

July 21, 2009

Dear Dr. Freeman,

Over the last month Autism Canada has had an overwhelming response to the article written by Taline Sagharian, our correction of the introduction and our request for feedback on this matter. The reoccurring question for everyone is if the government of Ontario is not discharging children from the government funded IBI programs based on benchmarks then what clinical criteria are they basing their clinical decision on? There is an assumption that is being made by many. The assumption is that what is being used is the "Continuation Criteria". Can you please confirm this to be true or not?

Autism Canada has taken the time to review the RAPON document dated February 2009, which includes the continuation and discharge criteria. On behalf of Autism Canada and our readership, we have a number of items we are requesting clarification on. It is our intention to share this letter and your response to our readership so we kindly ask that you respond accordingly.

- 1) Page 1, Paragraph 4 states "Using a variety of objective tools..." was not referenced. Therefore Autism Canada would like to request a comprehensive reference list of the "variety of objective tools" you referred to.
- 2) Page 1, Paragraph 4, last sentence "no one single source of information in isolation from other relevant findings is used to determine when a child will be discharged from IBI". Please provide a list of examples of "other relevant finding" that would determine when a child will be discharged from IBI.
- 3) Page 1, Paragraph 5 sentence stating " to create the document, the clinical directors reviewed relevant literature, other IBI decision-making criteria and consulted with an external clinical expert". No reference was given for the "reviewed relevant literature". Please provide the formal systematic review of the literature to us as well as the critical appraisal of the literature documents. Autism Canada would be happy to assist the Government of Ontario, Regional coordinators and yourself in the process of formalizing a critical appraisal of the literature and performing a formal systematic review, with the

assistance of University professors who are experts in research methodology and evaluations.

4) Page 1, Paragraph 5 states "the criteria were considered best evidence." Again, this is confusing to families and therefore we need a comprehensive list of the evidence with references that was collected to make this statement.

5) Page 2, Paragraph 6 states "Clinical directors and regional program psychologists use various sources of information." Again there was no reference for this statement. Please provide Autism Canada of a list of the "various sources of information".

6) Page 2, Paragraph 7 states "RAPON and its clinical directors have continually advocated for the highest ethical standard". Autism Canada is happy to hear this and would like to know if a formal ethical evaluation has been done for the continuation/discharge criteria. If so, we would like to request a copy. If a formal ethical evaluation has not been done then Autism Canada would like to work with the Government of Ontario, Regional providers and yourself to find an independent arms length University professor of bio-medical ethics who would write a formal ethical evaluation of the continuation/discharge criteria.

7) Page 2, Paragraph 8 states "The continuation criteria document is a draft because when it was created the Ministry of Children and Youth Services had just established an expert clinical panel for the Autism Intervention Program to review available research evidence and best practices regarding assessment and decision-making process for the provision of IBI". Autism Canada is happy to hear this document is only a draft and assumes that an ongoing review of available literature is being done since the document is now over 3 years old. In the past 3 years since the document has been written your literature review is no longer valid since other studies have come out that indicate the opposite of your finding. Also the document "Region 6 Autism Connection: Early Intensive Behavioural Treatment 4-Way Agreement. Stockton, CA: Author: 2004. Accessed on-line March 31, 2006, at <<http://www.sjcoe.org/EIBT.doc>><http://www.sjcoe.org/EIBT.doc>" is no longer valid and has been pulled from their website. Their criteria have now been deemed "corrupt". The 4-Way's continuation guidelines have been deemed "discriminatory and favor the special interests of agencies". Autism Canada would be happy to speak with you about the 4-Way continuation criteria used in the US and how it is deemed invalid and therefore no longer a credible reference.

8) Page 3, paragraph 1 the sentence "IBI is a time-limited intervention" has no reference. Autism Canada would like you to provide us with the formalized critical appraisal of the literature and a formal systematic review of the literature that would quantify this statement to determine whether this statement is based on the present scientific literature.

9) Paragraph 3, the sentence "research indicates that children maximize their benefits within 2-3 years". The purpose of the referenced studies was not to determine the amount of time the maximum benefits are received, therefore the statement above is not

supported by the references given and is conjectured from the studies. Autism Canada will be approaching some of the authors to obtain written statements of their opinion of their research being used to support such a statement and to be used as the primary evidence for an untested, unevaluated continuation criterion.

10) Page 5, Review of the Literature. This document was prepared in 2006, the field of Autism is rapidly progressing, and it is recommended again that a formalized up-to-date critical appraisal of the literature and a formal comprehensive systematic review of the literature be used to quantify any statements that would require references in the document. The presented review of the literature is deemed out of date. The studies referenced had inadequate sample sizes and were not designed to measure the time-to-maximum-benefit. It is recommended that a formal up-to date critical appraisal of the literature and a systematic review of the literature be done by someone trained at the PhD level in research methods and critical appraisal. Autism Canada would be happy to work with the Government of Ontario, Regional Providers and yourself to find an arms-length PhD trained University Professor who would do an updated formal comprehensive systematic review of the literature on this topic.

11) Page 5, Review of another program's clinical criteria. This program mentioned above has been removed from the SJCOE.ORG website and is no longer used and has been deemed invalid. In addition, it seems that this Program has never been scientifically validated and we recommend that if a continuation criteria is to be developed, that it should first be evaluated using appropriate research methodology.

12) Page 7, MARKERS. Please provide Autism Canada a copy of the piloting of these markers, and its evaluation studies. If these markers have not been piloted and scientifically evaluated then Autism Canada would be happy to work with the Government of Ontario, Regional Providers and yourself in providing assistance in finding an arms-length University professor who would be willing to set up a valid and reliable evaluation program to determine if the markers are: 1) actually measuring what they were designed to measure (validity) 2) can be used over time and with different children (reliability) 3) determine interaction and covariates of progression in children 4) develop appropriate statistical evaluation measures to determine clinical versus statistical significance, and 5) to provide expertise in program planning and evaluation of the markers.

13) Page 9, Discharge Criteria. Much more work is needed here since the discharge criteria has never been validated or evaluated. In point #12 above, if the MARKERS were tested and evaluated as being valid, reliable and effective then the implementation of the MARKERS by the Government on Ontario, Regional Provider and yourself could support the discharge criteria and could be used to discharge children from the program. However, since the criteria has never scientifically been studied or evaluated, it would be inappropriate and unethical for any health care provider or board certified behaviour analyst to cease funding a treatment that could be benefiting a child without knowing if their discharge criteria are scientifically valid to make such a decision. It is also

inappropriate and unethical to discharge a child into an alternative environment such as the current special education system in Ontario. An environment that is clearly not conducive to the child's needs.

Was the clinical criteria developed by RAPON ever evaluated by an arms length university to determine if the criteria was valid, reliable, effective, and ethical? Such an evaluation could not be done by the government itself or by anyone who has any investment in the present IBI program. Autism Canada would be happy to negotiate and assist the Government of Ontario, Regional providers and yourself in finding an arms length University-based group to assess and evaluate the continuation criteria if this has not been already done. If it has been done we would like to request a copy of the assessment.

Once again, Autism Canada would be happy to work with the Government of Ontario, RAPON, the regional providers and yourself in updating the literature review, formulating a critical appraisal of the literature, conducting a systemic review of the literature and developing a design and implementation strategy of a scientifically valid evaluation tool to determine if the present continuation criteria and discharge criteria is scientifically and ethically valid to be applied to children with autism in Ontario. Autism Canada would also be happy to work with all relevant parties in the development of adequate programs and services for children with autism in the school system.

On behalf of families of children with Autism in Ontario, we hope a timely response will be sent.

Sincerely,

Laurie Mawlam
Executive Director

*Changing Minds, Changing Lives.
Changing The Course OF Autism.*