



Summer 2019 | Theme: Down Syndrome

Authors describe some of the joys and challenges they and their church have experienced in loving and living with someone with Down syndrome.

A Church Enlivened by Grace

by Diana Ackner

First Reformed Church, Scotia NY

If we believe that we are all children of God who are made in God's image, then all people are welcome in God's family whether their development is "typical" or not.

When our daughter Grace was born, we did not know the challenge of believing this statement for our family and those around us, including our church. Grace was born with Down syndrome and had four holes in her heart. The road ahead was long and rough. We needed help. We needed God, our church, and lots of prayer.

Every week we faithfully dragged to church the oxygen tank, the diaper bag, and the child-in-the-car-seat carrier, and took up an entire pew. Soon Grace was baptized, and we embraced the hymn, “Guide Our Feet While We Run This Race.” Our pastors were delighted that we took the time and energy to come to church and share our beautiful girl and our story.

As Grace got older, she could be loud and unpredictable, but we persisted in trying to educate the congregation about her needs. Because her personality won over people, they were not afraid to ask questions to learn what they needed to do to be her friend. We had to speak up when people said hurtful things or reacted inappropriately. The congregation had much to learn and had to listen and be patient. When Grace was diagnosed with leukemia at 4 ½, God was with us and our church family was there for Grace and for us in that new long road.

As Grace grew, our church family watched over her as she navigated the church building on her own. Everyone learned not to allow her to leave the building. Church buddies learned to be patient when conversing with her and not to underestimate her abilities. They supported her when she wanted to go to Camp Fowler without mom and dad. The camp volunteers that week were church family members, and Grace has been going to Camp Fowler ever since. Church and camp

both are homes away from home for Grace, and they have played a major role in her 18 years.

When we encounter anyone with a disability—Down syndrome or otherwise—we can acknowledge that they are a child of God, worthy of our love, by practicing patience and kindness and by asking respectful questions that lead to understanding.

Student, Servant, Best Friend

by Scott Ludwigsen

Middlebush Reformed Church, Somerset NJ

I have been attending Middlebush Reformed Church for almost three decades. During this time my children grew up in the church. Each was baptized and confirmed at Middlebush, and all have started their professional careers and moved out of the area. When they return home for the holidays, they look forward to seeing their Middlebush Reformed Church friends who are returning home at the same time.

During these three decades I have met and served alongside many great people from Middlebush. I have served as an elder and deacon. I've taught Sunday school and been a member of the Trust Fund, Memorial Fund, personnel team, church softball team, and church choir. The people I have served with

have become more than just my church family—they are my prayer partners and my friends as well.

One of my best friends at Middlebush is Bobby Maehr. He is 20 years younger than I, but he is the first person who greets me as I walk into our church breezeway each Sunday. Bobby gives me a big smile, a handshake, and a hug every Sunday morning. Everyone in the church knows Bobby, and he offers many happy greetings each Sunday.

Bobby is not the pastor, an elder, or a deacon. He is a confirmed member, an usher, a loyal Sunday school student, and he serves the congregation by pulling the giant rope in our bell tower each Sunday to let the surrounding community know that church is about to begin. Bobby is an athlete, a son, a brother, a nephew, a cousin, and a friend.

For the past quarter century, Bobby and I have shared a Sunday school class together. Some call me his teacher, but I feel as though I am spending time with a friend reading Bible stories and writing in our prayer journal. It's hard to say who gets more out of Sunday school class, Bobby or me. We talk, we laugh, we pray, and we enjoy our time together every Sunday morning.

One more thing: Bobby has Down syndrome, but that does not define him.

Middlebush Opens Its Arms

by Brenda Maehr

Middlebush Reformed Church, Somerset NJ

When a child with a disability is born, it's natural for parents to wonder why God allowed this happen to us. It is a question that people have asked for centuries. When Jesus walked the earth, people asked him whose sin was to blame when a child was born blind. He replied that it was not due to an individual's sin, but was for the "glory of his Father in heaven."

Families of children with disabilities can face many trials and tribulations along the road of life. When our son Bobby was born with Down syndrome and a rare congenital heart defect, it was devastating. Through the people of Middlebush Reformed Church, we learned that God still cares for us. I never darkened the door of a church until he was about five. At Middlebush, we received a warm welcome and learned there were others with Down syndrome. We felt love and compassion and recognized that God is our greatest ally.

A Gift from God

by Martha Schreiber

Fellowship CRC, Etobicoke ON

My youngest daughter was due on my 45th birthday. My husband picked out her name—Mathea, meaning “gift of God.” Although she was given a diagnosis of Down syndrome within minutes of her birth, it seemed an appropriate name. Perhaps my husband gave the wisest words in the hours after her birth: “Enjoy her as a baby because she is a beautiful baby.” And despite tears shed at her diagnosis, we did enjoy her as a baby. She displayed everything to love about babies: she was tiny, cute, content, loved to be held and cuddled. Yesterday, as I am writing this, she turned 12.

For me, my youngest daughter embodies the Disability Concerns motto: “Everybody belongs, everybody serves.” Mathea has a wonderful sense of belonging. She doesn’t question it; she just accepts that she belongs in her family, in her church, and thankfully, in her school. In our family, she considers herself an equal to her two older sisters and knows her place within the extended family. On Sundays she loves to go to “our church,” as she says.

As for serving, I can see that, at the age of 12, Mathea has the gift of prayer and the gift of worship. Mathea loves to lead in mealtime prayers. Her older sisters may roll their eyes at her long prayers, and I am reminded of my late grandfather's long mealtime prayers. Mathea will pray for everything that's important to her, even remembering people in our church we have been praying for.

Mathea loves our church and the worship service. She loves to sing and has never complained about boring sermons. All three of our daughters are gifted in music. Although not as musically gifted as her sisters, Mathea loves to stand beside the worship leaders and either conduct the congregation in singing, play air cello or flute, or sing (or hum) her heart out. When the offering is received, she has to put an offering into the plate. Once when her father forgot to pass her the offering, I had to take her to the back of the church to catch up with the deacons, so she could add her offering.

Recently she came home from a GEMS sleepover with a spontaneous testimony, "I'm happy to believe in God." Many people have commented to us what a blessing she is—a true gift from God.

Missed Opportunities for Belonging

by Jeannette Versteeg

Bethel CRC, Listowel ON

Having a child with Down syndrome sends you on a lifetime journey of advocating. Although our son Evan is now in his later teen years, we have found that our church is still not prepared for a child with Down syndrome.

From the moment a child is born with special needs, time becomes consumed with doctor and specialist appointments. Every next step—finding day care, preparing for school, or entering a new church program—means more time advocating for your child. I am willing to advocate for him, but I had hoped that our church would take the initiative with our family. When he started Sunday school years ago, I did not mind making a plan for the leaders to set up a class that would work.

We're frustrated that there has been only one year for Sunday school we did not have to advocate. As parents, we get tired of the process, and find it difficult to send Evan to any church activities except those he attends with us. A few times leaders have encouraged our child to be more active in the church programs, but they have not worked to accommodate his needs within the programs.

Our church has done a great job of addressing problems for people with physical disabilities but not for those with intellectual disabilities. Now that Evan is in his teens, we want him to have a close, constant connection to the church that is independent of us, his parents. The church needs an advocate so the next children do not get left behind.

Individuals engage and encourage Evan, but the church and its youth programs are missing out on the joy that full inclusion could bring. Our child is missing out on friendships, mentoring, and youth events others experience.

Editor's Note

Transformed by Relationships

Studies have long been circulated claiming that more than 80 percent of women choose to end their pregnancy when prenatal testing reveals the fetus has Down syndrome. Some have pushed back, saying the percentage is inflated and lacks nuance. There's always more to the story than a number or a percentage can capture.

When it comes to life with a disability and conversations about abortion or euthanasia, the issue of projection leads us to assume certain things about what life will be like for people with disabilities and their families. Usually suffering is assumed—inevitably by people *without* disabilities—that then asks whether such a life is worthwhile.

Theologian John Swinton says, “Within a society that uses the criteria of independence, productivity, intellectual prowess, and social position to judge the value of human beings, there will always be questions relating to the value of people with certain disabilities.”

Often, however, people’s lives and worldviews are radically transformed through encounters with people with disabilities. Friendship and loving relationships with people with disabilities change lives, reshape priorities, and alter visions of God and humanness.

The articles in this issue—all written by those who know personally someone living with Down syndrome—capture some of the challenges and the personal transformation the authors have experienced through those relationships.

— Terry A. DeYoung

Ways to Get Involved

Without monetary support for Disability Concerns, we wouldn't be able to share these stories. To help us make sure that "everybody belongs, everybody serves," would you please consider praying for us and making a financial contribution? It's quick, it's easy, and it's a gracious and beautiful act of obedience.

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Upcoming Themes

Fall 2019—Deaf and hard of hearing

Is American Sign Language your heart language? Did you grow up with a Deaf sibling or Deaf parent? Do you use hearing aids or have a cochlear implant? Please tell us your story (400 words) by **July 29**.

Winter 2019—Medications

Many of us need to take medications—for pain, for rheumatoid arthritis, for seizures, and for other reasons. Medications can

improve quality of life and can cause side effects. If treatment of a disability or mental health challenge involves medication for you or a loved one, please tell us your story (400 words) by **September 30.**

Additional Formats Online

You can find this issue in a variety of alternative formats (print-friendly layout, audio, Spanish, and Korean) in the *Breaking Barriers* section of the Network website at bit.ly/bbsummer2019.

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