

# How Disability Affects the Family

## Unique Challenges, Unique Joy



### How Churches Can Support the *Whole* Family

People often ask why Joni and Friends uses the phrase “people affected by disability” instead of simply saying “people with disabilities.” While we do say the latter when appropriate, the former helps highlight an often-overlooked reality: **Disability impacts more people than just those who are disabled!**



#### Diagnosis

“I don’t care if it’s a boy or a girl; as long as the baby is healthy, I’m happy!” Have you ever heard someone say something along those lines? It’s not necessarily a bad sentiment, but this perspective will often leave parents unprepared for news that their child is going to be less than “healthy.” Whether it happens in the womb or after birth, the expectations, anticipation, dreams for your child may change in an instant when a doctor gives an unexpected diagnosis. Questions may surface like, “Is this my fault? Should I have done something differently? Why is God doing this to me?” or even, “Should I consider an abortion?”

Imagine the comfort an expectant mother would feel if she attended a church where people and families like hers are already included, celebrated, and wanted.



#### Missed Milestones

Grief is often cyclical. The pain a parent feels at their child’s initial diagnosis may be reawakened as they are reminded how very different their child’s life will be from their “typical” peers. Missing out on things like learning to read, team sports, driver’s licenses, college, independent living, and marriage can all trigger new cycles of grief in parents of a child with a disability.



#### Relationship Dynamics

Marriages and siblings are both impacted by disability. Siblings of a child with a disability may feel like they need to suppress sharing their needs because they observe how much of their parent’s energy and effort goes into caring for their sibling. Or, they may grow to resent their sibling’s neediness. While one is motivated by love and the other by resentment, both have detrimental effects on the family. Marriages can take on new relationship dynamics, too. For example, if one parent is the primary caregiver of their child with a disability, the other spouse may feel neglected when so much of their husband or wife’s emotional and physical energy is spent caring for their child.



#### End of Life Care and Legacy Planning

As parents age they begin asking questions like, “Who will care for my child when I’m in need of care myself?” And, “Will my child have the financial resources they need when we’re gone? Who will help them manage that?” Understanding and anticipating these worries can help church leaders provide meaningful (and often practical) support.

## The Myth of “The Good Life”

Most of us have, without even realizing it, an idea of what the “good life” looks like. Going to school, finding a job, getting married, having kids, and retiring to leisure and travel sounds pretty good to most of us. And while there’s certainly nothing inherently wrong with a life lived like this, for many this life trajectory just isn’t possible. Does that mean God has put the “good life” out of reach? Far from it. Consider this statement from Joni and Friends’ founder, Joni Eareckson Tada, a quadriplegic since the age of 17:

*“I would rather be in this wheelchair with Jesus than walking without Him.”*

Being unable to use your hands and feet is unlikely to appear on anyone’s wish list. But for Joni, none of these things compare to knowing Christ. Her statement finds its roots in scripture...

*“Yes, everything else is worthless when compared with the infinite value of knowing Christ Jesus my Lord. For his sake I have discarded everything else, counting it all as garbage, so that I could gain Christ...”* PHILIPPIANS 3:8 (NLT)

If people with disabilities can offer any challenge to their “healthy” peers perhaps it is this: God’s plan for their life is no less joyful, no less meaningful, and no less blessed than anyone else’s. When our churches reflect and affirm this biblical truth, we provide a powerful counter-cultural message that highlights not only the beauty of the gospel, but the value of people with disabilities. May your church be a place where every family can find Christ and hear his voice saying,

*“Come to me, all of you who are weary and carry heavy burdens, and I will give you rest.”* MATTHEW 11:28 (NLT)

## 24/7 Care

Because chronic conditions and disability don’t go away and often require 24/7 caregiving, providing support requires churches that are built for running a marathon, not a sprint. The well-intentioned “let me know if you ever need anything!” is unlikely to get many responses. Instead, offer to do specific tasks! These offers should be:

### Specific

Be as specific as possible. “Can I bring dinner to you this Thursday?” “Can I help watch the kids sometime this week?”

### Frequent

Don’t take one raincheck as a closed door. Keep offering!

### Free of Advice

Avoid “helping” by offering unsolicited advice. Approach as a learner and be willing to enter their world on their terms. Advice comes after trust and understanding are built, and those both take time!

### Gospel-Centered

“We love each other because (God) loved us first” (1 John 4:19, NLT). Let our motivation to serve come from a heart filled with the love of Christ.