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CHILDHOOD AUTISM IN CANADA: SOME ISSUES RELATING TO BEHAVIOURAL INTERVENTION

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TABLE OF CONTENTS

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INTRODUCTION

The 2004 decision by the Supreme Court of Canada in the *Auton* case brought the issue of childhood autism and the availability of particular behavioural therapies into sharper focus for Canadians.[2] This document looks at childhood autism, its diagnosis and increased prevalence. In particular, it provides an overview of the behavioural intervention that led parents to seek a court decision on provincial funding for their autistic children.

WHAT IS AUTISM?

Internationally, the most widely used definition of autism is based on the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) published by the American Psychiatric Association. Although autism was first included in the third edition of the DSM in 1980, it was the fourth edition of the DSM (DSM-IV-TR), released in 2000, that placed "Autistic Disorder" in a group of five "Pervasive Development Disorders" (PDD) that also comprises "Rett's Syndrome," "Childhood Disintegrative Disorder," "Asperger's Syndrome," and "Pervasive Development Disorder Not Otherwise Specified (PDDNOS)."[3]

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(1) This paper benefitted from the helpful comments of Dr. Normand Giroux, Psychologist and Associate Professor at the Department of Psychology of the Université du Québec à Montréal, and Dr. Carl E. Stephens, President and CEO of the St. Amant Centre in Winnipeg.

(2) See Marlisa Tiedemann, *Health Care at the Supreme Court of Canada I: "Auton (Guardian ad litem of)* v. *British Columbia (Attorney General),"* PRB 05-19E, Parliamentary Information and Research Service, Library of Parliament, Ottawa, 4 August 2005.

(3) The World Health Organization publishes the *International Classification of Diseases*, which is currently in its 10th edition and is referred to as ICD-10. While it has different codes for PDD conditions, the definitions and diagnostic criteria are substantially similar to those provided in the DSM-IV-TR. This has helped to reinforce worldwide scientific consensus on the diagnosis. See Laura Schreibman, *The Science and Fiction of Autism*, Harvard University Press, Cambridge, MA, 2005, p. 56.

In practice, Rett's Syndrome and Childhood Disintegrative Disorder are generally treated separately: the former is a very rare disorder which affects only young girls and has clearer biological markers (e.g., slowed head growth); the latter, even rarer, is the gradual loss after age 3 and before age 10 of previously well-assimilated abilities, and therefore virtually impossible to diagnose in early childhood.

The other three disorders – Autistic Disorder, Asperger's Syndrome, and PDDNOS – are often collectively referred to as "Autism Spectrum Disorders" (ASD).(4)

Medical tests cannot be performed to indicate the presence of any form of ASD. Instead, the diagnosis is based on the presence or the absence of specific behaviours. According to the DSM-IV-TR, children diagnosed with either Autistic Disorder or Asperger's Syndrome must show:

> Qualitative impairment in social interaction, as manifested by at least two of the following:
>
> - Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
> - Failure to develop peer relationships appropriate to development level;
> - A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest);
> - Lack of social or emotional reciprocity,(5) [as well as:]
>
> Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
>
> - Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus;
> - Apparently inflexible adherence to specific, non-functional routines or rituals;
> - Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements);
> - Persistent preoccupation with parts of objects.(6)

(4) ASD is not defined in international medical classification codes, and many organizations, including the Canadian Psychiatric Association and Autism Society Canada, use ASD and PDD synonymously. In this paper, ASD refers to "Autistic Disorder," "Asperger's Syndrome," and "PDDNOS."

(5) DSM-IV-TR, 299.00 and 299.80.

(6) *Ibid.*

What differentiates Autistic Disorder from Asperger's Syndrome is a "qualitative impairment in communication" manifested by at least one of the following:

- Delay in, or total lack of, the development of spoken language;
- In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
- Stereotyped and repetitive use of language or idiosyncratic language;
- Lack of varied, spontaneous make-believe play or social imitative play appropriate to development level.(7)

In contrast to children with Autistic Disorder, those with Asperger's Syndrome do not demonstrate any significant delays in language or cognitive development. This is why Asperger's Syndrome is sometimes labelled "high-functioning Autism" and considered by some to be a less severe disorder. However, this apparent advantage of Asperger's Syndrome can be offset by the sometimes dramatic psychological consequences of the disorder. Whereas autistic children are typically not interested in others, children with Asperger's Syndrome want to interact but cannot do so appropriately and are therefore much more likely to be rejected by other children.

The PDDNOS category is used for children with a severe and pervasive impairment in the same abilities as those used to diagnose any of the other four disorders, but for which certain criteria are not met because of late age onset, and atypical and/or sub-threshold symptomatology. This is particularly important for Asperger children. Due to the normal development of their cognitive abilities, they are difficult to diagnose properly before age 4 or 5, until the impairment in social interaction is revealed in the school environment. Before that age, children who are thought to have the disorder are usually classified under PDDNOS by the age of 2 or 3 until a clear diagnosis can be made.

ASDs are 3 to 4 times more common among boys than girls. There is neither a known cause nor a known cure.

(7) DSM-IV-TR, 299.00.

INCREASE IN THE NUMBER OF DIAGNOSED CHILDREN

According to Statistics Canada, the number of "persons with autism or any other developmental disorder" was just above 69,000 in 2003, or about 1 in 450 Canadians.(8) The rate seems to be much higher for school children. According to Autism Society Canada, there has been a steep rise in the number of school children with the disorder in the three provinces that monitor this increase with reliable statistics: Saskatchewan, Quebec and British Columbia.(9) Preliminary results of an epidemiological study conducted at Montreal Children's Hospital in the 2003-2004 school year found a prevalence rate of 0.68% (or 1 per 147). While higher than the rate that was reported in the literature 15 years ago, this prevalence rate is consistent with other recent studies in the United States and United Kingdom, where rates of around 0.6% (or 1 per 167) have been reported.

The reasons for this apparent increase are difficult to pinpoint. The recent figures may be driven by a rise in the condition among young children or, alternatively, by a series of other factors, including a broadening of the definition of autism, increased public awareness, improved symptom recognition and diagnosis, and improved survey methodology. A recent study in the United Kingdom published in the *American Journal of Psychiatry* provides some support for the latter hypothesis, but its results will need to be replicated in other contexts before they can be deemed conclusive.(10)

EARLY INTENSIVE BEHAVIOURAL INTERVENTION (EIBI)

A great number of therapies are available for autism, including special diets and pharmacological treatments. However, "few people would argue with the statement that today the treatment of choice is that based on the behavioural model. In fact, behavioural treatment is

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(8) Statistics Canada, *Canadian Community Health Survey 2003*; numbers compiled for the Library of Parliament.

(9) Autism Society Canada, *Canadian Autism Research Agenda and Canadian Autism Strategy: A White Paper*, March 2004, http://www.autismsocietycanada.ca/pdf_word/finalwhite-eng.pdf.

(10) Suniti Chakrabarti and Eric Fombonne, "Pervasive Developmental Disorders in Preschool Children: Confirmation of High Prevalence," *American Journal of Psychiatry*, Vol. 162, No. 6, 2005, pp. 1133-1141; Susan Ruttan, "Autism on the Increase But No One Knows the Exact Numbers," *The Province* [Vancouver], 9 February 2004; Susannah Benady, "Reason for Rise in Autism, Other Disorders Unclear," *Medical Post*, Vol. 40, Issue 42, 9 November 2004.

the only treatment that has been empirically demonstrated to be effective for children with autism."[11] There is also a great variety of approaches using the behavioural model grouped here under the generic label of "early intensive behavioural intervention."[12] In its extensive review of 10 treatment models incorporating behavioural techniques and early intensive intervention, and the related existing literature, the American National Research Council stated in 2001 that:

> The available research strongly suggests that a substantial subset of children with autistic spectrum disorders are able to make marked progress during the period that they receive intensive early intervention, and nearly all children with autistic spectrum disorders appear to show some benefit. However, the research to date is not at a level of experimental sophistication that permits unequivocal statements on the efficacy of a given approach, nor do the data support claims of "recovery" from autistic spectrum disorders as a function of early intervention.[13]

Early Intensive Behavioural Intervention (EIBI) is a generic term for the therapeutic approaches that have evolved from the work of Dr. O. I. Lovaas in the last 35 years. This method teaches small, measurable units of behaviour systematically. Every skill the child with autism does not demonstrate is broken down into small steps. Each step is taught by presenting an instruction. A prompt is added if necessary. Appropriate responses are followed by consequences that have been found to function effectively as reinforcers. Upon repeated trials, as learning takes place, prompts and reinforcers are faded. Simple responses are built systematically into complex and fluid combinations of typical, age-appropriate responses. There is a gradual progression from one-to-one to small group to large group instruction.[14]

The first scientific study of EIBI for autism with careful experimental design and controls was conducted at the University of California at Los Angeles from 1970 to 1984 by Dr. Lovaas. It involved the parents extensively and focused on 19 very young children with

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(11) Schreibman (2005), p. 133.

(12) Also often called "early behavioural intervention," "intensive behavioural intervention," or "applied behavioural analysis." These different labels indicate differences of approach, but the key principles are shared.

(13) Committee on Educational Interventions for Children with Autism, National Research Council, *Educating Children with Autism*, National Academies Press, Washington, D.C., 2001, p. 166.

autism. Given an average of 40 hours per week of one-on-one treatment for two or more years, 47% of the children recovered to the point of being indistinguishable from their normally developing peers. An additional 42% achieved substantial gains versus a control group.(15)

Citing the Lovaas study, the U.S. Surgeon General stated in a 1999 report: "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."(16) Without denying the potential benefits of EIBI, some recent studies have been more reserved in their evaluations of the treatment, pointing to the need for more large-scale research.(17)

FUNDING FOR FAMILIES

For an ideal EIBI treatment, children should be in therapy for 40 hours per week, 7 days per week, 52 weeks per year. However, not all autistic children, and not all parents, can sustain such an intensive intervention for long periods. For example, the St. Amant Centre in Winnipeg offers a very structured preschool program that involves about 35 hours of one-on-one therapy each week (5 of which are provided by the child's family), and operates for 49 weeks each year. Families must become an integral part of the treatment program to ensure generalization of their child's new skills outside of teaching sessions. In Quebec, different programs are offered in an attempt to provide more flexibility to the families.

The cost of EIBI is a major concern for governments. For example, as an intensive treatment involving specially trained staff, the St. Amant Centre preschool program costs $57,000 per child per year, including all infrastructure and operating costs, and is publicly funded in its entirety. In Quebec, it can cost between about $15,000 and $55,000 a year in personnel alone,

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(14) A detailed description of different behavioural approaches can be found in: C. Maurice, G. Green and S. C. Luce, eds., *Behavioral Intervention for Young Children with Autism*, Pro-Ed, Austin, TX, 1996.

(15) O. I. Lovaas, "Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children," *Journal of Consulting and Clinical Psychology*, Vol. 55, 1987, pp. 3-9; J. J. McEachin, T. Smith and O. I. Lovaas, "Long-term Outcome for Children with Autism Who Received Early Intensive Behavioral Treatment," *American Journal on Mental Retardation*, Vol. 97, No. 4, 1993, pp. 359-372.

(16) U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General*, U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, Rockville, MD, 1999, http://www.surgeongeneral.gov/library/mentalhealth/pdfs/c3.pdf.

depending on the intensity of the program and the hourly rate of the professionals involved (psychologists, speech therapists, EIBI technicians, specialized educators).

In Canada, most provinces have agreed to partially fund the treatment for preschool children; for example, up to $20,000 per child per year in British Columbia and New Brunswick. When such a ceiling is in place, most families will opt for a less intensive program if they cannot afford the difference. EIBI funding for school-age children is available in British Columbia, but it is significantly lower. In other provinces, EIBI funding specifically designated for school-age children is either not offered, or it is integrated with other autism, special education and disability programs.

EIBI AND THE *CANADA HEALTH ACT*

At present, federal funding for health care is allocated on a per capita basis to provinces and territories who then distribute it through their health care systems to meet identified priorities. Criteria for federal cash contributions to the provinces and territories to support health services are defined in the *Canada Health Act*, primarily for hospital and physician services. However, each provincial health care program can determine what is included in the provinces' "insured health services."(18)

Thus, the *Canada Health Act* applies primarily to:

a) a "medically necessary" hospital service;

b) a "medically required" service rendered by a medical practitioner; or

c) "when the law of the province so permits," a "similar or additional service rendered by other health care practitioners."(19)

Since the Act does not specify which individual medical services are to be provided, this is determined by each province generally in conjunction with its provincial medical association. Therefore, to be wholly or partially covered by a province's health insurance plan, EIBI would have to be included as a specific treatment in the province's list of

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(17) See, for example: Canadian Coordinating Office for Health Technology Assessment, *Behavioural Interventions for Preschool Children with Autism*, August 2001; Alberta Heritage Foundation for Medical Research, *Intensive Intervention Programs for Children with Autism*, February 2001.

(18) *Canada Health Act*, section 2, http://laws.justice.gc.ca/en/C-6/text.html.

(19) *Ibid.*, section 9 on comprehensiveness.

"similar or additional services" along with the "health care practitioners" who render such services.(20)

This position was outlined very clearly by the Supreme Court judgment in the *Auton* case involving an autistic child from British Columbia:

> The *Canada Health Act* and the relevant British Columbia legislation do not promise that any Canadian will receive funding for all medically required treatment. All that is conferred is core funding for services delivered by medical practitioners and, at a province's discretion, funding or partial funding for non-core services, which in the case of British Columbia are delivered by classes of "health care practitioners" named by the province.(21)

The freedom of each province to include or exclude a specific treatment in its insured non-core services explains the notable differences among provincial programs for the treatment of autism.

Another important legal issue is EIBI funding for school-age children. In March 2005, the Ontario Superior Court of Justice ruled that, by ending funding for its Intensive Early Intervention Program when children reached the age of six, the Government of Ontario had violated the rights of 35 children coming from 30 families.(22) The Government of Ontario appealed the decision, and hearings began in December 2005 before the Ontario Court of Appeal. The key element in the decision will be the demonstration that the therapy is efficient for older children and adults. If the judgment is upheld, provincial governments could be forced to extend their EIBI preschool programs to all individuals diagnosed with ASD. Alternatively, the provinces may decrease the level of funding for each individual as a result of the extension.

CONCLUSION

Autism is a complex disorder, and comprehensive understanding of its full dimensions remains elusive. Because provincial health care funding is often tied to evidence of

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(20) The decision to include a service as well as to determine the level of its potential funding remains the prerogative of each province.

(21) Supreme Court of Canada, *Auton (Guardian ad litem of)* v. *British Columbia (Attorney General)*, [2004] 3 S.C.R. 657, 2004 SCC 78, 19 November 2004, http://www.canlii.org/ca/cas/scc/2004/2004scc78.html.

(22) *Wynberg* v. *Ontario*, http://www.canlii.org/on/cas/onsc/2005/2005onsc13356.html.

the effectiveness of particular therapies, it is imperative that increased research be done in this area. As EIBI becomes more available, there will be opportunities for randomized clinical studies and standardized approaches to measure outcomes.