Breaking Barriers everybody belongs • everybody serves

Fall 2017 (Learning from children with disabilities)

Learning from Joel and from God

by Michael Van Beek

Faith Church (RCA), Dyer, IN

Joel was the most aggressive young boy I'd ever encountered, inside or outside our church's Reflectors ministry. Joel lives with diagnoses of fetal alcohol syndrome, autism, and disruptive mood dysregulation disorder. His behaviors can escalate to the point of biting, hitting, spitting, tearing objects from walls, or throwing chairs. On a few Sundays, he's even worked himself up to the point of vomiting. Even though he's only 7 years old, Joel is strong, quick, and not afraid to use whatever he can (including his body) to express his anger.

For his first few weeks with us, none of the proven techniques we practiced for de-escalating behavior seemed to be working; in fact, they only seemed to increase his hostility. Sadly, I thought that our relationship would become one based solely on CPI (Crisis Prevention

Institute) interventions. I remember many days coming home and crying because I felt I had let him down in some way. I began questioning myself during my time with him; facilitating the space where he could receive God's love and peace seemed like an impossible task.

My prayers went from asking God to help Joel to asking God to help me. And then one day, overwhelmed and feeling completely lost with Joel, I just sat and surrendered. I knew I needed to stop trying to change him and start changing myself—not just to meet him where he was but to stay there with him, too. It was in the moments of doing this that I first felt we had relationship. I began getting cards from Joel, written in crayon (often apologizing for a previous incident), and videos of him just saying "Hi."

In effect, Joel was saying to me that if I ride out this storm with him, I would see that God is present in stormy places. And if I am patient enough, then I would also see God's grace amid the mess. As that's come to be, I've heard Jesus say to me, "This is what I have done for you. I did not force you to do or to be anything; I loved you regardless, and your obedience in this love toward Joel is how you know me. I love you."

We still have attacks and fits, but now, in a sense, we have

them together—in faith and with assurance that God is at work!

It is well with my soul.

Sophia, Shoelaces, and Seeking Vocation by Eric Steele

Embody Christ Fellowship (RCA), Holland, MI

Just days after completing our home study for a specialneeds adoption, we received a phone call about a newborn girl with Down syndrome and a severe heart defect whose adoption had fallen through because she had Down syndrome. They wanted to place her as soon as possible so that she would begin to bond and fight to stay alive. We packed into a minivan and headed east to New York City to meet Sophia Grace Steele.

Sophia's heart condition was much more serious than we were led to believe. Once we had her home, it was too risky for Sophia's health to do a traditional baptism in our Episcopal church, so it happened in two parts—first in our home with family and godparents and later with the

congregation.

Because Sophia's birth parents are Hispanic and Italian, when Sophia turned 15, our pastor worked with me to develop a Quinceañera service that would be meaningful to her. First Reformed Church in Holland has a culture open to adapting important events, and the church has celebrated Sophia's accomplishments in Special Olympics too. Her participation gives fellow parishioners a comfortable conversation starter to build meaningful connections with her.

Personally, Sophia has helped me to follow God's leading in ways I did not expect but now embrace. When Sophia was adopted, I worked as a supervisor with the family court in a residential treatment center with adjudicated youth. Because the youth participated under court order and not personal desire, the culture was adversarial. The strenuous effort required with less than satisfying outcomes made me restless about my vocational life.

Meanwhile, Sophia was learning to tie her shoes—not as a goal or an objective at school, but on her own. It took Sophia two years of practice, with support and encouragement from her big brother. She was tenacious,

maximizing every skill at her disposal, and was excited to share her progress.

Feeling greater satisfaction about a little girl with Down syndrome learning to tie her shoes than about working with adjudicated youth, I resigned from the court system and sought work with adults and youth with developmental disability and/or mental illness (DD/MI).

Over the past 10 years, I have helped to open a residential treatment center for youth on the autism spectrum, and have taken on a variety of roles (administrator, day program manager, and case worker for 150 adults with DD/MI). Currently, I provide community living support for five men; my own disability (schizophrenia) allows me to work 12 to 15 hours weekly.

Two Lessons in Love by Kristin Brouwer

Trinity Reformed Church, Orange City, IA

Four years ago when I transitioned from a school classroom teacher to children's director, I soon realized that what happens in the classroom at school doesn't always happen in the ministry areas of the church. Parents

of children with disabilities are placed in church programming, and it often ends up being miserable for parents, teachers, and the child. Parents of children with disabilities need to be fed and filled at church.

Each child is made in the image of God, whether they have a learning disability, physical disability, food allergy, or higher sensory needs. Each child deserves to learn and grow as a disciple of Jesus. As we try to love, teach, and lead the children, I have found they actually teach us much more along on the way.

Here are two lessons I have learned about and from children with disabilities.

First, many children with disabilities have "Spidey sense." Spiderman (the super hero) has an extraordinary ability to sense imminent danger, and I often notice something like Spidey sense in children who don't really fit in. It may be Down syndrome, slurred speech, or autism spectrum disorder, but many children with a disability demonstrate an extraordinary ability to sense emotions, details, and other feelings. As a result, they have an incredible gift of being the hands and feet of Jesus. They seem to have a deeper understanding of Jesus' presence in their lives, and

they radiate acceptance. Many notice small details like papers on the floor, which they'll pick up and throw away. They can be overjoyed by small things that happen or are given to them. They have given me joy, high fives, and hugs on some of my yuckiest days.

Second, I have a richer view of God and his love for me because of these friends. It's not fun when I'm chasing down a child, or holding someone tight who needs heavy pressure, or losing my patience for asking a child to do something for the 100th time, or avoiding someone who is swatting or trying to hit me. But inevitably, they'll soon look at me with a cheesy, big smile and eyes sparkling, and come over to give me a hug, high five, or knuckles—and I am overcome with love.

This must be a picture of how God feels about us when we act out spiritually. We run, and God chases. God speaks, and we don't listen. God holds us tight while we try to swat and get loose. God loves each of us and keeps chasing, speaking, and holding on even when we are hard to love.

Upcoming themes

Winter 2018: Employing people with disabilities Do you employ a person with a disability, or have you had someone with a disability do contract work for you? What have your learned by giving this person a chance? Please send us a note (no more than 400 words) by October 25.

Spring 2018: Welcoming worship

Churches can help people with disabilities feel welcome (or unwelcome) in their worship. Do you have a story about welcoming (or unwelcoming) worship? Please send us a note (no more than 400 words) by February 21, 2018.

Email: mstephenson@crcna.org • tdeyoung@rca.org

Ketchup Moments

Angie Walker

First Reformed Church, Grandville, MI

Every winter our Sunday school kids are given a bingo sheet they can complete. Each square has something different for the child to do. For example, squares might say "make a card for the pastor," or "recite a Bible memory verse." For kids with special needs, we make accommodations if needed. Kids get a prize for completing one or more rows. If they compete every square they get to go out to lunch or have lunch brought to them at school by Lynne, our Sunday school director, and me.

When we first introduced this activity, we were excited by how many kids completed the entire bingo board. One girl, Alina, was thrilled to have completed hers and couldn't wait for us to bring her chicken nuggets, French fries, and chocolate milk at school. Even though she is nonverbal, we could see her excitement bursting from inside.

When the day came, Lynne and I did our best to have a conversation with Alina, knowing her way of communicating is not through words, and while this was difficult, one thing was very clearly communicated—her extreme love for ketchup!

At first we helped her open only two packets of ketchup, but by the time lunch was done she went through seven! She would slow down or stop eating when her ketchup was gone and wait until we helped her open more.

Lynne and I learned that a simple thing like ketchup created a special connection between Alina and us. From that time forward, we knew each time we lunch together, we needed to bring lots of ketchup.

Finding and creating "ketchup moments" are vital to relationships. Some of the ketchup moments we had with other children include simply listening to them and allowing them time to share with us; but honestly, the simple act of bringing lunch made them feel important. Thank you, Alina, for your help in teaching us this!

Editor's note

Everybody Serves

If you'll forgive a father for bragging on his child, our daughter Nicole has a gift for living in the moment. She doesn't worry about the future nor have regrets about the past. Some people pay thousands of dollars to take classes in mindfulness, but Nicole has it down pat.

You wouldn't know this when first meeting her, though. People first notice that she can't speak, uses a wheelchair, and needs assistance for all the tasks of daily living. Many people walk by her without acknowledging that she's even there.

My friend and co-editor of this newsletter, Rev. Terry DeYoung, walks with a cane. After he graduated from seminary, several churches expressed interest in calling him, but upon meeting him and seeing his disability, interest cooled. We humans tend to notice difference and to judge differences negatively. That's too bad, because that tendency inhibits our ability to see someone's giftedness if they live with a disability.

Kids, including kids with disabilities, are a blessing to families and to churches. CRC and RCA Disability Concerns ministries have a variety of resources including videos, webinars, and more for your church to learn how best to engage in ministry with children who have disabilities (network.crcna.org/disability).

-Mark Stephenson

© 2017 Disability Concerns ministries of the Christian Reformed Church in North America and the Reformed Church in America. *Breaking Barriers* is published quarterly by CRC Disability Concerns, 1700 28th St. SE, Grand Rapids MI 49508-1407, and P.O. Box 5070, STN LCD 1, Burlington ON L7R 3Y8; and by RCA Disability Concerns, 4500 60th St. SE, Grand Rapids MI 49512-9670. Rev. Mark Stephenson, director of CRC Disability Concerns (888-463-0272; mstephenson@crcna.org), and Rev. Terry DeYoung, coordinator for RCA Disability Concerns (616-541-0855; tdeyoung@rca.org), edit *Breaking Barriers* together. Permission is given to make copies of articles as long as the source is recognized.

A collaborative disability ministry of the Christian
Reformed Church in North America and the
Reformed Church in America
www.crcna.org/disability • www.rca.org/disability