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\$11-million 'insult'

Court orders province to cover treatment costs but parents say amount is woefully inadequate

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The provincial government hails it as up to \$11 million in new funding for children with autism spectrum disorder.

But the head of a provincial advocacy group for the proper treatment of autism describes it as an insult.

Sabrina Freeman, executive director of Families for Early Autism Treatment of B.C., said the \$11 million will be woefully inadequate to cover treatment that the B.C. Court of Appeal has ordered the government to provide.

"It's kind of like an insult," Freeman said.

"There's so much wrong with this, it's hard to know where to start."

Until now, children over the age of six have not been eligible for any autism treatment funding from the province.

But the Court of Appeal decision



CREDIT: Bruce Stotesbury, Times Colonist

"Tah-dah!" Robert twirls a ribbon to the piano playing of music therapist Johanne Brodeur, who's very much in tune with lives affected by autism. Special Report by Jeff Rud in Monitor, page D1. against the province last October mandated treatment be extended to children until their physicians deem it is no longer of benefit, in effect making the province responsible for funding treatment of older autistic children.

The Ministry of Children and Family Development announced last week that new funding for children 6-18 would be available beginning April 1.

The release said direct funding of up to \$6,000 a year will be available to families for the purchase of extended autism-intervention services for outof-school hours.

Details of the program are sketchy, say parents.

"I haven't heard anything about it," said Karen Anthony of Victoria, whose 10-year-old son Ryan is among those who will be eligible.

"Eleven million dollars -- they haven't really said where that goes and who that goes to."

The ministry release said families will be able to use the money "to choose qualified consultants, behavioural interventionists and other therapists who best suit their children's needs."

The ministry said the new funding builds on a broad range of services already provided by four ministries -- Health Services, Health Planning, Children and Family Development and Education.

The release said the funding model is interim, "as responsibility for services to children and youth with ASD will be moving to the community-living governance authority once it is established." More detailed information will be available to parents in mid-March, according to the release.

But Freeman said no matter what the model for the new funding looks like, it will be inadequate because it will provide only up to \$6,000 annually per child.

Freeman said Lovaas therapy, the only scientifically based treatment for the disease, can cost as much as \$60,000 annually per child. That intensive, one-on-one therapy is based on 30 years of research by Dr. Ivar Lovaas of UCLA and his contemporaries. Freeman said Lovaas therapy basically helps a child with autism spectrum disorder put his life together "brick by brick."

"You cannot set up a treatment program for \$6,000," Freeman said. "It's just ridiculous. Believe me, I wish we could do this program for \$6,000."

Anthony's son has been on Lovaas therapy for six years. The family has gone heavily into debt and her husband has taken on supplementary work to pay for therapy that costs thousands of dollars a year, she said.

"We've basically been doing it on our own," Anthony said. "We wouldn't be going into debt unless we thought it was a worthwhile thing."

Anthony said her son's medical needs have been unfairly ignored for years.

"His medical needs have to be properly accommodated, like any other B.C.

citizen," she said. "His rights and freedoms are being violated on a daily basis."

Freeman said the government bulletin on the new program also lumps treatment for these children in with things such as respite, supported child care and parent support.

"This is completely different," Freeman said. "This is treatment that they (government) have to provide. Four judges have already told them they have to provide it and have recommended it be provided through the Health Ministry."

Children age six and under who have autism spectrum disorder are currently eligible for direct funding of up to \$1,667 per month, or about \$20,000 a year. Even that still leaves them well short of what is medically necessary treatment, Freeman said.

"Is our government paying one-third of a kid's chemotherapy treatment?" Freeman said. "Of course not."

Still, those parents are worried about their funding when the province goes to the new community-living governance authority, Freeman said.

In 2000, a group of parents with autistic children sued the province over a lack of funding for treatment of autism, resulting in B.C. Supreme Court Justice Marion Allan ordering the government to provide "medically necessary" treatment to these children.

A government appeal of the decision was heard last October. Not only did the court uphold the first ruling, it also ordered the province to provide treatment to all children under the autism spectrum disorder -- not just those under seven -- until physicians say it is no longer beneficial.

The government is appealing to the Supreme Court of Canada. A spokesman for the Ministry of the Attorney General said the provincial government would have no comment on the case while it is before the courts.

Meanwhile, 23 of the same families involved in the original B.C. lawsuit have launched another legal action against the government.

The families had originally asked for certification of a class action against the government in 2000, Freeman said. She said the government's lead counsel insisted that the class action wasn't necessary and that a decision in favour of the children's rights would immediately change government policy.

That promise was not kept, Freeman said.

"They basically are reneging on the deal (the lawyer) made," she said.

The suit, which includes the Anthony family, is asking for reimbursement and the cost of future treatment for all 23 families.

The World of Autism

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