A Parent's Guide to DISABILITY

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> *“The goal is not to avoid falling or needing help. The goal is to be seen, asked, heard, believed, valued as we are, allowed to exist in these exact bodies, invited to the party and encouraged to dance however we want to.”*
>
> **— Rebekah Taussig,**
> ***Sitting Pretty: The View from My Ordinary Resilient Disabled Body***

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This guide will help you learn how to talk to teens about disability by asking these questions:

- ✓ How does our culture view disability?
- ✓ What does Scripture say about disability?
- ✓ What is (and isn't) respectful disability language?
- ✓ How can we show hospitality to young people with disabilities?

Containing Multitudes

When you read the word *disability*, what image comes to your mind? You may imagine a person who uses a wheelchair, someone who is blind, or a person with a condition such as Down syndrome. Perhaps you think of a person who is "on disability" due to an injury that keeps them from being able to work. Maybe disability has touched your life personally because you or a family member live with one.

From historic ideas that people with disabilities were being cosmically punished, to modern notions that sentimentalize their personhood, there are many confusing and even dangerous messages about disability that your teen may encounter. Opening up a nuanced conversation on disability can help teens and parents alike in having the mind of Christ about all who are made in God's image. Together, families can look to God's Word, listen to the voices of people with disabilities, and cultivate a humble approach to conversation.

Whether disability feels concrete and near to you, or abstract and far away, your perspective on it has likely been shaped by your experiences and your place in history. Like other major cultural topics such as race and gender, thoughts on disability have developed (and regressed) over time in ways that have powerful effects on our world today.

Disability is a topic that touches every aspect of human life, from the political and cultural to the personal and spiritual. While this Parent's Guide will draw upon all of those spheres, its ultimate goal is not to overwhelm you with knowledge but to provide helpful context that can inform a fruitful, ongoing conversation with your teen.

Reflection questions:

- ✓ What did you grow up believing about disability?
- ✓ How has disability shown up in your personal or social life?
- ✓ How have you seen disability depicted in popular culture?

How have people historically thought about disability?

Humanity has a complicated (and mostly quite dark) history when it comes to the treatment of people with disabilities. Early civilizations often viewed being born with a disability as punishment from God for sinful behavior or evidence of demonic possession. The same belief held throughout the Middle Ages, often resulting in people with disabilities being sent to monasteries and hospitals where monks and priests tried to conjure healing through exorcism, prayer, and incantations.

At times, these beliefs gave way to horrific treatments intended to expel the devil from people with disabilities, including torture. In some cases when attempts at exorcism seemed to fail, people with disabilities were executed.

During the Renaissance, the belief that disabled or mentally ill people were demon-possessed began slowly shifting to the belief that they were sick. People with mental illnesses and cognitive disabilities were sent to a rapidly growing number of asylums. In the midst of this oppressive era, there were glimmers of progress: in the 1500s, for example, Benedictine monk Pedro Ponce de León is believed to have become the first person to develop a method for teaching the deaf.

The idea of disability as God's punishment was also prevalent during the colonial period. Largely seen as a mark of moral failure, disability not only led to harsh treatment of individuals but to their families who were stigmatized and shamed. As the Industrial Revolution began, injured workers became a new class of people with disabilities, leading to eventual legislation entitling such workers to compensation. Educational efforts for people with disabilities started to emerge, primarily for people who were deaf or blind. People with mental illness remained largely looked down upon and otherwise mistreated.

As Social Darwinism and eugenics caught fire in the mid-to-late 1800s, inhumane practices such as forced sterilization and forbidding people with disabilities to marry became widespread. Some regions in the early 1900s passed laws forbidding "unsightly" people from entering public areas. And yet, some positive shifts began to happen as legislative acts addressed rehabilitating veterans with disabilities, which led to a similar act for civilians.

The mid-to-late 1900s saw the rise of many disability debates that still exist today: Should people with disabilities live independently? What is society's responsibility to people with disabilities? Who defines what an able body is or isn't?

Reflection questions:

- ✓ What stands out to you about the history of disability?
- ✓ How have you seen incorrect beliefs about disability influence modern life?
- ✓ How do you think religion has shaped the way people think about disability?

Where are we now?

As legislation and opportunities for people with disabilities have progressed over the past century, the brutality of prior generations may seem like a thing of the past. And yet, inhumane treatment and eugenics are not as far from us as we'd like to believe. Modern media and medicine alike too often promote a belief that people with disabilities are unwelcome and even unworthy of life.

Simultaneously, disability activism and discourse are expanding in never-before-seen ways that challenge preconceived notions about the life, value, and needs of people with disabilities. Research developments around cognitive differences such as autism spectrum disorder and dyslexia have shed light on the ways that such conditions not only have challenges, but unique abilities such as heightened creative thinking or contextualization.

Perhaps the largest generational shift—and one that teens may be especially interested in—is the effort to amplify the voices of people with disabilities rather than merely listening to the people who care for them. Parents of children with disabilities, for example, have profound insight into the life of a person living with physical or cognitive differences. Their opinions and observations are important. But there has long been a cultural tendency to listen to caregivers over and above people with disabilities themselves—the only ones who fully, experientially know what it is like to live inside their own mind and body. The goal is not to silence caregivers. Instead, it is to turn up the volume on voices that have too often been muted.

Many such voices emphasize rejecting ableism—discrimination that favors people with able bodies—in all its forms. This looks like more than ensuring there are ramps for wheelchairs in public places or accommodations for neurodiverse students in school, though these are certainly part of disability advocacy. In addition to physical inclusion, advocacy against ableism emphasizes talking about and to people with disabilities with respect.

For example, some people with disabilities point out that they are often infantilized in conversation. This may look like:

- calling someone "cute" simply because they have physical differences
- speaking slowly or loudly to someone in a wheelchair with no knowledge of whether or not they have a cognitive disability
- addressing caregivers or companions of a person with a disability rather than the person themselves

Infantilizing often gives way to sentimentality as well, in which able-bodied people default to idealizing people with disabilities as heroic characters. Disability activist Stella Young terms this type of objectification “inspiration porn.” Writer Andrew Pulrang, who has had lifelong disabilities, citesnews stories of disabled students being elected prom king or queen as an act of charity from the rest of the student body as examples of inspiration porn.

The problem is not a girl with Cerebral Palsy being crowned queen of her high school. Instead, inspiration porn fails to honor the whole person at the center of the story—reducing their humanity to their disability and operating under the assumption that kindness shown to them is an act of charity.

While opposite ends of a spectrum, sentimentality and brutality are inextricably tied together by a common problem: thinking of a person not in terms of their inherent value as someone made in God’s image. Reducing someone to a symbol of hope or inspiration may not harm them physically, but it diminishes them societally. Both ways of thinking fail to agree with God about who He says each person is: a whole person, fearfully and wonderfully made (Psalm 139:14).

Reflection questions:

- ✓ How do teens in your life talk about disability?
- ✓ What, if any, generational shifts in thinking on disability have you personally observed?
- ✓ How do you think sentimentality affects people with disabilities?

How is disability represented in popular culture?

Traditionally, the answer to that question has been "not very often or well." Over the past several years, however, there have been some positive shifts in disability representation. Some stories, however, still communicate negative and even dangerous ideas about people with disabilities.

Let's take a look at a few examples of recent, teen-focused content that include characters with disabilities to consider the good, the bad, and the discussion-worthy.

Dyslexia and Demigods: The *Percy Jackson* series

What's good: Rick Riordan's *Percy Jackson* books, films, and television series feature a main character with dyslexia. Early in the story, Riordan shows Percy struggling to participate in school as letters appear like indecipherable code to him. In the films, this is depicted visually, attempting to give viewers a glimpse into what reading with dyslexia may be like. The *Percy Jackson* stories shed light on the emotional challenges that can come with feeling different and incompetent based on something an individual can't control.

Percy learns he is an ancient Greek demigod whose dyslexia results from his brain being wired to read Greek rather than English. Some of his fellow demigods also have dyslexia, which creates a common bond and shared experience among the characters.

Percy also has ADHD, which causes him trouble focusing in the human world but enhances his ability to hyperfocus within the world of the Greek gods. His hyperactive tendencies give him the agility, intensity, and maneuverability to prevail in dangerous situations.

What's bad: Percy finds belonging and solace by leaving the human world and entering the realm of deities. While the stories are fantastical and not intended to be prescriptive, some children and teens may need guidance in considering how differences like dyslexia and ADHD include both challenges and benefits in the real world.

Some Christians may have mixed feelings about the Percy Jackson franchise as it depicts false gods and goddesses. While the series is presented as fantasy and is not didactic, some believers may want to consider a conversation about how the story features a system of belief incompatible with Christianity.

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What's discussion-worthy: Dyslexia affects 20 percent of people and is responsible for 80–90 percent of learning disabilities. Whether dyslexia has impacted your family or not, it's a near-certainty that it is part of life for friends or classmates.

Together, parents and teens can consider questions such as:

- ✓ How have dyslexia or other learning differences shown up in your personal or social life?
- ✓ How do teens in your life think about learning differences like dyslexia or ADHD?
- ✓ The shift in stigma and perspective on learning differences over the past 30 years has been significant—what are your thoughts or feelings about that change?

Love You to Death: *Me Before You*

What's good: This book series by JoJo Moyes and the subsequent films do not shy away from sharing how discouraging and depressing living in a disabled body can feel. Will Traynor is a wealthy young banker who is left paralyzed after an accident two years prior to the time of the story, and Louisa Clark is hired as his caregiver.

Eventually, the two characters fall in love as Louisa helps Will see joy in his life and does not allow his cynical perspective on his condition to deter her from showing him how much beauty he can still experience. The stories show that a person in an able body and a person in a disabled body can enjoy a romantic relationship despite their differences.

What's bad: Louisa learns that Will has decided to end his life through assisted suicide. She sets out to convince Will that his life is worth living, telling Will she wants to spend her life loving him just as he is. Louisa is heartbroken when, even after falling in love with her, Will not only still intends to follow through with his plan but feels that it is the best thing he can do for Louisa. Without him, Will argues, Louisa can live her life to the fullest, free of being bound to Will as a caregiver.

Eventually, Louisa accepts Will's decision, feeling she needs to honor his autonomy. At the end of *Me Before You*, Louisa travels with Will to Switzerland where he goes through with his original plan to end his life at a clinic called Dignitas (which is a real place).

The books and film conjured strong opinions in general and especially among people with disabilities. Many disability activists were horrified by the story's themes, as the ending seems to indicate that Will is right—life is not worth living in a disabled body. This, of course, stands in sharp contrast to the Christian belief that all lives are precious.

The story's portrayal of autonomy is equally incompatible with a Christian perspective on human life. Will believes that because he cannot do what he used to do, he no longer has a reason to live. In doing so, he reduces his value to his capacity for productivity, proficiency, and even play—all of which are meaningful, but none of which are ultimate. Will's emotional pain should not be dismissed, to be sure. But the idea that the only answer to it is death stands in opposition to the God we know to be the author and creator of life.

What's discussion-worthy: Louisa initially believes that her mission is to convince Will that life is worth living because he can still have meaningful experiences. Then, she believes that letting Will decide to go forward with his plan to die is an act of respect. Both of these beliefs reduce Will's inherent value as a human being. His worth lies not in his capacity for experience but his very essence. This flawed, even alarming plot arc provides ample fodder for discussion.

Together, parents and teens can consider questions such as:

- ✓ How can Christians respect someone's autonomy while ultimately upholding the value of life?
- ✓ What might it look like to invite a person with a disability into belonging and community rather than thinking of spending time with them as a favor or one-way relationship?
- ✓ How does the belief that productivity defines human value show up in your life?

Man in the Mirror: *Wonder*

What's good: This beloved 2012 book by R.J. Palacio—and the subsequent 2017 film featuring Jackson Tremblay, Julia Roberts, and Owen Wilson—focuses on Auggie, a 12-year-old boy with a genetic condition that causes significant facial differences. Auggie's care during his early childhood meant being homeschooled for elementary school. *Wonder* tells the story of Auggie entering a traditional middle school.

The first section of the book is told from Auggie's perspective. He faces cruelty and exclusion from other students. Just as Auggie starts to feel as though he has made friends, he overhears one of them say that he wishes Auggie would stop following him around. It's a heartbreaking moment that sheds light on an important truth for children and teens to understand about disability: differences in someone's body or mind do not mean they are any different from anyone else when it comes to the desire to belong.

The second part of *Wonder* is written from the perspective of Auggie's sister, Via, who is four years older than Auggie. This section illuminates what it can feel like to have a sibling who requires a higher level of care from parents, as well as how it can be challenging when one's sibling isn't accepted by a social group.

One section comes from Summer, a student who decides to become Auggie's friend despite criticism from classmates. Jack, the boy who wishes Auggie would stop following him around, helms a chapter, as does a student named Miranda who lies at summer camp and says that she has a brother with a deformed face in order to receive attention.

Wonder doesn't shy away from the often complex social and relational dynamics surrounding disabilities, including the true meanness and manipulation often aimed toward people with differences. This book cultivates empathy without leaning on sentimentality and helps readers understand the shared desire for belonging in everyone.

What's bad: Some readers with disabilities similar to Auggie's have flagged a few concerning elements of the story: namely Via's interest in genetics and intent to "help" future children like her brother. The book is vague about what that "help" would entail. Since genetic research on disability can be ethically murky and has been linked to eugenics, this is a note to consider.

Some readers also find Auggie's character to have a lack of agency, seeing some of his actions as rather passive. When other characters hurt him, Auggie is expected to forgive quickly and easily. Rather than Auggie taking much action in the book, he is typically acted upon by others. Auggie is also the only person with a difference depicted in the book, which some readers find to be a poor representation of schools and societies.

What's discussion-worthy: *Wonder* may help teens (and even adults!) identify and acknowledge some of the confused or negative feelings they experience around disability.

Parents and teens might find opportunity for honest, growth-oriented conversation via questions such as:

- ✓ What has your experience of people with disabilities been like in school?
- ✓ What social dynamics have you witnessed between people with differences and people with able bodies?
- ✓ How might you learn more about the way your current social spheres—school, church, etc.—respond to disability?

What's the best way to talk about disability?

While there are some clear dos and don'ts when it comes to speaking about disability, it's important to note that not everyone agrees on vocabulary or phrasing.

For example, many people with disabilities prefer what is known as "person-first language," which this guide features (to put it simply, "person-first" follows the formula "people with disabilities" rather than "disabled people").

However, others prefer "identity-first language," noting that their disability is nothing to hide. As a general rule, able-bodied people may find it most helpful to use person-first language when posting online or talking to a general audience. In personal conversations with people with disabilities, it may be best to ask for their preference of terms.

Many people with disabilities prefer person-first language because it avoids terms that portray them as victims. For example, "wheelchair-bound" implies a state of suffering while many people who use wheelchairs experience them as liberating or simply a useful aid.

Whether person-first language is preferred or not, many terms have historically been used to describe people with disabilities that are now considered outdated and degrading. While cognitive disabilities were long described as "mental retardation," the term has been repeatedly weaponized and is considered insulting to the point of being a slur. Terms like "crippled," "lame," and "deformed" are similarly off-putting, indicating that someone with a physical disability belongs in a different class of person than those with able bodies.

Many people with disabilities find the internet—specifically social media and online forums—to be a meaningful place for discussing their limitations and bonding with others who share them. Parents with teens who have disabilities may want to talk about such communities with their teens and check out any spaces they are spending time in online. Some online communities can be life-giving sources of knowledge and friendship, while others may not be appropriate for teens or in keeping with a Christian perspective on disability or the value of human life.

In these digital spaces, people often develop a language of their own for talking about their bodies and experiences. For example, some people with disabilities are reclaiming the derogatory term

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"crip" as a positive term that resists ableism and discrimination. In general, these reclaimed terms are considered vocabulary that only the disability community should feel empowered to use.

Some people are also changing their view on what qualifies as a disability. For example, at least one ministry is shifting its view on deafness from being a disability to being a language barrier.

Since language and understanding are continually evolving—and not everyone agrees on the perfect terms—it's nearly inevitable that teens (and adults!) will make mistakes in the way that they speak about disability. Humility, a willingness to listen, and openness to differing opinions can go a long way in shaping meaningful conversations about disability and, all the more, with people who have disabilities.

Reflection questions:

- ✓ What disability terms or types of language have you encountered?
- ✓ Who in your life currently informs the way you speak about disability?
- ✓ How might disability language inform the way we think about people with disabilities?

How does the Bible talk about disability?

Throughout Scripture, God makes clear that each and every human is:

- ✓ Made in his image (Genesis 1:27)
- ✓ Fearfully and wonderfully made (Psalm 139:14)
- ✓ His dearly beloved child (Ephesians 5:1)

Before anything else, the Scriptures emphasize that God's unconditional love does not change based on a person's differences or disabilities. Neither does the inherent value, dignity, and truth that each person bears God's image.

With that context in mind, let's take a look at a few Biblical passages that include people with disabilities.

In 2 Samuel 9, we find the account of Mephibosheth. King David opens the story by asking if there is anyone left in the house of Saul to whom he can show kindness as an act of honor to his dear friend (and Saul's son), Jonathan. A servant explains that there is one person left, Mephibosheth, "a son of Jonathan; he is lame in both feet."

David asks that Mephibosheth be brought to meet him. When the man arrives, he bows before David and describes himself as a "dead dog" to whom a royal like David would not typically pay attention. But David flips the script. He tells Mephibosheth that he will be given back all of the family land that had been taken from him and invites him to eat at his table like a son of the king.

Reflecting on Mephibosheth, Amy Kenny writes, "To David, Mephibosheth is not a nameless exile who cannot enter his court; he is the son of David's beloved covenantal partner, Jonathan (1 Sam. 18: 1–4)… David restores Mephibosheth's land and position in society… The narrative gives us an imagination for how disabled and nondisabled people can interact in the beloved community, and it starts with a nondisabled person extending an invitation and reparation to disabled people."

Kenny links the table where David and Mephibosheth enjoyed food and friendship to the banquet table where all who are in Christ will gather in the life to come. At that table, we will feast with the Son of God who endured disfigurement on our behalf, and whose perfected body still bears the scars of the crucifixion.

That very Son of God often physically healed people during his ministry, but that bodily healing was not all He provided. As Jesus healed the man who was born blind, He not only restored his sight, He reframed the man's story. When Jesus' disciples asked him whether the man or his parents' sin had caused his blindness, Jesus told them that neither was correct. Instead, God's work was on display in the life of this man and Jesus' interaction with him.

Jesus' miracles of healing are profound in their physical impact but the picture is seen most fully when we consider the spiritual, emotional, and relational elements as well. In drawing near to people society had rejected or considered sinful, in touching their bodies and engaging them in conversation, Jesus offered a glimpse of the kingdom to come. Like David with Mephibosheth, Jesus painted a new picture of what life can be like: a table where all are not simply allowed, but welcomed.

Reflection questions:

- ✓ What makes you feel truly included?
- ✓ What might it look like to follow the examples of King David and, ultimately, Jesus in welcoming people of all abilities?
- ✓ What's one thing you've learned that you'd like to continue praying about, researching, or discussing?

Sources/Further Reading

- *Sitting Pretty: The View from My Ordinary Resilient Disabled Body* by Rebekah Taussig
- *Psychosocial Aspects of Disability, 2nd Edition*
- *Disability in the medieval period 1050-1485*
- *2.1: Historical Perspectives on Mental Illness*
- *Conceptualizing disability: Three models of disability*
- Pedro Ponce de León

- A Parent's Guide To Autism and ADHD
- Don't infantilize me: Combating everyday examples of ableism
- "You Are So Cute" : The Nicest Insult I Have Ever Gotten
- The Infantilization of Elders and People With Disabilities
- Non Wheelchair User Etiquette
- Percy Jackson and the Olympians
- *Me Before You* by JoJo Moyes
- *Wonder* by R. J. Palacio
- Review: Wonder by R.J. Palacio
- The Yale Center for Dyslexia & Creativity
- The Infantilization of Elders and People With Disabilities
- Person-First and Identity-First Language
- My Body Is Not a Prayer Request: Disability Justice in the Church by Amy Kenny
- Inspiration Porn and the Objectification of Disability: Stella Young
- How To Avoid "Inspiration Porn"
- Being Deaf Is Not A Disability
- *The Bible, Disability, and the Church: A New Vision of the People of God* by Amos Yong
- *Disability and the Way of Jesus: Holistic Healing in the Gospels and the Church* by Bethany McKinney Fox
- *Flannery O'Connor: Writing a Theology of Disabled Humanity (Studies in Religion, Theology, and Disability)* by Timothy J. Basselin
- *Becoming Friends of Time: Disability, Timefullness, and Gentle Discipleship (Studies in Religion, Theology, and Disability)* by John Swinton