

# Funding cut off for autism care

## ■ Penticton mother swears by alternative treatment for her autistic son, but province won't pay for it while new plan for autism treatment is being studied

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**B**arbara Rodrigues says the province is penalizing her and her autistic son for the actions of other parents who are taking the province to court over funding.

"I don't know why we are being punished for helping our child," said the Penticton mother. "I told the social worker the government has nothing to offer me at this point, but money."

Rodrigues was picketing the Kelowna Ministry for Children and Families office recently, and walked the sidewalk in front of Penticton's Cherry Lane Shopping Centre, to raise awareness of her plight.

Until a month ago, the Ministry for Children and Families (MCF) was giving families like the Rodrigueses \$1,000 a month for what the ministry called "in-home day care."

The ministry helps pay for day care already available in the community and such support as behaviour consultants, speech language workers and occupational therapists.

But some families have decided alternative treatments such as the Lovaas method better meet their children's needs.

In Jeremy's case, Rodrigues says she has letters from his pediatrician and family physician stating the treatment is a preferable alternative for him.

The \$1,000 allocation is a quarter of the \$4,000 a month the Rodrigueses are paying to have Jeremy undergo the behaviour-modification program.

Almost a year ago, the Rodrigues' started experimenting with the Lovaas autism treatment out of Los Angeles. Five months ago, they began the treatment in earnest. It doesn't come cheap.

Lovaas will cost the couple a minimum of \$40,000 a year. Currently, Lovaas trainers are all based in the United States.

Barbara Rodrigues and three Penticton students received training in the technique, which involves intensive monitoring of her son Jeremy's actions 36 hours a week. Every three months, a Lovaas trainer analyses progress and fine-tunes the steps.

This fall, what seemed like a workable funding arrangement with MCF fell apart.

In two cases unrelated to the Rodrigues story, the government faced lawsuits from Lower Mainland families seeking funding for Lovaas and other alternative treatments.

The province has withdrawn funding.

"At this point in time, provincial bodies are meeting with autism representatives about an overall plan for everyone in the province that is to be tabled later on in the fall," said MCF area manager Doug Hughes. "At this point in time, we do not have authority to do individualized funding for Lovaas treatment."

In Surrey, Michelle Auton is taking the government to court in a class-action suit on behalf of 120 B.C. families. The Rodrigueses are not one of them.

Auton says Lovaas has been scientifically proven to be the best treatment for autism. On that basis, she claims it should be mandatory and the province should pay for it.

The Autistic Society of B.C. says Lovaas is but one of several forms of treatment that may be right for a child. The problem is a lengthy waiting list for even generic services in a community.

"These families are really desperate," said program director Deborah Pugh. "They are faced wherever they go with a wait list, or treatment inappropriate for the autism spectrum."

The tendency is to slot autism into special needs, said Pugh, and send a child to the neighbourhood special needs day care regardless of whether or not staff are trained for autism.

"I'm not saying kids should go to a segregated situation," said Pugh. "But they should go to a situation where staff can offer a meaningful program."

A small-scale structured program with visual symbols, that walks a child carefully through daily activities has a good chance of making inroads.

"It takes a lot of training," she said. "You can't expect a neighbourhood day care to know how to do that."

"In my experience a lot of families come to us complaining they were never made aware of the programs available to children on the autism spectrum," said Pugh.

Lovaas is not for everyone, Pugh pointed out. Some do well; others don't.

"We would like the government to look at cases individually regarding funding, if they can make a case and show some data, such as that there is increased language use, or decreased temper tantrums."