

Talking about Life



Can Science Perfect It?

by Sheila Harding

How the presence of a disabled child in our lives can be a blessing.

As the mother of a child with serious disabilities, I ought to have something useful to say about the treatment of disabled children in Canada today, but I don't really know where to begin.

There is good news and there is bad news.

On the one hand, children with disabilities are accommodated within our communities in increasingly significant ways, with substantial resources available for those support systems. On the other hand, there is increasing pressure to ensure that, in the future, there will be fewer such children. Antenatal diagnosis of significant (and, sometimes, relatively insignificant) disability typically results in a decision to abort the child.

It is becoming standard care in Canada to offer maternal serum screening (MSS) for Down Syndrome, neural tube defects and Trisomy 18 to all pregnant women, unless other risk factors lead straight to amniocentesis instead. See data from the 2002 Health Canada Perinatal Health Report "*Congenital Anomalies*

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in Canada," <http://www.phac-aspc.gc.ca/publicat/cac-acc02/index.html>.

The impact of prenatal diagnosis where elective terminations are performed is evident. Where Down Syndrome is diagnosed, abortion rates have risen to around 70%, yet, ironically, the prevalence of Down Syndrome in the community remains constant because more older women are having babies in western, technologically dominated societies. In Alberta, mothers younger than 20 years have 4.8 Down Syndrome babies per 100,000 births and mothers older than 45 years have 428.6 babies per 100,000. In 1999, Alberta's abortion rate for DS was 27% but I expect that, as MSS becomes the norm, the Canadian termination rates will rise, and our communities will be immeasurably impoverished as a result.

As I struggled to find something useful to write, I found myself engaged in some e-mail correspondence with a colleague who has an interest in, and a heart for, so-called "*special needs*" children. He is wary of church and organized religion, but asks good questions and my responses have apparently struck a nerve with him. Perhaps they will also be of interest to CMDS members.

Some brief personal background for those of you who don't know the Harding family: Our younger son, Ross, had a very rare, x-linked metabolic syndrome called Menkes Disease, which is generally considered to be fatal in infancy. Antenatal diagnosis of this disorder is available to known carriers, who are typically identified (as I was) following the birth of an affected son. In our situation, experimental treatment gave us ten years with Ross (1986-1996) and protected him completely from the neurological injury that is the usual cause of death.

The correspondence that follows was triggered by the July 4, 2006 CMAJ guest editorial (Sandra Rodgers and Jocelyn Downie, Abortion: Ensuring Access, CMAJ 2006; 175: 9), and by an article in the Globe and Mail (C. Smyth, A Difficult Choice and the Follow-through, July 12, 2006, p A14). The latter article is the first-person story of a woman and her husband, both in their 40's, highly educated, well travelled, financially secure, athletic, who discover that their unborn child will be severely disabled. The article chronicles their decision to abort and its aftermath.

My colleague asked what my feelings were about the article, saying my ideas helped him understand his own feelings and the origins of his ethics.

"My feelings?" I replied, "Are you sure you want to know?" I wrote, "I read the article through tears, with a

sick emptiness in my gut. It's tragic from beginning to end, for all concerned. I'm very aware of the depth of anger, of injustice I feel on behalf of this aborted child who didn't meet the standard, and all the other children who are similarly judged.

I am deeply saddened that this couple, so capable in so many spheres, didn't feel 'capable of raising a severely disabled child.' If not them, then who? And what if they do go on to have that perfectly healthy, treasured, only child who proves to be merely average academically, who hates athletics, or who (perish

the thought) subsequently becomes disabled in infancy or childhood? Who simply doesn't cooperate with being their trophy child, the perfect accessory to their perfect lives? I know, I know...you'll remind me that, by then, they'd be hooked, and go on to be the great parents that they have the potential to be. The same would have been true with the child (oops-foetus) they terminated, but they didn't give her the chance to be their teacher. They have been deceived by the Cult of the Perfect Child, and they have no idea how much they've lost. I'm sad for them. They will almost certainly be haunted by their choice. As C.S. Lewis said in another context, '*...her absence is like the sky, spread over everything.*'

I contrast their decision with that of one of my mentors, a specialist in a very narrow field. His wife is a nurse. He was still in training. They were newlyweds, still childless, and both were working on the same unit when an infant came into their care, severely affected with a congenital syndrome in Dr. Fred's area of expertise. She was on the ward for weeks while the system sought a suitable 'medical foster family.' As Dr. Fred tells the story, he and his wife skirted the conversation for weeks until one finally raised the possibility of adoption. As they said to one another,

'If not us, then who? Who are we to judge the parents who decided they couldn't cope if we, with all of our education, skills, and resources, can't find it in ourselves to step in?'

So, they did. And nobody else in our milieu even knew the story-she was simply their daughter, one of several kids by then, and most people assumed it was her syndrome that had prompted Dr. Fred's choice of discipline. I was let in on the story only after Ross was born, as Dr. Fred shared with me the various coping strategies for managing life when his daughter's needs encroached on his clinical duties.

Written by an MD mom on the *Be Not Afraid* website (www.benotafraid.com, July 14, 2006):

'As parents, we expect to teach our children many things, but we don't always stop to think what we can learn from them.'

I spent 23 years as a student, being thoroughly indoctrinated into a culture in which people are stratified by their ability to perform well on intelligence tests, but I could never have predicted that this amazing little girl with Down syndrome, who lived only 2½ years, would turn out to be the best teacher I ever had...If we could look at ourselves and one another without judgments or preconceptions, we would see that the things we most fear, the things we think of as limitations, may turn out, in the end, to be our greatest strengths.'

And from Morris West's *The Clowns of God* (ISBN: 06880044900), the story's Christ-figure, holding a little girl with Down Syndrome on his lap, is addressing a gathering of people.

'(This little one) is necessary to you. She will evoke the kindness that will keep you human. Her infirmity will prompt you to gratitude...She will remind you every day that I am who I am, that my ways are not yours, and that the smallest dust mite whirled in the darkest spaces does not fall out of my hand...I have chosen you. You have not chosen me. This little one is my sign to you. Treasure her!'

And from Robert & Suzanne Massie's *Journey* (ISBN 0394490185), whose son had haemophilia.

'...doctors are left to their own prejudices. Much of what passes under the guise of medical counselling really consists only of saying no, of advising the safe way, the way of least resistance. Not long ago, I attended a medical symposium and heard a famous geneticist talk learnedly about the need for "objective" counselling in cases of genetic disease. Fine. Then he concluded his remarks with a highly subjective sentence saying that he could not imagine a family who would not wish to avoid the emotional and financial stress imposed upon them when a haemophiliac is born. If genetic counselling is to be meaningful...they must be counselled not only to fear, but to be brave enough to live with a question...A child with a genetic illness is a perpetual question, pushing us to seek answers to this dilemma of nature and God.'

The author of the *Globe & Mail* article says, '*I hate the sanctimonious people who have made this more difficult than it has to be.*'

I sure don't feel that way. I feel sad, angry, dismayed, troubled, for sure, and grateful. I'm grateful that nobody knew about Ross's genetics until after he was born. We

did not have to battle throughout the pregnancy, for what has now become known as a '*defiant birth*.' The Menkes literature would group us as those 'unable' to accept termination as a 'solution.' Our abhorrence of abortion as a solution to difficult circumstances is apparently a disability in and of itself, in the view of some. We are 'genetic outlaws' (<http://www.businessweek.com> for an article by Elizabeth Schiltz, mother of a child with Down Syndrome, Assistant Professor of Law in Minneapolis). I'm grateful for Terry, and that he and I agreed when offered experimental therapy that gave us the time we had with Ross. I'm grateful that Terry willingly relinquished the high-powered career for which he was educated, to be Ross' full-time dad. I'm grateful for families and friends who supported us, who gave us courage when we faltered, who helped us to know that we didn't need to be afraid, even though we often were. I'm grateful for the health care colleagues who went the second mile again and again and again. I'm grateful for Ross himself, and all that he brought into our lives.

I hope that people who choose to go through the termination of a less than perfect baby find something like 'The Compassionate Friends' to help them with the burden of their pain, and their guilt and shame (the article's words, not mine). It's the kind of situation that easily kills a marriage. Are you starting to wish you hadn't asked?" I said to my colleague. "I'll stop now."

"No," he replied, "I wish you could write more. I'm just not sure how you get people, who have not experienced something, to really understand, and how do you accept them in their state of ignorance? I told you about the Genome Canada meeting, where the idea was that 'technology could eliminate all genetically different children,' and I only felt what a tremendous loss that would be and how much our humanity would be diminished if we did not have such children to show us the way."

"It's counter-intuitive," I replied, "that the presence of one of these children in our lives might be anything other than a burden, unless one has the privilege of entering into their stories. Maybe the answer is to educate people early. I'm confident that many of my son Ross' classmates from Kindergarten to Grade 5, have gone into the world with a different take on this from many of their

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peers. I think you would appreciate the memory book they collated for us. It includes a story from one of his Grade 5 teachers about Ross' return to class after yet another hospitalization. His classmates had lots of questions. Ross suggested that an article I had written might answer many of their questions and his teacher was able to overcome her concerns about the potential repercussions of a politically incorrect discussion (Article in a Pro-Life publication)!

So, after lunch, Ross and I proceeded to the front of the room. I read to the children a mother's chronicle of the medical condition of her child and how this had changed the way she viewed euthanasia. It was a technically complex paper, written for an audience much older than the young people sitting before me. But they sat there spellbound, listening to her description of the trials that their classmate had endured since birth—the multiple surgeries, the catheter, the bladder infections, the deformities of his skeletal system, the lack of physical strength and the many, many hospitalizations. For most of his classmates, this was the first time that they'd ever heard what Ross had been dealing with in his life.

Ross then proceeded to speak, perched on the edge of his chair in the centre of the room. He began by telling the children that he did not want them to pity him. He loved his life and everything that it brought to him. He told them not to worry...that he could 'handle the pain.' But he confessed that he had one terrible fear that some well-meaning doctor might see him in pain and decide to 'help' him by removing that pain forever. 'I'm not afraid to die,' Ross told us. He said that he had tremendous faith in the Lord Jesus Christ and that he knew that there was a special place for him in heaven, but he wanted to go when it was His time, not when someone on earth decided he'd had enough. 'I know I'm not perfect, but all of us have disabilities of some sort. I can deal with mine. I'm OK,' he said.

At this point, I had a profound realization that I was experiencing a holy moment in my life because, one by one, the students began to raise their hands and to speak to 'Ross the Teacher.' They began to witness about their own faith and how it had helped them in their lives. They shared some of the crosses they were bearing—the frustration of dealing with cerebral palsy, attention deficit disorder and foetal alcohol effects. There was an air of respect and empathy and wisdom during that discussion that I'd never seen before in a group of

children. I went home that evening, still somewhat awed by what I had observed...


While he was alive, nobody ever dared to suggest that Ross was a burden, but after he died, a surprising number of people spoke to us about the relief 'we must' have been experiencing. One 'friend' fretted to me about, 'how Terry would handle the guilt he would undoubtedly experience as a result of the relief he must be feeling.' How convoluted is that?! We learned to reply,

'You're right, he was indeed a burden-as sails are to ships, and as wings are to birds.'

The spinnaker for our new sailboat arrived last week. The graphic on it is a line drawing of a bird in flight, a commemoration of sorts.

How do I accept folks in their state of ignorance? Not always very well. I try to accept the people without also accepting the ignorance. If I have the energy and the equanimity, I try to respectfully question their assumptions and what they think they know. I'm fully aware of the extent of the support that we had in caring for Ross, and that many have had no similar experience of being well-supported over the long haul by family, friends and communities of faith. As my dad was fond of saying, 'It's hard to learn navigation in the middle of the storm.' Nevertheless, hard is not the same thing as bad, and I remain convinced that it is wrong to end human life in anticipation that it will be a struggle. You may recall the quote from a Swahili Warrior Song during the introduction to the movie, *Lorenzo's Oil*:

'Life has meaning only in the struggle. Triumph or defeat is in the hands of the gods. So let us celebrate the struggle.'

I know that some churches are a total embarrassment in this regard, but for the most part Terry and I experienced Christian community the way it's supposed to be. There is now a L'Arche community forming in Saskatoon. I would love to see some sort of elective or community experience happening in that context for our students and residents. Some of them might yet be teachable on this.” 

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Treating UK Women as Harvestable Crops

UK scientists are offering infertile women thousands of pounds off the price of IVF treatments if they agree to "donate" their eggs for use in biomedical research, meaning cloning. The slippery slope is sliding before our eyes and the UK continues its headfirst plunge toward Brave New Britain.