BEYOND SUFFERING
A Christian View on Disability Ministry

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The Gift of People with Down Syndrome

By Stephanie O. Hubach

My family lives in the heart of Lancaster County, Pennsylvania—home of the largest Amish population on the East Coast of the United States. Yes, our neighborhoods have homes without electric power, farms with windmills, and women who wear head coverings accompanied by men clothed in black. And our county roads are well-traveled by horse-drawn buggies. Several years ago, my youngest son, Tim, started getting annoyed with this particular form of slow-moving traffic around us, especially if he was on his way to work. The Amish presence in Lancaster has a unique and beautiful influence on the collective culture here, yet Amish buggies can slow us down, and their presence requires a different kind of care and concern while driving.

One day, while on the way to work, Tim's annoyance was on full display. As we pulled into the opposing lane of traffic to safely pass the horse-drawn carriage ahead of us, Tim burst into song. To the tune of "Holy, Holy, Holy" he warbled, *"What are you doing here? Go and get a c . . . a . . . r!"* Apparently, an unwillingness to accommodate others in their differences, and our dislike of how those differences inconvenience us, is universal. You see, my 29-year-old son Tim has Down syndrome. Oh, the irony of it all.

The Last Children of Down Syndrome

A different shade of irony colors "The Last Children of Down Syndrome," a December 2020 article in *The Atlantic* that explores hard questions behind the high abortion rate of children with Down syndrome in Denmark. While operating from a posture that is protective of a "woman's right to choose," writer Sarah Zhang is clearly troubled by the underlying implications of the decisions that women are exercising in practice. The abortion rate of children with Down syndrome stands at 95% in a country that prides itself on being accepting and supportive of diversity. This translates into the births of only 18 babies with Down syndrome in 2019—in the entire country.

Why the disconnect? "Denmark is not on its surface particularly hostile to disability. People with Down syndrome are entitled to healthcare, education, even money for the special shoes that fit their wider, more flexible feet. . . . *Yet a gulf seems to separate the publicly expressed attitudes and the private decisions* [emphasis mine]," Zhang writes. In her well-researched, lengthy article Zhang reflects, "The decisions parents make after prenatal testing are private and individual ones. But when the decisions so overwhelmingly swing one way—to abort—it does seem to reflect something more: an entire society's judgment about the lives of people with Down syndrome."

Several key themes emerge in Zhang's writing. And these themes explain the devastating drop in babies born with Down syndrome in Denmark. They include the role of eugenics, a profound sense of risk aversion by parents, and a societal obsession with achievement. While the story is researched in and written about Danish society, there are parallels to life in the United States. We too are a country that increasingly embraces diversity, yet we have an abortion rate that, while not as high as Denmark, still results in the vast majority of children diagnosed in utero with Down syndrome being aborted.

How can we better understand the issues that influence a society's judgment of Down syndrome? How can we learn to actively value people with Down syndrome and become better in tune with the unique gifts they bring to society and to the Church? How can we joyfully embrace the genuine sacrifices that inclusion of those with notable differences requires of us? How do we demonstrate love to both the unborn baby with Down syndrome and the expectant mother who is processing a diagnosis of Down syndrome in utero—at the same time?

A Primer on Down Syndrome

Psalm 139 makes no distinctions when the psalmist reminds us, so beautifully, of God's unique, cherished design of human beings:

> "For you have formed my inward parts; you knitted me together in my mother's womb. I praise you, for I am fearfully and wonderfully made. Wonderful are your works; my soul knows it very well." (Psalm 139:13–14)

For people with Down syndrome, the presence of an additional 21st chromosome represents a distinct way they are fearfully and wonderfully made. They possess 47 chromosomes instead of the typical 46, and the inclusion of this additional genetic material results in a collection of discernible characteristics and an increased likelihood of various medical conditions. These include heart defects, gastrointestinal anomalies, respiratory vulnerabilities, thyroid disease, hearing loss, vision impairment, speech difficulties, intellectual disability, sleep apnea, an increased risk for childhood leukemia and an increased risk for early-onset Alzheimer's disease in adulthood. And this is not an exhaustive list.

Down syndrome can also co-occur with autism. Since Down syndrome is a syndrome, it is simply a collection of possible conditions and characteristics, not a complete or certain collection. A child with Down syndrome may be born with a heart defect, for example, but never develop thyroid disease or leukemia. Intellectual disability occurs over a broad spectrum, with the vast majority of people with Down syndrome experiencing only mild or moderate cognitive impairment. With medical and educational advances, both the lifespan and quality of life for people with Down syndrome have dramatically improved in American society over the last 50 years.

The name "Down syndrome" was adopted in 1961 to honor Dr. Langdon Down who first recognized the collection of features that are characteristic of Down syndrome while working at the Earlswood Asylum in England during the 19th century. The underlying cause for Down syndrome is not known, but the incidence is correlated with maternal age. As a woman ages, the statistical probability of giving birth to a baby with Down syndrome increases as well. While that probability increases with age, especially over age 35, approximately 80% of babies with Down syndrome are born to women under 35 years of age, due to the higher birth rates in general for younger women.

While originally prenatal screening for Down syndrome was only recommended to expectant mothers age 35 or older in the United States, in 2007 the American College of Obstetrics and Gynecology adopted a new approach to offer screening to women of all ages. With the introduction of non-invasive prenatal testing (NIPT) a probable Down syndrome diagnosis can be obtained as early as 11 weeks into the pregnancy. This is not good news for babies with Down syndrome. According to the Center for Disease Control (CDC), live births of babies with Down syndrome currently occur in one out of every 700 births in the United States.

The Role of Eugenics

Prenatal testing for Down syndrome has its roots in the eugenics movement which originated in England in the late 19th century and was funded and promoted in the United States during the early 20th century. Sir Francis Galton, who was a cousin of Charles Darwin, first coined the term eugenics, which means "good genes."

During the Industrial Revolution social-economic challenges had risen dramatically. Western society struggled to deal with an influx of immigrants, increasing poverty, and a variety of social ills. The aim of eugenics was simple—to multiply the desirables while eliminating those society deemed undesirable. As Galton stated, "What nature does blindly, slowly, ruthlessly, man may do providentially, quickly, and kindly." In order for this intentional version of natural selection to take place effectively, Galton argued that eugenics "must be introduced into the national conscience, like a new religion."

Indeed, many religious organizations and churches jumped on board the eugenics bandwagon in the early 1900s. As Christine Rosen states in *Preaching Eugenics*, "science…could neither satisfactorily inspire nor maintain strong sentiments in its devotees. Only religion could do this." Finding an affinity with the social gospel—the idea that the kingdom of God can be brought to its fullness on earth through the efforts of humanity—the eugenics movement and the liberal Protestant church linked arms. Rosen goes on to observe that "the aim of the movement was, in principle, the aim of the churches: the improvement of the human race." The Catholic Church and conservative Protestant denominations and congregations largely rejected both eugenics and the social gospel during this era.

Once the philosophy was in motion, real-world consequences followed. Efforts by pioneers like Dr. John Langdon Down, who believed in the educability of people with intellectual disabilities, were soon overrun by the push for increasing segregation, institutionalization, and sterilization of "the feebleminded" in the name of bettering society.

While de-institutionalization of people with intellectual disabilities has occurred over the last 50 years and forced sterilization of people with disabilities has been outlawed, eugenic philosophy and methods are still active in the selective abortion industry via prenatal testing. As Zhang of *The Atlantic* notes, "Few people speak publicly of wanting to 'eliminate' Down syndrome. Yet individual choices are adding up to something very close to that." Zhang also observes, "[Down syndrome] was one of the first genetic conditions to be routinely screened for in utero, and it remains the most morally troubling because it is among the least severe. It is very much compatible with life—even a long, happy life."

Zhang proposes that ordinary parents have been thrust, by the medical community, into becoming "moral pioneers" without the experience, the background, or the accurate information with which to make such life-and-death decisions. In Nazi Germany, people with disabilities were considered to be "life unworthy of life." What is a life unworthy of life? What is a life worthy of life? How prepared is the average person to articulate well-founded answers to such questions, especially under pressure in a doctor's office? On what basis do most people make such a decision when faced with a positive test result for Down syndrome in utero? Zhang soberly reminds us, "Recent advances in genetics provoke anxieties about a future where parents choose what kind of child to have, or not have. But that hypothetical future is already here. It's been here for an entire generation."

Autonomy and Eugenics

The Scriptures, from the very first chapter of Genesis, provide the Christian with the foundation to evaluate these questions. We have heard it so often that we fail to marvel at its profound simplicity.

> "So God created humankind in his own image, in the image of God he created him; male and female he created them." (Genesis 1:27)

As image bearers of the living God, our value is unmovable in His intentional identification with us. And our mission is unchangeable in His task for us to carry His character into the world. As Dr. John Kilner writes in *Dignity and Destiny*, "Being the image of God turns out to mean having a special connection with God and indeed being a meaningful reflection of God."

The fall of humanity, through our first parents' sinful quest for autonomy from our Creator, did not negate the image-bearing connection to God as the basis of our value, but it did distort our image-bearing reflection of the character of God. Not only does the Fall impact our relationship with God—and therefore our ability to accurately reflect His character—it has ongoing ramifications on our relationships with self, others, and nature. Chromosomal abnormalities are simply one example of a disruption with nature. (They are not, as Jesus clearly stated in John 9, a result of personal sin.)

As such, disability can be understood as a normal part of life (something to be expected) in an abnormal world, a world where human life is not operating as it was originally designed. On this side of Eden, all human life is still worthy of life. The further scientists explore the human genome, the more we realize how many anomalies we all live with: we simply don't experience known effects from them. So, ability and disability occur along a spectrum, across every aspect of our personhood.

As image bearers of our Creator, even with a distorted reflection of him, professor Jerram Barrs of Covenant Seminary says, "Scripture calls us to recognize that everyone we're going to meet is made in the image of God, and that means they're glorious. That's to be our first response: to see the glory of the person . . . and to treasure all the things that are good, admirable, and beautiful about the person as a person made in the image of God."

Is that the first thing we think of when we see a person with a developmental disability? Do we see them as glorious? Do we look, first and foremost, for ways in which we see the goodness, truth, and beauty of God in them? The sad paradox of eugenics is not only how subtly it influences our thinking, but also how its aim is to allow humanity to be autonomous decision-makers about whose life is worth living. It repeats the error of the first sin in the Garden. It is a quest for God-like power without God-like character.

Applying the Gospel to Eugenics

In December 2020, Nate Shurden, pastor of Cornerstone Presbyterian, in Franklin, Tennessee, and his wife Christy were blessed with a baby girl, Lila, who was born with Down syndrome. Lila is the youngest of five children. Reflecting on the gospel implications of Down syndrome, Nate says "The reality of their need for Christ is as real and pertinent as anyone's. We're no less needy than they are of the most important realities of the gospel. That's a really counter-cultural message that lays a platform for gospel witness."

Every one of us is equally in need of the saving work of Christ on our behalf, and uniquely in need of the transforming work of the Holy Spirit to change us to more and more reflect the character of Christ. We can be prone to perceive people with Down syndrome as the ones who need our help. Yet, we all stand before God together in need of *His* help.

The good news of the gospel isn't about making people with Down syndrome more like you and me, it's about making all of us more like Christ. The gospel is the good news of the saving reign of Jesus. It is a reign that brings the coming of his kingdom to push back the ramifications of the fall in every arena of life: starting with our personal relationship with God himself, and spreading into the arenas of relationship with self, with others and with nature.

Contrary to the social gospel message, the reign of God comes through his power, not ours. And it will not come in all its fullness until the ultimate consummation of Christ's kingdom. To the degree to which Christ's kingdom is revealed in this lifetime, it only *ever* comes in ways that are consistent with the character of God himself. Dr. Amos Yong of Regent University reminds us in *Theology and Down Syndrome*, "science and technology remain omnipresent not only in terms of the possibilities they introduce to better lives of people with Down syndrome, but also in terms of *the threats they continue to pose* (emphasis mine)." From the ideas we embrace to the applications of science that we employ: they're all meant to be handled in a way that is consistent with carrying God's character into the world, which exists in the tension of the already-not-yet-ness of the coming of the kingdom of God.

The Risk Aversion of Expectant Parents

A major theme of "The Last Children of Down Syndrome" is the "profound risk aversion" on the part of expectant parents. Fear plays a powerful role in parents who have children with Down syndrome and those who aborted their children with Down syndrome. One researcher studied the decision-making behavior of parents who received a positive Down syndrome test result and noted, "The women who chose abortion feared the worst possible outcomes." Even acknowledging the possibility that a child may not be severely impaired by Down syndrome, in the end, "the uncertainty just becomes too much."

Many parents of children with Down syndrome will testify to a period of mourning after their child's diagnosis is confirmed, whether in utero or after birth. The grieving is not a grieving over the child they have, but over the loss of expectations of what their lives would be like, unconscious expectations that many do not realize they carry.

Zhang makes a profound insight on this experience: "[Nothing] is guaranteed with any kid, of course, but while most parents go through a slow realignment of expectations over the years, prenatal testing was a rapid plummet into disappointment—all those dreams, however unrealistic, evaporating at once." In other words, all of the oxygen is sucked out of the room in a single moment. Reflecting on that experience, Nate Shurden responded, "I wouldn't have put it that way at the moment, but it felt like being robbed of something that actually God never promised would be mine."

What makes this experience of receiving a diagnosis even more fear-inducing is the way the information is often delivered. Bruce and Cynthia Young, both professors at Covenant College, reflect on the way they learned their seventh child, Isaiah, had Down syndrome. Cynthia Young says, "I didn't understand what the word 'syndrome' meant. I thought that everything I read about would happen. So, I was just waiting for things to show up, not realizing that some of that might not happen."

For Cynthia and Bruce, Isaiah was immediately whisked away to the neo-natal intensive care unit (NICU), where the staff refused to let her breastfeed even though Cynthia was a trained lactation counselor. The Youngs were not allowed to take Isaiah home when Cynthia was discharged and were provided little explanation. "We were just so upset by the whole NICU nightmare that once he came home, we were thrilled to have him back."

For Nate and Christy Shurden, because of Christy's age (41) at the onset of her pregnancy with Lila, the obstetrician automatically conducted non-invasive prenatal testing (NIPT). When the NIPT came back with a 90% probability of Down syndrome, the Shurdens declined further testing. Christy relayed that the doctor was unfriendly, her tone was negative, and her delivery of the news was devastating. The physician's approach added weight to the experience. Christy remarked, "I kept hearing her voice of 'I'm so sorry.' I think if her voice had been, 'It's going to be OK,' if she'd said it in a different way, it would have been so much easier. I found out on a Thursday, and I cried all weekend. I was devastated."

A Christian Response to Fear

Accurate information on Down syndrome does help to alleviate unfounded fears about what it means to have a son or daughter with that extra special amount of genetic material. Yet informational knowledge alone is not enough. Zhang notes that "parents who made the unusual choice to continue a pregnancy after a Down syndrome diagnosis" were "more willing to embrace uncertainty." For Christians, our willingness to embrace uncertainty ought to be directly tied to our confidence in the character of God. As Bill Massey states, "Christians have a huge advantage that other people don't have. [We know that] God has good and wise purposes."

Nate Shurden says we need to recognize "He's made this choice for us. And if He has loved us in the way that He's loved us, and secured eternity for us on the back of His own Son and the sacrifice He's made, how will this choice that He has made for us not also be for our eternal good and the blessing and unfolding of His redemption? He's inviting us into a deeper experience of His love."

Not only is God's character trustworthy, but we need to be reminded that God writes our stories, not us. This is significantly counter-cultural. Tim Locke, pastor of East Cobb Presbyterian Church in Marietta, Georgia, and father to Matt, a 17-year-old with Down syndrome, says that in today's culture, "everyone's writing their own stories." Nate Shurden says, "It is really good that He's writing our story. He's in control of it and not us. And that's an act of faith. That not an easy thing—I don't say that flippantly—I've had to continue to learn that and will, I'm sure, continue to have to learn that. But let's believe what He tells us."

In the wake of all their adverse experiences with the NICU, Cynthia Young describes her role in Isaiah's life as straightforward. It was as if God said, "I need you to do this one thing: be his mother." Cynthia has embraced that call. It has been a walk of faith for 23 years.

Tim Locke makes another observation about parenting children with disabilities. One of the myths, he remarks, is that "God only gives children with Down syndrome to special people. No. God makes us special. It's not a special type of person—it's the person you become that's a beautiful thing." In *The Atlantic*, Zhang quotes a woman who had chosen abortion after an in-utero diagnosis of a fetal anomaly. This mother's words were chilling: "I have guilt for not being the kind of person who could parent this particular type of special need. Guilt, guilt, guilt."

This is where the hope of the gospel is so powerful. As Christians, we ought to know, more than anyone, that none of us comes to life as the type of person we need to be. All of us have made choices in life that produce guilt, guilt, guilt. This woman is not "the other." She is one of us, a sinner in need of the saving grace of Christ, a human being who is painfully aware of her finiteness and her limitations. Christ offers life, even to those who have not chosen it for their unborn child. He's lived a perfect life on our behalf, died a perfect death on our behalf, and been raised to life to secure our redemption.

Because God writes our stories, He also provides us with every ounce of forgiveness that we need, and the indwelling power of the Spirit that we require to live it in a way that honors Him. That's really good news, for all of us and especially for families who struggle with a diagnosis of Down syndrome.

Pushing Past Our Obsession with Achievement

In the closing pages of the article on "The Last People of Down Syndrome," Zhang wonders about society's obsession with achievement, and how this informs our perceptions of people with Down syndrome. Reflecting on a conversation she had with a parent, Zhang ponders,

> Down syndrome is defined and diagnosed by a medical system made up of people who have to be highly successful to get there, who likely base part of their identity on intelligence. This is the system giving parents the tools to decide what kind of children to have. Might it be biased on the question of whose lives have value?

Personal quests for achievement can also weigh heavily on a woman's decision-making process in the face of a prenatal diagnosis. Drawing from research conducted in New York City in the late 20th century Zhang writes, "middle class white women especially seemed fixated on the idea of 'selfishness.' The women she interviewed were among the first in their families to forgo homemaking for paid work; they had not just jobs but careers that were central to their identity." This connection between identity and achievement is significant, and perhaps cuts to the heart of the matter. As a society, we've made personal identity about what we do, how we perform, and what we accomplish.

While Zhang recognizes that emphasizing the capabilities of people with Down syndrome is an "important corrective to the low expectations that persist" she also acknowledges that "it does not capture the full range of experiences, especially for people whose disabilities are more serious . . . ." Then she makes the most powerful statement: "Jobs and college are achievements worth celebrating, like any kid's milestones, but I've wondered why we so often need to point to achievements for evidence that the lives of people with Down syndrome are meaningful."

Learning to Value What God Values

If we have to make a name for ourselves, tremendous pressure exists, not only on us but on the backs of our children. However, the power of the biblical story is that God has already named us as His image bearers. We carry His name. If we have come to Christ in repentance and faith, we are also named as His adopted children. Trusting in Christ's perfection in exchange for our imperfections means we have nothing to prove in this life. Not a single thing. Can we put our energies into creativity and contributing to culture? Absolutely. As His image bearers, we were made for that express purpose, with a catch, that our mission is to reflect His glory, not our own. And as Shakespeare says, "Ah, there's the rub."

One parent Zhang spoke with relayed a story where she was asked, "What are you most proud of about your son that is not an achievement or milestone?" Zhang was struck with the power of that question "because of how subtly yet powerfully it reframes what parents should value in their children."

So, I asked that same question of the parents interviewed in this article. Valerie Massey, Will's mom, replied through tears, "Just who he is. So much fun. A great sense of humor, kindness and politeness."

Regarding Matt, Tim Locke responded, "He has relational skills, tenderness, compassion, and a refusal to do anything until everyone is there. He wants to show love and kindness and respect to other people, which is really fun to be a part of. He's very tender. I love that about him." Debbie Locke added, "I'd echo that. His heart is more Jesus-like than anyone in the family. Matthew has a better grasp of and grip on the gospel. In that aspect, I'm actually in awe of him. He sees people."

Cynthia Young shared, "It's humbling for me to see that Isaiah understands his sin, his repentance is sincere, and his asking for forgiveness is genuine."

All of us need to learn to see the gifts of people around us. Opening not only our hearts but our lives is essential to secure lasting change for people with Down syndrome who have historically lived on the margins of society, and often, on the margins of the Church. It's not enough to invite people with differences into our midst, we need to allow who we are and how we function to be transformed by their presence.

Nate Shurden said, "True inclusion and diversity requires sacrifice. At the heart of it, there's got to be a gospel center. There's got to be a connection to Christ's sacrifice for us. True inclusion required the death of the son of God, so reconciliation always requires death. True reconciliation. That's where the gospel comes in. God wants to do that with the story of Lila."

In the face of eugenics-rooted prenatal testing and the heartbreaking availability of selective abortion, we can easily lose sight of the reality that there are two souls at stake. As a friend recently reminded me, "There are souls at stake in the womb and souls at stake who have a womb." Our privilege is to advocate for life for both of them. This abundant life comes through knowing the saving grace of Christ, abdicating our personal thrones, and embracing that He writes our stories.

The Church's call, as Dr. Harvie Conn states in *Evangelism: Doing Justice and Preaching Grace*, is "not only to proclaim the kingdom, but to exemplify it." We need to be a place that not only shares the gospel with people with disabilities and their families, but that celebrates their presence in our midst. May we as a denomination continue to grow in grace as we seek, more and more, to learn to exemplify the upside-down life of the kingdom of God.

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