

PROCEEDINGS IN THE DOUGLAS FIR ROOM

The House in Committee of Supply A; E. Walsh in the chair.

The committee met at 2:45 p.m.

ESTIMATES: MINISTRY FOR CHILDREN AND FAMILIES
(continued)

On vote 21: ministry operations, \$1,481,539,000 (continued).

[Excerpt regarding Autism Action Plan]

[1500]

R. Thorpe: Last year we were promised that the autism plan would be out in the fall. Why did it take so long to complete the autism action plan? Why was it released only in the very late days of May this year?

Hon. L. Boone: It wasn't a plan that just came from this ministry. We were working with three ministries: the Ministry of Health, the Ministry of Education and ourselves. It took a great deal of time for us to come to a unanimous decision as to how we could best move forward on this, and we've done so. The report that is out there has been widely acclaimed by the Autism Society of B.C., and I believe it will go a long way to take us in the right direction in dealing with autism in this province.

R. Thorpe: I think the families with autistic children in British Columbia have felt ignored. I think that people were hoping that this was truly going to be an action plan, and I see the word "action" is on here. What, in the minister's opinion, are the five action-oriented components of this plan?

Hon. L. Boone: Well, we actually have them here. I guess one of the main things that I wanted to talk about was how it. . . . And what parents said to us is that giving them access to information so that they have that information, which is a directory that's provided to families, so that they can find out where to turn. . . . A number of them found that it was very confusing and that in fact it was difficult for them to find information. That's an action that I think has been really important.

The implementation of the screening tools to assist professionals to identify risk indicators for autism during routine health visits is also very important, because we found that many of the health professionals out there were not necessarily identifying autism, or were identifying it wrongly. So that, I think, is very important.

Building on our partnership for training -- that's an action plan that I think is extremely important. We're coordinating our responses between the ministries so that we are centring this on the child, so families can avoid repetition and actually find where services are. And we're developing accountability with a set of standards and performance measures -- expectations. I think those are actions that are widely acclaimed and that the Autism Society out there and those that have an autistic child are happy to have.

R. Thorpe: I wonder if the minister could tell us what part of the action plan deals with the commitment to early intervention.

Hon. L. Boone: There is strength in early intervention and treatment there, with improving the access to appropriate and effective treatment for children between the ages two to five who have been diagnosed with autism. Better access to

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information and training. . . . Communities and regions will have improved ability to diagnose, assess and develop treatment plans for children with autism. Those are some that I think are the indications to move in the direction of early intervention.

R. Thorpe: What is the total amount of funds in the ministry dedicated to dealing with autistic children?

[1505]

Hon. L. Boone: There is \$3.43 million in behavioral support for children with autism. Then they have access, of course, to total family support and developmental services for all children with disabilities, and that's \$63.64 million.

R. Thorpe: So if I understood it correctly, that \$3.4 million is earmarked specifically for the autism project. The \$63 million is a larger envelope. What percentage would that larger envelope. . . ? What would your experience say is directed towards autistic children?

Hon. L. Boone: About 10 percent.

R. Thorpe: So it looks like we're looking at roughly \$10 million for autistic children, in total. How much of that, then, do you believe is earmarked in this plan and in your day-to-day operations for early intervention and treatment?

Hon. L. Boone: The \$3.43 million is clearly identified for early intervention. That is the move of the ministry towards early intervention. Of the \$63.64 million, a good portion goes into early intervention, but it's very difficult to say how much of that goes to autistic children, because in fact they may go into a program and not be identified as being autistic and receive services and then receive some other services on top of that. But there is no sort of division saying that this goes to an autistic child or to a non-autistic child, because they may be receiving the support services at a child development centre that is incorporated to do everything.

R. Thorpe: How many autistic children are there in British Columbia?

Hon. L. Boone: Approximately 1,100.

[1510]

R. Thorpe: How many of those are under the age of five?

Hon. L. Boone: We think it's about a third, but we'd have to confirm that.

R. Thorpe: I don't expect the ministry to have exact numbers, so just directional numbers are good. Based on your recent experience, how many children under the age of five. . . ? How many newly identified autistic children are we finding each year in British Columbia?

Hon. L. Boone: Actually, some of the figures here are ones that I've been trying to grapple with. I've been talking to some of the professionals to figure out why these changes were happening -- whether it's diagnosis, whether we're now diagnosing people more or whether there is in fact more autism in the province. In 1982 there were 3.46 children per 10,000 that were diagnosed with autism, and that has increased to 12.44 per 10,000 in 1997. We have about 40,000 a year, so that's about 48 children per year.

I don't know, and I'm getting different answers as to whether it's better diagnosis or whether there's a reason why this is happening. Nobody's been able to give me a definitive answer as to why there's been that increase in the number of autistic children in the province.

R. Thorpe: When I read page 3 of the "Autism Action Plan," it says: ". . . intervention, and particularly early intervention, offers significant hope for lessening the effects of autism." That's a quote from "State of Science in Autism: Report to the National Institutes of Health," 1996. When I take that and couple that with a statement up at the top of the report, where it says: ". . . early intervention for children between age zero and five can provide tremendous and lasting benefits" -- when I take those things as obviously identifying early intervention and working on those as extremely important. . . . But when I read down through the things that I think we're talking about, which you're going to do in the action plan, I don't see -- unless I don't understand -- a whole bunch of action-orientated strategies to deal with children now. I'm wondering if perhaps I'm not reading this correctly. Are we a little bit too tied up here in some approaches, and do we have to. . . ? Perhaps the minister can tell me whether they address this or not. You're working on a plan. I understand that part; I accept that part. But can there not be a parallel system -- or is there a parallel system? -- for the kids, the young children under the age of five, where people are saying this early intervention is so important? What are we actually doing to get to the children? Never mind setting up the information systems and the training, what are we doing for the children?

[1515]

Hon. L. Boone: I just want to remind the member that this was developed with the parents of autistic children. This is what they wanted us to do; they wanted us to give them a broad range of things. One of the first things we're doing, I guess, is identification. The sooner you can identify a child as being autistic, the sooner you can start to provide services.

The education and training is a very strong part of early intervention. The education of individuals in the infant development program, some of the training to assist with physicians, some of the training for educators -- all of those things are there to assist us in providing a broad range of services to the autistic community.

R. Thorpe: I certainly don't want to be confrontational about this subject. As the minister knows, there's one child in my particular riding that. . . . I try to work very closely with the family, so I want to come across as helpful.

But surely the minister's not suggesting to me that the families of autistic children didn't say they wanted an action plan to deal right now. . . . Surely, all the parents with autistic children under the early. . . . That's all they wanted -- these things here? Is that what the minister's saying? Or did they in fact want an action plan to deal right now with their children who suffer from autism?

Hon. L. Boone: I can tell you that when this plan was revealed and reviewed with the B.C. Council on Autism, our

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staff received a great round of applause. They were in fact extremely pleased with this report. Clearly we did not review this with every parent of an autistic child in the province. But we did broadly consult; we did get input from that sector -- and strong support from them.

R. Thorpe: I want to be very clear here. My questions at this point in time do not have to do with Jeremy Rodrigues. We'll get to those a little bit later.

The minister mentioned the autism council. Who serves on the autism council?

Hon. L. Boone: There is a range of parents and professional staff. We don't have the names of those. We can get those names to you if you so choose.

R. Thorpe: Thank you. That would be useful.

No. 4 under here on early intervention and treatment says: ". . . investigate a range of support models and funding options." What kind of funding options are we looking at? What's our broad -- for lack of a better word -- shopping list of options? What are they?

[1520]

Hon. L. Boone: We could do it either through, possibly, direct funding to parents or through direct funding through a program -- or through a staff-directed. . . . So we're looking at how we might best meet the needs of those communities and those individuals out there. It may be one; it may be all; it may be different things. We have to figure out how we can best meet those needs.

R. Thorpe: When will those decisions be arrived at?

Hon. L. Boone: The time line is an "over the years" period of time. We are starting some of the consultations within the next couple of weeks, going out to some of the broader parents next fall, and hopefully we will have the policy implemented by next fiscal year.

R. Thorpe: Are you looking at one-size-fits-all throughout the whole province of British Columbia, or are you going to pilot some of these programs to see whether they work or need modifications before being implemented on a provincial basis?

Hon. L. Boone: I guess it's a little bit of both. We want to go out and give a menu of services that are available, recognizing that one size doesn't fit all. However, we do want to make criteria the same, so that the criteria are the same regardless of where you are and so that you don't find different criteria in different regions. But you may find that a parent may want different services in different areas. We're trying to work so that we can make those services available, depending on what is required.

R. Thorpe: What role do you see parents and families playing in this early intervention with their children?

Hon. L. Boone: I think anybody would recognize that parents have to play a very strong part in this. One of the parts that you see with regard to the training is helping parents to learn so that they know how they can do early intervention, how they can assist their child themselves. Parents have to play a very major role.

[1525]

R. Thorpe: When you're developing your policy and your criteria, and when you've talked to parents and families, have they suggested to you that the lack of flexibility is a major obstacle in dealing with their children? And if they have, what are we doing to overcome that?

Hon. L. Boone: Yes, they have, and that is why we are doing a review of all our services to try and make them more commonsensical. We've found that sometimes parents get access to a service, and it's not really the service they need, but they take it because they don't qualify for something else. That's why we're doing the review of the many different support services we have.

We have a huge number of them out there: the infant development program, supported child care, early intervention, speech and language services, audiology, behavioral support for children with autism, summer programs for the deaf and blind, school-age therapy, the at-home program, family support services, respite, child and youth care workers, homemakers, parent support, associate family services and nursing support services. All of these services are available, and sometimes we find that -- you are correct -- we're inflexible and the rules don't apply, so things just don't work as well. That's why we're doing a review all of these programs to see if we can bring some common sense there.

R. Thorpe: The words certainly are encouraging. How do you then take flexibility and your application of common sense and get it right to the front-line worker? How does that work?

Hon. L. Boone: That's the real challenge -- to make it so that we understand what we want. The outcome of the review that we're doing is. . . . We're looking for a single definition of children and youth with special needs; a clear vision of services for children and youth with special needs and their families; a comprehensive, integrated set of policies, procedures, guidelines and standards; a renewed partnership with community stakeholders and agencies; and a consistent eligibility screening and assessment and planning approach.

I won't pretend that it's going to be easy to achieve this. Nor is it going to be easy to implement those things, but we will do our best to do training with our staff so that they're aware of any changes and so that they can work within whatever new policy comes out, to make sure that children are served.

R. Thorpe: Is it fair to suggest that front-line workers who are working every day in the field with children and families, and who have to deal with developmentally disabled people and their families, have been lacking in training in that area? Is that a fair statement, or would the minister like to make any comments on that?

[1530]

Hon. L. Boone: I wouldn't say that it's altogether fair. I'd say that the information in this field is changing so rapidly that it is sometimes difficult for our staff to keep up with the

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up-to-date information and data. That's why the training in the action plan is so important. We will certainly do our best to make sure that we are kept up to date there, but we have some very good staff that do the best. . . . But this is changing so fast that it's sometimes hard to keep up to date.

R. Thorpe: I do know that you have some very good staff, because I get to work with them in my riding. This may be the appropriate time for me to say that in my riding, Okanagan-Penticton, the people at Children and Families that my office and I deal with do a very professional job. Certainly we have some issues that we have to deal with from time to time, but for the most part, in my particular riding we handle them very professionally. And I think they are a reflection of the people that live in the community I represent.

Let me say this, hon. Chair. Often it's been my experience, in my different lives, that sometimes we forget that the best resource is right underneath our noses, and we don't even tap into it. What I'd like to strongly suggest -- and I'd just like the minister's comments -- is called the mother, the father or the family. Somehow -- and I don't know how it would work; I would never dream of knowing how it would work -- I would encourage people from the ministry and also the parents to bring open minds -- not that we have a policy, that it's in a book and these things are boom, boom, bang, bang, bang, but that people really actually focus in on these children with autism. It's a give-and-take, and we learn, and everybody focuses in on the child.

I just wonder if I could get some comment. If that's the intention that's flowing from the minister through the deputy and assistant deputies, and by the time it gets all the way down. . . . Are we trying to build a spirit of cooperation so that Jeremy -- I'm just going to use Jeremy as the example, because that happens to be the young fellow and the family that I know -- can have the benefit of his parents working together

and staff working together, the professionals and the volunteers? Is that the intent, and when are we actually going to see those results at the grass-roots level?

Hon. L. Boone: Yes, that is the intent. I appreciate the member's comments. I think you've really touched on the nub of a lot of the problems we have out there and the anxiety that parents and staff have in trying to deal with a system that sometimes hasn't worked for them. We need to make the system work better for our staff. We need to make the system work better for the children out there. That is the goal. I think we'll see some changes taking place pretty quickly, but I'm not going to tell you that it's going to happen overnight. We will work as quickly as we can, because we know that the sooner we deal with some of these issues, the sooner we can get some changes. Our children will profit from that.

R. Thorpe: I just want to ask a couple of questions with respect to the Rodrigues and Jeremy. This has been and continues to be a very, very difficult situation. Given this autism action plan, the willingness to bring families and parents much more into the treatment, the statements on early intervention and the statements on families, what kind of hope could the minister give to Barbara, Joe and Jeremy Rodrigues? We have seen progress, then we've seen a falling back, and then we've seen progress. For whatever reason, this particular case seems to be locked up in. . . . It's in gridlock; that's probably the best way for me to say it without offending too many people. In the spirit of cooperation and moving forward, what hope can we provide for Jeremy? He's five years old now; it's important. What hope can he receive, perhaps not overnight but in the very near future?

[1535]

Hon. L. Boone: Unfortunately, as I understand it, the problem with this particular case is that they want a particular treatment -- Lovaas treatment -- and the ministry does not provide one particular treatment. There are a number of different programs out there for autistic children, but we have said that we will not provide one particular treatment. We have offered a range of supports to them and will continue to offer support services to the family, including home support child care and at-home and other family services. We will continue to do those things. But as a ministry, we do not provide Lovaas treatment, or any other particularly named treatment, for autistic children.

R. Thorpe: To be very clear, the Rodrigues family receives \$233 per month under an at-home program. That's what they receive today.

We talk about this plan, and we talk about bringing families in. We talk about working with children. The family has seen progress with their son having Lovaas. For the record, just so the minister knows, I have provided my air miles to fly the instructors up from California once and, I believe, New Jersey the other time. In Barbara and Joe's eyes, this is what's needed for their child. I think -- and I'm going to give ballpark figures, because I don't know exactly -- the ministry was providing \$1,000 to \$1,200 a month to the family for the care that they deemed to be in the very best interest of their child. They saw progress.

Now we want to take that option away from them. We want to give them \$1,600 a month for day care when they, as parents and family, don't believe that's in the best interest of their child. In the spirit of this action plan of early intervention, of having families work together, of providing options. . . . Can the minister tell me that spending \$1,600 a month and having a child in day care is a better option for that child than \$1,000 or \$1,200 a month and the community helping out with Lovaas, as the family. . . ? Can you tell me how that's in the best interest of the child?

Hon. L. Boone: I don't think it's appropriate to get into an individual, case-by-case assessment here. We'd be here forever. But as a ministry, as I said, we have not gone into individualized funding. We have not made that decision; we have not gone down that route at all. There are many. . . . Lovaas is just one of many treatments or therapies out there for autistic children. It's not a matter of saying that this is only for this one child. This would be a decision that would have to be implemented provincially. It would be a costly one, and one that. . . . We have not made the decision to go that route.

[1540]

R. Thorpe: I'm going to try not to get too excited about this. But I'd like the minister to explain to me how it can be more costly to provide a family \$1,000 a month for the care that they want for their child than costing the province of British Columbia \$1,600. How can that be more costly?

The problem is that the ministry has a credibility problem. I'm laying one on a platter for you to enhance your

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community credibility. This is an autism action plan. It gives you the opportunity to actually take some action. It says, on page 2: "Services should also meet individual needs" -- meet individual needs, not everybody treated the same -- "and allow for early intervention." That's what it says.

These issues do not have to be political issues. It's about the Jeremys, and Jeremy just happens to be the young individual in my riding. But you know what? There are Jeremys throughout British Columbia. When you're trying to work through these programs, when the ministry has been accused of being ineffective, bureaucratic and more orientated toward system, why can't you step aside and say: "Actually, we can do something to help a child"? Why is that such a tough decision to make? Should it not be about providing service to the children? Is that not what this is about?

Hon. L. Boone: Lovaas treatment is estimated to cost between \$40,000 and \$60,000 per year. If we were to do that for every child, then it would be about \$43.2 million. Those are decisions, as I said, that the ministry has not chosen to make. We will be looking at bringing in an array of services. Lovaas may be one of them; there may be others as well. But we will be bringing those forward in our action plan as to how we intend to proceed in providing services and therapies for children with autism.

R. Thorpe: The minister has a very serious responsibility in British Columbia. She's charged with the responsibility of making decisions to look after children. You know, hon. Chair -- and I'm sorry to have to do this -- this government rails at the Alberta government because they don't look after people. But who pays for Lovaas in Canada? Alberta does. And this family was thinking of moving to Alberta so they could look after their child. That is a crime to have to happen here in British Columbia.

Nobody's asking the province to pay \$40,000 for Lovaas. What they're asking is to reinstate the \$1,000 they were getting before, instead of the \$1,600 that they do not believe is going to help their child. That will save you money. Our community will look after the rest. I'm sorry to raise my voice, but this is a very important subject to me, and it's very important to Barbara and to Joe and to Jeremy. I ask the minister to step outside the box and to take her responsibilities seriously and be prepared, as a minister of the Crown, to make a decision for the children of British Columbia.

Hon. L. Boone: As I said earlier, that is why -- and I can appreciate the member being upset and disturbed about these things -- we are reviewing all of the support services for disabled children. That is why we are looking to remove some of those barriers, those blockages, to take down some of those areas. At this particular time, as I said, we do not give individualized funding for Lovaas, but we will be reviewing all of the services. Hopefully, something can come of those things that will assist the Rodrigueses.

[1545]

I'm not going to make a decision here today to say that I will be providing individualized funding for Lovaas, but I will say that we will be looking at how we can apply some of the criteria and bring some common sense to some of these decisions that may apply to what you're talking about with regard to the \$1,000 versus the \$1,600.

R. Thorpe: I do appreciate that comment from the minister. I just want to point out that this says "action plan." It doesn't say "review plan"; it says "action plan." I would be pleased if the minister would commit to me to meet after the estimates with whatever staff is appropriate to deal with this on an individual basis.

I believe that that is a case. . . . There are many more Jeremys in British Columbia. I am prepared, as a member of this Legislature, to work with the minister and the ministry to get some of these issues dealt with as quickly as we can while we're developing the programs to service the rest of the autistic community of British Columbia. I would appreciate a commitment from the minister that we could deal, after estimates, with whatever staff is appropriate to address some individual issues.

Hon. L. Boone: Certainly. We're always willing to work with you.