Dear [Redacted]

Re: Your request for access to information under Part II of the Access to Information and Protection of Privacy Act (the Act) [Our File #: HCS 36 2014]

On August 13, 2014, the Department of Health and Community Services received your request for access to the following records/information:

"I am requesting under the Access to Information act briefing notes, information notes, discussion papers and/or reports on autism, since January 2014.

The Department has reviewed your request in the context of the Act. I am pleased to inform you that partial access to these records is granted. Portions of the enclosed records have been removed in accordance with subsections 30(1), 30(4)(g)(i) and 30(4)(g)(ii) of the Act. Those sections provide as follows:

30(1) The head of a public body shall refuse to disclose personal information to an applicant where the disclosure would be an unreasonable invasion of a third party's personal privacy.

30(4) A disclosure of personal information is presumed to be an unreasonable invasion of a third party's personal privacy where

a) the personal information relates to a medical, psychiatric or psychological history, diagnosis, condition, treatment or evaluation;

(g) the personal information consists of a third party's name where

(i) it appears with other personal information about the third party, or

(ii) the disclosure of the name itself would reveal personal information about the third party.
Section 43 of the Act provides that you may ask the Information and Privacy Commissioner to review the processing of your access request or you may appeal to the Supreme Court Trial Division. A request to the Commissioner shall be made in writing within 60 days of the date of this letter or within a longer period that may be allowed by the Information and Privacy Commissioner.

The address and contact information of the Information and Privacy Commissioner is as follows:

Office of the Information and Privacy Commissioner  
2nd Floor, 34 Pippy Place  
P. O. Box 13004, Stn. A  
St. John's, NL A1B 3V8  
Telephone: (709) 729-6309  
Facsimile: (709) 729-6500  
Email: oipc@gov.nl.ca

In the event that you choose to appeal to the Trial Division, you must do so within 30 days of the date of this letter. Section 60 of the Act sets out the process to be followed when filing such an appeal.

Please be advised that a copy of our response to your request will be published on the Office of the Public Engagement's website five business days after the response is mailed to you. If you have any further questions, please feel free to contact Cheryl Joy, ATIPP Coordinator, at (709)729-7010, or by email at cheryljoy@gov.nl.ca.

Sincerely,

BRUCE COOPER  
Deputy Minister

/cj  
/Encl.
Services for Children with Disabilities Including Autism – March 5, 2014

- There is considerable attention being given to timely access to services for children with autism.

- This attention extends across my department, as well as the Department of Education. Together we are working to ensure our programs are optimized and we have committed to an ongoing working relationship with the Autism Society.

- In addition to our collaborative approach, we are accessing valuable research from the University of Toronto, which will assist us in enhancing our support mechanisms for children with autism.

- The department is also currently partnering with Eastern Health to analyze the wait time for assessment of autism and access to occupational therapy and speech language pathology services.

- Approximately 30 per cent of children diagnosed with autism involved in intensive ABA intervention will be able to be integrated into the regular educational stream by the age of seven.

- When the Intensive ABA Program was first piloted in 1998-99, there were 35 children enrolled. In January 2014, there were 340 children availing of the program.

- The Department of Health and Community Services invests approximately $10.5 million annually in the provision of programs and services for children with autism and developmental disabilities, including the ABA Program. (Funding also includes services for older individuals with intellectual disabilities)
• As part of that investment, the department funds 71 Child Management Specialists and 33 Behaviour Management Specialists to deliver programs to children and youth throughout the province. (Behaviour Management Specialists also support adults with intellectual disabilities.)

• Budgets 2011 and 2012 included several initiatives to increase the support of children with autism:
  
  o $2.9M per annum to extend the ABA Program for children with autism from school entry to grade three.
  o Funding of $595,000 for several new positions (to support autism and other disabilities/conditions):
    • 4 new Occupational Therapist positions (2 in Eastern and 1 in each of Western and Central)
    • 2 Speech Language Pathologists (1 in Eastern and 1 in Labrador-Grenfell)
    • 1 Social Worker (to support a new Developmental Team in Western)
  o $255,000 to support the Autism Society of Newfoundland and Labrador (ASNL), for a total HCS annual grant of $507,500 in 2013-14.

• In Budget 2012 there was an increase in the hourly wage for home therapists from $13.58 to $13.83 an hour, effective July 1, 2012. This rate has increased from $9.62 in 2006.

• Since 2005 there has been an additional 60 full time allied health equivalent positions added to the RHAs budget for services to support individuals with autism and other disabilities. This has resulted in:
  
  o 20% increase in full time equivalent physiotherapy positions;
  o 30% increase in occupational therapy positions;
  o 29% increase in speech language pathology positions; and,
  o 14% increase in audiologist positions
Services for Adults with Autism
March 5, 2014

- Our government is working to ensure that individuals diagnosed with autism and other disabilities, including children and adults, have access to quality health care and medical services when and where they need it.

- The Department of Health and Community Services invests approximately $10.5 million annually in intervention services for individuals with developmental disabilities, including autism. (This includes the ABA Program for children up to the end of grade three)

- The Department of Health and Community Services has progressively increased annual funding to the Autism Society of Newfoundland and Labrador, from $40,000 in 2001-02 to $507,500 in 2013-14.

- The grant is used to support the operational costs and programming to clients of all ages, including a focus on adults with autism.

- The Autism Society provides advocacy as well as parent/family support, summer programs and other core programs to individuals with autism.

- In addition to the services provided by the Autism Society, adults with autism in NL may be eligible to access specialized services and supports through the RHAs if they meet program admission criteria.

- My department has recently recruited an Adult Disability Consultant position. This position will help inform service delivery challenges for adults with Autism Spectrum Disorder and other disabilities and aid us in program improvements.
Autism Assessment
March 13, 2014

- Pediatricians, psychiatrists, and psychologists with demonstrated clinical competency in autism diagnosis can make a diagnosis of autism.

- There are currently 4 developmental teams in the province, one in each RHA that assess and diagnose children for autism. All team members are trained in autism assessment and diagnosis.

- In Eastern Health there are 4 developmental pediatricians who are part of the developmental team. In addition there are some child psychiatrists who are also diagnosing in consultation with the developmental team.

- In the remaining three regional health authorities, the diagnosis is made by a pediatrician who is part of the developmental team.

- There are a very limited number of private pediatricians who provide assessment and diagnosis services. (2 pediatricians in Eastern Health, and 1 in Western Health provide some private services).

- These private providers can refer children for SLP, OT and ABA therapy.
Autism

Explain the breakdown and locations of the new positions allocated for autism and developmental conditions.

There are 30 new positions allocated to support services for children with autism and other developmental conditions. There will be;

- 1 Developmental Pediatrician
- 20 Child Management Specialists
- 1 Social Worker
- 1 Clinical Lead
- 3 Occupational Therapists
- 4 Speech Language Pathologists.

The location of these positions will be determined in consultation with the Regional Health Authorities.

Will these new positions be enough to reduce the wait lists?

These new positions will begin to address the waitlist for services. The ongoing work on the recommendations of the Centre for Research in Healthcare Engineering (CRHE) review will also create efficiencies and reduce wait list times.

When will they be in place?

Most of the positions will be in place by October 2014 to allow the RHAs time to recruit. 2 of the 20 Child Management Specialists positions will be in place in July 2014, 10 in October 2014, with the remaining 8 Child Management Specialists positions to be in place in year 2015.
## Children Actively Receiving ABA Therapy – May 31 2014

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Count</th>
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<tr>
<td>Kindergarten</td>
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<tr>
<td>Grade 1</td>
<td>47</td>
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<tr>
<td>Grade 2&amp;3</td>
<td>83</td>
</tr>
<tr>
<td>Total</td>
<td>381</td>
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Title: Maximum allowable hours of home therapy under the Applied Behavioural Analysis program (ABA)

Issue: Client request to increase maximum number of ABA home therapy hours from 15 to 17 hours for the coming summer months for his child with Autism Spectrum Disorder (ASD).

Background and Current Status:

- ABA Home Therapy is a component of the Provincial Direct Home Services Program (DHSP) that is available to children diagnosed with autism.
- The goal of treatment is to promote social and language development and to minimize behaviors that interfere with adaptive functioning and learning.
- Preschool children diagnosed with ASD are eligible for up to 30 hours per week of Intensive ABA home therapy, Kindergarten children are eligible for up to 15 hours and children in Grades 1-3 are eligible for up to 10 hours. Programming is individualized to each child’s assessed developmental and/or behavioural needs.
- These maximums were developed following from the recommendation of a working group initiated by Minister Kennedy. The 30 hours for preschool was based on Lovaas, (the creator of ABA therapy) recommended 25-40 hours per week. Given children were in school for half a day in Kindergarten, a maximum of 15 hours was introduced to help children transition to school and for school-aged the maximum of 10 hour as children are already in school all day.
- There is currently no research to determine the efficacy of ABA for the grades 1-3 population.
- Children involved in intensive ABA receive assessment; program development, monitoring and evaluation from RHA staff trained and certified as Senior Therapists (ST). Home Therapists (HT) implement skill teaching programs and behavioural interventions developed by ST through one on one interaction with children on a daily basis. The HT are employees of the parents/caregiver.
- The primary concern with the program, consistently identified by parents, is the recruitment and retention of HT. The primary issues are wages and lack of benefits as well as geography; clients in rural areas have much more difficulty recruiting a qualified HT.
- As of February 28, 2014 there were 345 children in the province availing of the Intensive ABA Home Therapy program. This represents 61% of eligible families. Almost 40% of eligible children are not accessing the service largely due to challenges in recruiting and retaining HT.
- This has been recognized provincially as a critical issue and there have been proposals submitted previously outlining the problem and possible solutions.
The purpose of home therapy hours is to supplement the work of the ST. It is meant to be ongoing while the ST is working with the child and family. A family is eligible for a service if they can recruit and retain a HT; they are not entitled to benefits that can be accrued.

To change policy to allow an accumulation of hours not used due to a lack of HT would have enormous implications for a program already experiencing exponential growth.

For each hour of direct home therapy delivered by a HT, a ST must develop and support the programming resulting in increased workloads for ST.

In 2002, as a result of Human Rights Hearing, there was a ‘no waitlist’ ruling to provide ABA to children with autism. It is important to note that other children with developmental disabilities such as fetal alcohol syndrome, cerebral palsy, Down syndrome, are often waitlisted for intervention services as the ‘no waitlist’ ruling does not apply. Further pressures to increase service to children with autism will result in children with other developmental disabilities having to wait even longer for service. Research supports that early intervention is most effective for all children with developmental disabilities not just children with autism.

Alternatively, to allow for an increase beyond the maximum in one case is precedent setting for other cases. This case is not exceptional; it is unfortunately all too common. 30-40% of eligible families are not accessing ABA therapy largely due to this issue.

Given the cohesiveness of the group of families accessing services we could anticipate that one exception without any exceptional circumstances would be noted and further requests might follow.

Other programs under Community Support Services, such as Home Support, also have a maximum number of hours and do not allow for carryover of approved hours.

The Department of HCS is committed to continuous quality improvement and is open to reviewing programs and improving services. We have undertaken a pilot project in one area which allows for individualized funding; a more flexible approach to service delivery. The results of the evaluation of this initiative will be used to inform changes in other program areas.

We are also conducting an evaluation of the recent increase in service eligibility for ABA therapy, from preschool aged children only to children up to and including Grade 3. Again the results of this review will be used to inform program improvements.

Prepared / Approved by: Annette Bridgeman/Angela Batstone/C. Deputy Minister or Designate
Approved by: Minister
Month Day, Year