to write this book, I discovered that self-care typically falls to the bottom of the list for caregivers of loved ones with IDD. If that rings true for you, please join me as we journey toward empowerment, inspiration, and encouragement. I'd like to share ideas to heal, teach, and lift your heart and soul.

A FEW NOTES OF ENCOURAGEMENT

- Keep an open mind.
- Remember that this is YOUR journey.
- Don't listen to the nay-sayers. They don't know your story.
- Don't limit your thinking.
- You are the expert when it comes to your child.
- You are capable, worthy, and loved.

HOW TO USE THIS BOOK

The following pages discuss my journey of raising a child with a disability. I hope it will be a resource, a comfort, and a source of encouragement.

- Consider using it as a book study on your own or with your family.
- Use it as a resource guide for parent groups, support groups, or guilds.

- If you're reading it on your own, find someone to share your experience with, such as a good friend or trusted family member.
- Use it as a companion to any counseling or therapy that's helpful for you.
- Give it as a gift to a family member or friend who is caring for a loved one with Down syndrome. You may even offer to read and discuss the book with them.
- Share it with your physicians or other specialists so they may share it with other families.

Most importantly, take your time going through the pages. And feel free to jump to chapters pertinent to where you are in your journey today.

I'm so glad you're here!

Chapter One

Off to a Good Start

We were very fortunate to get local support services almost immediately, and at the tender age of 3 weeks, Kevin started physical therapy in our home. The program was initially called Infant Stimulation and is now known as Early Childhood Intervention. These early intervention programs offer a variety of coordinated services for infants and toddlers with disabilities, from birth to three years of age, and their families.

Search the internet for your state with the prompt: **Early Childhood Intervention**. They offer evaluations, support, and therapies. Additionally, they provide support and resources to assist families and caregivers in enhancing their child's learning and development through physical, occupational, and speech therapy. See the **Resources** chapter for links to these services.

When these caring and kind physical and occupational therapists came to work with Kevin, he loved the process and adapted quickly to the exercises they used. They arrived every week with different physical activities to work on his core strength and help improve his muscle tone. Low muscle tone is prevalent in babies with Down syndrome, so this physical exercise was critical to his development. Of course, we had homework to do the same exercises daily until they returned the next week. The activities included rolling him on an exercise ball, reaching for items, and helping him move his arms and legs multiple times daily.

It really was fascinating to watch him adapt to these movements. The therapists said it was a coincidence, but even at three weeks, he was already reaching predominately with his left hand. And yes, today, he's a leftie!

The physical therapy visits lasted a year, and I know they made all the difference in Kevin's physical development. Most importantly, these therapists taught me how to help him, and I'm so grateful for their knowledge and patience.

Speech and language development is an important milestone for all children. Partly due to his cognitive disability and partly because he had so many ear infections as an infant, Kevin was only making sounds and pointing rather than trying to form words. Another one of the life-changing services we received through Early Childhood Intervention was speech therapy. He started at age one with an emphasis on sign language. Although his receptive language (cognition) was quite good, his expressive language (speech) wasn't developing. If you have a child with any kind of speech delay, I encourage you to consider sign language. Kevin wanted to communicate but didn't yet have the physical skills due to low muscle tone or the cognitive ability to form words. Within six months, he was using over 50 signs!

He started with simple signs like mom, dad, drink, and eat, and his vocabulary continued to grow from there. When we responded to him with a sign, we also said the word. The speech therapist assured us that he would drop the sign once he was more confident with the word. They were right!

KEVIN MEETS A HORSE

We lived within walking distance of a horse farm. The only horse Kevin had ever experienced was a soft plastic horse with a button that played music. He knew the signs for both "horse" and "music." When he saw the horses for the first time, he signed "music." I kept signing and saying "horse," but he persisted with "music." Aha! He was waiting for the

horse to make music. What a smart little boy! Another celebration! (More about celebrations in Chapter 7.)

Heart Trouble

Kevin's other challenge was that he was born with a heart defect, Patent (Persistent) Ductus Arteriosus, or PDA, a hole in the aorta that fails to close on its own after birth. The initial diagnosis was a minor heart murmur, and we were directed to see a pediatric cardiologist.

One month after Kevin's birth, we drove to Odessa, Texas, an easy 30-minute drive from our home, and met with Dr. Tierney. He was much older than we expected, and we, as young parents, were skeptical about his abilities. However, without any technology or special equipment, he immediately diagnosed Kevin's PDA with his stethoscope. His years of experience were all he needed.

Even the surgeons at Children's Hospital in Dallas were impressed that Dr. Tierney could find the tiny hole as it was quite small. I believe it was perfectly orchestrated by God for Dr. Tierney to still be in practice and have exactly the experience Kevin needed.

HEART DEFECTS AND DOWN SYNDROME

Approximately half of all infants born with Down syndrome have a heart condition. These conditions can have serious effects, and these babies must receive medical treatment.

Some children with Down syndrome will show symptoms of their heart condition at birth, and some may even be diagnosed in utero. However, not all newborns will have obvious symptoms, so it is crucial to have an echocardiogram, a test that uses ultrasound to see if the muscles and valves of the heart are working, in the first two or three months of life.

Since Kevin suffered from chronic ear infections, his surgery couldn't be performed until he was clear of any infection. To clear up the ear infections, the surgeons suggested ear tubes. At just ten months, Kevin had ear tubes put in on a Monday in Midland, Texas, followed by heart surgery the following Thursday in Dallas, Texas.

I can't begin to describe the stress, worry, and fear I was experiencing. To add to our concerns, we learned that Kevin had a low white blood cell count two days before the surgery, which could have indicated leukemia. My heart dropped as I imagined the worst. I was so distressed already and didn't think I could handle one more thing.

They kept testing him, and through what I can only describe as a miracle, his count came up in time for him to have the surgery. They repaired his heart, and we were back home within four days. Another miracle, for sure.

For months after the surgery, Kevin had weekly blood tests to be sure he didn't have leukemia. I will never forget how brave he was! Kevin was just 11 months old and would reach out his hand so they could get a blood sample. He never cried or complained. In fact, he was always smiling. I was so grateful when the white count numbers finally stabilized.

Within a week of his heart surgery, Kevin pulled himself up for the first time! My mom was visiting to help me take care of him. She walked in to get him up from a nap and yelled, "He's standing up!"

Standing up was a huge milestone and the beginning of his journey to walking. We bought him toys to walk behind and encouraged him to pull himself up. It was an extended journey as he gained strength and confidence. By the time he was 2, he was going everywhere! And boy, was he happy about his newfound freedom!

CONSIDER THIS:

1. Begin to document your journey. You can create a handwritten account, a digital document, scrapbooks, or record events on a calendar so you can remember the milestones for your child.
2. What therapy services could your child benefit from right now? Speech, physical therapy, occupational therapy?
3. Have you contacted ECI (Early Childhood Intervention) for children birth to age 3 to get these services started?
4. Has your child experienced any medical condition beyond their primary diagnosis of Down syndrome? Do you have the specialists you need? Where can you go for referrals?
5. What moments can you celebrate?

About the Author



Linda Bonner is a bestselling author, speaker, coach, and disability advocate.

Her mission is to provide hope, encouragement, and trusted resources for families of children with Down syndrome and other intellectual and developmental disabilities (IDD).

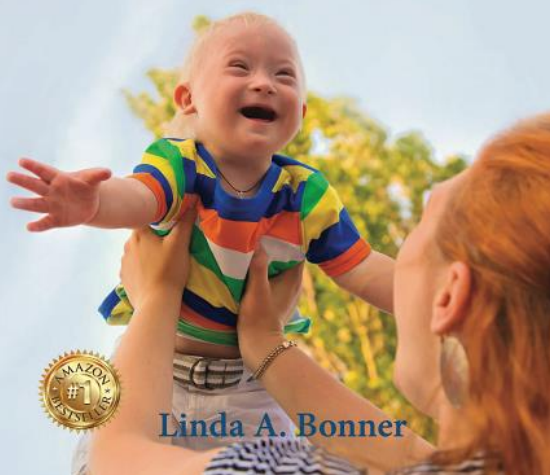
With a focus on dignity and belonging, Linda encourages families to build a life rooted in connection, confidence, and community and to see all the possibilities for their loved one.

www.blessedwithextraordinary.com

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