

# Breaking Barriers

*everybody belongs everybody serves*

ISSUE #78 SUMMER 2008

A Ministry of Christian Reformed Disability Concerns

## Blessed Be the GLUE That Binds

Krista Mason

It's Sunday morning at Providence Church. We've actually made it to our seats before the preworship music is over! As we settle in, we look like the arrival of a hurricane. Beads of sweat drip from my forehead as I unload the contents of my son Ben's backpack. We bring along every possible engaging (and quiet, nonbuzzing, nonbeeping, non-speaking) toy to occupy him through the singing at the start of the service.

Then the best part of the day happens for Ben!

Ben has autism. Staying for the whole service is tough for him. Usually we get through the worship music. Then a wonderful thing happens. On this Sunday Nick slips into the seat just behind Ben. It could be Jordan, or Ryan and Jeremy, Rachel, Reuben, Nate, or Mike



Ben (front center), his mom Krista (back left), with some of Ben's friends.

and Jason. These young people are part of Ben's GLUE team. GLUE stands for Giving, Loving, Understanding, and Encouraging. People from CLC Network helped our church set up the GLUE teams.

When these young people committed to the GLUE team for a 12-year-old kid with autism I would guess that they had ideas about doing something good. Or maybe their

moms encouraged them. Or maybe they have a sister with special needs, and God had woven into them a tender heart. They have varied reasons and motivations, but I can tell you (and my eyes fill as I type this) that for each of them, when their turn to do GLUE team for Ben Mason rolls around, what gets them out of bed is this: Ben is their friend.

Just that. Not a whole lot more or less. Ben has friends.

As a parent, and especially a parent of someone considered "disabled," my heart longs for others to SEE Ben. See him beyond the unusual stuff like the jumping and flapping, or the odd and constant noising. I yearn for people to see Ben my son who is loving, creative, fun, playful, and smart. Beyond this, I yearn for reciprocity, for true relationship. In God's power, that miracle has taken place.



Here's what it looks like. As Nick slides into his seat behind us, Ben turns to him. Both boys give each other smiles that fill the room. They are friends who are, in a real, simple, and beautiful way, happy to be together.

After singing with the congregation, they head off to spend the rest of the morning together. As I watch them walk away, my mother's heart is deeply stirred by the beauty of their friendship. This is community. This is right. If my heart is stirred, how much more stirred is the tender heart of God.

And I am deeply thankful.

Krista Mason and her husband David have two children: James, who is 14, and Ben, 12. For information on GLUE teams, contact Kim at CLC Network, 616-245-8388 or [kluurtsema@clcnetwork.org](mailto:kluurtsema@clcnetwork.org).

## Theme

In this issue we focus on *autism* and include stories, resources, description, and a meditation. Most of the articles in this issue were submitted by our readers.

Our next issue will focus on cerebral palsy, and the Winter 2009 issue will be a literary issue. **If you have personal experience with cerebral palsy, please send us a note or story by August 15, 2008. If you live with a disability, please send us your poems, short stories, artwork, or photographs by November 15, 2008.** Items submitted for the literary issue do not have to be about your disability. Please do not submit anything longer than 500 words; all items may be edited for length.

# Obsession is a Super Power

Peter Davis

It's two in the afternoon, and I've just had lunch. I sit down at my easel and examine my pencils. Some are hard and create faint lines that are an absolute pain to erase. Others are soft and will make thick, dark lines that smudge if I'm not careful. I make my choice and begin to draw. I quickly become absorbed in my work and make rapid progress, stopping only to sharpen or switch pencils. I ignore distractions (forget YOU, telephone!). Eventually I am surprised to discover that it is dark out; I must have turned on the lights in my room. I'm starving.

Some people have productive days. I have single-minded days.

In fourth grade I learned that I have a type of autism called Asperger's Syndrome. This knowledge helped to explain my various oddities. I found certain clothing uncomfortable, including blue jeans and buttoned shirts, and I avoided strong smells and loud noises (including the deafening church organ). I suffered in classes filled with children who thought 100 decibels made an

appropriate indoor voice. What I could eat was what I could stand, and what I could stand was bland.

My speech isn't as stunted as my wardrobe or my diet; my vocabulary is alive and well. Classic autism cripples speech, but Aspergers unbalances it. I can happily talk for hours about computer games, long after even the most patient listener is bored to tears. When it comes to social niceties, I'm clueless. I hesitate to acknowledge greetings, knowing they could lead to conversation. My fear of embarrassment squelches my dreams of friendship. I can't tell if an innocent comment could be considered offensive, leading to shame and isolation. If conversation is a dance, I don't know the steps. Socializing is easy and even fun to most people, but to me, it is a trial.

Eye contact is a critical part of human communication and recognition. For many of our friends in the animal kingdom and for most of us with autism,

eye contact equals aggression. When I'm talking to people, they may be offended that I don't meet their eyes, but I feel distracted by a staring contest. Thus, remembering names and faces is a constant struggle. If only everyone wore name tags.

After failing time and time again, it's tempting to give up on communicating with the world outside my family. This would be a mistake, as my greatest support has come from other people. Although I have encountered some misguided teachers, many of my instructors helped make my school life bearable. One teacher even recognized my talent for art; she directed me toward a career in what I had thought was just a stress reliever.

Sometimes, the worst part about being different is feeling alone, but I know that I am not alone. I am comforted that there are others like me and that they may profit from what I have learned. I'm connected to others by my private love of art too.



*Peter Davis and Shannon Harris, Peter's special education teacher for five years at his high school.*

*Peter Davis is a sophomore at the College for Creative Studies in Detroit, majoring in Animation and Digital Media.*

## My Tips for Asperger's and Social Ineptitude

- You should recognize your assets—such as your ability to focus on your interests—rather than concentrating on your shortcomings.
- The sooner other people know why you act the way you do, the sooner your life gets easier. Start educating!
- If you can't remember what someone's name is, just ask. Most people forget the names of half of everyone they meet anyway.
- If you don't understand what someone means, ask for an explanation. Admitting that you don't know is embarrassing, but screwing up because you misunderstood is worse.
- Learn to recognize sarcasm, if you can.







## resources

**Book:** *Autism and Your Church: Nurturing the Spiritual Growth of People with Autism Spectrum Disorders* by Barbara J. Newman. Published by Faith Alive (phone 800-333-8300), this unique resource offers practical ways to welcome and include individuals with autism spectrum disorders into the full life of your congregation.

**Websites:** Many websites have information about autism including those listed below. Although Disability Concerns believes that you will find helpful information at these sites, we do not guarantee the accuracy or appropriateness of all of their content. Please use discernment as you read.

American Academy of Pediatrics Autism Information:

[www.aap.org/healthtopics/autism.cfm](http://www.aap.org/healthtopics/autism.cfm)

Autism Collaboration—links to many organizations:

[www.autism.org](http://www.autism.org)

Autism Speaks—awareness, advocacy:

[www.autismspeaks.org](http://www.autismspeaks.org)

Autism Web—a parents' guide: [www.autismweb.com](http://www.autismweb.com)

Centers for Disease Control Autism Information Center:

[www.cdc.gov/ncbddd/autism/](http://www.cdc.gov/ncbddd/autism/)

Disaboom—connecting people who live with disability:

[www.disaboom.com](http://www.disaboom.com)

First Signs—early identification, intervention:

[www.firstsigns.org](http://www.firstsigns.org)

Kennedy Krieger Institute—research, treatment, education:

[www.kennedykrieger.org](http://www.kennedykrieger.org)

National Library of Medicine Autism Information:

[www.nlm.nih.gov/medlineplus/autism.html](http://www.nlm.nih.gov/medlineplus/autism.html)

News—CBC, CNN, and many other news organizations have done features on autism. Go to any of their websites and search on “autism.”

**Blog:** Dave and Sandra Verhoeff started a blog about their son, Luke, who was diagnosed with autism September 28, 2007. Their story since September has been documented at [www.lukesjourney.com](http://www.lukesjourney.com). They welcome interaction and comments through email at [info@lukesjourney.com](mailto:info@lukesjourney.com). The Verhoeffs are members of Sahali Fellowship Church in Kamloops, BC.

**Book:** *Autism and Faith: A Journey into Community*. With articles written from a variety of faith perspectives, the booklet contains real-life stories and facts about autism, pastoral care, religious education, strategies for supporting families, tips for lay people, and a listing of religious and public resources. Available for \$5 (U.S.) from The Boggs Center, 732-235-9317.



## health corner

### Early Intervention Key to Child's Development

*Ann Kutudis-Kenien, ARNP, Regional Advocate for Classis Southeast U.S.*

Parents and other family members will not recognize autism or other developmental disabilities unless they are paying attention, see the issue, and seek treatment. Yet, we often choose denial when we suspect a problem.

After working in healthcare for 30 years, I expect medical professionals to recognize developmental delays such as autism by the twelfth month of life, but, human beings are not infallible. I've missed illnesses in my own family and had several of my healthcare providers miss my own illness.

Early treatment is our current approach in healthcare. We are now proactive. If a child is not screened in the first year of life for developmental interruptions, subtle clues may be missed. Critical treatment time is lost. If a pregnancy is identified as being at risk for a developmental delay, it is very unsettling but much support exists.

Information is plentiful. Please see the list of suggested resources in this issue of *Breaking Barriers*. I am more than happy to be able to assist anyone in locating help. You may contact me at Ann Kutudis-Kenien, 421 Whispering Oak Lane, Apopka, FL 32712. Phone: (407) 703-4456. Email: [kutudis@aol.com](mailto:kutudis@aol.com).

## Upcoming Workshops

**H**ealthy churches train their members in warmly welcoming people and encouraging them to use their gifts. Disability Concerns is offering training in a variety of settings over the coming months to help churches grow in their inclusion of people with disabilities. Here are opportunities coming this fall:

**Holland, Michigan:** September 20

One Body Together in Christ

Western Theological Seminary

Contact: Disability Concerns, 888-463-0272,

[disabilityconcerns@crcna.org](mailto:disabilityconcerns@crcna.org)

[www.togetherinchrist.us](http://www.togetherinchrist.us)

**Ancaster, Ontario:** October 18

Ancaster Day of Encouragement

Hamilton District Christian High School

Contact: Diaconal Ministries Canada, 800-730-3490,

[info@diaconalministries.com](mailto:info@diaconalministries.com)

[www.diaconalministries.com/daysofencouragement/easterncanada.htm](http://www.diaconalministries.com/daysofencouragement/easterncanada.htm)

**Calgary, Alberta:** November 1

Paliser Day of Encouragement

River Park CRC

Contact: Riky Goebel, 403-242-2887, [goebels@telusplanet.net](mailto:goebels@telusplanet.net)

[www.diaconalministries.com/daysofencouragement/westerncanada.htm](http://www.diaconalministries.com/daysofencouragement/westerncanada.htm)

**Palos Heights, Illinois:** November 13

A Compassionate Journey workshop

Trinity Christian College

Contact: Jan Visser, 708-307-2370, [jvcsm@sbcglobal.net](mailto:jvcsm@sbcglobal.net)

[www.christianserviceministries.org](http://www.christianserviceministries.org)



## meditation

### God's Ways Are Not Our Ways

Judy Feenstra

*"For I know the plans I have for you," declares the Lord, "plans to prosper you and not to harm you, plans to give you hope and a future." Jeremiah 29:11*

My husband and I knew something was wrong when the nursery attendant at our church asked if our son Jacob was okay. He didn't respond to his name when she called for him. Earlier that month we had Jake's hearing tested since loud noises did not surprise him. Nor did he make eye contact when I talked to him. At 18 months of age, his speech had regressed to four words which were difficult to understand, and he cried constantly. Jake was diagnosed with autism.

After two years of special education, Jake was doing well enough to be mainstreamed into a regular school setting with additional therapies on the side. Over the past five years while Jake has attended Christian school, he has excelled academically, graduated from the additional therapies he needed, and made friends. Most precious to me, Jake has asked Jesus into his heart and lives for him. One time, when I picked Jake up from preschool, he ran out to hug me. He pulled the sticker off his shirt which had his name on it and said, "Mom, Jesus made Jacob special!" Another time, I heard our daughter crying in the hallway at night. Jake heard it too and went to see what was wrong with her. She told him that the train horn had scared her. I heard Jake tell her that God would keep her safe. Then he showed her how to pray.

Jake, like most autistic children has periods of regression that usually occur during the interruption of normal routines. However, Jake knows that even though things in this world are constantly changing, God never changes. We thank God from whom all blessings flow and trust God for whatever lies ahead.

## Introduction to Autism

Jeff Raschka

**A**utism spectrum disorder typically appears during the first three years of life and affects a person's ability to communicate and interact with others. Autism is a complex developmental disability defined by certain behaviors, and it affects individuals differently and to varying degrees. There is no known single cause for autism, and it has no known cure. Before children with autism receive that diagnosis, they are frequently categorized as defiant, rude, and/or inattentive. The following are some early signs that can commonly be associated with people with Autism.

- Lack of or delay in spoken language
- Repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects

Autism is diagnosed much more frequently in children than it used to be. In 1997, one in every 10,000 children was diagnosed with a form of Autism. In 2007 one in every 150 children was diagnosed. Other articles in this issue suggest ideas for finding help.

*Jeff and his wife Jessica own A Puzzled World ([www.apuzzledworld.com](http://www.apuzzledworld.com)), a store for people with disabilities.*

The Christian Reformed Church is active in missions, education, publishing, media, pastoral care, advocacy, diaconal outreach, and youth ministry. To learn about our work in North America and around the world, visit [www.crcna.org](http://www.crcna.org).

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