

## THE CHALLENGES OF AUTISM:

a mother's perspective on 30 years' living with autism,  
published in *ANN: The Bulletin of A New Network Within The Presbyterian Church in Canada*, Vol. 3, No. 3, November 1999.

What do people think when they hear the word "autism"? Dustin Hoffman playing the lead role in Rainman a decade ago? Or famous fathers like Sylvester Stallone or Doug Flutie drawing public attention to the needs of autistic youngsters? For most of us, autism has doom-laden meanings. People with autism are among the most vulnerable and marginalized of human beings, and often their families with them. What do we know about autism? How are its victims disadvantaged? What can the rest of us do about it?

Autism, usually diagnosed in early childhood in its classic form, is a severe, lifelong and pervasive form of developmental disorder. More males than females are affected, in a ratio of 3.5:1. People with autism usually have normal physical appearance but impaired social, communication and thinking functions and repetitive or ritualistic behaviours. Two in five have no speech, and most others have difficulties with language or use it in exceptional ways. There are usually profound problems with social relationships and

the expression of emotions. One in four develops seizures in adolescence, and anxiety and/or depression are common among adults. Thirty years ago, the incidence of classic autism was calculated at 4.5 per 10,000 children born. It is now perceived that more people are affected with at least some characteristics of this pervasive developmental disability, and definitions have been broadened into "autism spectrum disorders." At least 22 of every 10,000 Canadians have some form of autism, a higher incidence than for Downs Syndrome or congenital deafness.

Introducing the term "early childhood autism" in 1943, the psychiatrist Leo Kanner stressed the "self-absorption" of children affected by the disorder, for which the coldness of their "refrigerator mothers" was generally blamed. Some parents of autistic children who are also professional specialists in this field--notably Lorna Wing in Britain and Bernard Rimland in the United States--have helped parents since about 1970 to understand the disorder and to know that autism is not caused by anything in the

psychological environment of the children.

Recent research on the brain and nervous system shows that autism is a neurological disorder that reflects significant under-development of the cerebellum, the part of the brain that co-ordinates physical movement and balance and the shifting of attention. Autism can occur with a wide range of measurable intelligence. John Ratey and Catherine Johnson in Shadow Syndromes (1999) see "nerds" and "geeks" who combine very high, focused intelligence with physical and social clumsiness as being at the mild end of an autistic spectrum. Genetic factors seem involved, with autism or a related neurological disorder striking some families more than others. But while research continues, there are not yet any medical methods of treatment or prevention.

How does autism affect the family? Having a child with autism is a "make or break" experience for parents and siblings. Other parents and caregivers can understand some of the burdens. Parents of babies and young children may go

without sleep and many of the pleasures of life. But most can soon forget the pain and deprivation and take pride in their children's development. Those who care for old or ill relatives have their lives and options constrained. But most know that it isn't forever, and they can usually remember better times. Parents of an autistic child face total, pervasive and lifelong responsibilities and live in perpetual tension and stress. While loving their child deeply, they may feel a profound sense of unfairness and rail against the fates or God. Perhaps, more than most, they may understand the questions and lessons of the Book of Job.

To survive, parents must juggle conflicting obligations—to their work, their other children, their own parents, and perhaps to other families who live with autism. A mother may be devastated or feel bound to devote herself utterly to defeating the autism. Her child seemed beautiful and whole as an infant, but she agonizes over the mysterious early signs that all is not well. She suffers the comments and criticism—even the uncomprehending pity--of relations, friends and neighbours. Why can't he sleep? Why doesn't he smile or respond? It must be her fault if he throws a tantrum in the supermarket or at church. Why doesn't he speak? She can't be much

good at parenting skills. Children with autism can now get school places in most jurisdictions, but services and resources are uneven and on the front line for budget cuts. Unmanageable behaviour may lead to exclusion. Parents must advocate for their children and co-ordinate any fragments of funding or services.

Childhood autism may be hard, but adult autism gets even harder, with very limited community-based resources designed for continued learning and practice of communication, social and self-help skills. People with autism have normal life expectancy, and most will require some degree of care or supervision throughout their long lives. Not all families can cope with the multi-faceted needs. Persons with autism form a significant part of people in institutions, and are the last to leave when an institution closes.

Jean Vanier's vision, expressed in Becoming Human and the whole L'Arche movement, offers hope based on faith for families who live with autism and thus outside the mainstream of society. L'Arche cannot directly serve all who are marginalized by mental disability. But it proclaims in word and example that people, whatever their gifts or limitations, are bound

together in a common humanity and each person has the same dignity and rights to life, care, home, education and work. People with mental handicaps often have particular gifts and qualities of the heart that are celebrated in the home life and relationships of L'Arche communities. The strong can find new levels of meaning in their faith and lives by sharing with the less able. A society, to be truly human, must be founded on welcome and respect for those who are weak and too often rejected.