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Identify Needs and Lead with Strengths

I met Becca at a playground when our children were three and four years old. As we watched our kids go down the slide, I noticed she kept apologizing for her son, Colton, because he had pushed my daughter out of the way a few times so he could go down the slide first.

Becca apologized for interrupting our small talk, saying, “I don’t want him to push your daughter. I’ll be right back.” She walked over to Colton and reminded him that everyone was entitled to their own turn. She reminded him not to push. She reminded him to use his words. Despite her being frazzled and full of apologies, I liked her immediately since she was doing what I had done in the past.

“I appreciate you helping him so the kids can take turns,” I told her.

“I’m sorry he’s so aggressive. He doesn’t have many words yet.”

“I get it,” I replied. “You don’t need to apologize. You’re up there, helping him navigate this situation.”

“I wish he wouldn’t push. This has been happening a lot lately. I want him to wait patiently.”

“He will—eventually. You’re doing a great job with him.”

Becca cracked a tiny smile, drew a deep breath, and whispered, “Thank you.” I noticed her eyes filling with tears.

“Being a mom is exhausting, isn’t it?” I said.

She wiped away a tear and nodded.
"All of us are doing the best that we can."

ACCEPTING AND EMBRACING DISABILITY

No one is perfect. I am *far* from perfect. Imperfection is part of the human condition.

When we scroll through social media, we are greeted with a curated version of other people's lives. Seeing a highlight reel is great, but life is rarely perfect. The competitive bragging we see on various platforms can sting when raising a child who isn't accomplishing as much as peers the same age.

As the parent of a child with multiple nonvisible disabilities (see the box on page 14), I often felt compressed in a narrow place when I scrolled through social media during the early years of my daughter's life. While other parents attended classes and discovered new playgrounds, I shuttled my daughter to speech, occupational, and physical therapies. I was exhausted. I sought help and answers as my daughter acquired new labels from medical professionals. I looked for a way to get to the other side . . . to a place that looked like the curated version of my Facebook friends' lives.

What If Your Child's Disability Isn't Visible to Others?

Nonvisible disabilities, often referred to as non-apparent disabilities, present differently in public than visible disabilities—they may not always be recognized by others in the same way as disabilities that require mobility aids or assistive technology. This often leaves you to find a way to help those in your child's social environment understand, and it's not always easy. I've learned over almost a decade how to navigate various domains of my child's life to promote respect and compassion—and I have helped her learn how to advocate for herself as she matures. I'll pass on what I've learned throughout this book.

Over time, I began sharing the less glamorous parts of our lives. I shared pictures from advocacy walks. I shared videos of my daughter as she acquired new words. In time, I shared about overcoming struggles as I watched my daughter become a reader. I shared these things on social media and my blogs, so other parents whose lives weren't perfectly curated would begin celebrating all parts of their children too.

As I mentioned in the Introduction, many people treat *disability* as a four-letter word. They try to replace it with terms like *special needs* or *differently abled*. This happens because many people think of disability as a negative thing . . . something wrong with someone. As parents of disabled children, we know our child's disability is part of who they are. It's part of our child's identity and isn't something to be ashamed of.

"One billion people, or 15% of the world's population, experience some form of disability," according to the World Bank Group. Sit with that for a moment. *One Billion People*. That is a significant minority group. As parents of disabled kids, we are not alone.

THE LANGUAGE OF DISABILITY

As a parent of a disabled child, you will hear a dizzying array of terms used to describe conditions that fall under the wide umbrella of disabilities. It's important to recognize that how disabilities are categorized depends on the purpose of the classification. The following is one way to conceptualize disabilities in a broad sense. As you'll see in Chapter 2, when schools formulate Individualized Education Programs (IEPs) for students, they use a different breakdown.

Types of Disabilities

Disabilities take many forms and affect individuals in unique ways. Below are broad categories that cover many common types, though individual experiences will vary and there is often some overlap.

- **Chronic medical conditions:** persistent, long-term health conditions that often lack a cure and continuously impact various aspects of a person's physical and mental well-being. Chronic medical conditions include asthma, Crohn's disease, diabetes, epilepsy, and multiple sclerosis.
- **Communication disorders:** trouble understanding, using, or processing different forms of communication. A communication disorder can affect someone's ability to hear, speak, or understand language. Communication disorders can vary in severity, from mild to very serious. They can be present at birth or develop later in life.

- **Developmental disabilities:** a group of conditions that can affect how a person's body, learning, language, or behavior develops. These conditions start during childhood and can continue throughout a person's life. They cause limitations in different areas because of problems with the developing nervous system. These limitations can manifest as delays in reaching milestones or difficulties in thinking, moving, seeing, hearing, talking, and/or behaving.
- **Hearing disabilities:** conditions in which an individual has a partial or complete inability to hear sounds. Hearing disabilities can range in severity from mild to profound. They can be present from birth or can happen later in life. Hearing disabilities can impact a person's ability to perceive, understand, and communicate through spoken language or other auditory cues.
- **Intellectual disabilities:** a developmental condition that can impact an individual's cognitive functioning and other skills, such as language, social interaction, and self-care. These limitations can lead to a slower or different development and learning trajectory than individuals without intellectual disabilities.
- **Learning disabilities:** disorders that impact how people learn, process, and comprehend subjects like reading, writing, and math. They can also hinder higher-level skills such as organization, time management, abstract reasoning, and memory (both short-term and long-term). These disabilities are rooted in biological differences. Heredity also plays a role, as learning disabilities often run in families. Importantly, learning disabilities are unrelated to intelligence, meaning they do not reflect a person's overall intellectual capabilities. Most learning disabilities do not resolve or disappear over time; individuals typically do not outgrow them.
- **Mental health disabilities:** various conditions that impact a person's thoughts, moods, and behavior. They refer to various mental health conditions such as anxiety, depression, obsessive-compulsive disorder, and post-traumatic stress disorder. These conditions affect cognition, mood, and behavior, leading to challenges in functioning and daily life activities.
- **Neurodevelopmental disorders:** conditions that affect how the brain develops, works, and processes. They can make it harder for people to learn, communicate, and interact with others. ADHD and autism are examples of neurodevelopmental disorders.

- **Neurological disorders:** conditions that impact various parts of a person's nervous system, including the brain, spinal cord, nerves throughout the body, and the autonomic nervous system. These disorders can affect individuals physically, cognitively, and emotionally. Examples of neurological disorders are epilepsy and migraines.
- **Physical disabilities:** impacts a person's ability to move, use their hands, or maintain stamina. These disabilities involve limitations or disabilities that restrict the function of one or more limbs. They can be temporary or permanent. Physical disabilities can arise from various causes, including inherited or genetic disorders, serious illnesses, or injuries.
- **Sensory processing disorders:** involve challenges in processing and responding to sensory information (such as movement, sound, or touch), leading to responses that can impact behavior and everyday functioning. Neurodivergent individuals, such as those with autism or ADHD, are often affected, sometimes being overwhelmed by sensory input, and other times not noticing it as much or being under-responsive.
- **Vision disabilities:** conditions that partially or entirely hinder a person's ability to see. Individuals with vision impairments have difficulties that regular glasses, contact lenses, medication, or surgery cannot correct. Even with glasses or contact lenses, they may encounter challenges in performing everyday tasks. Vision disabilities arise when an eye condition affects the visual system and its vision-related functions.

This list shows that some disabilities are visible while others are hidden. Some children have visible and nonvisible disabilities, while others have disabilities that are nonapparent to others as they go through life.

> A year after we met on the playground, Becca recounted how she felt when filling out a form for medical assistance for Colton. There was a question asking her whether or not her child was disabled. She had to acknowledge Colton's disability if she wanted him to qualify for the secondary insurance she needed to pay for all of his medical expenses and therapies. Due to internalized ableism, she hesitated before checking the box to attest that Colton was disabled. However, acknowledging Colton's disability on that form was a salient moment. It helped her understand that her silly, handsome, and headstrong son had a disability . . . it was part of him.

It's essential to know that using the word *disability* will get your child the services, funding, and care they need. If calling autism a disability (see the box below) provides your children access to what they need, then put the word *disability* on it.

Are Neurodivergence and Neurodiversity Disabilities?

Neurodivergence and neurodiversity challenge the traditional view of disability. In *Against Technoableism: Rethinking Who Needs Improvement*, Ashley Shew explains that identifying as neurodivergent aligns with the disability community in that social norms and expectations can make neurodivergence disabling, just as different architectural designs can highlight physical disabilities. Shew clarifies that autistic individuals and those with ADHD originated the concepts of neurodivergence and neurodiversity, but the larger disability community has embraced them. Some people use neurodivergence to resist being labeled as disabled, while others see themselves as part of the disability community.

Disability Models

There are several lenses, known as *models*, for viewing disability. There are individualistic or deficit-based models, which include the charity model, the economic model, the medical model, and the moral model. In other words, disability is viewed as a deficiency, a weakness, or something to be fixed. Some models are asset-based, such as the human rights and social models of disability. Each model considers the perceived causes or origins of disability, the appropriate actions or responses to address disability, and the deeper meanings or implications associated with disability. The medical and social models are most frequently discussed in the literature and the ones you're most likely to encounter.

Medical Model of Disability

- Views disability as a problem in the body's systems or functions that is considered inherently abnormal or unhealthy
- Aims to bring the body's systems or functions back to a state considered "normal" or typical

- Expects individuals with disabilities to follow the advice of health care professionals
- Uses clinical and medical language within health care, mental health, and educational settings
- Perceives disability as an individual defect, emphasizing the need to cure or eliminate disabilities for a higher quality of life
- Notes that messages conveying low expectations and fear of disability can result in limited opportunities for individuals with disabilities

Social Model of Disability

- Acknowledges that disability is not the fault of the individual but a result of societal barriers
- Views disability as the result of how individuals interact with an environment that doesn't provide the necessary accommodations for their needs and differences
- Emphasizes the importance of removing societal barriers rather than fixing individuals
- Advocates for eliminating physical, social, and communication barriers to ensure full inclusion in the community
- Considers disability one aspect of a person's identity, similar to race or gender
- Believes the mismatch between the disabled person and the environment creates barriers
- Focuses on changing the environment and society rather than changing individuals
- Seeks to end discrimination against people with disabilities through education, accommodations, and barrier-free spaces
- Recognizes that eliminating disability would hinder the appreciation of diverse ways of being in the world

Most of us have beliefs that fall into more than one model. I believe the social model values disabled children for who they are and reflects the idea that we, as parents and society in general, must change to meet their needs.

Person-First Language versus Identity-First Language

Person-first language puts the person before their diagnosis, whereas identity-first language emphasizes a person's diagnosis first.

Person-First Language	**Identity-First Language**
Person with a Disability	Disabled Person
Person with Autism	Autistic Person
Person with Dyslexia	Dyslexic Person
Person with Visual Impairment	Visually Impaired Person

The disability community debates whether to use person-first or identity-first language. As the parent of a person with multiple nonvisible disabilities, I often use person-first language since it allows me to recognize my daughter, reaffirming her personhood rather than focusing on her disabilities. She vacillates between person-first and identity-first language, so I follow her lead.

People with disabilities usually prefer one term or another, so it's best to take a person-centered approach, asking the person how they choose to identify (for instance, "Do you prefer person- or identity-first language?"). Check the Resources at the end of this book for some articles on person-first versus identity-first language.

Knowing that many children in elementary school may not have a preference, this book will tend to use person-first language.

High-Functioning and Low-Functioning

High-functioning and low-functioning are insulting and flawed concepts. Neither of these labels is a compliment. The way someone functions can vary from day to day and year to year. Furthermore, these labels pit people with disabilities against each other regarding accessing the support they need. In *Demystifying Disability: What to Know, What to Say, and How to Be an Ally*, Emily Ladau suggests:

> Consider a conversation between a parent of a young child with a disability and the child's teacher. Rather than referring to the student as "low functioning" in math, the teacher can say, "I've noticed your child needs more support in completing his math assignments" or "Your child might benefit from extra support to complete her math homework." Such language is simple, straightforward, and respectful without placing a harmful label on the student.

THINKING ABOUT STRENGTHS

How do you talk about your child when someone asks about them? Do you lead with their strengths or weaknesses? Do you talk about their successes or their struggles? Do you label them?

Here's an example of how I talk about my daughter, who sparked the idea for this book:

> "My child is 14. She's highly organized, motivated to complete her schoolwork on time or ahead of schedule, and works diligently to achieve good grades. She has a gorgeous singing voice and sings in her school's chorus. She learned another language at a young age and continues to study it. She loves the water and participates on a summer swim team. She probably swims nearly a mile during every practice! She doesn't complain when she has to dive into a chilly pool when her coach gives directions. My daughter is a caring older sister who loves her little brother. Even though he bugs her often, she thinks of him as her best friend."

Describing a child's strengths is essential since it positions them positively. No one is perfect. Not the high school valedictorian or the quarterback of the football team. Since many people would not lead with a nondisabled person's flaws, *we shouldn't talk about a disabled person by what they cannot do*. We should see the whole child and talk about the fantastic things that person *can* do.

Let's be honest. *Everyone* has needs. There's nothing special about them. You will see the phrase *higher support needs*, but you won't see the term *special needs* used in this book.

ELIMINATING DEFICIT-BASED LABELS IN SCHOOL

Over the years, many well-meaning teachers have used deficit-based labels when discussing children. For instance, they might say, "Kylie is a struggling writer" or "Joe is below grade level as a reader." Instead of doing this, it's essential to talk about what a child needs to grow. It's crucial to adopt language that is individualized and actionable. The language should put the onus on adults at all levels—from the classroom to the school district office—so we can provide children with what they need to grow.

I'm on a family advisory committee in our school district. This is a small group of parents (whose children have IEPs) who meet with the director of special education quarterly. One thing I've proposed is using more inclusive language. For example, *general education* instead of regular *education* (also, *higher support needs* instead of *lower functioning*). Six months after proposing the idea, the director reported working with her staff to be more intentional with their words in meetings, on paperwork, and about students.

Adult language should start with strength and then name the actionable teaching to provide the next step. Here are two strength-based examples that put the child's strength first and then explain what they'll need to grow:

- Kylie will use her public speaking skills to lead her peers in a writing process share session in three monthly end-of-workshop share sessions.
- Given third-grade level nonfiction reading material, Joe will deploy his interest in social studies to write three details from the passage in his own words with 85% accuracy on three out of four consecutive assignments.

Melanie Meehan discussed the language used to talk about students with high needs. In *Every Child Can Write: Entry Points, Bridges and Pathways for Striving Writers*, Melanie wrote, "While I grapple with *any* term, striving implies effort, and I want to believe that everyone is wired and willing to *try*; people don't *choose* to struggle." Let's remove references like *struggling writers* and *low reading levels* from our conversations about kids. We can shift our language so we're positioning students in a way that ensures they're striving to do their personal best.

ON TO THE EVALUATION PROCESS

With the foundation you've established in this chapter, you're prepared to dive into the evaluation process. The next chapter focuses on trusting your gut (since you are your child's first teacher) when it comes to getting your child evaluated in an educational setting.

In fifth grade, Colton invited a friend over to their house for a play date. The boys were still playing in the backyard when the other child's mother arrived to pick him up. Becca invited her to sit on their patio while the boys kicked soccer balls around in the backyard.

Becca had only met this boy's mother once before but fell into an easy conversation about their wonderful sons, both of whom faced challenges. The other mom casually mentioned her son's intellectual and mental health disability in the conversation. Becca shared one of Colton's early diagnoses relevant to their discussion about how school was going. She didn't flinch when Becca mentioned Colton's challenges, and Becca didn't blink when she told Colton's mom about her son's disabilities.

After they parted, Becca texted me about the conversation. "Seven years ago, when we met on that playground, I never would have shared Colton's diagnosis with a virtual stranger." Information like that was held close by her and was shared only with people she could trust. But her mindset had changed since she'd applied for medical assistance years earlier. Becca understood Colton's disabilities were one part of who he is. There was no shame in talking about them! Communicating openly with others about who our children are—their strengths and their challenges—normalizes disability.

Tip for Cultivating Joy: Use social media mindfully. While social media is a fantastic way to stay in touch with friends and family, it can also make you feel down. Reduce your use of social media platforms that leave you feeling disheartened.

Self-Care Tip: Slowing your breathing down is one way to manage stressful situations. Rather than waiting for stressful moments, practice slow breathing techniques now! Extended exhalations are associated with slowing the heart rate, which lessens the stress response. (You can read about this at *www.psychologytoday.com/us/blog/the-athletes-way/201905/longer-exhalations-are-easy-way-hack-your-vagus-nerve*.) While I'm partial to using longer outbreaths and Box Breathing to decrease my stress level, it's essential to find breathing exercises that work for you. (See Self-Care Resources.) Practice one or two breathing exercises for a few minutes daily so they're well-practiced and ready to be activated when you are stressed.