

Breaking Barriers

everybody belongs everybody serves

ISSUE #73 SPRING 2007

A Ministry of Christian Reformed Disability Concerns

FASD Brings Need for Support

Name Withheld

I had four small biological children and a loving husband; life was good. Then God placed a two-and-a-half-year-old terror into our home. She came for a long weekend as a foster child and stayed. We adopted her three years later.

I became overwhelmed and highly stressed, and my family, over the years, became quite dysfunctional. The outside community—extended family, church, school, and friends—all had difficulty believing what I said as a parent about the new addition to our family. Our adopted child has partial Fetal Alcohol Syndrome with a severe degree of disability. She has one of several diagno-



FASD

Fetal Alcohol Syndrome Disorder

ses described by the umbrella term, Fetal Alcohol Spectrum Disorder (FASD), which describes a range of disabilities that may affect people whose mothers drank alcohol while they were pregnant.

The harsh realities of the effects on individuals with FASD are vast. There may or may not be physically associated signs. Common problems include learning disabilities, inability to foresee consequences, inability to learn from previous experiences, inappropriate and/or immature behavior, lack of organization, poor abstract thinking, poor adaptability, poor impulse control, poor judgement, and communication issues. As a result, people with FASD may experience secondary disabilities such as mental-health problems, inability to live independently, problems with employment, a disruptive school experience, trouble with the law, imprison-

ment, inappropriate sexual behavior, and alcohol or drug problems.

Our two-and-a-half-year-old is now 19. She functions at an emotional age of about 10 and a social and cognitive age of about 12. Studies show that children with FASD do not reach their full maturity until their mid to late thirties. All the common problems associated with the disorder are evidenced by her. We have been able to curtail some of the secondary disabilities by supervising her every moment. If she will not reach full maturity until her mid to late thirties, more supervision lies in store for years to come.

Supervision includes constant one-on-one attendance with her. We have safes in the house for keys, money, and valuables (those with FASD tend to steal); and a keyless lock on the house (to prevent others with whom she may come in contact from entering our home). In addition, she is

never alone with any male siblings or younger siblings. My husband sometimes describes our life as a prison within our own home.

Statistically, there are large numbers of children affected by FASD, and the percentage of these children that come into the protection of Children's Aid Societies is huge. We, as Christians, motivated by our beliefs and values to adopt children, are an uninformed group. I have been told that God never



did you know...?

U.S. citizens who are age 70½ or older may make contributions to Disability Concerns tax free from their traditional or Roth IRA. Gifts qualify for all or part of the required minimum distribution. Please contact Disability Concerns for more information on this opportunity. Thanks so much to all of you who have contributed to our ministry with your time, talent, and treasure.

places us in a situation that is beyond us, but sometimes I question it. Everybody may belong, but sometimes serving needs support.

May this article help others become more aware of this invisible disease. Let us, as a Christian community, learn more about FASD and strive to support families and individuals with this devastating disability.



on the web

Resources for

- Worship including two Disability Concerns Powerpoint presentations
- Accessibility and Awareness
- Caring Ministry including an article on ways to include children with special needs in youth programming
- Print and Internet

Past issues of *Breaking Barriers*

Your thoughts about the new Breaking Barriers format

The CRC as a model for inclusion



letters

Thank you for your copy of *Breaking Barriers*. It proved helpful with information about how, with compassion, to help churches enfold and embrace members who have disabilities.

In "Help with Inclusion" (winter 2006), the parent is told to "Never bring your child back to Sunday school." Why didn't the parent report such a comment to her council? The teacher needed to be confronted about such a comment and dismissed from voluntary services. She has shamed someone who already has experienced so much shame.

If the parents would have taken this to their council, they would have had an opportunity to share with their council the needs their child has, and could have asked the council if they would be willing to learn more about what autism is all about. This kind of approach brings sensitivity of the subject to the church leaders and can provide a time of healing to the parents—they get an opportunity to tell their story about what it's like to have a special-needs child.

Our covenantal responsibility is to provide church education to all members of the congregation, no matter what disability or learning style they have.

All of us need to learn to use our voices when this happens and expect our churches to address such issues, especially in dealing with children who have disabilities. We need to advocate for them every time.

God bless you in your work.

Sincerely, Judy De Wit

In *Breaking Barriers* (winter 2006) Ms. Barbara Newman had a short article, "Help with Inclusion," in which were three true or false questions.

The second seemed to criticize a Sunday school teacher for asking the parents of an autistic child not to bring the child back to her class because the teacher (or staff) could not handle him.

As a psychiatrist (now retired), this apparent criticism raises many questions for me. Since the child was "returned" to his parents, I can assume that the child was, in some manner, "dropped off" at the Sunday school class, although possibly with some explanation.

I'm a bit familiar with Sunday school administration and the recruiting of teachers for this activity. I have never been aware of an "applicant," more likely a "recruit," for the position of Sunday school teacher who had any training in providing a classroom environment or teaching approach that would accommodate an autistic child. Even if the parents were to stay, I would anticipate the average teacher and average pupils to have a considerable challenge, unless they were given some instruction in advance.

Regarding the rejection of the child in the wheelchair, I am reminded of an incident that occurred in a CRC in Chicago in spring 1961. A black family was turned away by the janitor, because the service had already started (never an exigency when my family was tardy).

People challenged in ways that significantly impact what people are accustomed to must recognize their role in the situation and must be prepared to allow an educational process to (often painfully and gradually) re-shape the expectations and coping mechanisms of those who are impacted

Sincerely and with compassion,
J.F. Girard Rooks, M.D.

Because De Wit and Rooks ask factual questions about "Help with Inclusion," we asked the author to comment:

Although the "true/false" quiz in my article was not meant to communicate criticism to any party involved, only awareness, I will give you a few more details to the story.

When a child is born with Down Syndrome, for example, the parents know immediately about that condition. Autism, on the other hand, was a recent diagnosis for this child of three. That term had thrown the parents into a "foreign country" of specialists, treatments, and adjustments. They did not yet have a roadmap for advocacy or expectations. The church, too, had no system in place.

There are good ways to set up encounters with leaders and peers in Sunday school—none of that was in place. There are good ways to give information to church leaders in general—none of that was in place. The parents continued to be faithful to their church home of several years because the family and the church had no other idea what was available. Once contacted, the church was very receptive to providing a place for that child to use his gifts and receive support for his needs. They were a perfect example of the last true and false question—wanting to include but not knowing how. Now they know how.

God used that story in my life as an impetus to provide more information. My book, *Helping Kids Include Kids with Disabilities*, was birthed from these events, and I am thankful for an opportunity to learn through the experience of this church and family.

Barbara J. Newman

We have enjoyed your newsletter and appreciate the increased acceptance of persons with disabilities within our denomination. Your newsletter helps in that growth, as many people have a desire to include everyone but have very little idea of what that involves. The more we can educate people, the better they will understand the issues that some of us live with every day.

Our children, some of whom have extra challenges, have grown up in the CRC and have experienced a variety of levels of acceptance and sometimes, sadly enough, rejection. Those times were and still are painful. But thankfully there are many more positive experiences to remember, and we look forward to continued growth and understanding.

Everyone does belong and everyone can serve if given the opportunity.

In Christ's name, Aurelia Spronk

Thank you once again for your *Breaking Barriers* newsletter. I always look forward to reading it!

I have two adult kids. Janis Brink is 52 years old, and Bob Brink is 49 ½ years old. Both are educable but developmentally delayed since birth. They are residents of our dear Bethshan Association, and they work in the Elim Christian Services sheltered workshop. They enjoy working there with their peers! Not much competition there which is good for them! They, too, enjoy reading your newsletter.

Keep up the good work for all Gods' "precious jewels"! We need you.

God Bless you all everyday!

Dorothy Brink-Schutt

Send Us Your "Caregiver" Stories

Mark Stephenson, Director of Disability Concerns

My wife and I can recount hundreds of stories about people who helped us in a multitude of ways when we dealt with lengthy hospitalizations and the need for respite care. For example, a number of people brought in meals and did our laundry during a six-and-a-half month stretch when my wife was hospitalized for a high-risk pregnancy, then our youngest children were born extremely prematurely. At another time, many people came on Sunday evenings to care for our disabled daughter, Nicole, so that my wife Bev could attend church at least once a Sunday.

The next issue of *Breaking Barriers* will focus on caregivers. Do you have a story to tell about giving care to a loved one with a disability? An incident in which a caregiver especially helped you to come to terms with your disability? Thoughts about the special challenges and joys of being a caregiver? A time when someone treated you thoughtlessly? A way you were especially helped by someone else? Please send your stories to disabilityconcerns@crcna.org or mail them to Disability Concerns, 2850 Kalamazoo Ave. SE, Grand Rapids, MI 49560 USA.



health corner

Allergies and Irritants

Ann Kutudis-Kenien and Elly Van Alten, Disability Concerns Regional Consultants (and nurses) from Classis Southeast US and Alberta North

The Canadian Lung Association (www.lung.ca) and the American Lung Association (www.lungusa.org) both recommend, "If you or someone in your family has asthma, you will want to see an asthma specialist." Specialists can provide allergy testing and options for treatment.

We don't usually think of asthma, allergies and sensitivity to irritants as disabilities, but the challenges are real and can keep some people away from church.

Airborne allergies and irritants: According to Barb Opperwall, a nurse practitioner in pediatric allergy care, one-third of adults have irritant reactions (which feel just like allergic reactions) to some odor. For some people, colognes and perfumes are irritants—just like air pollution. If you have seniors in your church, the chances are good that some of them have chronic heart or lung conditions as well. The air that they breathe should be as clean as possible. Out of consideration for others, please do not wear any cologne or perfume to church. Also, please don't smoke on the church grounds. Many churches post notices in their bulletin and in church asking people to avoid these behaviors. But while you are at it, why not quit smoking altogether?

Food allergies: When making food or bread for church, please be prepared to answer questions about your ingredients. Label foods that contain nuts, hot pepper, and garlic, which tend to be the most common allergens. Consider offering gluten-free bread and grape juice for communion. Also, carefully follow parents' directions about what their children may and may not eat. According to Opperwall, "Some food allergies can be life-threatening. When we are skeptical about someone who says that she has a health problem, that's not only insensitive, but hurtful."



resources

Large Print *Breaking Barriers*: With this issue, each church that receives a bulk subscription to *Breaking Barriers* will receive one copy of our newsletter in large print. Feel free to make as many copies as needed.

Web Site: www.thesightseer.org

Designed especially for people with visual impairments, the Sight Seer brings printed information broadcast to a specially tuned radio or the Internet. Programming includes books, news, old-time radio shows on Saturdays, worship services on Sundays, and much more. Monthly program guides are available upon request.

Conferences in 2007:

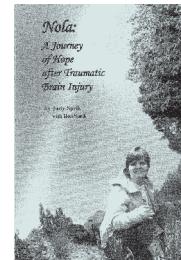
April 28 – Ancaster, Ontario area. "Surround and Support." Focus on caring ministry in the church. Opening speaker: Rev. Mark Stephenson, Director of Disability Concerns. Also, readings and discussion led by Jon Terpstra, author of *The Boys*, which describes his wife's three brothers who lived with and passed away from Duchenne Muscular Dystrophy. Location: Ancaster CRC. Sponsored by Disability Concerns Canada Committee. For more information contact Katinka at Disability Concerns, 800-730-3490 or email boerk@crcna.org.

September 8 – Grandville, Michigan area. "One Body Together in Christ." Focus on encouraging churches to include people with disabilities and their families in the church and to use their gifts for service. Keynote speaker: Sondra Williams who lives with autism. Location: Trinity CRC in Grandville. Sponsored by Disability Concerns Michigan Committee. Cost: \$20.00. For more information contact Virginia at Disability Concerns, 888-463-0272, or email disabilityconcerns@crcna.org.

September 28-29 – Chicago area. "Through the Roof." Focus on equipping and training God's people to bring people and families affected by disability into the light of Christ's love and use their gifts in the body of Christ. Keynote speaker: Joni Eareckson Tada. Location: Trinity Christian college, Palos Heights, Illinois. Sponsored by Joni and Friends, Chicago. For more information contact Jane Voss at Trinity, 708-293-4907, or email jane.voss@trnty.edu.

Book: *Nola: A Journey of Hope after Traumatic Brain Injury* by Judy Sprik with Ron Sprik.

If you are struggling in any way as a head injury survivor or as a caregiver, you will find encouragement as well as ideas for finding help in this story of Nola Sprik and her parents, Judy and Ron. To purchase this book, written by the wife of a CRC pastor, send a check for \$12.00 to Ron Sprik, 3513 Las Vegas Dr. NE, Belmont, MI 49306.



Magazine: *Special Education Today*

A magazine for families and church leaders that addresses special ministry needs from a Christian perspective. Published quarterly by LifeWay Christian Resources, a division of the Southern Baptist Convention. For more information, email subscribe@lifeway.org.



Note: most of the text in the above list of resources was taken directly from the promotional materials of the companies that produce these resources.



meditation

A letter to God

Janette Schaafsma

Out of the depths I cry to you, O Lord. (Psalm 130:1)

It's night—a nighttime of the soul for me: anger, frustration, helplessness, fear, sorrow and grief, heaviness of spirit, pain of soul, aloneness, sadness. I feel sidelined, forgotten, useless, and abandoned. Tears flow from my eyes. I am cut off from the land of the living. I feel cut off from you, my God. Do you hear me when I cry out to you for relief?

I feel like a crumpled piece of paper blowing in the wind. Rheumatoid Arthritis (RA)—so what?? It's not cancer! Get a grip, woman. People have more important things to deal with than a solidly middle-aged lady with aching joints! No elder calls, no deacon or deacon's assistant. I guess they're very busy people. Am I being punished, God? Is it too much to hope for some genuine interest or encouragement from people who are supposed to serve?

My husband does so much for me, but feels so helpless. He has so much to do—at work and at home. My children rarely call; they're all so busy, I know a card or a short letter would be so wonderful! All wishful thinking. I'm afraid I do understand, but why?

I sometimes feel like a leper. People see me and think "that could be me"—don't touch, don't look! How will I continue? The older I become, the harder it is to keep going and to contemplate my future. The only One who sees and knows all knows exactly what I am going through in my body, mind, and spirit. He seems not to care or to want to do anything about it. In the night, I wrestle with him in my mind and heart.

I've had RA for over 30 years. People just get tired of it all. Do you, Lord? Should I just stop bothering you with my prayers and requests for healing? Just grit my teeth and bear it?

I've been writing here at the kitchen table in the middle of the night! Maybe it's a letter to you, Lord. Please write back soon.

I wrote the lament above four years ago; here's the rest of the story. The Lord has given me a new life! The joint replacements have taken away much of the pain. A brand-new medication (plus the old ones) continue to control the RA. The hard work of physiotherapy also helps. I praise the Lord! Thank you! Thank you, Lord!

Fingerless Woman Exercises Stewardship

By Dr. Dirk W. Vander Steen, Christian Reformed World Missions

Laraba owned nothing. Even her fingers were gone; only stubby thumbs remained. Her feet seemed hopelessly deformed until doctors restored a walking surface to her toeless feet. After surgery Laraba spent months on her hospital bed with heavy casts on her legs.

I met Laraba there at the Benue Leprosy Settlement where my wife and I began our CRC missionary career in 1965. As Laraba recovered from surgery, she did embroidery by holding a needle between the stub of her thumb and the palm of her hand.

Stitch by stitch she followed the pencil lines I traced for her on little pieces of cloth. These embroideries of a text or short proverb took her weeks to complete. My wife and I still treasure them today.

Laraba embroidered one text on her own when I left for a tour of leprosy clinics in a remote area. When I returned, she smiled and beckoned me to come to her bed to see her work, which she thought was a Bible text in English. With great care she copied with



Laraba, right, enjoys a ride.

thread a text she found on a bolt of cloth: "36 x 40 yards; Made in Czechoslovakia."

She gave me of her best. It was a moment I will always treasure.

I praised her for making "such a beautiful, meaningful cloth for me." She lifted her fingerless hands, and said with some reprimand in her voice, "I make use of what I have."

Ever since then I have felt the consequence of these words. Most of us have been given ten fingers for God to work with, and to use in service for God's kingdom. Just think what we could do, collectively, if all of us, as God's stewards joined Laraba in making use of what we have!

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.

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