

Breaking Barriers

everybody belongs • everybody serves

Fall 2015 (Children, youth, and “hidden” disability)

Blake’s Frightening Surprises

by Amy Wigger

Immanuel CRC, Hudsonville MI

I heard my name being shouted from across the park. It was a frantic call for help, one I was surprised to hear. As I walked closer, I realized what was happening. We were at a park for a superhero-themed fundraising event. Because sounds often trigger anxiety for our son Blake, I was prepared and had brought earplugs for him. What I had not anticipated—nor had Blake ever experienced—was his absolute terror from seeing people dressed in costumes.

Blake is a beautiful boy with big brown eyes. From all outward appearances Blake is a typical kindergarten boy. However, Blake has a sensory processing disorder. Almost daily Blake fights battles that are invisible to others. As his mother, sometimes I am the only one who can anticipate or explain that he is not always typical. His special needs are invisible to others—until they are very obviously not, and Blake is covering his ears and crying and asking me to help him make it stop. The only thing that can help is removing him from the situation affecting him.

It is difficult to describe, especially as a five-year-old boy, what is being felt physically and mentally when Blake's senses are taken over, and he is so overwhelmed that he experiences fight-or-flight. What would be simple for most people—deciphering a make-believe scenario or filtering extra sights, sounds, and smells—is beyond difficult for Blake. If broccoli is on the menu for dinner at our house, it is not just an unpleasant odor for him; it is gag-inducing.

He attends a wonderful school that frequently holds chapel in the gym. When school began, he could not convince himself that the sound in chapel was survivable. If he could, he would run as fast and far as possible in the opposite direction. When there is a situation we know might have a risk of being too loud and overwhelming, we use earplugs and make sure that either he, his teacher, or I can place them in his ears so that they block out as much sound as possible.

We are still figuring out what Blake's triggers are. We are getting better at anticipating his needs. And we are thankful for a community of believers that tries to do the same for him.

Themes

Fall 2015—Children, youth, and “hidden” disability. This issue describes some of the realities of growing up with

disabilities that are not visible, such as mental health challenges, learning disabilities, dyslexia, and Asperger syndrome.

Winter 2016—Abuse and disability. More people with disabilities experience physical, sexual, and emotional abuse than the general population. Breaking barriers of silence and secrecy can help people understand the experience of abuse and respond appropriately. If you have a disability and have experienced abuse, and are willing to share your story, please send us a note describing your experience by November 30.

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Opening Doors for Nathan

by Karen Van Dam

The Promise (RCA), Hemet CA

I found out my son Nathan had autism when he was one and a half years old. He started receiving therapy a year later and was nonverbal until age 7 or 8. Now 11, he's a sixth-grader in a special program at Rancho Viejo Middle School in Hemet. The school's peer buddy system works great for him. When he tells me school is "too hard," I know he is making progress.

Nathan's "stimming" or self-regulating behavior is shutting open doors. If any door stands open, he shuts it. If I intervene, he gets upset. If someone is in the doorway or if they attempt to close the door, he will push them out of the way so that he can shut it. A behavior therapist and I are working on this behavior, but it takes time.

I want Nathan to get out in the community so he can be more independent. I take him to stores so he learns how to shop and use money. I take him to restaurants so he learns appropriate behaviors. As a single mom, going out with him can be a challenge when he cries or screams, and when people question my discipline and ask why I "don't get after him."

My family is very understanding and helpful. They accept Nathan for who he is and relieve me occasionally so I can have a break. When we go out to eat or on vacation together, they're not embarrassed by Nathan's behaviors.

A previous church I attended didn't seem receptive or helpful toward us. If I put Nathan in the children's service, I would be called to get him. If I kept him with me in worship, people considered him disruptive—so I visited other churches. My current church offers a children's service, and Nathan is assigned a buddy so the teacher can focus on all the kids. I haven't been called to get him at all, which I'm grateful for. I wish more churches were like this.

Reminiscing about Life with Dale

by the Bulthuis family

(Editor's note: Contributors include Dale Bulthuis, his mother Sharon, and siblings Linda and Bill. Dale was a member of Suburban Life Community Church in Darien IL when he died in 2011.)

Dale (from an autobiography found after his death): When dad had a weekend to talk I would look forward to game time. We got a lot of board games and I also loved hearing stories of fiction and started reading C. S. Lewis and begged my brother that I could read *The Hobbit* and I begged him again to read *The Lord of the Rings* and yet again to read *The Silmarillion*. My dad and mom and family played baseball and badminton outdoors together. We went on a bike tour of our own choice with close friends of the family.

Sharon: Dale developed hydrocephalus at age 8 due to a lesion on the end of his brain stem. His thought patterns were unusual, but his disability was such that he fell through the cracks in school and in life. He had a difficult childhood and struggled to get his homework done. As an adult he was accepted in the singles groups until they coupled up, and he was left out. His shunt functioned well from age 15 to 38, and he became independent and lived

alone. I let him go by faith, but the fear I had entertained happened: his shunt malfunctioned and he died alone.

From Linda's eulogy: Dale entered my life when I was 8 years old. Dale had a different way of looking at the world, even as a toddler. He could be a little brat at times, struggling to survive with two older siblings and with little brother Billy. Dale struggled much, worked hard, and managed to graduate from high school. The person who kept Dale most grounded at the time was my brother Bill. He stepped up, loved his brother, and became Dale's best friend through the formative years.

From Bill's eulogy: Dale, when you spoke, you knew what you were thinking. The rest of us could only guess. Those of us who knew you best could guess pretty well. Your lack of inhibition was refreshing and, occasionally, infuriating. I guess that would make it a "refreshing fury." You had guts, Dale, guts without glory. Showing up at my doorstep, unannounced, in the pouring rain, with your bicycle, 15 miles from your home. It was not uncommon for you to ride your bicycle in the snow, let alone the driving rain. You always rode your bike. Everywhere. I remember in high school getting up at daybreak on a hot summer day and going for a bike ride through the woods. We'd easily log 20 miles on squiggly, wooded trails before lunch. You loved to ride back then, and that never changed. I miss you Dale.

Facing Challenges with a Smile

by Lauren Jordan

Christ's Community Church (RCA), Glendale AZ

My doctor said, "You are very sick, and your baby is going to be born extremely premature. If we can keep you and the baby stable until next week, the survival rate goes up quite a bit, to 60 percent. Your child could be hearing impaired, visually impaired, and physically impaired. She may be on ventilators, other machines, and medicine for the rest of her life."

Our church prayed deeply. Haley Grace Jordan was born the next week, weighing 1 pound, 12 ounces.

After surviving the trauma of her early birth, Haley had a hard time adapting, learning, retaining, and speaking. By second grade, the gap between Haley's educational "intake" and her peers was getting wider. Haley's younger sister passed her in size, caught on quicker, and asked more questions. Through the years Haley has been unable to adapt to loud and fast-paced environments. She copes by separating from others, ringing her hands, and throwing fits, but she never really regroups.

In church she may seem rude, refusing to do what is asked, but going to the front for the children's message is a devastating experience for her. Because we don't have

children's church or Sunday school for children her age, she gets antsy during the sermon, often sighing long and hard, unable to sit for long without a break or a snack.

I frequently have to explain to family, friends, co-workers, teachers, and others that Haley's coping skills are different from most kids. She cannot process too much input and often withdraws and clings to family. She doesn't run up to give you a big hug and a kiss. In fact, the more attention you give her, the more she withdraws. She told me recently that she would never join the dancing team at church because she fears she would make a mistake and doesn't want to mess up the dance.

Spending longer days at school so she can keep up with her peers, Haley faces challenges with a smile. She has been a fighter ever since she was born; she makes me incredibly proud and humbled. My heart aches for the struggles she endures, and I feel guilty, angry, scared, and responsible for her hurt.

I am truly thankful for those who are patient, kind, and don't take her shy behavior personally. I know God has big plans for her, and if part of that plan is enlightening the church and the world about hidden disabilities, then here we go!

Survival in Noah's Structured Ark

by Rebecca Rozema

14th Street CRC, Holland MI

I am greeted this morning by a wolf howl from my middle son; he and his stuffed wolf are sitting wrapped in a blanket reading one of his many books instead of doing the morning school checklist. I say a quick prayer and brace myself for the morning struggle. Noah is a unique boy. I often say that he just doesn't fit the box but that he will make his way in the world.

Noah has many diagnoses—Asperger syndrome, sensory processing disorder, ADHD, anxiety—but really they all wrap up into who he is as a person, my sensitive Noah. If you met him on the street you wouldn't know of his struggles, the stress of parenting him, or the planning required to get him through a day. He has bright eyes, a quick smile, many talents, and will talk to anyone. He loves animals and will stop to pet and kiss any dog that he can find, but he needs his own finely structured ark to survive.

Noah's struggles come when things don't go as he thinks they should, when routines are out of sync, when others perceive things differently from him, or when sensory input becomes overwhelming. Noah lives life in extremes. He wants life loud or silent. He's obsessed or completely uninterested. He feels comfortable or freaks out.

When things don't work as he had planned, he is quick to turn on himself and others at home, at school, with friends, or wherever he might be. He might hit, kick, or throw things. When he was little, these meltdowns were easier to handle. Now that he is older and bigger, I wonder: will someone get hurt this time and how badly? Who is hearing and seeing this? Will they understand? Am I, his mother, doing everything I can for him?

While we try to help Noah manage his life and keep it as predictable as possible, there is only so much a parent can do. We do not live on an ark and cannot control every aspect of life. I can advocate with school, church, and get every therapy possible. In the end, he must learn the skills to go out on his own and interact. I pray every day that Noah will find his place in this world, for I know that God placed him on this earth with a purpose, but how it hurts a mother's heart to see her child struggle.

Editor's Note

Grim Statistics and Hope

Prison authorities consider childhood reading proficiency a key for predicting future prison cells needed. A child not reading at grade level by the end of third grade is four times less likely to graduate from high school than peers reading at grade level, and six times less likely if the child is also from a low-income family. Those not graduating from

high school are six times more likely than graduates to be incarcerated.

Besides incarceration, 43 percent of people with learning disabilities live at or below the poverty level; 48 percent of them are out of the workforce or unemployed. These statistics affect a significant number of North Americans since 10 percent of us have a learning disability—80 percent of whom have difficulties with literacy.

Most learning disabilities fall into the category of “hidden” disabilities, the theme of this issue. These grim statistics call us to action. As Christians, we need to support early childhood education that includes special education and early intervention to give kids with hidden disabilities and kids from impoverished homes a better chance at success in a society that requires literacy skills.

Children with hidden (and visible) disabilities are “indispensable” members of the body of Christ (1 Corinthians 12:22). Inclusion in the full life of the church will bless the church as well as these children and their families. Besides spiritual nurture, involvement in a loving church community fosters hope that God and other people value them. Hope just may be the best vaccine for future incarceration, and hope is what living in the light of the empty tomb is all about.

—Mark Stephenson

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