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Globe & Mail

POSTED ON 19/06/06

Arbitrary policy does a number on disabled teen

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Neil was born with problems and it's fair to say they grew as he did. He was adopted when he was five weeks old and was cared for by an apparently loving family until he was 15, when his aggression and size made him too much to handle.

Neil, who is now 19 and weighs about 300 pounds (140 kilograms), has **fetal alcohol syndrome**, attention deficit disorder and pervasive developmental disorder.

His emotional volatility was difficult enough for his parents to handle when he was a small child -- but when he became a young man in a big, powerful body, they had to turn to the government for help.

The government subsequently placed him in several foster homes but none of them worked out. After bouncing around for several years, he ended up living in a cabin in a quiet, lakeside community on Vancouver Island. His adoptive mother, Fiona Gow, helped settle him there and arranged for the seven hours of one-on-one care that he has been getting, daily, through disability support from the Ministry of Children and Family Development.

When he was a child, the government recognized its responsibility for helping care for him. But last year the government's newly created bureaucracy, Community Living B.C., saw a way to get rid of Neil's file.

CLBC -- a Crown agency that provides support to people with disabilities under the motto "good lives in welcoming communities" -- commissioned a psychological report on the grounds that because Neil was about to become an adult, he would be subject to new criteria for eligibility.

Neil was unquestionably mentally disabled throughout his entire childhood, but somehow, miraculously, at 19, government bureaucrats thought he would suddenly be able to care for himself.

The psychological report was prepared by Dr. Barbara Burnside, who among other things had to determine Neil's intelligence quotient.

The CLBC has three criteria for providing services to adults: their disabilities must have manifested before they were 18, they must have measured significant limitations in two or more adaptive skill areas -- and they must have an IQ of 70 or below.

Dr. Burnside found that Neil qualified on the first two criteria, but not on the third. Because he had an IQ of 79 he was deemed smart enough to take care of himself. The CLBC decided his disability support, which amounts to some \$77,000 a year, would end on his 19th birthday.

Ms. Gow, who has a different surname than her adopted son, said she was stunned by the decision.

"Disbelief," she said when asked what her first reaction was. "I thought that could not possibly be. I didn't see how anyone in their right mind could say such a thing. It filled me with despair."

Studies have found the average IQ for adults with fetal alcohol spectrum disorders is 79, but their living skills are often far below their IQ levels. More than 80 per cent of them are incapable of independent living -- and Neil was clearly in that category.

"Although Neil's IQ scores were not in the range that defines eligibility for services from Community Living Services, his adaptive behaviour was markedly challenged," Dr. Burnside wrote in her report.

"Health and safety issues are relevant here. Without the supports now in place, Neil would be extremely vulnerable to his own aggressiveness and impulsivity. He could do significant harm to himself and the community without support."

Dr. Burnside recommended continued support -- but the CLBC disagreed.

"I do understand that Neil has presented significant challenges and that your family has worked hard to get support services in place for him. I hope that you are able to identify other sources of support," Dale Chandler, manager of CLBC in Victoria, stated in a letter to Ms. Gow.

With his birthday fast approaching, Ms. Gow began a desperate search for other sources of support. There were none.

She appealed to the CLBC, but was rejected again.

Case closed?

Not quite.

"I realized a judicial review was our only hope," Ms. Gow said.

That's when Frances Kelly, a sympathetic lawyer with the Community Legal Assistance Society, came into the picture.

Ms. Kelly zeroed in on the arbitrary IQ criteria, and persuaded a judge of the Supreme Court of British Columbia that the CLBC had overstepped its authority.

Mr. Justice Eric Chamberlist said in a ruling last week that not only had the CLBC cut off Neil without legislative authority, but it had also unfairly failed to hear the merits of his case, by ignoring Dr. Burnside.

Judge Chamberlist quashed the CLBC decision and ordered a reconsideration of Neil's eligibility, without using the arbitrary IQ cutoff.

A spokesman for the CLBC said the decision is under legal review and the agency will decide what to do once "the impact on CLBC" has been determined.

The impact on the organization? What about the impact on Neil? His impaired mental functioning is caused by brain damage that is permanent. So too should be the government's commitment to his care.

What the CLBC should really be doing is drafting a letter of apology to Neil's family -- and launching a review of all those other disabled "adults" who have been cut off over the years, based on an unjust IQ rule.

Yesterday, Ms. Gow let out a heavy sigh when asked what she'd have done had Neil's benefits ended this year on his 19th birthday.

"I can't even bear to think about it," she said. "It would have been unimaginable."

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