

# Breaking Barriers

*everybody belongs everybody serves*

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A Ministry of Christian Reformed Church  and Reformed Church in America  Disability Concerns

## Theme

Fall: When parents find out that their child has a disability, many grieve the child they thought they would have as they come to love the child God has brought to them. This issue of Breaking Barriers is devoted to parenting a child with a disability.

Winter: In what ways has living with a disability made an impact on serving in the church offices of deacon, elder, and minister? Please tell us a story about a joy, triumph, or challenge you and your church have encountered. Please send us articles (500 words or less) by November 10, 2011.

Spring: Among other things, living longer increases the incidence of disabilities. How has your church accommodated or assisted aging adults with disabilities—and/or their children? Send us articles by February 10, 2012.

# At Work on Anna's Angel Wings

Angie Kimmel, member of Peace Reformed Church, Eagan, Minnesota

“How wonderful that God chose you to raise such a special angel!”

Really? Well, thanks God, I guess, but why me? Why do I deserve to be a “chosen” one?

Only parents of typical children ever share this “special blessing” with me. Those of us with “special angels” are thinking, “God made a choice? God chose my child to be disabled?” Does God really sit in heaven and say, “Hey, let’s make a disabled child.” That seems like a cruel God. Perhaps parents who specifically choose to adopt a child with special needs are the ones who deserve a pat on the back.

I love my child. Indeed, Anna is a blessing. But I believe that, in God’s gift of human freedom, occasionally children are born with special needs—more as a result of chance than anyone’s choice. If you play the “conception game,” sometimes the result is not exactly what you planned, wanted, or hoped for.

Parenting a child with special-needs is a challenge. It is tiring, messy, and difficult. Most of us are simply trying to make it work with the hand we have been dealt. We want to raise our child to use those limp or flapping hands for good—or just to feed themselves. We want our child to be part of the group, to have friends, and not to be stared at because she is different.

Anna can be smart and sassy, curious and rude, a bossy leader—just like any other kid. She is also different. Anna can't run or walk, but she is constantly told to slow down when she speeds down the hallway in her power chair. Other kids are allowed to be kids, but Anna must be good, behaved, and on task—all the time. Other kids get tired, bored, and angry; they whisper to their friends, or tell a classmate they hate the science teacher when he assigns too much homework. Anna's desk is positioned at the back of the room so her power chair won't be "in the way," and she is seated next to an adult aide so she can be always on task. Anna can't giggle or gossip with friends during a school assembly because she has to sit in her chair, in the back and out of the way, by the teachers.

Yes, my child is special. She is also different. She wants to walk without braces on her legs; she wants to run and not slow down. She loves the pool because in water she can stand, walk, float, twist, dive, and swim; she is a mermaid.

Unlike many adults, when kids are curious about Anna they ask her questions directly. My favorite kid questions are asked primarily by little boys: "Hey, can you let me have a turn driving your chair? How fast does it go? Do you ever hit stuff...on purpose?"

My child is special, but I am no angel. She is the one with wings. When my sister died suddenly, Anna told us it was okay and that Aunt Marti was lucky. She was going to have her own power chair in heaven "because everyone up there gets one." My angel, in her power chair, is just experiencing heaven here on earth. Now, if she could just receive some wings then she wouldn't need to run—she could soar.

# Olivia's Small Steps and Huge Heart

Karen Van Epps, member of First Church (RCA) in Albany, New York

Grandparenting a six-year-old with multiple disabilities has awakened me and her family to grow in Christian courage and understanding. Our Olivia does not speak, is not toilet trained, and works hard to accommodate herself to low muscle tone. Every day brings a new challenge for her and for us, but her gentle, sweet demeanor encourages everyone. I never forget God's grace when witnessing Olivia's continued determination.

Many times have I said, "This child is addictive!" God has helped me understand and accept that she causes us to think and act differently from a family that has typical children. I am humbled by her small steps toward growth, steps we often take for granted but ones that take her a long time to accomplish. We all clapped and jumped for joy when she finally walked independently at age four. We hovered over her when she entered preschool with a walker and smiled with tears of joy when she entered kindergarten walking into school holding the hand of her aide. Olivia loves school, and she attempts to socialize with peers and take part in all activities. She still tumbles and falls but regroups and starts again. God has given her such determination!

Eating has progressed from spoon-feeding to eating small morsels independently. It's with some sadness that I watch her eat because she is so far behind her three- and one-year-old brothers, who jump right into meals with vigor.

It was a huge social triumph to watch her summer participation in an organized sport conducted by the "Miracle League" in

our area. She was so welcomed by the other special-needs participants, and she and her mom hit the softball and ran the bases. She wore her braces and had such strength to play!

Giving thanks for small accomplishments never ends, for I know that as each day closes God hears my concerns and desires, my gratitude and praise. His love never ends. I dearly love this blessing from God, and I have fourteen other grandchildren who share this space with her. I continue this journey as best as I can, praying always for energy, motivation, wisdom, and understanding so that Olivia can reach her full potential.

God is with us in our corner. I can feel him here.

## **Overwhelming Grace**

Melissa DeVries, member of Neerlandia CRC, Neerlandia, Alberta

After eight years of infertility struggles, my husband, Ryan, and I became first-time parents to a beautiful baby girl, Savannah Grace. Shortly after birth she was diagnosed with a rare genetic condition, and five months later with a seizure disorder. At ten months old, she functioned at a one-month-old level. We were cautioned not to expect her to develop any further than that.

Our lives were forever changed when we were given Savannah's diagnosis. We struggled with anger toward God and asked why he answered our prayers for a child this way. Then we experienced extreme guilt. How dare we question God's gift to us? Didn't we cry out to him for a child? Yet, when he sent us a baby that has disabilities we had the audacity to question why we weren't given a healthy child. What kind of Christian parents were we?

When we think of everything that she will miss in life, we get tears in our eyes. We grieve that we won't hear her first word, see her walk, ride a bike, graduate from school, or get married. We feel overwhelmed when we think that she will be completely dependent on us for her entire life as her advocates, caregivers, and best friends.

Friends and family aren't always sure how to approach my husband and me. We have been given words of sympathy, promises of God's sovereignty, and the reassurance of perfection in heaven. This has been encouraging, yet we still want to hear wishes of happiness and bright tomorrows for this life. Savannah may not be perfect in the eyes of our world, yet we can say that she is perfect for us.

We love Savannah with all our hearts and cannot imagine life without her. We don't want to have Savannah's entire life to be surrounded by sadness and grief. We want her to hear laughter and joy. So some days we swallow selfish tears of pity and tuck away our worries and sorrow.

Savannah has taught us patience, true sacrifice, and love, even though she can't always return our love. When Savannah's seizures come frequently, all she can do is cry or sleep. But when she does not experience seizures, she returns our love in her own special way. She loves to sit with us and listen to us sing while she sucks on her soother. These are very special times for my Ryan and me!

Our goal for Savannah's life is that she remains surrounded by love at all times. We pray that God will give her body relief from her seizures. We secretly hope for a miracle that one day she might



hold up her head or sit without assistance. We desperately pray that somewhere in her mind she is able to comprehend the love that we shower on her.

Savanah has shown us what true parenthood is all about. As uncertain as the future is, we know that she is held in the palm of God's hand. What greater comfort for a parent is there than that?

## **No Regrets, but Significant Struggles**

Bev Roozeboom, member of Calvary CRC, Pella, Iowa, and author of *Unlocking the Treasure: A Bible Study for Moms Entrusted With Special-Needs Children*

Do you ever regret having adopted your son?" my young friend asked me. We had met for lunch to catch up on life. She was filling me in on the frustrations of their ongoing home renovations, her weariness over her baby daughter's sleepless nights, and her excitement about her mom's upcoming visit. Then she asked about my son's high school graduation. I explained that because of his severe anxiety disorder, he chose not to attend the ceremony. She looked at me with disbelief as I related that, for our son, the thought of standing in front of so many people was a huge mountain—one he simply could not perceive climbing. I also told her this bothered my husband, Steve, and me much more than it bothered our son.

Ever since our child was very young, we've continually had to adjust our expectations and dreams. Sometimes we've accepted these adjustments with ease; other times not so well. Milestones-not-met are particularly difficult.

My friend asked if our son was always “like this.” I told her we knew he had special needs when we adopted him, but had no idea our primary challenge would be his battle with mental illness. I gently filled her in on his early years: his inability to sleep, his extremely difficult behavior, his aggression, his impulsivity, and his emerging learning disabilities. I shared our worries and fears that, as parents, we were doing something wrong. I told her that he was eventually diagnosed with bipolar disorder, ADHD, and generalized anxiety disorder. I explained that while some of his issues improved as he got older, other have continued to worsen, especially his anxiety.

So the question on the table was, “Do you ever regret adopting your son?” I wanted to avoid giving my friend a pat, “perfect” answer. I breathed a silent prayer for the right words and sincerely answered, “No, I honestly have never regretted adopting our son. I know without a doubt this was in God’s perfect will. My husband and I do struggle, though, with what his disabilities have brought to our lives.”

I shared with her some of our ongoing struggles and told how we yearn for more freedom now that our son is out of high school. We would love to experience an empty nest! We envision our future bringing new and different challenges, and are realizing that we will continue to parent him well into adulthood.

I also told her God has taught us the valuable life lesson that “it’s not about me.” All of life is first—and always—about God and his glory. This journey has brought us closer to God than we ever dreamed possible. As we experience difficulties and trials, we also experience his grace, love, and strength. We press on and



the glory goes to him. We know our journey is far from over. Yet we step into the future confidently, knowing he is there.

## More Online

Due to space limitations and the tremendous response to our parenting theme, several more articles can be found online:

- Told at Michael's birth that an institution would be best for her son, Pat Doolittle of Holland, Michigan, describes the fullness of Michael's life today at age 43.
- Since the time of Gene's premature birth, Nancy Bodyl (Lebanon, New Jersey) has been a relentless advocate for her son, who's now a student at Penn State University.
- It has taken decades, but Lynda Tiggelman (Zeeland, Michigan) acknowledges that although her dream for son Matt is different from the reality, that's okay.
- Pam Menton (Glenville, New York) says she could not be more proud of son David, 22, who shares his life generously with others.
- Loral Falvo (Holland, Michigan) describes "deliberate parenting" to teach children skills, expectations, consequences, and discipline.
- Quoting Psalm 139, Joanne Schep (Thunder Bay, Ontario) reflects about the meaning of her three children (two of whom have disabilities) being knit together by God in the womb.

- Though most people first notice daughter Jessica's developmental delays, Lori Maxfield (Zeeland, Michigan) advocates for Jessica's many gifts.
- Ruth Stevenson (Pella, Iowa) says that she reveled most in the simple pleasures and accomplishments of her late son Mark, who had Hunter syndrome.
- Whatever grief or struggle we must endure, we can take comfort, says Rev. Simon Wolfert (Surrey, British Columbia), because our pain is God's pain.
- Brian, who has intellectual disability, taught his mother Marla Van Dam (Howard City, Michigan) that life is about growing in love and sharing with others.

To read more, go to [www.rca.org/disability](http://www.rca.org/disability) or [www.crcna.org/disability](http://www.crcna.org/disability).

## **Editor's Note**

### **Resources for Parents**

When God calls on parents to raise a child with disabilities, the work takes on challenges beyond what other parents may face. As my wife, Bev, and I raised our daughter, Nicole, we plowed through uncharted territory (for us) as we searched out the best ways to raise her, given her severe, multiple impairments. Bev was especially good at finding resources for us to read so that we could find some help. Here are a few good resources available today.

Unlocking the Treasure: A Bible Study for Moms Entrusted with Special-Needs Children. You can read some of author Bev Roozeboom's story in this issue of Breaking Barriers. Her book began as a resource for a Bible study/support group for moms, and includes a Bible study guide to be completed over several weeks as well as brief stories from the experience of mothers.

Receiving David: The Gift of a Son Who Taught Us How to Live and Love. Faye Knol presents a tender and joyful memoir about her late son, David, who lived with severe physical and intellectual disabilities.

Dancing with Max: A Mother and Son Who Broke Free. With realism and humor, Emily Colson writes this memoir about life so far with her son, Max, who has severe autism.

Parents of Children with Disabilities: A Survival Guide for Fathers and Mothers. Press and Gena Barnhill both have academic training in special education, raised a child with Asperger's syndrome, and led a support group for parents of children with disabilities. Their book provides emotional understanding and practical suggestions for raising a son or daughter who has disabilities.

In addition to these, many resources can be found online as well. Other parents who are raising children who have disabilities are the best resource. There may be a parent/guardian support group in your area, and most parents connect with others through school, therapy programs, and places where people with disabilities gather. Finally, Christ has called his church to support, encourage, and engage people with disabilities and their families in ministry. If a church is functioning well, it will be a community

where everybody will know that he or she not only is welcome, but also belongs and is encouraged to use his or her gifts fully in service to God.

—Mark Stephenson

## **With a Pure Heart and Voice**

Janet Paduano Cardillo, member of Colonial Church (RCA) of Bayside, New York

I prayed that God, who so loved the world that he gave his only Son, would bless me with a child, and he did. However, my child has autism.

So begins the challenge.

For years I had turned my back on the Holy One who created all things. How could he send a Savior and then allow this child of mine to have autism? What was I to do? I thought God was not with me or my daughter since he did this to us, so I relied only on myself to save her. The anger, bitterness, confusion, and isolation of autism had robbed me of the blessing of having a life, a child, and most importantly a Savior.

For so many years I believed my daughter Grace and I had only each other. The wearier I grew, the more I yearned and cried for someone to care for us, to watch over us, to help us. Then I was led to a vacation Bible school program at the Colonial Church of Bayside, and this was the verse of the day: “Have I not commanded you? Be strong and courageous. Do not be afraid; do not be discouraged, for the Lord your God will be with you wherever you go” (Joshua 1:9).

And so begins the triumph.

I began to realize that God had never turned his back on me or my girl. He was always with us and calling—not just me, but US—and this time I answered, “Yes, Lord.” I surrendered my life to the Lord and now enjoy the blessing of salvation. I worship in love and faith with my Colonial Church family. I feel the full blessing of having a child with autism because I see her through the eyes of the Lord.

Grace is always in church with me. She comes to praise team rehearsals, and during worship she stands before the congregation while the team sings. Grace is beginning her own relationship with Jesus!

And so begins the joy.

I believe Grace can hear the Lord calling her, and she is saying “yes” to him. Yes is one of the few words that she can express clearly and convincingly. She tries so hard to say his name, her mouth moving but with no sound. After much prayer and devotion and blessings from God our Father, even though Grace may not clearly say the name of Jesus, she can now sign “Jesus.” She can say “God” and “I love you.”

God blessed me with Grace and he is blessing Grace with a voice. Grace is beginning to sing! This 13-year-old, who is diagnosed as having severe autism and cannot speak in full sentences, sings “Jesus Loves Me” and “The Bible Song” with a pure heart and voice. Grace is beginning to recite Deuteronomy 7:6, “The Lord your God has chosen you out of all the peoples on the face of the earth to be his people, his treasured possession.”

She is wonderfully and masterfully made. Grace is a child of God, and God does not make mistakes.

So we are no longer alone. We have a Savior, we have each other, and we have a church family. Even though we still have the challenge of autism, we will forever have the triumph of life with Jesus Christ, and we will continue to cherish and nurture the joy, singing “Jesus Loves Me!”

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