



EMPOWERING YOUR CHILD TO FLY

A Family's Guide to
Early Childhood Inclusion

JANI KOZLOWSKI, MA



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Preface

In 2022, I fulfilled a lifelong dream to write a book about early childhood inclusion and my personal and professional experiences.

I am an early childhood educator with a disability.

I am the daughter of a parent with a disability.

I am the mother of a son with a disability.

That book is called *Every Child Can Fly: An Early Childhood Educator's Guide to Inclusion*.

It's filled with stories from my own experiences in life as a mother, as a pre-K teacher in the classroom, and through my work as a speaker and technical assistance provider for early intervention, early childhood special-education programs, Head Start and child-care programs, and state-level early childhood leaders.

Because of these personal and professional perspectives, I decided to write that book to support early childhood educators to feel confident and competent in serving all children, including children with disabilities or suspected delays. When I wrote *Every Child Can Fly*, I didn't let my husband read it until after it had gone to print. I didn't want to question myself, worry that I revealed too much or too little, or get his story of our parenting journey mixed up with mine. So ultimately, he read the book in its entirety after it was a done deal. One thing that really resonated with me was that he said how helpful the book would have been during the time that we were "in the thick of it" ourselves as parents of a child with a disability.

I stepped out of my comfort zone when writing that book, because in it I shared that I was born with a rare orthopedic impairment called *Spondylometaphyseal dysplasia* or SMD. It is a form of dwarfism, and I stand at four feet six inches tall. I am a "little person," which is the preferred term for many people in the United States who have the medical condition of dwarfism. SMD is a relatively "tall" form of dwarfism. Many little people have shorter arms and legs, but my arms and legs are proportional to the rest of my body. People typically regard me as just a petite lady, albeit a very petite lady. In addition to being a little person, I have significant curvature in my spine and have dealt



with pain in my joints throughout my life. Many months of my childhood were spent in recovery mode from more than twenty orthopedic surgeries. I had a few surgeries that included recovery in something called a spica cast, which is a cast that starts right under the armpits and goes all the way down to the toes. In seventh grade, and again during my senior year of high school, I had a type of surgery called a spinal fusion. Due to the curvature in my spine, the doctors had to “fuse” vertebrae



together so my spinal cord would be protected. As a result, I spent several months of my senior year wearing a medical device called a halo as I recovered.

In college, I had my first hip-replacement surgery and used crutches for a time as I walked around on campus. I refused to use a handicap sign in my car because I didn’t want people to think that I was “handicapped.” I struggled a great deal to be seen the same as everyone else, as most children do. These experiences shaped me as a person, and I am proud of the fact that I have been able to overcome many challenges. Over time, I have even learned strategies for coping with the stares. Being a little person with a big smile is very powerful. My size makes people look at me, and my smile disarms them. They mostly smile back. Children almost always smile back.

As an adult, I now have artificial joint replacements in my hips, knees, and ankles. My legs are bionic. My spine is fused from the base of my skull to the middle of my back. I cannot turn my head from side to side or up and down. I use my torso to turn my head. Sometimes I feel as though my skeletal system is a jigsaw puzzle with pieces that don’t quite fit together. I’m kinda funky on the inside, in ways that you would know only from looking at an X-ray.

SMD is a condition that I have, but it is not who I am. It has been significant in my life, however, because of all of the surgeries and because it affects my height and my joints and my spine. I have had some very difficult experiences living as a little person in this world, mainly because I look different from everybody else. Even though I have achieved a great deal of success in my life as an early childhood professional, as a wife, and as a mother, the truth is that people still stare at me in the grocery store. Out in public, people judge me by my size and my disability.

I inherited SMD from my father, so he was also a little person and had difficulty walking. My mother would pull us around in a little red wagon on long walks.

My dad dealt with many of the same struggles as I have and overcame many challenges. My father was born and grew up in Buenos Aires, Argentina. In the Latin culture, it is especially difficult to be a

short-statured man, but my father didn't let his height affect his dreams. He was a motivated student and successfully graduated from medical school.

When my parents decided to have a child, they went to many doctors to find out if there was a chance that my father's condition could be passed down to his offspring. They were told not to worry, that my dad's condition was not genetically inherited. Years before in Argentina, he had been told that his condition was called rickets, which is caused by a lack of vitamin D in childhood. Even though my father was a doctor himself, he was terrified of having surgery and didn't really follow up on his own health care or even ask that much about it. My mother became pregnant without concern. At first all was well, although I was born prematurely and weighed only three pounds, three ounces at birth. I had to be in the intensive care unit for quite some time before my parents could bring me home, but other than that they didn't think that there would be any issues. For a time, that was true.

As a child, I viewed disability through the lens of how other people reacted to my father when they first met him and how he responded to those reactions. His strategy was basically not to take himself too seriously. My father was a psychiatrist and jokingly called himself "The Shrink." He even had a personalized license plate on his car that read SHRINK, and he loved it that people laughed every time he got out of the car. Like me, he rejected the notion of the label of *handicapped* and taught me how to disarm awkwardness through a smile or joke. He taught me not to worry so much about the stares because they were just human nature. He said that the world is like a field of blue flowers, and when a pink flower appears in the field, what do you do? You look at it!

My parents doted on me. I was a princess to my father and mother. Both of my parents showered me with love and attention, for which I will be forever grateful. I always felt cherished.

It was only over time that my parents learned that I have the same skeletal issues as my father. As a result, my father learned the truth of his own condition through the process of finding out how best to care for his child. And through it all, my mother cared for both of us. My father dealt with a great deal of guilt throughout his life because he felt responsible for my disability.

I often think of the Smokey Robinson song "The Tears of a Clown" when I think of my him. He presented a happy and secure exterior, but I wonder if that was a mask for his true feelings. Were there tears when no one was around? My father had a large personality, which may have been to



compensate for his small stature. It's hard to know exactly how he felt because my father died many years ago. My mother was there for me through it all. She remarried and found happiness with my stepfather and is a doting granny to my son.

My dad had a lot of demons. His work was listening to other people's problems. He lived with a lot of physical pain. People always stared, and he lived with the effort of trying to make it seem that everything was okay. I think that my dad also could not stand to see the struggles that I experienced. My mother once told me that before a surgery, my dad would say, "This is all my fault." I remember going into the operating room once and telling the doctor to please tell my dad that it's not his fault. Now as an adult, I can imagine the immense guilt and pain that it must have brought him. As a mother myself, I can't even fathom how difficult that must have been. For some parents, guilt is the biggest feeling they have when they learn that their child has a disability.

Our son, Ricky, was born in Ukraine, and we adopted him when he was seventeen months old. Ricky overcame many obstacles from those early months of deprivation in the orphanage, and later he dealt with attention deficit hyperactivity disorder (ADHD). ADHD is marked by inattention (difficulty with maintaining focus), impulsivity (acting hastily), and being overly active. He received special education services throughout his school years, and Ricky is a successful young adult today. I learned a great deal from him throughout his childhood and continue to learn from him. He is resilience personified! The experience of raising a child with a disability taught me about the importance of maintaining high expectations for children, even when we want to protect them from frustration or disappointment. Ricky is an amazing person, and I am a very proud mama. But those struggles during his childhood were difficult for our family.

Ultimately, my husband did read my first book, and afterwards he said, "Jan, you have to adapt this for families. They need this information too." This seemed like an exciting opportunity. How can I take the information from *Every Child Can Fly*, a book for early childhood educators, and reframe it to share with families? Thinking about this reminded me of a story I told at the beginning of the first book about Valentine's Day. It went something like this:

When I was in preschool, I had been out of school for a couple of months for a surgery and my recovery. The recovery involved a spica cast, and I was unable to walk, stand, or even sit up in a chair.

Being away from school for multiple weeks seemed like a really long time to me as a child. My teacher reached out and asked whether my mother might be able to bring me to school to celebrate Valentine's Day with the class. My mom thought it was a great idea because she knew how much I missed my friends and how much I loved Valentine's Day. I loved the candy hearts and cupcakes with pink frosting. I loved the little foldable cards

sealed with a sticker or lollipop. I loved the mailboxes that we used to make. We would trade valentines with everyone in the class, and everyone decorated a mailbox for their cards. I loved it all.

I remember feeling nervous about going into the classroom after what felt like such a long time. Because of the spica cast, my mother had to carry me around everywhere. As you might imagine, I worried about what would happen when my friends saw me in my body cast. Would they stare at me? Would they even remember me? But my mother felt that it was important for me to reconnect with my friends at school. She and my teacher assured me that it would be fine. And you know what? It was fine. It was better than fine, because not only did I have my own Valentine's Day mailbox, but everyone had made me a valentine. While this is not really a story of the common definition of inclusion, it is a story about a time when I felt included. It is a story about membership. It is a story about belonging. It is a story about supporting a child to build friendships and connect with her peers.

Now that I've had time to reflect (and tell that story a gazillion times in presentations), I see the point of the story a little bit differently. Think about this story from a child's perspective. Or shall I say, think about it from a *self-conscious* child's perspective. Sure, I loved Valentine's Day, but did I really love it so much that I wanted to be in the spotlight in front of my friends, wearing a full-length body cast? To be carried into the classroom by my *mother*? As a kid, what I wanted more than anything was just to fit in. To be just like everyone else. I didn't like being different, and certainly not *special*. I hated the stares. I hated when I overheard other children ask their parents, "What's wrong with her?" So, I'm pretty sure that the thought of returning to school mid-recovery was daunting to me at best.

But the story cannot be understood without thinking about it from my mother's perspective too. She wanted me to see my friends. She wanted me to have some fun. She wanted me to feel that sense of belonging and love. But I know my mother, and one of the best gifts she ever gave me was the gift of determination. She knew that if I were going to be successful in this world, or even just okay in this world, I would need some fierce determination.



I was going to need some serious grit and resilience. I was going to need to be the kind of child who faced her fears and even became friends with feeling uncomfortable. My mom knew that I needed to learn how to be the kind of child who went to the party wearing a smile and carrying thirty little pink cards adorned with lollipops. While writing this book, I asked my mom to share some of her thoughts and memories from that time. What advice would she give to parents who are “in the thick of it?” She said, “Don’t do anything for your child that he or she can do for themselves. Encourage independence, celebrate the successes, and look forward to the next milestone.” Very solid advice!

When I became a mother myself and then learned that my child also has a disability, I found myself up against quite a paradox. My own mother’s gift of determination was always on my mind when I parented our son. Yet, I struggled with a strong Mama Bear tendency. My nature is to nurture. More than anything when my son was younger, I wanted to protect Ricky from pain. I didn’t want him to feel uncomfortable, and when he expressed fear, my instinct was to figure out how to remove the fearful thing.

I’m not proud of this tendency I had as a parent. Fortunately, my husband was more of the “gift of determination” type of parent, and always held the highest expectations of Ricky. My husband had the confidence in our son that he would be able to figure things out for himself. Rick knew that Ricky could be uncomfortable or fearful in a situation and find his own inner resources to plow right through. Our son received the underlying message of this parenting approach as “You are capable. You are competent. You can do hard things. I believe in you.”

Rick was also more likely to be the one challenging Ricky to solve problems rather than just giving him the answer. He would suggest that Ricky think about the options or possible solutions, and I typically would sit there and stew because I could tell that the problem solving was making Ricky uncomfortable. Figuring out solutions is hard work!

This Mama Bear tendency continues for me to this day. For example, I’m more inclined to cook something for Ricky rather than teach him how to cook the meal. I’m more likely to do his laundry for him than to force him to do it himself. There are pros and cons to both of our inclinations. Ricky never questions whether his Mom will be there with nurturing, love, attention, and care. Those are constants in his life. My husband is certainly nurturing and caring in his own way, but he also is more likely to make Ricky do his own laundry or cook his own food. Pretty reasonable expectations for a young adult, don’t you think? We have found that the collaboration between the two of us that comes from our different styles of parenting is beneficial and supportive. Neither Rick nor I am the “perfect” parent. We have our strengths and blind spots when it comes to parenting. One important consideration, however, is that a child can benefit from all the different approaches through collaboration with other adults in their life. These collaborations can happen through parent-to-parent relationships as well as relationships with other important adults, such as family members, friends, educators, and other professionals.

Through the perspectives I hold, and through the strategies I have learned from others, I hope to share with you both the practical and the personal: practical strategies for navigating the early intervention and early childhood special education systems, along with my own personal stories as a mother and wife, as a daughter, and as an educator. Supporting children with disabilities and their families is a passion for me. I have dedicated my professional career to early childhood education, and I care deeply about young children of all abilities. I know that you are reading this book because there is a child in your life whom you love dearly who may have just been born or recently diagnosed or may have started doing or saying things that worry you. The early years are a critical period of child development. Children develop rapidly during the first five years of life, and for children with disabilities the early experiences in our education system can be consequential. I hope this book will give you some answers to your questions and ideas as to how to navigate the complicated systems of early intervention and early childhood special education. This can be an uncertain time for parents and families, and I hope that this book will ease some of your worries.

One thing that I remind myself of during times of uncertainty is that the need for acceptance and belonging is universal. Each of us is unique. We are each living in a body that we did not choose. We all face challenges. We each bring something to give to this world, and we all are important partners in ensuring the success of the next generation. Children depend on us to get it right. They depend on us to know that we are all worthy of love, happiness, and the opportunity to achieve our greatest potential.



Acknowledgments

This book would not have been possible without the help of a group of families who agreed to let me interview them so that I could share their stories and photos throughout these pages. Family stories bring the content to life, and I am forever grateful that they have shared their stories with me and with the readers! My heart overflows with gratitude and love for these spectacular humans.

Andie Amosson

Jaclyn Joseph

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Olivier and Hilda Bernier

Terri Leyton

Ben Riepe

Arielle Branch

Amanda Lovette

Eileen Spahl

Judy David

Jacquece Moore-Law

Latisha Stuckey

Kristin Jones

Leah Mullen

Paulina Vargas

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You all inspire me daily. Thank you for helping to make this book come to life, and for sharing in my joyous passion for inclusion for young children and their families. We are a mighty fleet!





Introduction



“Inclusion is not a ‘place’ but a culture that we create when practices are based on rights, inclusive belonging, and contribution.”

—PATRICIA HAMPSHIRE AND PATRICK MALLORY (2021)



While writing *Every Child Can Fly: An Early Childhood Educator’s Guide to Inclusion*, I spent lots of time thinking about families and the relationships between families and educators. What are the most important components in the family-educator relationship? What makes for a successful partnership? Those questions then led me to think specifically about the family in this whole dynamic. What would have helped me the most during that challenging time when we were “in the thick of it” with our own young child?

This book is an attempt to answer that question. Although almost as soon as I began to write this book, I wondered: How can I answer those questions for families when my experience was only just that, *my* experience? The experience of one mom is not anywhere near the experience of every parent and family—and our experience is unique to boot! As I shared earlier, we became parents through adoption, so I do not have the experience of giving birth or of parenting a child younger



than seventeen months of age. In addition, Rick and I are a white, middle-class, English-speaking, U.S.–citizen, heterosexual couple and have the lens that those characteristics allow. Our viewpoints, therefore, are limited—a single story. Experiences of children and families are varied and diverse. As Nigerian writer Chimamanda Adichie says, “The single story creates stereotypes, and the problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story” (Adichie, 2016). Adichie reflects that stories matter, but also that many stories matter. I believe that all experiences of children with disabilities and their families matter, so it was critical to include other family perspectives in the creation of this book.

Ultimately, fifteen families agreed to be interviewed. Their stories are woven throughout these pages and the reflections they shared with me also informed decisions about the kind of content to include. Even still, not every viewpoint is represented here. We know that all families are different and unique. You may be in this role as a single parent, grandparent, sibling, stepparent, foster parent, or as a related or unrelated auntie or uncle. I believe that family members, guardians, and friends of the family often serve the same important role as our traditional notion of the parent. Therefore, I have elected to use the terms *parent* and *family member* interchangeably throughout these pages. Whether a parent is biological, adoptive, assigned, or chosen, the function of the role remains the same and should be respected as such.

I believe that families can learn some of the most important lessons from other families, so you’ll find family stories, photos, quotes, and lessons learned throughout this book. The stories I was fortunate to capture reveal a fierce love for children. A common thread throughout our stories is the passion we feel for lifting this young child high to the sky in the hope that the world will one day benefit from the amazing gifts the child will contribute.

These were the prompts and questions I used in my family interviews:

1. Tell me about your child.
2. If you could describe your child in three words, what would they be?
3. What are your child’s greatest strengths? How do they use those strengths to help them reach their goals?
4. What has been a great success that your child achieved?
5. What were/are your hopes and dreams for your child? Did you have a vision for them early on? How did that develop?
6. What were/are your fears and worries?
7. Tell me about an important memory from your parenting experience.
8. What is your happiest memory? When did you feel the proudest?

9. When was a time that you felt the most grief or sadness? How did you cope?
10. If you could do it all over again, what would you do differently?
11. If you could share one lesson you learned from your parenting experience with other parents going through it right now, what would it be?

To say that I learned a lot from the interviews is the understatement of the year! My worldview of early childhood shifted over the course of these conversations, and I have been in the early childhood education field for more than thirty years.

MY STORY

My work in the field started when I worked as a preschool teacher for a diverse and spirited group of four-year-olds. Actually, I started out in the field when I worked as a nanny all through college. Yes, I was Jani the Nanny. The energy that young children bring to the world has always inspired me. Being around children makes me happy! Even as a child myself, I had always wanted to be a teacher. For a time, I was just a little intimidated by children who are taller than me, so teaching preschool fit the bill. Each child came to my classroom with unique strengths and abilities that unfolded before my eyes throughout our time together.

That journey led me to support Head Start teachers as an education and disability services manager, and later to provide support through workshops and technical assistance to Head Start programs across the country. I taught at a community college, and later I designed child-care quality initiatives and drafted policy as an administrator in the North Carolina Division of Child Development and Early Education. Then, I supported other child-care leaders to do the same. About ten years ago, I started working at the national level, providing technical assistance for leaders through projects funded by the federal Office of Head Start and Office of Child Care within the Department of Health and Human Services, Administration for Children and Families. Now I serve as a technical-assistance specialist for the Early Childhood Technical Assistance (ECTA) Center at the Frank Porter Graham Child Development Institute at the University of North Carolina at Chapel Hill. Through my work at ECTA, I provide support to the state's early intervention and early childhood special education leaders working to support children with disabilities and their families.

My perspective on the work changed radically when I became a mother. Suddenly, the need for inclusive early childhood services became urgent to me because I experienced firsthand the way that *exclusion* can impact a child. For children aged three to five in the United States, the special-education system, more often than not, places children with disabilities in segregated classrooms. Rather than placing children with disabilities in classrooms with their peers without disabilities, they are often put into classrooms where every child has a disability.

Every child **BELONGS**
 Every child is **UNIQUE**
 Every child has **STRENGTHS**
 Every child has the **POTENTIAL TO FLY**



Whether your child has received a diagnosis or they are exhibiting behaviors that worry you, *Empowering Your Child to Fly: A Family's Guide to Early Childhood Inclusion* can help. Discover advice for navigating the early intervention and special education systems from an educator who has experienced these systems as a child, as a parent, and as a professional.

- Understand screening, evaluation, and assessment.
- Discover helpful resources.
- Explore your role as an advocate for your child.
- Learn how to work with your team of specialists and educators.
- Discover strategies to identify your child's strengths and consider a future vision for your child.
- Explore ideas for creating learning spaces at home and embedding learning into everyday routines.
- Discover how to do all of this while staying healthy and strong, with a sense of balance in your life.



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