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## Early remedy stirs controversy

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*Times Colonist staff*

A new \$1.6-million intensive treatment program for local pre-schoolers with autism and related disorders is generating both hope and controversy.

Organizers at the Queen Alexandra Centre for Children's Health tout the program as a breakthrough for the approximately 25 Capital Health Region youngsters it will serve.

But critics say the new program is a sham being used to circumvent a Supreme Court decision that last July directed the province to fund medically necessary early intensive behavioural intervention for children with autism.

Autism is a neurological disorder that strikes approximately one in 1,000 children. It has varying symptoms but it generally affects a child's ability to communicate and socialize.

There is no cure, but intensive, early therapy is widely considered to be the

most effective form of treatment.

The Autism Early Intervention Program, based at Queen Alexandra, is now beginning to offer treatment for youngsters suffering from autistic disorder and related Asperger's syndrome and pervasive developmental disorder-not otherwise specified, said program team coordinator Donna Seedorf-Harmuth.

The new program is unprecedented in the B.C. public health-care system when it comes to the scope and hours of therapy offered.

Similar new provincial programs are also now being implemented in Delta and the Central Okanagan with more on the drawing board.

"There are so many families who have been so disillusioned in the past," Seedorf-Harmuth said. "But this program is going to really be a blessing for so many families."

"We know that this early intervention will make a difference for these children."

*Please see* AUTISM, A4



Three-year-old Andrew, part of a new program for preschoolers with autism, enjoys his favourite food, instant noodles, with sister Jessie and guinea pig Sammy. Andrew's mother, Lindsay Neilson, says she is thrilled with the program.

*Darren Stone/Times Colonist*

The province's remedy for autistic children is a fraud, says the executive director of the B.C. chapter of Families for Early Autism Treatment. But a parent whose son is in the pre-school program says she is "thrilled" and expects him to progress.

# Autism: Program stirs hope and controversy

## • From Page A1

Critics within the B.C. chapter of Families for Early Autism Treatment (FEAT) strongly disagree.

They contend that the only science-based early intervention program is based on the theory and data of Dr. Ivar Lovaas, a renowned PhD in psychology at UCLA, which mandates an intricate program that requires 40 hours of concentrated and co-ordinated therapy a week and costs between \$45,000 and \$60,000 annually per child in the first few years.

The province's new programs, according to FEAT of B.C. executive director Sabrina Freeman, are a "fraud."

"It's not even a shoddy replica [of the Lovaas program]," said Freeman in an interview from her Langley home-office. "That would give it too much credence. It's basically day care that is being labelled as Early Intensive Behavioural Intervention."

Last July, the B.C. Supreme Court ruled that the provincial government had violated the constitutional rights of four B.C. children with autism by not providing effective early treatment. The court ruled that such therapy was medically necessary and directed the government to fund it for all B.C. children with autism spectrum disorder.

The matter continues to be before the courts with the government appealing and the families cross-appealing. The province is appealing the Supreme Court's ability to rule on what is medically necessary for children with autism. The parents of the four children involved in the original case are appealing the early intensive therapy remedy now being implemented by the province, saying it is not adequate.

"This case raises much broader issues than funding for autism," said B.C. Attorney General Geoff Plant. At the crux, according to Plant, is the question "can health care be subject to judicial review?"

"Who is to make health care policy?"

he added. "Is it to be elected representatives of the people in government or the courts?"

Linda Reid, minister of state for early childhood development which inherited the first wave of these early intervention programs from the previous NDP government, said the court directed the province to provide effective treatment for children within the autism spectrum, but did not mandate a specific treatment such as Lovaas.

"We understand this to mean a range of treatment," said Reid, a former special education teacher. "Autism treatment is not a one-size-fits-all proposition. There is no single intervention that is going to suit every child with autism."

Freeman characterizes the province's new programs as "a bunch of speech and language pathologists muddling around, trying to do their best."

A key problem, she said, is that there are no sufficiently qualified consultants at the head of the three new programs.

Meanwhile, services are already being provided through the new Queen Alexandra program, which has an annual budget of about \$1.6 million.

Besides Seedorf-Harmuth, the program will include a full-time psychologist, and the equivalent of 1½ speech-language pathologists and 1½ occupational therapists by the time it hits full stride in September. It also will include 25 part-time "autism interventionists" — staff with a variety of backgrounds including psychology and early childhood education.

Seedorf-Harmuth said these interventionists will deliver comprehensive, individualized programs in a variety of areas such as communications, self-care, readiness and attention, socialization, self-regulation, fine and gross motor skills, and pre-academic skills. Programs are being developed for delivery through pre-school, at home, in organized play groups and even on the playground and will

"honour the family's hopes and dreams for their children," Seedorf-Harmuth said.

The program is open to children between the ages of two and school entry. Seedorf-Harmuth said it should be able to accommodate all area children in the targeted disorders.

The new program is a major upgrade to what Queen Alexandra has offered in the past, Seedorf-Harmuth said, because it includes sufficient resources to provide at least 20 hours a week of direct therapy per child. In the past, the Queen Alexandra service has been good quality, she added, but there simply haven't been enough hours to go around.

"I'm thrilled," said Oak Bay parent Lindsay Neilson, whose three-year-old son Andrew is part of the new program. "I really look forward to the progress he'll make through this."

FEAT's Freeman, however, slams the new B.C. endeavour, saying it is "a fraudulent process being passed off as Early Intensive Behavioural Intervention."

"These people wouldn't know EIBI if they tripped on it," she said, comparing the program to a paramedic being asked to perform brain surgery.

In past years, many B.C. parents have been stretched to the limit trying to fund their children's private Lovaas program, said Freeman. Some families have remortgaged their homes, while others have moved to Alberta, where the treatment is funded by the government.

Freeman said there are about 600 B.C. children under the age of six who could benefit from legitimate early intervention and that the province's new program is only initially accommodating about 75 of them. The rights of the remainder of B.C. pre-schoolers with autism spectrum disorder are being breached, she said, as are the rights of all B.C. children over the age of six with such disorders.

FEAT would like to see the new programs scrapped and one of two solutions implemented, with either: the province providing therapists and consultants with billing numbers so that autistic children could receive what it deems proper treatment; or the province simply providing block funding to families to administer their children's programs themselves.

Seedorf-Harmuth said the new program, in contrast, is offering comprehensive, co-ordinated service to all families, regardless of socio-economic status, and represents a more effective use of resources. She adds that some families simply don't have the time or the ability to effectively administer their child's programs.

Freeman finds this argument patronizing and paternalistic. She says the government's program has effectively set up a "system of controlled monopolies" in the autism treatment service sector.

Reid said the first three programs implemented represent just the initial wave of the province's early intervention efforts. She said the province has contracted UBC to evaluate these programs with "intense scrutiny" as they operate, providing the research base that critics argue is lacking.

"The bottom line is that these programs are brand new," Reid said.

Requests for proposals for programs that will comprise the second wave of early intervention close Tuesday and the goal is to add to the range of choices for parents of autistic children in B.C.

Reid said she hopes a Lovaas provider is among those coming forward with proposals.

"I would be delighted to see that," Reid said. "The door is absolutely open. Our focus is for choice for families and success for kids."