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Canada Suit Seeks Aid for Autism Victims

By CLIFFORD KRAUSS

VANCOUVER, British Columbia Nov. 6 - Beverley Sharpe wondered what was wrong when her 2-year-old daughter, Allison, did not talk. Something seemed askew when her child would not respond to a rolling ball but would find great pleasure from running her hands repetitively through a bowl of soaking beans.

A diagnosis of autism resolved the mystery. But the Sharpes' marriage broke up and Ms. Sharpe was left to pay for Allison's intensive therapy on her own.

Ms. Sharpe dug in her heels. She refurbished and rented out her garage and rented out several more rooms of her West Vancouver house to pay for the 36 hours of therapy Allison needed every week from four therapists, costing more than \$1,400 a month. She also joined a group of parents with autistic children in filing a suit in 1998 seeking public financial aid to meet the children's needs.

The case has since wound its way through the British Columbia provincial courts and has reached the Supreme Court of Canada to become one of the most important cases touching social policy to come before the high court in years.

Provincial governments are now paying for some services for autistic children, but overall Canadian autistic children currently have fewer legal rights than American children with the same neurological disorder.

The American children are entitled by federal legislation to receive educational therapy in their public schools, although services are spotty, depending on how well the local district complies.

But if Ms. Sharpe gets her way, the Canadian rights for the autistic will leapfrog those in America with a health care entitlement that would cost the provinces several billion dollars a year.

"This kid will get what she needs if I have to get a second job flipping hamburgers," said Ms. Sharpe, a 43-year-old government meat inspector, speaking of her daughter, who is now 10. "If you need a wheelchair in Canada you get it, if you need radiation you get it, if you are blind we have schools for you, but if you are autistic you get nothing. Why does my kid get nothing?"

Ms. Sharpe and the other parents involved in the suit contend that they have a constitutional right to have their children's therapy entirely paid for by the government, just as a cancer patient is covered by the Canadian government health insurance system, which serves every citizen.

Not to be equally covered, the parents contend, means their autistic children are being discriminated against in violation of the Charter of Rights and Freedoms, Canada's Bill of Rights.

A decision is expected early next year, and it has the potential to open up a cascade of lawsuits from people with a variety of other disabilities not now covered, including dyslexia. That is why the autism case has stirred resistance from the provincial governments, which say they cannot afford the added burden to a health-care

system that is already stretched financially and forcing many people to wait for services.

"Demands always exceed resources, and choices have to be made," British Columbia's attorney general, Geoff Plant, said in an interview. "Government is better positioned through science and policy analysis to make these decisions than the courts are."

Mr. Plant estimated that if all the autistic children in the province received the intensive therapy that parents like Ms. Sharpe say is required to give autistic people a chance to function independently, it would cost British Columbia more than \$250 million annually, of a total health budget of \$9 billion.

He said if all 13,000 children with special needs in the province were similarly entitled, it could cost the province as much as \$1.5 billion. "Health care funding would have to be radically reconceived," Mr. Plant concluded.

The parents of the autistic children contend that intensive early therapy may be expensive, but not as expensive as sending autistic children to group homes, then institutionalizing them for the rest of their lives, as now often happens when they reach adulthood.

Estimates of how many people in Canada are autistic vary. But as in the United States, the number of diagnoses of autism here is growing.

Proponents of more intensive therapy for autistic children have embraced a treatment called Lovaas. It is named after O. Ivar Lovaas, the Norwegian-born psychologist working in the United States in the 1980's who pioneered it. The therapy concentrates on intensive one-on-one behavior-modification training using repetition and rewards.

Canadian universities lag behind the United States in research and training therapists in this area, advocates for the autistic here say. They add that American parents have been more aggressive in using the courts to expand treatments for the disorder because they are better organized and they are better financed by charitable groups.

But Canadian parents are catching up, and there are now more than 20 court cases in this far less litigious society.

In one case, in the Ontario town of Pickering, parents of a severely autistic child have brought a case before a child-welfare judge accusing their local school board of child abuse for not providing a suitable educational program for their son. In another Ontario case, 29 families are suing the provincial government demanding that it pay for autism therapy beyond the age of 5.

This year, the Newfoundland and Labrador Court of Appeal upheld a case involving a 6-year-old child, requiring the provincial government to eliminate waiting time for autism services.

Here in British Columbia, a mother is suing the Abbotsford school district in the provincial Supreme Court for preventing a therapist she hired for her 7-year-old son from accompanying him to class. The mother contends that it caused him emotional and physical damage and forced his removal from school.

Provincial governments are responding to the lawsuits by increasing funding for autism therapy. The British Columbia government in 2001 began offering families with autistic children under age 6 payments of \$16,000 a year per child to purchase approved therapies and \$5,000 a year for older autistic children. Ontario, the largest province, doubled financing for autism to \$66 million this year. But it is the case now before the Supreme Court that has the most potential to lead to sweeping change because Canadians are entitled to reimbursement for most of their health needs.

"If we can create this national right, every child with autism will have opportunities," said Sabrina Freeman,

executive director of Families for Early Autism Treatment of British Columbia, whose daughter, Miki, is autistic.

Miki, who is 16 and in the 11th grade, spun around, sang endlessly at the top of her lungs and twirled her feet incessantly as a toddler. Her family could not even take her to a restaurant or a library.

After 13 years of Lovaas treatment, however, she is able to play six instruments and takes part in school jazz and concert bands at a fine arts school. Her mother hopes she will someday work in the recording arts field.

"These kids are not a write-off," Ms. Freeman said. "Every child with autism has the right to an opportunity. It's their human right."



Bayne Stanley for The New York Times
Beverley Sharpe, with her daughter, Allison, says in Canada "if you are blind we have schools for you, but if you are autistic you get nothing."



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After special treatments, Miki Freeman, 16, who is autistic, plays in two school bands. "These kids are not a write-off," says her mother, Sabrina.