

An Unlikely Masterpiece

by Stacia McKeever
Featured in Answers magazine

When it comes to people with disabilities, Christians need to rethink what it means to be “fearfully and wonderfully made.”

We were thrilled with the news of our first child, a son whom we would name Kieran, after struggling with infertility for several years. Like most parents, we began dreaming about our life with him soon after we found out God was knitting him together in my womb: tossing around a football in the backyard, teaching him about Jesus, starting the first day of school, helping him earn a driver’s license, shepherding him to become a man who would love God and his family. The Lord was so good in giving us this child.

His birth was eventful, and at Kieran’s two-month checkup the doctor heard a heart murmur, which led to a diagnosis of supravulvar aortic stenosis (obstruction of the aorta). Kieran also wasn’t gaining weight, wasn’t sleeping well, and spent most of his time screaming.

We trudged to our local children’s hospital almost weekly, visiting one expert after another, trying to find answers that would explain the strange cluster of symptoms. Finally, when he reached nine months, after multiple blood tests and more doctor visits, a geneticist called me and said, “He has Williams syndrome.” With those words, we were abruptly shoved onto a path that we hadn’t even been aware existed. I called my husband with the results, and he left work immediately. We spent the rest of the evening sitting on our couch, grieving, and trying to figure out what Kieran’s new future looked like.

As we would later find out, Williams syndrome is a “spontaneous” deletion of about 25 genes occurring at conception on the long arm of the seventh chromosome. Researching it brought up phrases such as physical disabilities, intellectual disabilities, developmental delays, speech delays, fine-motor issues, visual-spatial problems, IEPs, heart condition, blood pressure problems, renal stenosis, speech therapy, occupational therapy, physical therapy, and the list went on.

As tears flowed down my cheeks, I remember thinking, “There must be a good God in the midst of all this. It can’t be any other way.”

Giving Space to Pain

Through our Bible study over the years, we knew that the pain this diagnosis caused could only make sense if there is a good God who created a very good world that sin has corrupted. If there is no infinitely good God of the Bible, if there is no way to say, “This is what life should look like,” if we are all just haphazard arrangements of chemicals bound together over time, then the term

disability is meaningless. It would mean that this random arrangement of chemicals isn’t any better or worse off than any other arrangement of chemicals. And the pain we felt, as we grappled with this new diagnosis, had no logical basis.

Yet even with that knowledge settled firmly in our hearts and minds, we continued to grieve. My friend Georgia shared a thought that helped us give space to the hurt: “Knowing the truth doesn’t take away the pain.” Nor should it. Part of the curse is experiencing the pain of death and all that accompanies it.

Like so many others, as we picked up the fragments of our broken dreams and began to piece them back together in new ways, we tried to make sense of the puzzle we were working on. Did God create Williams syndrome? Is there purpose in disability?

Who Fashioned Kieran’s Chromosomes?

We were firm in our pro-life belief that the Lord knits every baby together fearfully and wonderfully from the moment of fertilization (Psalm 139:14). But where do those with disabilities fit into that belief? Was our son really a masterpiece of the Creator?

As we’ve mined the depths of the Bible’s teaching on God and his sovereignty, we’ve come to accept that just as he is involved in the intricate workings of the universe, he is also involved in the intricate workings of conception. As such, in his goodness, he gave our son (and each one of us) a specific genetic combination, which in our son’s case included a deletion on part of one of his chromosomes.

When God called Moses to ask the Egyptian pharaoh to release his people, Moses made excuses. He pointed out to his Creator that he was “slow of speech and of tongue.” So the Lord responded to him, “Who has made man’s mouth? Who makes him mute, or deaf, or seeing, or blind? Is it not I, the Lord?” (Exodus 4:11).

In this passage, God is taking credit for making some people blind and some deaf. Reflect on that with me for a moment.

Over the years, we’ve let that truth sink into our souls. We run toward the belief that, while the world may call Williams syndrome a “spontaneous” mutation, we call it a providential one. Before you balk at that, think about this. The genetic mutation that pervades every cell in our son’s body has visible effects—from his facial features to his heart and kidney problems to his learning disabilities. Yet, that’s true of all of us. Much that we associate with our basic identity is influenced by our genes.

Every one of us is suffering from 6,000 years of the curse. In fact, which one of us would say that we have a

completely perfect body and mind? Our problems may not be as apparent as Kieran's, but we have them just the same. And we were all knit together carefully and with great purpose—in all our physical imperfections—by the same good, kind, loving Creator for his purposes.

To put it another way, how many mutations—or which specific mutations—separate the “normal” people from those with “disorders”? If, as pro-life people, we're not prepared to say that God created and fashioned each and every person, at what point do we say, “Yes, you manifest the handiwork of God, but you don't”?

One theologian defined disability this way: “We are disabled to the degree that we cannot properly fulfill the creation mandate in Genesis 1:28 . . . [where] God speaks to Adam and Eve to ‘fill the earth and subdue it’” (Dr. Mark Talbot's message “Longing for Wholeness: Chronic Suffering and Christian Hope,” DesiringGod.org). How many of us can say that we're able to perfectly fulfill God's dominion command?

Of course, we understand that our actions have consequences. In some cases, the actions of parents before the birth of their child can have dire consequences on the baby. For example, if a mother consumes too much alcohol while she's pregnant, her baby can be born with fetal alcohol syndrome.

We also understand that something may happen to the baby during development, such as what happened with my cousin, Karen, who was born with hydrocephalus. The doctors didn't catch it until she was three months old, leaving her severely disabled. Until she passed away a few years ago, she was nonverbal and used a wheelchair to get around. Yet God is still the ultimate author of life, and he is in control.

And we have the hope that we will see her again in heaven, where she'll have a perfect body, free from the curse. Because we have received the gift of salvation through Jesus, we look forward to experiencing eternal life with her as she runs and plays and converses in ways we can only imagine.

Created with Disabilities for a Purpose

Each individual is handcrafted by the Creator to display his glory.

As we dove into the world of therapies and ongoing doctor visits, engaging with those who were walking on the same path we were, the prophet Isaiah reminded us that each individual is handcrafted by the Creator to display his glory (Isaiah 43:7; see Romans 11:36).

And we learned what Jesus, the Creator of our son, taught his disciples: “As [Jesus] passed by, he saw a man blind from birth. And his disciples asked him, ‘Rabbi, who sinned, this man or his parents, that he was born blind?’ Jesus answered, ‘It was not that this man sinned, or his parents, but that the works of God might be displayed in him’” (John 9:1–3).

Although mutations, diseases, disabilities, and suffering are part of the curse and are the result of our general

sin in Adam, they aren't necessarily a direct result of any specific sin that we've committed. Jesus makes this clear here. Although the man and his parents were sinners, his blindness wasn't the direct result of a sin that they had committed.

This man was blind, and the rest of us were also created as we are in order to display the amazing works of God in our lives. Kieran is a walking banner for the works of God.

The Real Source of our Value

We've seen an argument among the pro-life community that somewhat reflects Jesus' teaching, but it puts the emphasis in the wrong place. In a Williams syndrome group on social media, someone posted her thoughts about a mom who had her unborn baby killed because the baby had been diagnosed with Williams syndrome: “If she only knew how much of a blessing our children are, if she could only see how much they contribute to society, surely they would change their minds.”

Another video that occasionally floats around the pro-life community features the singer Andrea Bocelli's story of how the doctors urged his mother to kill him before he was born because he was blind. The video's message is, “Look at how much Andrea Bocelli has contributed to our society through his music; think what we would be missing if he had been aborted.”

What's the difficulty with these two examples? The danger is that the worth of a person is tied up in his or her contributions, his or her work, instead of each person's inherent value as an imagebearer of God. If we begin to assign the value of human life on what we do rather than who we are as people created in God's image, then we shift the argument for life from an absolute standard (“God says do not intentionally take the life of someone who bears my image”) to one that is utilitarian at best. It makes some people less valuable—and more disposable—than others.

It's Still Difficult

It is certainly true that each child is a gift and blessing from God. And we've experienced that with Kieran. He has a quick smile, a huge laugh, a friendly countenance, and a love for God that puts me to shame. But disabilities bring difficulty as well.

It is hard to watch your child struggle with tasks a child who is developing typically can do easily. Continual hospital visits are overwhelming. Medical bills rack up quickly.

When we contend for the value of life because of “the good he brings to the world” instead of emphasizing that our value is based on God's Word, we may, perhaps, miss another purpose in suffering and disability.

I appreciate Paul's perspective on suffering in 2 Corinthians 1:8–11. He begins, “We do not want you to be unaware, brothers, of the affliction we experienced in Asia. For we were so utterly burdened beyond our strength that we despaired of life itself. Indeed, we felt that we had received the sentence of death.” (Incidentally,

Paul's despair here and his next comments show how false that old adage really is: "God won't give you more than you can handle.")

Then he concludes, "But that was to make us rely not on ourselves but on God, who raises the dead. He delivered us from such a deadly peril, and he will deliver us. On him we have set our hope that he will deliver us again."

We serve a God who gives grace for every day and every situation. Disability and suffering show us very quickly that we cannot rely on ourselves and that we desperately need the Holy Spirit to work in our lives to bring comfort, strength, wisdom, and all his fruit. These difficulties can lead us to a deeper relationship with our Savior and his Word as we depend on him. Even in disability, God is working to conform us to the image of his Son.

When we gloss over the hard parts of disability, we aren't being honest about real life in a cursed, fallen world, and we can't accurately minister to others who find themselves in these difficult situations. Paul was honest about what he was going through; he pointed to God, and he invited fellow believers to share in what he was going through so that others will see "the works of God" and praise the Lord.

Sadly, in many cases, disabilities cause people to turn away from following Christ, but our attitude should be

the opposite. Christians, of all people, should recognize that each person bears the image of God. When the Lord brings someone with a disability across our path, we need to seek to get to know him or her first as an individual, finding out who he or she is as a person. And, in some cases, we might discover how we can be the tangible hands and feet of Christ, not out of pity but out of a love for Jesus and those he has created.

In fact, Jesus commanded, "When you give a feast, invite the poor, the crippled, the lame, the blind, and you will be blessed, because they cannot repay you. For you will be repaid at the resurrection of the just" (Luke 14:13-14).

In God's family, "the parts of the body that seem to be weaker are indispensable" (emphasis mine, 1 Corinthians 12:22). Having Kieran in our lives has made this passage take on a much more personal meaning for us.

Throughout our journey, the Word of God has been powerful in changing and forming our own perspective on those with disabilities. Most importantly, we are thankful that God, in his goodness, has given our indispensable son for his good purposes.

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