

# Fighting for a Better Life

By Susan McClelland

**Like most eight-year-olds**, Sebastian Wynberg thrives on surfing the Internet and playing with friends. It's hard to imagine that only a few years ago this bright, blue-eyed Toronto youngster could not relate to other people or communicate with them, and spent his days obsessively spinning the lids of pots or the wheels of toy cars. Sebastian has autism, a neurological disorder that interferes with brain development and afflicts at least 30,000 Canadians. Despite being autistic, Sebastian now lives a more normal life thanks largely to a ther-

apists with repeated reinforcement of behavioural, social, linguistic and academic tasks. "Intensity is the major factor," says Dr. Peter Szatmari, a child psychiatrist at McMaster University in Hamilton. "The more intense the behavioural intervention, the better the child will do."

Unlike the United States, where ABA programs are widely funded, public

responded to the therapy as quickly as his brother. In an effort to get more help, the Wynbergs and 20 other families are suing the Ontario government for \$75 million, claiming their kids have been denied medical treatment.

Their hopes have been buoyed by a similar case in British Columbia, where, on July 26, a provincial Supreme Court judge ruled that the

B.C. government discriminated against autistic children by failing to provide funding for an ABA-based program, called Lovaas Autism Treatment. The government is appealing the decision. In her ruling, Judge Marion Allan found that the government violated the Canadian Charter of Rights and Freedoms, and recommended ways the provincial health ministry could fund ABA-based programs. Lawyers for the B.C. petitioners plan to ask for compensation for the 30 families involved, which could amount to several million dollars. Sabrina Freeman, executive director of the B.C. chapter of Families for Early Autism Treatment, a national nonprofit group, says the judgment could affect the availability of treatment across Canada. The Langley, B.C., sociologist, and mother of 12-year-old Michelle Tamir, one of four children named in the suit, adds: "A judicial decision is setting out what the health system must fund. This is unprecedented in Canada."

The ABA system was developed in the 1940s when psychologists used it to help people with neurological and cognitive problems. In the 1960s, California psychologist Ivar Lovaas used ABA principles to develop a program for autistic children. Several models have evolved from Lovaas's work, usually involving up to 40 hours a week of

## Parents of autistic kids turn to the courts in search of funding

apy based on a system called applied behavioural analysis (ABA). For five years, he has spent more than 30 hours a week in one-on-one instruction to dramatically improve his social and learning skills. So dramatically, in fact, that next week, Sebastian will join a Grade 2 class and begin attending school on a regular basis for the first time in his life.

He has come a long way in overcoming the problems in social interaction, communication and behaviour typical of autism. From the age of 2, Sebastian had difficulty learning to talk, lacked understanding of social relationships and engaged in repetitive activities such as rocking,

hand-slapping and becoming fixated on objects. The ABA-based therapy that transformed his life, many researchers say, is the most effective treatment for autism. It involves sessions in which therapists intensively engage stu-



Freeman and daughter Michelle: a B.C. victory

dollars have generally not been available in Canada. As a result, only those parents who can afford the estimated \$40,000 in annual costs are able to provide the full range of ABA-based therapy for their children. To cover the costs, many parents borrow heavily, as the Wynbergs did. The couple—Simon Wynberg is a classical guitarist and his wife, Robyn, a stay-at-home mom—have another autistic son, Nathaniel, Sebastian's identical twin, who has not



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# Health

instruction. For the treatment to be effective, experts say, therapy must be undertaken for a prolonged period of time, in some cases several years. That makes the therapy expensive, especially since many families have to hire U.S. specialists, because few Canadians are trained to do ABA with autistic children.

But research shows the approach generally works. In a 1987 study by Lovaas of 19 autistic children who received 40 hours a week of treatment for two years, nine successfully completed Grade 1 without assistance. And eight were able to complete the grade in special classes. "We know that all children benefit," says psychologist Isabel Smith, an autism specialist at IWK Grace Health Centre in Halifax. "Some are no longer even classified as autistic."

Other research has shown that ABA-based therapies can work wonders, particularly if children start treatment before the age of 5. And some provinces are acknowledging ABA's effectiveness. Earlier this year, after the Ontario families filed their lawsuit, the provincial government allocated \$19 million for ABA programs for children under 5. And in Alberta, as a result of a 1996 lawsuit, the government now funds a pilot project for 15 children between the ages of 2 and 5 in Edmonton.

Even children with mild autism have trouble functioning in a regular classroom, says psychologist Susan Bryson, director of the autism research unit at Toronto's Hospital for Sick Children. "And virtually all of them require living situations with some supervision—in many cases a lot," she adds. In a report compiled in British Columbia, an economist estimated that by providing a Lovaas-like treatment starting at a young age, taxpayers save about \$1.5 million over the life of an autistic person. The reason: without treatment, many autistic adults spend their lives in supervised settings.

Until recently, the response to autistics' special needs has been minimal. Parents repeatedly told *Maclean's* that it took them months, and often more than a year, to get an appointment with a specialist—and even longer to get a diagnosis. Public programs available for



*Robyn Wynberg  
and Sebastian:  
transformed*

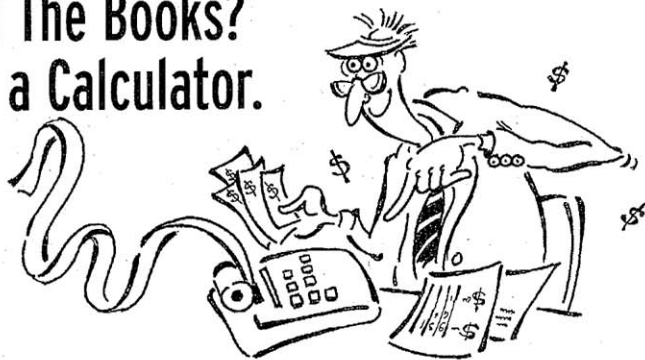
autistic children mostly focus on speech, language or occupational therapies. Although such programs work for some children, experts say they don't address all the problems the way ABA-based programs do. Funding is, at most, for a few hours a week. "It's clear," says Bryson, "that these kids have been grossly underserved by the system."

Halifax geologist Philip Finck, father of a seven-year-old autistic son, Laurence, agrees. "In a country that is supposed to have universal health care," he

says, "these kids have been robbed." For years, Finck and his wife, Elizabeth, have lobbied the provincial government to help cover the costs of their child's therapy. Now, Finck says, he and at least seven other families in the province are considering suing the Nova Scotia government.

Like many parents of autistic children, the Fincks have spent more than \$75,000 on Laurence's treatment and gone heavily into debt as a result. But, they say, the debts seem insignificant compared with Laurence's progress. The child, who begins Grade 1 next week, reads at a Grade 2 level and plays happily with other children. Finck says his son may never be cured of autism, but he hopes the child will be able to live independently, have relationships and hold down a job. In the end, asks Finck, isn't that something all parents want for their children? ■

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