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Behavioural  
Interventions for  
Preschool Children  
with Autism

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**Canadian Coordinating Office for Health Technology Assessment**

**Behavioural Interventions for  
Preschool Children with Autism**

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August 2001

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Declaration of any conflicts of interest of authors: None declared.

# EXECUTIVE SUMMARY

**Introduction:** Autism is a neurobehavioral syndrome characterized by deficits in reciprocal social interaction, impaired reciprocal verbal and nonverbal communication, and restricted and repetitive patterns of behaviour, interests and activities. An increasing number of Canadian families are requesting assistance in obtaining therapies for children with autism. This may be attributable to many factors ranging from an actual change in incidence, an increase in prevalence, greater awareness, changes in diagnostic criteria, the development of instruments to aid diagnosis and assessment, insufficient resources to meet the needs of children and families, and/or an increased number of informed parents with a desire to improve the outcome for a child with an autism-related condition.

**Objective:** The objectives of this study are to present a summary of evidence and expert opinions regarding behavioural therapy, and describe Canadian issues and initiatives, an analysis of legal case findings in the area, and key factors that influence the provision of services to preschool children with autism in Canada. This report does not purport to be a critical appraisal of primary studies but is a systematic review of the literature which summarizes recent reviews and expert opinions regarding behavioural therapy.

Specific questions addressed in this review are:

1. What is the evidence and expert opinion of respected authorities regarding behavioural therapies and outcomes in preschool children with autism or pervasive developmental disorders based on available research and clinical experience?
2. What is the current practice regarding behavioural therapy for preschool children with autism or pervasive developmental disorders in Canada?
3. What legal cases related to treatment for autism have occurred or are pending in Canada? What legal cases have occurred outside of Canada?
4. What factors influence the delivery of services to children with autism in Canada?

**Methods:** Published literature was obtained by searching a number of databases. These searches were supplemented by hand searching and searching the Internet. Information regarding current service provision and Canadian initiatives was based on contacts identified in a survey previously commissioned by the British Columbia Ministry for Children and Families, and discussions with contacts formed as a result of research forum discussions with the Canadian Autism Intervention Research Network (CAIRN).

**Results:** Based on the secondary reviews evaluated in this report, there are few published controlled primary studies regarding the efficacy of behavioural interventions; most have methodological flaws that make interpretation of results difficult. Study design in this area could benefit from the inclusion of an adequate control group and the application of consistent outcome measures used for all children enrolled in a study, administered by the same, blinded assessor at the beginning and end of the study. There are some systematic reviews that largely concur in their conclusions. Existing evidence suggests that behavioural intervention, including a minimum intensity of approximately 20 hours per week of one-to-one applied behavioural analysis, can improve aspects of function, in particular performance on IQ tests, in children with

autism. However, it is not possible to define the sufficient number of hours per week of intervention that are required for a positive outcome. There is little guidance regarding cessation or modulation of the level of intensity for behavioural therapy. Within the last two years, many provinces in Canada have initiated pilot projects to deliver behavioural intervention to children with autism. These projects are based on behavioural strategies whose characteristics have demonstrated some success.

Canadian judgments in legal cases of parents claiming appropriate treatment for autistic children have not yet reached a level constituting legal precedent in any province. In a legal case in British Columbia, where parents sought funding for therapy for children with autism, a proposed model of early intervention was accepted as an effective treatment for autism spectrum disorder for children below six years of age. Decisions made in other jurisdictions offer little guidance on how Canadian courts of authority are likely to resolve claims for provincial funding of services.

The delivery of services to children with autism has been influenced by the introduction of universal healthcare to Canada, the shift to community-based programming and integration, as well as the evolution of the classification system for diagnosis.

**Discussion and Conclusion:** Though limited, findings of existing studies suggest that preschool children with autism exhibit cognitive and functional improvement when receiving behavioural intervention with applied behavioural analysis for approximately 20 hours per week or more. It is not clear, however, which subset of children with autism derive the most benefit, which components of therapy are integral to positive outcomes, whether similar results would be observed in older children with autism, whether there are definable long term functional benefits, or whether reported gains in IQ translate into happier people with greater functioning in the community.

It is important for policy makers, program developers and clinical researchers to consider identifying pre-treatment characteristics of those receiving therapy, measuring treatment fidelity, evaluating progress in therapy to determine whether therapy is or continues to be of benefit, and comparing the value of early intensive behavioural therapy to other early interventions for autism.

Methodological flaws in the primary studies that were examined in reviews suggest that standard measures for assessment, continued evaluation of progress, and long term functional outcomes are required in future study design. Improved research methods would provide more reliable evidence about therapeutic effectiveness and would assist in the planning of individualized treatment programs aimed at more successful outcomes.



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# Abbreviations

ABC:	Autism Behaviour Checklist
ABA:	Applied behavioural analysis
ADI-R:	Autism Diagnostic Interview-Revised
ADOS:	Autism Diagnostic Observation Schedule
ANAES:	L'Agence Nationale d'Accreditation d'Evaluation en Sante
ASP:	Asperger's disorder
BCOHTA:	British Columbia Office of Health Technology Assessment
CAIRN:	Canadian Autism Intervention Research Network
CAN:	Cure Autism Now consensus group
CARS:	Childhood Autism Rating Scale
CAYAC:	Children and Youth Action Committee
CDD:	Childhood disintegrative disorder
CHAT:	Checklist for Autism in Toddlers
DSM-III:	Diagnostic and Statistical Manual of Mental Disorders, third edition
DSM-III-R:	Diagnostic and Statistical Manual of Mental Disorders, third edition, revised
DSM-IV:	Diagnostic and Statistical Manual of Mental Disorders, fourth edition, <sup>11</sup>
DSM-IV-TR:	Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revised
ECRI:	Emergency Care Research Institute
EISS:	Early Identification and Intervention Services Sub-committee
EIBI:	Early intensive behavioural intervention
IBI:	Intensive behavioural intervention
ICD-10:	International Classification of Diseases, tenth edition
IFSP:	Individual Family Service Plan
LEAP:	The Learning Experiences...An Alternative Program for Preschoolers and Parents"
MCSS:	Ministry for Community Social Services
PDD:	Pervasive developmental disorders (PDDs); clinical spectrum of disorders often associated with some degree of mental retardation.
PDD-NOS:	Pervasive developmental disorder-not otherwise specified (PDD-NOS)
PL-ADOS:	Pre-linguistic version of ADOS
TEACCH:	Treatment and Education of Autistic and Communication Handicapped Children (TEACCH)
VABS:	Vineland Adaptive Behaviour Scales

## **Definition of Terms**

For discussion purposes of this report, the following definitions apply:

**Autism:** diagnosis as defined by the DSM-IV-TR, DSM-IV, DSM-III-R, DSM-II or ICD-10 classification system, generalized to autism spectrum disorder for the purposes of discussion in this report, unless specified as classic autism. Autism spectrum disorder comprises: autistic disorder; pervasive developmental disorder-not otherwise specified (PDD-NOS) including atypical autism; Asperger's disorder (ASP); Rett's disorder; and childhood disintegrative disorder (CDD).

**Behavioural Intervention:** behaviourally based therapy developed to improve the symptoms associated with autism.

# 1. INTRODUCTION

## 1.1 Purpose and scope

An increasing number of Canadian families are requesting assistance in obtaining therapies for children with autism. CCOHTA received a request from its Scientific Advisory Panel (SAP) to undertake an evaluation of treatment and support for adults and children with autism.

Consultation with CCOHTA's Board of Directors and the SAP resulted in the project being short-listed as "treatment and support for children with autism." A preliminary literature search was conducted to identify potential non-drug candidates for assessment. A list of ten non-drug interventions was sent to 11 Canadian organizations and associations in order to identify related issues having impact on national policy decisions and standards of practice.

Following a meeting with representatives from consulted organizations and associations, three possible avenues were identified for the CCOHTA assessment: a summary of reviews; a systematic review of primary studies; or an environmental scan of treatment services in Canada. Efforts were underway by other agencies to undertake a review of the primary study data. There were inherent problems in conducting an environmental scan of service providers of behavioural therapy based on the inability to identify and track all public and private service providers in Canada. The consensus of those consulted was that a summary and analysis of reviews would be the most appropriate and feasible for an assessment given current efforts nationally and internationally. The assessment, initially entitled "comprehensive treatment programs for preschool children with autism," was narrowed in focus to cover behavioural interventions, Canadian issues and initiatives, an analysis of legal cases and service provision according to timelines and resources.

Specific questions addressed in this review are:

1. What is the evidence and expert opinion of respected authorities regarding behavioural therapies and outcomes in preschool children with autism or PDD based on available research and clinical experience?
2. What is the current practice regarding therapy for preschool children with autism or PDD in Canada?
3. What legal cases related to treatment for autism have occurred or are pending in Canada? What legal cases have occurred outside of Canada?
4. What factors influence the delivery of services to children with autism in Canada?

This report consists of a summary and qualitative review of published clinical evidence and expert opinions regarding behavioural interventions for autism; the status of current service provision and Canadian initiatives; an analysis of legal cases; and an evolutionary summary of factors that influence delivery of services to preschool children with autism in Canada. This report does not purport to be a critical appraisal of primary studies but is a systematic review of the literature that summarizes recent reviews and expert opinions in the area. The report also attempts to capture contemporary Canadian issues and initiatives regarding the provision of services to preschool children with autistic spectrum disorder.

## 1.2 Autism

### 1.2.1 Clinical Characteristics

Autism is a neurobehavioral syndrome characterized by deficits in reciprocal social interaction, impaired reciprocal verbal and nonverbal communication, and restricted and repetitive patterns of behaviour, interests and activities.<sup>1-3</sup> These symptoms generally appear prior to three years of age. Individuals with autism may exhibit hyperactivity; short attention span; impulsivity; aggression; self-injurious behaviours; odd responses to sensory stimuli; eating, sleeping, motor or mood abnormalities; and difficulty comprehending the environment, thoughts, emotions and needs of others.<sup>4,5</sup>

While autism involves dysfunction of the central nervous system, the aetiology of autism remains unknown in most cases.<sup>4</sup> There is a genetic component since approximately 2-5% of siblings of affected individuals also exhibit the condition.<sup>1,4,6</sup> Evidence suggests that autism is genetically heterogeneous, where two or more independent genetic mechanisms may lead to the disorder.<sup>7</sup> To varying degrees, different conditions that affect brain function such as maternal rubella, untreated phenylketonuria, tuberous sclerosis, herpes simplex encephalitis, and a number of chromosomal disorders have also been associated with autism spectrum disorder.<sup>8</sup> In some cases, autism is associated with environmental causes including thalidomide and anticonvulsants taken during pregnancy.<sup>9,10</sup>

As defined in the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV)*,<sup>11</sup> published by the American Psychiatric Association, autism is classified within a clinical spectrum of disorders known as pervasive developmental disorders (PDDs). This spectrum, often associated with some degree of mental retardation, comprises: autistic disorder; pervasive developmental disorder-not otherwise specified (PDD-NOS) including atypical autism; Asperger's disorder (ASP); Rett's disorder; and childhood disintegrative disorder (CDD).<sup>11</sup>

While the diagnosis of autism remains behaviourally based, the definition of autism has grown to extend past the confines of that originally described approximately 50 years ago by Leo Kanner.<sup>12</sup> The diagnostic labels and criteria for autism have changed significantly over time from that proposed by Ritvo and Freeman (1977; 1978) and of Rutter and Schopler (1978), to earlier versions of the *Diagnostic and Statistical Manual (DSM)*, specifically the *DSM-III* (1980) and the *DSM-III-Revised* (1987).<sup>13,14</sup> Currently, a diagnosis of autism is ideally determined by a multidisciplinary team. Teams may consist of experts such as neurologists, paediatricians, psychiatrists, and psychologists. Especially in rural areas, it can be difficult to access professionals with expertise in autism and related conditions who have specific training in diagnosis. Experts use set criteria presented in either the *DSM-IV* or the tenth edition of the World Health Organization's *International Classification of Diseases (ICD-10)*.<sup>15</sup> The *DSM-IV* has recently been revised, *DSM-Text Revision (DSM-IV-TR)*,<sup>1</sup> and the diagnostic criteria differ in that the term "qualitative" has been added to reflect the recent view that a range of qualitative abnormalities exists.<sup>16</sup> *DSM-IV* field trials suggest that autism is a robust diagnosis, where 82% of all individuals with the condition are correctly identified as having the condition (a sensitivity of 0.82), and 87% of individuals who do not have the condition based on the reference standard are correctly identified as being free of the condition (a specificity of 0.87).<sup>17</sup>

Because the severity of symptoms varies considerably between individuals, it has been suggested that autism be considered a spectrum disorder to include both autistic disorder and PDD-NOS as defined in the *DSM-IV*. *DSM-IV* diagnostic criteria are shown in Appendix I (Table 1 for autistic disorder and Table 2 for PDD-NOS). Each case can be placed along a continuum of symptoms ranging from mild to severe. PDD-NOS is intended to describe individuals who demonstrate impairment of social interaction, communication and/or stereotypical behaviour patterns or interests but who do not meet the onset criteria or the behavioural criteria, or meet neither the onset nor behavioural criteria for any other PDDs, schizophrenia, schizotypal personality disorder, or avoidant personality disorder.<sup>11,18</sup> While the diagnostic criteria for autism require the onset of symptoms prior to three years of age, approximately one-third of families of children later diagnosed with autism did not notice symptoms until 18 months, where symptoms related to language development become more apparent.<sup>11</sup>

Based on *DSM-III* diagnostic criteria, approximately 75% of children diagnosed with autism suffer some degree of mental retardation, as defined by having below average intellectual functioning (intelligence quotient [IQ] <70); however, affected individuals may exhibit uneven cognitive development or the presence of special skills.<sup>19-21</sup> Fewer children with autistic spectrum disorder exhibit mental retardation or associated medical conditions in comparison with children diagnosed with autism. Those severely affected by mental retardation tend also to suffer from epilepsy.<sup>22</sup> As many as a quarter of all affected individuals develop seizures with peak onset occurring during adolescence. There is disagreement regarding the rate of medical conditions associated with autism that is reflective, perhaps, on differences between population-based and clinically accrued samples and the proportion of individuals across studies that have moderate and severe mental retardation.<sup>23</sup> Approximately 10-30% of those with autism have associated medical conditions such as sensory impairment, tuberous sclerosis, and neurofibromatosis.<sup>21,24</sup> However, the state of mental retardation may be related to an inability to respond and communicate in typical ways at the time of diagnosis.

### 1.2.2 Testing for Autism

Autism can be diagnosed accurately in children by or before three years of age.<sup>25,26</sup> However, autism often remains unrecognized and undiagnosed until or after late preschool age because appropriate tools for routine developmental screening and screening specifically for autism were minimally used based on availability, accessibility or awareness by health care professionals. In 1,300 families recently surveyed, the average age at diagnosis of autism was approximately six years, despite the fact that most parents sensed that something was wrong by the age of 18 months and sought medical assistance by two years of age.<sup>15</sup> Less than 10% of these children were diagnosed at initial presentation, another 10% were told that their child would grow out of it or to return if their worries persisted. The remainder were referred to another professional at a mean age of 40 months. Forty percent of these children were given a formal diagnosis, 25% were told not to worry and 25% were referred to a third or a fourth professional. Over 30% of parents referred to subsequent professionals reported that little help was offered, while 10% reported that a professional explained their child's problems. Almost half of the families reported that the school system and other parents were of great assistance over time, more so than professionals in the health care community. The diagnosis of autism is often not made until two to three years after symptoms are recognized, primarily due to concerns about labelling or incorrectly diagnosing the child. However, early diagnosis of autism and early intervention

facilitates educational planning, provision for family supports and education, management of family stress and the delivery of appropriate medical care and treatment.<sup>15</sup>

Until recently, there was little training in medical school or pediatric specialty programs on autism, its diagnosis, effective therapies or where to obtain them. Efforts are underway to increase awareness of the early signs of the disorder and strive towards earlier accurate diagnosis.<sup>15</sup> Given that other conditions, such as fetal alcohol syndrome and children with low cognitive functioning,<sup>19,27</sup> may also exhibit symptoms similar to autism, the difficulty with exact diagnosis becomes complex. Diagnosis and management of autism spectrum disorder presents paediatricians with a challenging task in that there is no laboratory test specific for autism, it is a neurobehavioral phenotype that is believed to have diverse aetiologies. Judgement regarding the presence or absence of a constellation of behavioural symptoms is subjective and depends on the physician's understanding of and experience with the disorder. Coupled with government department reluctance to fund programs without definitive diagnosis, this results in the exclusion of many children from potentially useful programs. The report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society recommends that developmental surveillance be performed at well-child visits from infancy through school-age, that autism specific screening be performed on all children failing routine developmental surveillance procedures using the CHAT (Checklist for Autism in Toddlers) or the Autism Screening Questionnaire, and that children with autism receive audiologic assessment and lead screening.<sup>15</sup> While parents, educators, and health care professionals identify signs and symptoms characteristic of autism, a clinician experienced in the diagnosis and treatment of autism is usually necessary for accurate and appropriate diagnosis.

Different tools have been developed to assist in assessing very young children.<sup>8</sup> There is a need to increase awareness among professionals involved in early child care to familiarize the community with the signs and symptoms of autism to recognize possible social, communicative and behavioural indicators of the need for further diagnostic evaluation.<sup>26</sup> Specialists and primary care physicians are encouraged to become familiar with at least one autism screening tool and perform screening on all children.<sup>16</sup> Various diagnostic instruments, rating scales and checklists have been devised to complement categorical diagnosis and serve both research and clinical purposes. While these tools have been developed to aid detection of autism, it has been suggested that additional validation is needed to assess their sensitivity and specificity across populations.<sup>16</sup>

Prior to assessment, a child and family must be able to access an assessment program. Access to such programs is extremely limited with long waiting lists at precisely the time that children require the most services, and when they may benefit most from intervention. There are also major challenges in the comprehensive assessment of a child with suspected autism spectrum disorder. The first challenge is making a definitive diagnosis based on *DSM-IV* criteria and standardized autism spectrum disorder specific evaluation tools. The second is searching for aetiological disorders associated with autism spectrum disorder.<sup>14</sup> Specialists trained in evaluating children with autism spectrum disorder will assess the child's overall developmental status and determine whether there is coexisting mental retardation and whether the child's social skills are significantly below their global level of functioning. The Vineland Adaptive Behaviour Scales (VABS), for example, are used to measure the child's social and emotional development. VABS were designed to provide a dimensional assessment of dysfunction in the



areas of reciprocal social interaction, communication, activities of daily living and motor development that are associated with autism.<sup>13,28</sup> This is then compared with the child's overall developmental status or IQ. In addition, specialists use one or more comprehensive standardized assessment tools specific for autism spectrum disorder.<sup>16</sup>

The Childhood Autism Rating Scale (CARS), a widely used tool developed before the *DSM-IV* was published, is based on the observation of behaviour. This scale has the advantage of capturing factors such as the age of the child and the intensity of specific behaviours; however, it may not fully reflect information about cognitive and social development in young children. Also developed before publication of the *DSM-IV* criteria, the Autism Behaviour Checklist (ABC) is a behavioural checklist containing 57 items divided into sensory, body and object use, language, social and self-help categories. The Gilliam Autism Rating Scale consists of a checklist for parents based on *DSM-IV* diagnostic criteria. Items are grouped in categories addressing social development, communication, and stereotypic behaviours.<sup>16</sup>

The Autism Diagnostic Interview-Revised (ADI-R),<sup>29</sup> a semi-structured interview for parents, and the Autism Diagnostic Observation Schedule (ADOS), an observational scale for children and adults, are complementary diagnostic instruments that document separately the presence of abnormalities in social reciprocity, communication, and restricted, repetitive behaviours.<sup>16</sup> These tools contain a diagnostic algorithm that confirms that an individual has the specific pattern of deficits defined as autism.<sup>17</sup> The ADI-R has been found to have good specificity but poor sensitivity at detecting childhood autism at 20 months of age.<sup>29</sup> These tools are intended to be used by experienced clinicians as part of a comprehensive evaluation within a specialty clinic.<sup>16</sup> While the ADOS was originally developed for use with children with verbal ability, a pre-linguistic version is also available (PL-ADOS).<sup>17</sup> The ADOS and the PL-ADOS have recently been combined into a single tool that provides the same information for a broader range of age and developmental levels.<sup>16</sup>

The Cure Autism Now consensus group recommends that paediatricians use the CHAT for Autism in Toddlers (CHAT), supplemented by other means, to screen all children at 18 months of age.<sup>2,30</sup> This tool may not identify all children with variants of autism at 18 months. There have been difficulties with broad based implementation of such screening when done by multiple users and evidence is not yet available as to whether this is a good use of resources. A modified version of the CHAT is now being tested to address issues with sensitivity. An audiologic evaluation and a comprehensive speech and language evaluation are suggested for children with language delays whether or not autistic features are present. While early diagnosis is necessary for timely counselling, referral to an appropriate intervention program, and optimal management of medical issues, a lack of awareness of the symptoms of autism and difficulties in accessing assessment programs means that few children actually receive early diagnosis.<sup>31</sup> If a primary care physician is unfamiliar with comprehensive evaluation techniques, it is suggested that the child be referred to a team of specialists with autism spectrum disorder expertise.<sup>16</sup> The American Academy of Neurology and the American Academy of Paediatrics supported these recommendations and they have been endorsed by the majority of national organizations involved in child health in the United States. In the United States, preschool screening has been implemented and provisions are made for follow-up treatment. In the United Kingdom, availability of early screening varies between health authorities and the provision of behavioural intervention and specialist education is limited.<sup>32</sup> Current methods of screening for autism may

not identify children with milder variants of the disorder, children without mental retardation or language delay, or older children, adolescents or young adults.<sup>15</sup>

A review, based on 142 articles, summarizing subject selection and diagnostic procedures documented in the *Journal of Autism and Developmental Disorders* demonstrated that a majority of researchers reporting results between 1993 and 1997 reported the use of one or more standard diagnostic criteria in classifying their subjects.<sup>14</sup> However, researchers did not specify how the diagnosis was made in 68% of the studies. Studies usually did not include explicit discussion of whether dual diagnoses were included or excluded as part of the selection criteria. The need for careful identification of subject characteristics and diagnostic information are important issues to be considered in future research. The omission of important information has implications for empirically informed treatment-selection and replication of research results. Consequently, the current research literature has limited impact and applicability to real life situations.

### **1.2.3 Prevalence of Autism**

According to 23 epidemiological studies published between 1966 and 1998, the estimated prevalence rate for all forms of PDD was 19 per 10,000 individuals.<sup>22</sup> The overall mean prevalence rate of autistic disorder was five cases per 10,000 people; however, there are wide variations and considerable controversy about the actual rate of autism. For example, based on data collected in 1985, a prevalence rate of 10 per 10,000 was reported in parts of Nova Scotia, Canada.<sup>1,22</sup> While reported rates range from 2-21 cases per 10,000 individuals, it is unclear whether higher rates reflect differences in methods of diagnosis or assessment, improved recognition, and/or an increased frequency of the condition.<sup>11,33,34</sup> According to the Centers for Disease Control and Prevention, the overall rate of autistic disorder and autistic spectrum disorder in Brick Township in New Jersey was 4.0 cases of autism per 1,000 children and 6.7 cases of autism spectrum disorder per 1,000 children (aged 3-10 years). It has been estimated that in the United States there are 58,000-115,000 children with autism among the 57.6 million children from birth to 15 years of age.<sup>20</sup> A survey of Japanese children showed a prevalence rate of autistic disorder of 1.3 per 1,000 children and data from Sweden showed a prevalence of 1-2 per 1,000 among children aged 3-17.<sup>20</sup> According to the National Autistic Society in the United Kingdom, the prevalence rate for all autism-related disorders was 91 per 10,000.<sup>27</sup> Based on a survey of child development centres in Staffordshire, England conducted in 1998, a prevalence of 17 per 10,000 was noted for autistic disorder and 46 per 10,000 for other PDDs.<sup>35</sup> The ratio of affected males to females is 4-5:1.<sup>1</sup> Females with the disorder generally exhibit more severe mental retardation than affected males.<sup>1</sup>

Issues of access to assessment affect prevalence rates, especially in the preschool period. If many children are not identified until the age of five to six years or later, the prevalence of autism in the preschool population will appear to be lower than the actual prevalence. Prevalence rates described after 1994 are more likely to reflect current practice due to a change in classification criteria for diagnosis of autism. Controversy exists as to whether the higher rates reflect a real increase in prevalence and/or changes over time in diagnostic criteria for autism as well as greater awareness of the variability in expression of the disorder. Existing data preclude conclusions; however, comparative studies conducted within the same regions in which the same methods of ascertainment and the same diagnostic criteria are used at different points in time would be of assistance in answering this question.<sup>21</sup> Autism seems to be associated with

environmental factors interacting with a genetic predisposition, as yet identified broadly as autistic syndrome.<sup>9</sup> Further epidemiological research is needed to investigate the aetiology of this disorder.

#### **1.2.4 Prognostic Considerations**

The long-term prognosis of an individual with autism can be defined by measures of social adjustment, and the ability to work and to function independently. Language skills and overall intellectual level are considered as the strongest factors associated with prognosis. Children with autism are often unable to combine words into meaningful sentences. Affected children may speak only single words, confuse pronouns, repeat the same phrase in all situations or parrot what they hear, the latter, a condition termed “echolalia.”<sup>5</sup> Better outcomes are associated with higher intelligence levels and functional language prior to five years of age. Children with an IQ < 50 and/or a lack of communicative speech by five to six years of age generally have a poorer prognosis.<sup>8,36</sup> Most IQ tests require communication skills. Controversy exists as to whether IQ tests are a valid measure for children with autism. For this reason, if a child has limited language, communication or social skills, the child is likely to score lower on any attempts to measure IQ. Therefore, many children initially tested for autism are also classified as mentally retarded. Assessments of the effectiveness of programs are confounded when pre- and post- IQ measures are the sole basis of the assessment.

Regarding long-term outcomes, a 22-year follow-up study suggests that psychiatric morbidity reflected as admissions to psychiatric hospitals occurred in 16 of 39 cases of infantile autism while the mean duration as an inpatient was 562 days (range 0-6,778 days).<sup>37</sup> While follow-up studies suggest that only 10-15% of affected individuals live and work independently as adults,<sup>7,21</sup> partial independence is possible in about one-third of all cases while 50% may require substantial assistance. As adults, high functioning autistic individuals typically continue to exhibit problems in social interaction and communication, along with restricted interests and activities.<sup>3</sup> While there is little information regarding the longevity of individuals with autistic spectrum disorders, life expectancy would be affected by the presence of other conditions with implications for physical health such as epilepsy or tuberous sclerosis.<sup>33</sup> By adulthood, approximately one third of persons with autism have had at least two epileptic seizures. The probability of epilepsy increases throughout childhood, peaking in adolescence, and it is linked to mental retardation and motor deficits.<sup>20</sup>

While there is no “cure” for autism, experts recommend early diagnosis and intensive therapy to improve the child’s ability to communicate, to adapt to change, and to develop social skills.<sup>3,4</sup> For children requiring assistance, early intervention provides an opportunity for improvement.<sup>38</sup> Some therapeutic programs focus on developing skills and replacing dysfunctional behaviours with more appropriate behaviours. Intense, specialized, integrated programs, thought to produce the greatest gains, are those that build upon a child’s interests, offer a predictable schedule with parental involvement, teach tasks in a series of simple steps, actively engage a child’s attention in highly structured activities, provide regular reinforcement of appropriate behaviours and aim toward generalization of skills across environments.<sup>5</sup> Early intervention for autism must be effective, as indicated through measurable improvements to have an impact on prognosis.

A diversity of approaches to early intervention emerged in the 1960s. Behavioural principles of learning were applied to the treatment of children with autism and parents were taught how to use these procedures at home. Educational approaches were developed and classroom procedures for children with autism were explored. Behavioural approaches expanded in the 1970s and 1980s, whereas psychoanalytic applications declined based on a lack of data to support therapeutic effectiveness. In some cases, various approaches were integrated to form a unique service model.<sup>39</sup>

## **1.3 Behavioural Interventions**

### **1.3.1 The Basis of Behavioural Interventions**

Behavioural interventions have become a predominant approach in promoting social, adaptive and behavioural functioning in children with autism.<sup>8</sup> Behavioural therapy is the application of basic psychological principles of learning to human behaviour. Experimental analysis of behaviour, a science dedicated to understanding the principles by which behaviour is determined by environmental events, has led to the application of these principles to change behaviour. Applied behavioural analysis (ABA) refers to the application of these principles to improve socially important behaviours. A behaviour-analytic approach has important implications for the understanding of problem behaviours and is effective in replacing and/or reducing maladaptive behaviour.<sup>40</sup>

Therapy consists of a tremendous amount of structure and reinforcement provided at high intensity using precise teaching techniques. Behavioural interventions are specific approaches used to help individuals acquire or change behaviours by reinforcing adaptive responses and suppressing maladaptive behaviours. Children with autism exhibit maladaptive behaviours that are generally the first targets for intervention. After problem behaviours are under control, the intervention targets may start to deal with other aspects of the condition, such as improving communication and social interaction. Many current forms of speech and language therapy as well as educational interventions for children with autism are founded in similar behavioural principles and share common elements.<sup>18</sup> Programs may combine behavioural therapy with other approaches.

### **1.3.2 General Approaches and Components of Behavioural Interventions**

Behaviour modification methods can be divided into three general approaches: operant conditioning, respondent conditioning, and cognitive approaches.<sup>18</sup> Current behavioural therapy, primarily operant conditioning, is comprehensive and complex. At the most basic level, operant conditioning involves the presentation of a stimulus or antecedent to a child and then providing a consequence such as a reinforcer based on the child's response. A reinforcer could be anything that, when presented as a consequence of a response, increases the probability or frequency of that response, such as a desired item. As part of operant conditioning approaches, a functional assessment of possible reinforcers is required periodically to determine which reinforcers are most effective in shaping each child's behaviours. Behavioural therapy involves broad-based behavioural assessment, a variety of procedures to address a comprehensive behavioural repertoire and seeks long-term outcomes generalizable across different settings, related behaviours and situations.

Behavioural strategies can also be divided into three periodic categories:

1. *Antecedent* interventions that are implemented before a target behaviour is likely to occur;
2. *Consequence* interventions that are implemented following the occurrence of a target behaviour; and
3. *Skill development* interventions or *behavioural techniques* that are designed to teach new skills and alternative, adaptive behaviours to reduce the frequency and severity of maladaptive behaviours.<sup>8</sup>

Early behaviour interventionists considered autism as a syndrome of specific behaviours related to environmental determinants. Hence, it could be possible to change behaviours by manipulating environmental events. Antecedent interventions such as integration with typical peers; implementation of highly structured environments, activities, and daily schedules; as well as behaviour momentum procedures and those offering the opportunity for choosing the task to be taught have been used to reduce problem behaviours and treat non-compliance. Behavioural assessment consists of careful measurement of discrete behavioural and environmental events allowing precise determination of target behaviours, specificity in therapy implementation and evaluation of intervention effects.

ABA is the process of systematically applying interventions based on the principles of learning theory to improve socially significant behaviours to a meaningful degree. These include academic social skills, communication and adaptive living skills.<sup>41</sup> ABA is used to increase behaviours, teach new skills, maintain behaviours, transfer behaviour from one situation or response to another, and restrict and reduce interfering behaviours. Interventions require a demonstration of the events that are responsible for the occurrence, or non-occurrence of behaviour. Single case experimental design has been used to evaluate the effectiveness of individualized interventions and comprises most programs based on ABA methods. The process includes the selection of an interfering behaviour or behavioural skill deficit; identification of goals and objectives; establishment of a method of measuring target behaviours; evaluation of current performance; design and implementation of interventions that teach new skills or reduce interfering behaviours; continuous measurement of target behaviours to determine intervention effectiveness and ongoing evaluation. ABA may be divided into three approaches: discrete trial training (DTT), naturalistic teaching or errorless teaching, and incidental learning, along a continuum of adult directed instruction.

Trends in ABA include positive behavioural support, functional assessment and functional communication training. Positive behavioural support is a process whereby individuals are assisted in acquiring adaptive, socially meaningful behaviours and encouraged to overcome maladaptive behaviours. The goal of positive behavioural support is to teach functional skills as a replacement for problem behaviour. Behavioural support interventions usually involve changing aspects of the environment. Functional assessment is the process of gathering information that can be used to maximize the effectiveness and efficiency of behavioural support interventions. Primary outcomes of functional analysis include: a description of the problem behaviour; identification of events, times and situations predictive of problem behaviour; identification of consequences that maintain behaviour; identification of the motivating function of behaviour; and collection of direct observational data. Functional communication training is aimed at teaching an individual to use appropriate communication to obtain a desired item

instead of engaging in problem behaviour.<sup>41</sup> “Errorless” teaching used in some programs is used to teach new or challenging information or skills. ABA is used to maximize learning by ensuring that the individual experiences success and is somewhat dependent upon the skill and expertise of both the program developer and the therapist.

Some forms of behavioural intervention involve discrete trials, where a therapist presents an antecedent, the child responds, and the therapist presents an appropriate consequence.<sup>42</sup> In directive approaches, behavioural therapists control antecedents and/or consequences to shape a child’s response. Some interventionists use systematically applied reinforcement, prompting of a correct response, and fading of prompts and reinforcers to change behaviour. New learning experiences are chained to acquired skills to address a range of behaviours in children with autism. Consequence-based interventions comprise: interruption and redirection procedures; reinforcement-based interventions, to systematically reinforce desirable behaviours and reduce undesirable behaviours; and punishment procedures. Direct reinforcement, where the reinforcer is directly related to the behaviour, enhances generalization of the response across settings.

ABA and DTT are among the most controversial intervention strategies for children with autism.<sup>42-44</sup> This controversy revolves around outcome claims, exclusivity, extensive use, and personnel. There is controversy as to whether ABA and DTT can lead to recovery, as claimed in one particular study.<sup>44-47</sup> Controversy related to exclusivity pertains to whether ABA and DTT should be used to the exclusion of all other methods. While 40 hours of weekly DTT has been used, controversy exists regarding the extensive use of DTT and the appropriateness for some children and families. Most communities lack the resources, and families experience limitations that prevent delivery of services as intensive as those of Lovaas (1987).<sup>40</sup> Issues related to personnel have also made ABA and DTT controversial, in that school district administrators are being requested for one-to-one implementation of DTT programs in cases where such intensity may be inappropriate for the child.<sup>42</sup> Concern has been raised regarding the changes to ABA from the traditional approach, as well as the contributions of different disciplines and intervention approaches. Additional concerns have been raised on the tenet that ABA can be used to address virtually all aspects of the challenges associated with autistic spectrum disorder when minimal consideration has been given to the fact that different abilities and challenges may require different intervention approaches.<sup>48</sup>

Effective treatment for severe behaviour disorders may require early, intensive behavioural intervention (IBI). IBI appears to be a generic term that refers to behavioural interventions that are intensive and comprehensive. Intensive programs refer to more than the number of hours of treatment the child receives per week. Training, curriculum, evaluation, planning, and coordination are also “intensive.” Because true generalization of therapy effects means that newly acquired behaviours need expression in a variety of settings with a variety of people, behavioural interventions require the expansion of the role of therapy provider to include parents, teachers, siblings, and peers with a great sense of consistency.<sup>49</sup> If therapy is provided when the child is with parents, and at school with siblings and peers, a complete therapeutic environment is created to support generalization.

Skill acquisition interventions emphasize the development of alternative positive behavioural skills to compete with and replace inappropriate behaviours using functional communication training, social skills training, self-management training and differential reinforcement.<sup>8</sup> These

strategies consist of building complex behaviours by learning them in simple steps through shaping and successive approximations.

### 1.3.3 Program Options for Behavioural Intervention

**Lovaas Program:** Based on principles of ABA, the Lovaas program, developed by the University of California Los Angeles Young Autism Project under the direction of O.I. Lovaas, uses time-intensive (40 or greater hours per week) behavioural intervention techniques to treat children two to three years of age over a two to three year period. First stages of the program focus on teaching self-help and receptive language skills, nonverbal and verbal imitation, and the foundations of appropriate play through one-to-one DTT 40 hours per week. Parents are trained to apply the intervention during most of the child's waking hours.<sup>50</sup> The second stage of the intervention emphasizes the teaching of expressive and early abstract language and interactive play with peers. Advanced stages, taught at home and school, involve the learning of early academic tasks; socialization skills; cause-effect relationships; and learning by observation. Aggressive and self-stimulatory behaviours are managed by ignoring, time-out, shaping and the delivery of a loud "no" or slap on the thigh.<sup>50</sup> The treatment strategy requires the presence of a therapist trained at the Lovaas Institute; dependence on the treatment provider may limit the generalization of treatment effects across community settings.<sup>51</sup>

**Douglass Developmental Disabilities Centre Program:** Established at Rutgers University, this program is based on principles of ABA and behaviour intervention approaches.<sup>50</sup> Children progress through three classrooms from a segregated class to a highly structured group to an integrated preschool classroom. The segregated class provides intensive one-to-one DTT, largely based on Lovaas's model. The highly structured group maintains a two educator teaching session per child and focuses on skills needed to function in an integrated classroom. The integrated class is partially based on the Learning Experiences-An Alternative Program for Preschoolers and Parents (LEAP) as described below. The program serves both children with autism and normally developing peers. Families are visited by a member of the staff twice a month and are offered parent and sibling support groups.<sup>50</sup>

**Learning Experiences - An Alternative Program for Preschoolers and Parents (LEAP):** LEAP is a comprehensive preschool service, developed in Pennsylvania, by Philip Strain, designed for both children with autism and normally developing children. LEAP has the components of an integrated preschool program and a behaviour skills training program for parents.<sup>50</sup> The program contains aspects of behavioural analysis, but it is primarily a developmentally based approach. Services include parent involvement and training. The program does not provide one-to-one intervention; instead, services consist of 15 hours per week of classroom instruction provided by a teacher with a master's degree and an assistant who both implement the program with 10 normally developing children and three to four children with autism. A full-time speech therapist and contracted occupational and physical therapists also work with the children in specially arranged classrooms designed to support child-directed play. Individualized curricula are updated every four weeks.<sup>51,52</sup> The primary goal of the curriculum is to expose children with autism to typical preschool activities and adapt the typical curriculum for the children with autism only when necessary. Independent play skills are facilitated by using peer models and by prompting, fading, and reinforcing target behaviours.<sup>50</sup>

**May Institute:** The May Institute offers a developmentally sequenced program based on the principles of ABA and behavioural intervention approaches. Intensive in-home training (15 hours per week) is provided to children and their families for a period of six months. The in-home therapist and parents provide one-to-one intervention focusing on basic skills such as self-care, language, and the reduction of problem behaviours. Following completion of home-based treatment, the children attend one of the Institute's two preschool programs, "Step 1" class or the integrated classroom. Children attend the Step 1 class, comprised only of children with autism, learn basic skills to follow instructions, develop imitation, and work in highly structured small groups for the duration of a year. The integrated class, in contrast, includes normally developing children as well as those with developmental disabilities. The curriculum focuses on teaching skills that children need in general kindergarten. A service coordinator visits families every month, during which time the child's progress and the parent's concerns are discussed. The program offers group support and respite care for families as well as outside referral information.<sup>50</sup>

**Autism Preschool Program:** The Autism Preschool Program, based at the University of Manitoba, uses a variety of behavioural and language development methods similar to the Rutgers Autism Program. It is a collaborative program staffed by a multidisciplinary team and involves the university hospital, the provincial government, and local community resources. The intervention is directed by parents and day-care staff who are taught how to perform a functional analysis of behaviour and to plan and evaluate strategies for changing behaviour.<sup>51</sup>

**Princeton Child Development Institute Program (PCDI):** The program at the Princeton Child Development Institute is based on principles of ABA and behaviour intervention approaches and is used to serve only children with autism. Children are first evaluated so that individualized behaviour programs that target basic skills can be designed. Children in the day education and treatment program attend school 5.5 hours per day, five days per week, for 11 months of the year. Children participate in 30-minute classes with changes in activity and a change of classroom and teacher. Children are taught to use picture schedules to assist them with transitions throughout the day.<sup>50</sup> It has been suggested that this arrangement of the school day assists in generalization.<sup>51</sup> Picture schedules also help children to learn to initiate activities, make choices and encourage independence. Progress is periodically assessed and specific goals are revised. A home programmer may visit the family twice a month to help families implement behaviour programs that have been successfully achieved at school to maximize generalizability of these skills at home.<sup>50</sup>

Additional ABA programs include the Eden Programs, The Childhood Learning Centre, Yale Child Development, Bancroft, and Horizon. Another ABA approach is the Comparative Applied Behavioural Analysis to Schooling Program (CABAS). Descriptions of the IBI program in Ontario, the ABA program in Prince Edward Island, the ABA pilot program in Newfoundland, the ABA pilot program in Nova Scotia, the pilot programs in Saskatchewan and the ABA programs in Alberta can be found in section 5.2 of this report. There are a variety of ABA curriculum instructional and training materials available for use by families and health care professionals. Social Stories and social skill development are also behavioural interventions that are used to treat children with autism.<sup>42</sup>



Functional approaches that tend to be behaviourally oriented may be used in combination with other approaches based on the child's needs and unique learning style. The developmental approach places emphasis on specific developmental stages in an effort to re-establish developmental sequences that go astray. Many educators and clinicians tend to lean heavily toward either developmental approaches or functional and behavioural approaches to the virtual exclusion of integrating both.<sup>63</sup>

**Treatment and Education of Autistic and Communication-Handicapped Children (TEACCH):** The TEACCH curriculum, primarily a developmental approach, established in the United States at the University of North Carolina in Chapel Hill, focuses on structuring the environment to promote skill acquisition and facilitating independence at all levels of functioning. The program sometimes incorporates behaviour analytic approaches to control disruptive behaviours and enhance self-help skills. However, techniques other than behaviour analytic approaches are used to enhance language skills. Children are taught new, developmentally appropriate skills in a structured teaching environment on a one-to-one basis. Once a skill is mastered, children are taught to apply the skill in less structured settings. Independence is encouraged by an environment that relies on visual cues such as the use of "start" and "finish" boxes to signal the beginning and end of activities. Consultants visit each child's classroom regularly to provide information on how to adapt the classroom to meet the needs of each child.<sup>50</sup>

**The Denver Model:** The Denver Model is a developmentally based program that began in 1981 at the University of Colorado Health Sciences Center, Denver. Similar to the TEACCH program, the Denver Model aims to build upon the skills the child with autism has already gained. The child's individualized curriculum is developed around quarterly meetings between the parents and the treatment team. Goals, objectives, instructional plans and activities are discussed for the child's instruction across all settings. The Denver Model includes several teaching elements: shaping of natural gestures followed by conventional gestures; teaching motor-imitation skills related to language; and teaching the meaning and importance of speech. This model uses the tools of functional behavioural analysis; communication training; positive teaching of alternative, more conventional behaviours; and redirection to provide new behavioural strategies by which the child can achieve their goals.<sup>50</sup>

### 1.3.4 Considerations for Successful Intervention

Evidence to date suggests that young children who receive antecedent interventions such as early intervention programs that focus on the development of functional communication, social skills and personal independence may exhibit higher IQ and achieve more normal school placements.<sup>53</sup> More research is needed, however, in order to confirm long-term benefits of early intervention and to determine which specific interventions or components of interventions are most likely to promote more favourable outcomes in individuals across the autistic spectrum.<sup>46</sup>

The combination of intensive discrete-trial behavioural intervention and early chronological age of the child has achieved considerable attention. In the program described in 1987 by Lovaas, considered a pioneer of ABA, it was reported that 47% of 19 children under 46 months of age who received 40 hours per week of IBI achieved "normal" functioning as defined by an IQ in the normal range and successful performance in a regular first-grade classroom.<sup>54</sup> The results of

this study remain controversial. The evidence from Lovaas is based on ABA analysis for 18 months, entering children into school and observing performance. True independent replication of the reported effects along with a direct comparison of this type of training with other forms of behavioural treatment delivered at an early age are needed. There is controversy regarding bias in the treatment and control groups suggesting that the sex ratio in the Lovaas study greatly favours the intensive treatment group over the control group.<sup>55</sup> The fact that not all children benefited to the same extent suggests that other factors such as subject characteristics relate to therapeutic effectiveness. Major criticisms of the study were non-uniform participant selection, lack of clear standard diagnostic criteria for entry, the required intensity of the intervention for such young children, choice of outcome measures, and randomisation issues. Other investigators have adapted the program described by Lovaas by reducing the number of hours per week and the length of follow-up, implementing personnel other than university students as therapists, or eliminating the use of physical aversives, such as a slap on the thigh.<sup>53,56</sup> There is no indication concerning cessation of therapy or modulation of the level of intensity of behavioural therapy.

A replication study was recently published where children received early intervention based on the same treatment manual used by Lovaas (1987), and implemented by personnel who met the qualifications specified in the study but were independent of Lovaas (1987).<sup>57</sup> However, because of concerns related to cost and service delivery, intervention was less intensive than that in the Lovaas study. This follow-up study was designed to address criticisms of previous research. The participant pool consisted of a wider range including not only children with autism, but also children with PDD-NOS. The intensive treatment group, seven children with autism and eight children with PDD-NOS, received 24.5 hours per week of individual treatment for one year. Therapy was reduced over the following one to two years. The parent-training group, seven children with autism and eight children with PDD-NOS, received three to nine months of parent training. While groups appear similar regarding intake measures; follow-up with the intensive group outperformed the parent training group on measures of intelligence, visual-spatial skills, language, and academics but not adaptive functioning or behaviour problems.

The most effective behavioural interventions are likely to include a combination of antecedent and consequence-based interventions. The basic elements of IBI programs consist of: systematic use of behavioural techniques; intensive, direct one-to-one instruction by a therapist; and extensive parent training and support. The level of intensity of the behavioural therapy may vary depending on a variety of child and family characteristics, such as age, severity of symptoms, comorbid conditions, rate of progress, other health considerations, tolerance for the intervention, and level of family participation.<sup>58</sup>

The success of a well-designed behavioural intervention program is based on the completion of a thorough functional analysis of behaviour. Using functional analysis, interventions can be identified that are most likely to influence factors associated with sustaining maladaptive patterns of behaviours. The use of standardized functional assessment has afforded greater accuracy in the selection of therapies as well as the prediction of outcome. Social validation, the determination of the social acceptability of therapy procedures, is a measure of whether the nature and degree of improvement achieved by the children were apparent to community members not familiar with autism or behaviour therapy. How providers view treatment affects the uptake of behavioural interventions as a whole.<sup>8</sup>

## 2. METHODS

### 2.1 Review of Evidence

Published literature reporting on autism and behavioural interventions was obtained by searching a number of databases (see Appendix II). On the DIALOG<sup>®</sup> system, MEDLINE<sup>®</sup>, EMBASE<sup>®</sup>, HealthSTAR, ERIC and PsycINFO<sup>®</sup> were searched, resulting in 142 unique records. Retrieval was limited to contemporary literature entered into the databases between January 1995 and November 2000. CINAHL*direct*<sup>®</sup> was searched on Cinahl Information Systems, resulting in 43 records; no date or language limits were set. Database alerts/updates were established on Current Contents Search<sup>®</sup>, EMBASE<sup>®</sup>, ERIC, MEDLINE<sup>®</sup> and PsycINFO<sup>®</sup>. The Cochrane Library on CD-ROM was searched and updated to Issue 2, 2001. Web sites of health technology assessment and related agencies were also searched, as were specialized databases, such as the University of York NHS Centre for Reviews and Dissemination. The Google<sup>™</sup> search engine was used to search for a variety of information on the Internet. These searches were supplemented by hand searching of selected journals and documents in the CCOHTA library collection and the bibliographies of selected papers.

The study author reviewed the citations identified using this comprehensive search. Irrelevant studies were discarded based on the title of the article and the information in available abstracts. The following criteria were used in the final selection of studies for review:

- Inclusion of subjects with an identifiable diagnosis of autism or a related PDD, or the presence of “autistic-like-disorder;”
- The use of an intervention generally accepted as a valid behavioural procedure by professionals in the field of behaviour modification or ABA; and
- Publication in a refereed professional journal, professionally reviewed book, or a paper presented at a conference following peer review.

Studies with methodological flaws were not excluded; however, retrieval was primarily limited to secondary reviews. Based on evaluation of secondary reviews, while authors of primary studies of the therapeutic efficacy of specific behavioural interventions have drawn conclusions, generalization to a broader population of individuals with autism is difficult. Many of the published studies discussed in the secondary reviews report very small sample sizes, variable and inconsistent outcome measures, absence of an adequate control group, treatment failures are rarely reported, and variables that are predictive of a favourable response are seldom uncovered. Reviewers of this report were chosen based on their expertise, experience, willingness, and availability to provide comments and suggestions on various facets of the report.

### 2.2 Service Provision

#### 2.2.1 Issues

A consultation process with national organizations and associations, primarily identified using “Associations Canada: the directory of associations in Canada”<sup>59</sup> and “Guide to Canadian Healthcare Facilities”<sup>60</sup> to deduce the issues associated with topics requiring assessment was necessary to adequately define CCOHTA’s project objectives. A list of non-drug interventions

for children with autism was identified by a preliminary literature search. This list, along with a letter of request for feedback regarding associated issues having impact on policy decisions and standards of practice were sent to eleven consultants (Appendices III and IV). Non-responders were further contacted by telephone or email. Providers of feedback were invited for a single-day panel meeting to discuss the issues the group had identified.

### **2.2.2 Initiatives**

Information regarding current service provision and Canadian initiatives in the area were retrieved through contacts identified in a previously commissioned survey for the British Columbia Ministry for Children and Families<sup>61</sup> (Appendix V). Contacts formed as a result of research forum discussions with the Canadian Autism Intervention Research Network (CAIRN) also provided information. Where specific additional contacts were suggested, efforts were made to retrieve further information by area. Varying amounts of information were available for each jurisdiction. The information retrieved ranged from verbal correspondence to technical documents and preliminary data, depending on the program.

## 3. SUMMARY OF EVIDENCE

### 3.1 Results

Based on the Canadian Task Force Panel and Grading of Healthcare Evidence,<sup>62</sup> two documents rated as having level III evidence, were found using the search strategy and one was identified by a reviewer of this report. In the absence of Level I or Level II evidence founded on well-designed trial data, it was necessary to consider lesser quality Level III evidence, defined as the opinions of respected authorities, based on clinical experience, descriptive studies or reports of expert committees without explicit critical appraisal.<sup>62</sup> A summary of recommendations by working groups reported in these documents is presented in Table 1 of Appendix VI. The working groups, all from the United States, are: a panel sponsored by the New York State Department of Health; a collaborative work group sponsored by the California Departments of Education and Developmental Services; and the Maine Administrators of Services for Children with Disabilities Autism Task Force.

In considering the following results, it is worth noting that while autism remains behaviourally based, the diagnostic classification and criteria for autism have changed over time.<sup>13,14</sup> Additional validation of the diagnostic instruments, rating scales and checklists has been suggested in order to assess their sensitivity and specificity across populations.<sup>16</sup> Since autistic-like behaviours may be exhibited in children with other conditions, there may be a need for similar treatment services for these populations.

#### 3.1.1 Recommendations by Working Groups

**New York :** The guideline developed by an independent panel of professionals and parents (Guideline Panel) sponsored by the New York State Department of Health, Early Intervention Program recommends that principles of ABA and behavioural strategies be included in any intervention program for young children with autism. The literature search by the guideline panel resulted in 232 articles that reported use of behavioural and educational approaches for children with autism. As summarized in Table I of Appendix VI, five articles met the criteria for review by the Guideline Panel. Four studies that met criteria for evidence about efficacy, as set by the group, compared groups of young children with autism who received an IBI, a comparison intervention, or no intervention. The guideline cites evidence and associates recommendations with the levels of evidence. The Panel defined “strong evidence” as evidence based on two or more studies that met criteria for adequate evidence about efficacy and having at least moderate applicability to the topic, where the evidence consistently and strongly supported the recommendation. The Canadian Task Force levels of evidence are more restrictive than the evidence ratings for guideline recommendations cited in this report. In all four studies, groups that received IBI showed consistent significant functional improvements in comparison with control groups. While none of the four studies randomly assigned subjects to groups, according to the guideline, there did not appear to be any evidence of bias in assignment, and subject characteristics were equivalent based on baseline data collected by the study authors.<sup>18</sup>

The Panel evaluated one study that compared TEACCH, primarily a developmental approach, with a non-intervention control group, concluding that the study contained several methodological shortcomings. According to the Panel, the study did not use random assignment

to groups or assign independent outcome assessors for the intervention group. Despite the methodological shortcomings of the study, the Guideline Panel described the findings as consistent with the results of other studies indicating that parental involvement in the child's education improves generalization skills.<sup>18</sup>

Based on this review, the Guideline Panel recommended that intensive behaviour programs include a minimum of approximately 20 hours per week of individualized behavioural intervention using ABA techniques. The precise number of hours of behavioural intervention may vary depending on a variety of child and family characteristics. Age, severity of symptoms, rate of progress, other health considerations, tolerance for the intervention and family participation are considered in determining the frequency and intensity of intervention. In the studies reviewed by the Guideline Panel, effective interventions were based on ABA techniques used between 18 and 40 hours per week of behavioural intervention. What constitutes an intervention was variable. Interventions were described as those relying on discrimination-learning methods, discrete trial format, involving a program coordinator, parents and volunteers to administer the program for up to two years. The Guideline Panel recommended that the number of hours of IBI reviewed periodically and revised according to the child's progress. However, no indication was given to provide parents or practitioners with any means of knowing whether the therapy is working or how or under what conditions therapy should cease.

Therapists in an intervention program are to receive regular supervision from a qualified professional with expertise in applied behavioural approaches. Parent involvement is important to ensure that the behavioural outcomes, goals and strategies most important to the family are incorporated in the intervention. Parent training is encouraged in an effort to incorporate behavioural techniques into daily routines of the child and family and to ensure consistency in the intervention approach. It is recommended that training of parents in behavioural methods be extensive and ongoing with regular consultation with a qualified professional. The use of physical aversives is not recommended as part of a behavioural intervention program.<sup>18</sup>

**California:** The Collaborative Work Group on Autistic Spectrum Disorders (Work Group) sponsored by the California Departments of Education and Developmental Services recommends, based on consensus, that a program be founded on current research and effective practices, to include a variety of methods and approaches consistently applied in a variety of settings as determined by a multidisciplinary team. The Work Group recommends that programs be outcome based, founded on comprehensive assessment results, and reflective of an individual's needs. There is a need for programs to be provided by trained personnel and inclusive of entrance and exit criteria.<sup>63</sup>

Based on a review of five studies (Appendix VI, Table I), the Work Group recommend that ABA be used to assist a child in gaining skills and reducing negative or undesirable behaviours. An individualized approach is taken to select a developmentally appropriate method and level of program where several intervention methods are used. A formalized assessment of skills; including cognitive, language, socialization, adaptive behaviour, fine and gross motor and play, are conducted at intervals. Data are recorded to monitor progress and for troubleshooting problem areas. Generalization and maintenance of skills are to be built into the program, along with opportunities for mainstreaming with typically developing peers. Parent training and ongoing training of personnel is recommended.

The behaviour-analytic approach has extremely important implications for the understanding of problem behaviours as well as for the focus of early intervention programs. While formally conducted IBI programs provide between 37 and 40 hours per week of structured learning, studies indicate that children improve significantly with 20 hours per week.<sup>63</sup> Intensive programs refer not only to the number of hours the child is in therapy, but also the training, curriculum, evaluation, planning, and coordination of the program. Maintaining quality control over a child's program is an essential part of an intensive program. During the first six to 12 months, the majority of the time in an intensive intervention program emphasizes the remediation of speech and language deficits. This time period may later be divided between promoting peer integration while continuing to remediate speech and language deficits. Most communities lack the resources, families' experience and access, necessary to deliver services as intense as those of Lovaas therapy. Quality of teaching expertise, creativity, and use of research-based techniques may be as important as intensity when considering behavioural intervention.<sup>63</sup>

The Working Group also provided a summary of the highlights of the developmentally based TEACCH program. In this approach, structured teaching is used and differences in the rate and nature of development within and between children are taken into consideration.

**Maine:** The Maine Administrators of Services for Children with Disabilities (MADSEC) Autism Task Force reviewed information and research pertaining to eight interventions routinely used to treat children with autism with the goal of providing information to families, educators and service providers for decision making purposes.<sup>41</sup> The Task Force provided a descriptive account of ten studies or reviews documenting ABA-based interventions, concluding that there are peer-reviewed studies supporting the efficacy of ABA methods to improve socially significant behaviours in individuals with autism. While the Task Force reported that the results of these studies include what they considered to be meaningful outcomes, no direct analysis of the outcomes was given, nor was there detail regarding subject characteristics or intensity of intervention. Based on a study by Jacobson, Mulick & Green (1996), competently-delivered, early, IBI can offer unprecedented gains for children and taxpayers, quoting an estimated savings per child to age 22 of US \$200,000; to age 55, US \$1,000,000.<sup>41</sup>

The Task Force also reviewed information on the TEACCH program and concluded that while research by TEACCH shows promise, it has not as yet been substantiated as effective by independent researchers.<sup>63</sup>

### **3.1.2 Evaluations of Efficacy**

Five previously conducted assessments or critical reviews involving behavioural interventions for children with autism were identified and retrieved through networking and discussions with other health technology assessment agencies in addition to searching the University of York, NHS Centre for Reviews and Dissemination. A summary of findings is presented in Table 2 of Appendix VI.

### **L'Agence Nationale d'Accreditation d'Evaluation en Sante (ANAES)**

The ANAES, in France, first evaluated medical treatments and behavioural and educational programs for autism in 1994.<sup>64</sup> A literature search (from 1989 onwards) of four databases resulted in the identification of 218 abstracts in Medline; 157 abstracts in Excerpta Medica; 125 abstracts in Pascal; and 64 abstracts in Mental Health Abstracts review resulted in the identification of 23 studies. The review of four studies regarding behavioural therapies suggested that the symptoms associated with autism are ameliorated by IBI.

As reported by the ANAES, a study by Lovaas suggests that a certain level of intensity is required for therapy to be effective, without which individuals continue to exhibit symptoms of the disorder.<sup>54</sup> A long-term study by McEachin et al. suggested that 47% of recipients of IBI demonstrated favourable outcomes; however, this study was later found to be methodologically flawed based on subject selection bias. A study by Howlin, where study groups were equivalent in characteristics, showed that children who received IBI demonstrated favourable outcomes after 18 months of therapy. Significant improvements were noted in aggressive and ritualistic behaviours, social interaction with other children and parents, as well as functional abilities and communication. ANAES concluded that further research was necessary to determine whether the effects of therapy remain long term. The TEACCH method was considered experimental. No single treatment to date can cure infantile autism, though several reduce certain symptoms associated with autism, but it is difficult to compare treatment modalities with each other.<sup>64</sup>

### **Emergency Care Research Institute (ECRI)**

In 1999, ECRI, in the United States, reviewed comprehensive treatment approaches that attempt to simultaneously address most or all of the symptoms that characterize autism.<sup>51</sup> The behavioural approaches assessed in the ECRI report all emphasized early intervention, and included Lovaas, Rutgers Autism Program, LEAP, and the Autism Preschool Program. ECRI conducted a systematic and comprehensive search of approximately 29 databases to find information on comprehensive programs for their assessment. The search resulted in four studies pertaining to Lovaas therapy, and one study each regarding the Rutgers, LEAP and Autism Preschool Programs.

The evaluation of Lovaas by ECRI was based on an analysis of four of five identified studies due to a statistical anomaly apparent in one study. Analysis of the follow-up study on the Lovaas program suggested that children receiving  $\geq 40$  hours of intervention per week demonstrated a moderate, sustained increase in mean IQ compared to controls that received less than 10 hours of therapy per week. ECRI's analysis of a study by Sheinkopf and Siegel suggested that improvement in IQ could be achieved when the treatment program was applied with less intensity than that originally recommended by Lovaas.<sup>65</sup> The analysis provided evidence that improvements occurred in functional parameters, including a reduction in maladaptive behaviours, severity of symptoms and an increase in socialization. ECRI emphasized that the available evidence is only suggestive of treatment effectiveness.<sup>51</sup>

ECRI's evaluation of the Rutgers Autism Program was based on a systematic evaluation of the quality of evidence from a single group pre-post design study.<sup>66</sup> Because the study didn't use a control group and did not control for confounders such as maturation bias, ECRI concluded that the results of the study could not be interpreted regarding therapeutic effectiveness based on significant flaws in study design.<sup>51</sup>



ECRI evaluated one single group, pre-post design study of the effectiveness of the LEAP comprehensive preschool program. ECRI concluded that the small sample size, confounding effects of maturation, and poor generalizability of the children included in the study to the general population of children with autism precludes the use of this study in determining effectiveness.<sup>51</sup>

Evaluation of the Autism Preschool Program by ECRI was based on one randomised controlled trial. It was determined that only language development in the treatment group showed significant improvement compared to the control group.<sup>51</sup>

ECRI also evaluated TEACCH, the Denver Model and PCDI program data. Behavioural techniques are used in these programs; however, the former two programs were primarily considered as developmentally-based approaches and techniques in the latter program were not well described in the literature. According to ECRI, while the results of a study on TEACCH were statistically significant regarding the rates of improvement in treated and untreated children, these differences may not be of clinical significance. Regarding the Denver Model, ECRI concluded that because no control groups were used in the studies evaluated, the results could not be analysed due to fatal flaws in study design. ECRI excluded the study on PCDI because an unknown number of children dropped out of the study introducing a strong potential for drop-out bias which could not be corrected.

#### **British Columbia Office of Health Technology Assessment (BCOHTA)**

BCOHTA published a critical appraisal of the effectiveness of Lovaas therapy.<sup>67</sup> A systematic search of approximately 15 databases resulted in the identification of 1,200 abstracts in total. Approximately 150 articles met the minimum inclusion criteria set by BCOHTA. Instead of including all comprehensive programs for autism therapy and looking for associated evidence, as did ECRI, BCOHTA included all studies with a control group, selecting studies based on a minimal research design considered sufficient to draw efficacy conclusions. Only Lovaas and TEACCH programs had studies with control groups.

Four primary-data studies of early preschool IBI were identified. With the exception of one study, BCOHTA reviewed the same studies as ECRI regarding behavioural interventions. One substantive difference between the findings of these two agencies was in regards to a study by Sheinkopf and Seigel.<sup>65</sup> According to the ECRI report, this study provides some support to the Lovaas findings in terms of IQ changes; in contrast, BCOHTA found that it was a poorly designed, retrospective study and was too unreliable to draw support for Lovaas in terms of IQ benefits. BCOHTA concluded that while many forms of behavioural therapy clearly benefit children with autism, there is insufficient scientifically valid effectiveness evidence to establish a causal relationship between a particular regimen of IBI and the achievement of normal functioning. Because most of these children do not achieve normal function, the outcome targets described in this report may not accurately reflect the population as a whole. BCOHTA's primary concern regarding the Lovaas study was that without randomisation, one cannot tell whether or not the number of children achieving normal functioning is due to selection bias by possibly selecting higher functioning children for the 40 hour intervention group.<sup>67</sup>

## **Smith**

Smith conducted a search of articles published since 1980 and abstracts on ERIC, Medline, or PsycLit as of December 1996. Smith selected studies which met the criteria of including: children averaged five years of age or younger at treatment onset; children receiving direct services as part of a study, comprehensive services aimed at addressing multiple problems, reporting of data on treatment outcome, and appearance in a peer-reviewed journal. Based on these criteria, Smith reviewed 12 peer-reviewed outcome studies that included nine studies on behaviour analytic programs in 1999.<sup>68</sup>

Children in the University of California Los Angeles (UCLA) Young Autism Project, receiving the Lovaas program, achieved remarkably favourable outcomes 22-31 points higher on tests of intellectual and adaptive functioning than did children in control groups. They also achieved substantially less restrictive school placements. Partial replications of the UCLA project come from the May Centre, Murdoch University, and the University of California San Francisco (UCSF). Services at these sites were less intensive, averaging 18-25 hours per week, and less frequently supervised than services at UCLA; however, children at these other sites displayed gains. While small in number, the children receiving 25 hours per week of intervention in the UCSF study scored an average of 28 IQ points higher than those who were matched on cognitive ability and mental age, yet did not receive such treatment. Two-year follow up at the May Centre revealed average increases of 20-22 points. At Murdoch, little improvement was noted; the results may be attributed in part to staffing problems. The programs Douglass, LEAP and Princeton Child Development Program (PCDI) were school based, with 15-27.5 hr/week of service. Children in the school-based programs tended to enter group settings at an earlier stage than did children in home-based settings. The most favourable outcomes occurred in programs that provide the most intensive services; otherwise, no clear correlations were evident among treatment intensity, treatment model and outcome.<sup>68</sup>

Other psychoeducational interventions including TEACCH and the Denver Model were also evaluated. The author concluded that behaviour analytic treatment programs almost certainly yield short-term benefits and may yield long-term benefits, however, interventions based on different theoretical orientations, such as TEACCH and the Denver Model, appear essentially unvalidated at this time.<sup>68</sup>

## **Alberta Heritage Foundation for Medical Research (AHFMR)**

The AHFMR drafted an information paper on IBI programs for children with an autism spectrum disorder in September 2000.<sup>69</sup> The information paper summarized the analyses of ECRI, BCOHTA and Smith and provided a list of outcome measures from the studies analysed. AHFMR, in their conclusions, note that there is difficulty in conducting research on the efficacy of treatment programs for children with autism. Due to the methodological limitations and weaknesses of existing primary research, evidence regarding the efficacy and effectiveness of any single treatment program is not available. While it appears that children who receive behavioural intervention exhibit functional improvement, it is not clear that any single program is more effective than another. The most common outcome measure included in the studies was that of IQ; however, children with autism do not exhibit consistent patterns of performance on intelligence tests. Social interaction and communication are also important outcome measures for assessment.<sup>69</sup>

## **4. SERVICES PROVIDED IN CANADA**

### **4.1 Identification of Issues**

Consultation was initiated with national organizations and associations in order to deduce the issues associated with potential topics for assessment (Appendix IV). This was necessary to adequately define the objectives of the CCOHTA project. Seven (64%) of the consulted organizations/associations provided direct feedback regarding non-drug treatment related issues having realistic impact on policy decisions and standards of practice at the national level. While several issues were raised in relation to the potential candidate treatments initially proposed for assessment, for practical purposes, only those related to behavioural interventions are within the scope of this report.

Currently, there is some controversy regarding diagnosis of autism by a single physician or psychiatrist versus a multidisciplinary team. Diagnosis is difficult and children with other conditions may demonstrate similar behaviours or activities as those with autism. However, these children may also benefit from similar types of therapy. This problem is compounded by the need for timely assessment and intervention. Timeliness of assessment may vary by centre. Delays in diagnosis and access to assessment are problematic for certain therapies that would be most beneficial for some children. Some children are excluded from treatment due to delays in diagnosis. While tools have been developed to aid the detection of autism, the research forum suggested that additional validation of these tools is needed to assess their sensitivity and specificity across populations, as current methods of screening for autism may not identify children with milder variants of the disorder. Delays on the waiting list for publicly provided therapy for autism are sometimes longer than the amount of time for which most children are eligible for therapy. Publicly funded programs often have age criteria, which denies younger or older children from access to treatment or from continuing to access a treatment to the point where gains made may be lost.

Overall, the consensus of the representatives from the consulted groups suggested further research is needed, as published studies in the area are methodologically flawed. Based on the Canadian Task Force Panel and Grading of Healthcare Evidence, there are no properly randomised controlled trials (level I evidence) on this subject. At present, a limited number of studies with level II evidence consisting of controlled trials without true randomisation, case-control trials, and trials involving pre-post design exist along with level III evidence consisting of the opinions of respected authorities. In general, discernment is needed when evaluating information on method of treatment and comment is needed regarding the reliability of Internet sites. Professional groups have written guidelines for evaluating treatment options. Many treatment approaches exist for autism, only some of which have been scientifically researched. There is a lack of empirical research comparing programs such as ABA versus other approaches. There is a need to identify programs or program components that are critical to outcome, and a need to identify which programs or components of programs are most effective or appropriate for subgroups of children with autism.

The efficacy of IBI has been demonstrated; however, studies to date have not withstood rigorous assessment because their designs allowed room for bias. While future studies could benefit from the inclusion of an adequate control group and the application of consistent outcome measures

for all children, administered by the same, blinded assessor at the beginning and end of the study, it may not be possible to address all of these issues ethically in trials. Further tools are needed to assess progress and outcomes of intervention.

Controversy exists over claims of recovery, exclusive use, intensity, eligibility and personal needs in relation to behavioural intervention. It has been suggested that behavioural interventions are most effective when used in conjunction with other individually determined best practice methods; however, funding may be provided for behavioural interventions only. Following evidence of effectiveness, cost-effectiveness analysis is needed to determine whether an intervention is practical and warrants consideration for provincial funding.

Issues associated with the practicalities of therapy were also identified. Some behavioural techniques can be perceived as unnatural and repetitive. Aversives were used to reduce maladaptive behaviours in the past; however, there are fewer current accounts of punishment. There is some evidence that aversives are not effective and may be contraindicated. There is a tendency to be cued and stimulus dependent, thereby restricting spontaneous and generative flexible language use and generalization to natural environments.

It has been noted that effective early intervention programs work to systematically reduce cues and stimuli, and increase spontaneity and flexible language with generalization to more complex and natural environments. All interventionists such as parents, siblings, teachers and behavioural consultants must respond to the child in a consistent manner across all environmental settings. Tremendous amounts of time, collaboration, patience and practice are required to attain fluency. Adequate resources are essential to ensure that the requisite time and training are in place before an intervention begins in order to make the most of human and financial resources invested in effective early intervention programs. There are differences between family needs and health care needs and it can be very difficult to meet both; however, the consequences of not meeting these needs are profound, involving placement of children into care by the province, family breakdown, and primary caregiver breakdown. Many families are left without programming, therapy or respite from extremely exhausting care-intensive children.

Concern was expressed that while there has been an increase in the number of children with autism and related disorders in North America, existing facilities are not expanding and new facilities are not being developed. Few professionals and agencies are trained and experienced in the various forms of therapy and technology application for autism and related disorders. As a result, waiting lists for therapy are sometimes several years. Services are extremely limited and are provided on an irregular and consultative basis. Although most families in Canada cannot afford private autism assessment and treatment services, many families do pay for these services when reasonable access to equivalent services is not possible in the public health system. Some private insurance agencies provide some coverage, it is usually only enough to cover three to five sessions. In contrast, research suggests that children with autism derive the greatest benefit from services that are provided on a regular, intensive basis, as progress is more substantial for those who are involved in at least weekly support services. There is a need for continuity of therapy into and with the education system. It has been proposed that the benefits of preschool therapy may be lost if a child receives inappropriate programming or does not receive special programming once they enter the school system.

The consultation process also resulted in the identification of two provincial bodies working in this field: the British Columbia Ministry for Children and Families and the Ontario Office of Integrated Services for Children. These bodies were integral to retrieving information regarding program initiatives.

## 4.2 Initiatives

Information regarding current service provision and Canadian initiatives regarding behavioural interventions was retrieved through informal request to contacts identified in a survey previously commissioned by the British Columbia Ministry for Children and Families<sup>61</sup> and discussions with contacts formed as a result of research forum discussions with CAIRN. Varying amounts of information were available by jurisdiction. Some jurisdictions provided information regarding available services for children with autism and their families when behavioural therapy was not directly available. The information retrieved, summarized in Table 3 of Appendix VI, ranged in scope from verbal correspondence to technical documents and preliminary data depending on the program. Information, ranging in time from January 2000 to May 2001, was obtained for all provinces and territories. A list of contact information by jurisdiction is provided in Appendix V.

**British Columbia:** According to the Autism Society of British Columbia guide entitled “Services Guide for Children with Autism Spectrum Disorder-From Diagnosis Until Adolescence”,<sup>70</sup> in order to receive publicly funded behavioural support for a child, a referral to the service agency must be sought through an attending social worker. Currently, a range of family support and developmental services are provided to families of children with autism. The Ministry for Children and Families offers infant development; supported childcare; respite; occupational therapy and/or physiotherapy; home support; speech/language therapy; hearing services and child care workers. In addition, the Ministry offers a specific behavioural support service for children with autism. Currently, the budget for this service is \$3.4 million and is regionalized. While the original funding in 1992-93 was estimated to serve approximately 400 children, there has been no increase in funding and the program has a waiting list of over 400 children with autism (Randi Mjolsness, Special Needs Consultant, Ministry of Children and Families, Victoria: personal communication, 2001 Jan 19).

The Ministry currently serves over 1,300 children with autism through a variety of programs. Services are so heavily waitlisted that they are increasingly only being used for families in crisis dealing with dangerous behaviours.<sup>70</sup> While services of a consultant are expensive, there is an additional expense of hiring a team of specialists to implement a program for 10 to 40 hours per week.<sup>70</sup>

The Government of British Columbia has been involved in litigation proceedings regarding therapy and services to children who have autism since August 1998. Parties were claiming for the payment of both past and future costs of Lovaas Autism Treatment (LAT) against the Ministries of Education, Health and Children and Families. In July 2000, the Supreme Court of British Columbia found the Government of British Columbia to be constitutionally obligated to fund some form of effective early behavioural intervention for children with autism spectrum disorder.<sup>71</sup> The Government filed a Notice of Appeal to this preliminary judgment. The Ministries of Children and Families, Education and Health responded in November 2000 by submitted affidavits outlining components of a provincial program to provide effective early IBI

to children with autism spectrum disorder. On February 6, 2001 Madame Justice Allan released the final decision. The Supreme Court of British Columbia accepted the proposed government model as an effective treatment for children under six years of age with autism spectrum disorder and four petitioners were awarded a symbolic amount of \$20,000 each.

Following the reasons for judgment issued in July, 2000, representatives from the Ministries of Health, Education, and Children and Families and the Attorney General formed an inter-Ministerial committee to develop a proposal for an effective treatment program for children with autism under six years of age.<sup>71</sup> New funding has been approved for the implementation of a provincial program for children with autism under the age of six years. This new provincial program is a joint ministerial effort by the Ministries of Education, Health and Children and Families to provide effective early IBI based on scientific research and previously demonstrated success-based characteristics. Services to children over the age of six years, such as the behavioural support program will be reviewed to ensure that there is a seamless transition for children from the early IBI program. The community-based program will eventually operate in every region where there is a child under six years of age with autism spectrum disorder. The Ministry for Children and Families has completed contracts for the delivery of early IBI in three communities in the province. A second request for proposal will be issued in the spring of 2001 to expand access to intervention services in British Columbia (Randi Mjolsness, Special Needs Consultant, Ministry of Children and Families, Victoria: personal communication, 2001 Mar 23).

The provincial program will be implemented over a three-year period. By 2003, it is anticipated that the provincial program will be serving all children in British Columbia under the age of six with autism spectrum disorder (Randi Mjolsness, Special Needs Consultant, Ministry of Children and Families, Victoria: personal communication, 2001 Mar 23). Elements of the provincial program include:

- Inter-ministerial collaboration;
- Building expertise within British Columbia;
- Enhancement of current capacity;
- Supplementing existing early intervention services;
- Links to academia; and
- A Board-based advisory component.

The Program is based on the following previously demonstrated success-based characteristics:

- Minimum of 20 hours per week for each child with a therapist to child ratio of one-to-one intensity;
- Highly supportive structured teaching using a variety of strategies with positive behavioural support, delivered and supervised by qualified personnel;
- Multi-disciplinary team involvement to create a plan for intervention;
- Integration with typical peers of the same age;
- Functional, proactive and positive approach to ABA; and
- Family is an integral part of the team and the plan is reviewed over time to determine ongoing appropriateness.

A Co-ordinating Centre for the program will provide links between:

- Diagnosis and assessment
  - Enhanced diagnosis and assessment capacity for children under six years of age
  - Creation of multi-disciplinary teams in the regions
- Treatment intervention and implementation for community based programs
  - Enhanced early IBI services to augment regional capacity and expertise
  - Support and monitoring of early IBI sites
  - Alignment with other components of the provincial model
- Training
  - Identification of training needs and import expertise if necessary
  - Enhancement of the province's capacity and expertise to provide early IBI
  - Development and delivery of training in positive behavioural support
- Research and evaluation
  - Alignment with provincial and federal research initiatives
  - Links with academia
  - Child specific outcomes and program quality assurance measures
  - Recommendations for future service delivery

A provincial co-ordinator will be hired to co-ordinate the program and will work with four managers of each of the above components to ensure that community capacity will be built to train and deliver services to all children under the age of six years with autism spectrum disorder.

Evaluation and monitoring are critical components of the provincial program:

- 50% of children and families served in each program site will be selected at random and tracked over the course of their involvement in the early IBI program. The impact of the program on the child, family and community will be evaluated.
- Compliance with the terms and conditions of the contracts will be evaluated with each contractor.
- The outcomes of each program relative to the others will also be evaluated.

**Alberta:** In the province of Alberta, the Ministries of Health, Children's Services, and Learning provide support to children with special needs, including children with autism. Services within the Ministry of Children's Services are delivered through 18 local Child and Family Service Authorities across Alberta. Each of the regional authorities has a number of service providers that they fund.

Within the Ministry of Children's Services, Handicapped Children's Services (HCS) has a provincial policy that will provide funding to assist with the cost of individual IBI programs as early intervention only for children with a confirmed diagnosis of autism and PDD-NOS or atypical autism.<sup>72</sup> A medical practitioner in Alberta must make the diagnosis; the child must be eligible for HCS program and meet the following eligibility criteria:

- IBI programs can be provided to preschool children, prior to entry into grade one, to a maximum of three years of HCS funding per child. Children who are diagnosed early may require further therapy.

- The family must first access and utilize alternate sources for services or funding for IBI services. A primary source of alternate funding is Program Unit Funding (PUF). PUF is provided by the ministry responsible for education (Alberta Learning) to school authorities to meet the educational needs of children 30 months to six years of age with severe disabilities. School authorities purchase the services that children require, including IBI, through PUF (Tony McClellan, Manager, Special Programs Branch, Alberta Learning, Edmonton: personal communication, 2001 May 17).
- A comprehensive assessment of the child, completed by a multidisciplinary team, must be submitted to HCS outlining the child's intervention goals and rationale for the recommendation of an IBI program over other treatment options.
- The child must be monitored and evaluated regularly by the referring medical professional, by an associate, or the assessing multidisciplinary team, throughout their involvement in the IBI program, to assess progress.

The IBI program consists of the following components:

- Intensive one-to-one teaching primarily based on behavioural strategies.
- The development of a structured, routine program based on the child's individual developmental goals.
- The program can be combined with health therapies: speech/language services, physiotherapy, and occupational therapy as recommended by the assessing health professionals.
- The program enhances appropriate behaviour and functional skills.
- Parents are involved in training, reinforcing and generalizing the child's skills.
- The program is home-based with an emphasis on community integration to promote transition to community programs or school.
- The program must be formally supervised, administered, and evaluated by a credible, qualified service provider.
- The intent of the program is to improve the child's communication, academic, and social and behavioural skills to a level where he/she is able to move into the community and educational system without IBI programming or intensive support.
- A maximum of 40 hours of one-to-one IBI per week inclusive of all funding sources, may be provided to preschool children.
- The cost of materials and supplies per child are fixed at \$600 per year.<sup>72</sup>

A three-year pilot study was opened to all eligible children, resulting in approximately 130 children being served.<sup>73</sup>

The Society for Treatment of Autism Early Intervention Program recently conducted a program evaluation in the Calgary region,<sup>74</sup> where early intervention program involves play/activity-based behavioural treatment 30 hours per week. Individualized treatment goals target communication skills, social and emotional development, cognitive functioning, and daily living skills. Integration with typical peers is a critical component that is accomplished by having clients attend a community playschool, preschool, or kindergarten program with their intervention therapist. Formal assessments are completed with clients in the early intervention program at entrance, often during the second year, and at the time of discharge. The average length of time between initial and discharge assessments was 24 months. Paired sample t-tests were used to



examine group differences on specific measures administered at different times. While the gains achieved by children in the program are likely a result of both treatment and maturation, conservative alpha levels reported suggest that the results could not be attributed solely to maturation. *As a group, children receiving early intervention achieved significantly higher measures of cognitive ability, adaptive behaviour, socialization, and communication skills.*<sup>74</sup>

**Saskatchewan:** Saskatoon District Health, with support from school divisions in the Saskatoon area, are funding a pilot project to provide intensive early intervention to four preschool children three to four years of age who have a diagnosis of autism or PDD.<sup>75</sup> The program includes a centre-based clinical treatment program three mornings per week, an average of 10 hours of direct service per week, and home visits and support for community services. The first group of children began the centre-based component of the pilot project September 1999 and this component concluded August 2000. A new group of four children began in September 2000. The disciplines involved in the treatment program are speech-language pathology, occupational therapy, early childhood psychology, and special education. A program assistant provides carry-over of objectives between settings. Staff provides parent education through home visits. The cost per child per year is \$25,000; approximately \$10,000 of which is funded by the Ministry of Education and \$15,000 is funded by the Ministry of Health.<sup>75</sup>

In Fall 2000, Saskatoon District Health, the Autism Treatment Services of Saskatchewan and five Saskatoon School Divisions began a one-year pilot school-based program for children with autism. In each of the three school settings, a speech language pathologist and an occupational therapist work with six children for a concentrated 3-month period. Each child has an individualized program where he/she receives up to one hour of direct therapy per day twice a week. Informal evaluations thus far indicate that parents are pleased with the additional services. Funding committed to this one-year pilot program is approximately \$31,000 from Saskatoon District Health, \$15,000 from Autism Treatment Services of Saskatchewan, and the equivalent of \$11,000 from the five Saskatoon School Divisions.<sup>75</sup>

**Manitoba:** There are approximately 500-600 children diagnosed with autism living in the province of Manitoba.<sup>73</sup> A multisectoral steering committee with representation from the Department of Education and Training and Youth, Department of Family Services and Housing, Healthy Child Manitoba, St. Amant Centre, Manitoba Families for Effective Autism Treatment, Autism Society of Manitoba, Autism Outreach Program, and the Student Services Administrators Association of Manitoba oversee a demonstration to provide behavioural therapy to children diagnosed with autism.<sup>76</sup> The St. Amant Centre operates the project which supervises, teaches and supports families and therapists who direct intensive therapy to children in the home, preschool and school settings.

The purpose of the demonstration project is to show how an ABA/DTT therapy program could be provided for Manitoba children diagnosed with autism by establishing and supporting a local senior therapist, providing training and support to a number of therapists, and providing accountability for how therapy is done. The project applies specifically to approximately 15 preschool and school-aged children. Each child receives up to 40 hours of therapy per week, applied across environmental settings. Currently the Province of Manitoba, Department of Family Services and Housing, funds the demonstration ABA project through the Healthy Child Manitoba. The cost per child is approximately \$28,000.<sup>73</sup> Some families use their respite funds to

help defray a small portion of the cost of running a privately funded ABA program.<sup>73</sup> The St. Amant Centre and Manitoba Families for Effective Autism Treatment make key decisions about the implementation of the project jointly through a Working Committee.<sup>76</sup>

**Ontario:** The Ontario government has committed \$19 million annualised funding to the development of province-wide intensive early intervention services for young children with autism (Heather Martin, Director, Ministry of Community and Social Services and Ministry of Health and Long Term Care, Toronto: personal communication, 2001 Apr 11). This new program is for children who:

- Are five years of age or younger (children between the age of five and six years will receive up to 12 months of services if an individualized assessment determines this would assist their transition to school);
- Are diagnosed as having an autism spectrum disorder;
- Have been clinically determined to be toward the severe end of the autism spectrum disorder; and
- Reside within the province.

Through a tendering process, the Ministry of Community and Social Services has funded nine regional service providers to deliver these new services (Heather Martin, Director, Ministry of Community and Social Services and Ministry of Health and Long Term Care, Toronto: personal communication, 2001 Apr 11). The Ministry has also contracted with the Behaviour Institute, a private agency based in Hamilton, to provide training over the first two years of program implementation to the therapists who are being hired by the regional programs to deliver these services.

The regional programs are expected to:

- Assess children to confirm eligibility and determine service intensity;
- Prepare individualized service plans for eligible children;
- Provide between 20 to 40 hours per week of IBI based on the clinical assessment to determine what is most appropriate for the child;
- Develop a transition plan with parents, other professionals and school personnel to support the child's transition to the school system or other settings; and
- Provide training to families so they can support their child's therapy in the home.

Families have the option of receiving funding from the regional program to purchase services privately, if the private program meets the quality standards of the provincial initiative.

The Ministry's program guidelines for the IBI program include a description of previously demonstrated success-based characteristics, program requirements, and recommended steps for effective transition to schools.

The regional programs started to provide IBI or funding for private IBI programs in fall 2000. The number of children served is steadily increasing as trained staff becomes available (Heather Martin, Director, Ministry of Community and Social Services and Ministry of Health and Long Term Care, Toronto: personal communication, 2001 Apr 11).

The provincial training organization provides:

- A two-week introductory training course to therapists hired by the regional programs;
- Feedback on video tapes of therapists' interactions with children and on-site assessments of therapists' skills;
- A parent training course to staff of the regional programs who will then provide training to parents;
- Parent training sessions in all regions;
- Training to supervisors on how to develop and review IBI programs and how to develop and supervise staff;
- Monthly advanced training seminars with experts in the field; and
- A complete set of training materials and videos to be used as ongoing resources by the regional programs.

All IBI services, training sessions and materials are also available in French in accordance with the requirements of the Ontario French Language Services Act.

The Ministry has developed a data information system for monitoring and evaluation of the program. This data information system is collecting information on client demographics, assessment results, client services, service providers, service costs, and placement at discharge. This information will be used to analyse factors affecting children's outcomes, and to monitor performance standards in each region.

The Ministry is also developing tools to measure the quality of the IBI that is provided. Once available, these tools will be used by Quality Assurance teams to examine the quality of programs throughout the province. An external evaluation of the initiative is being planned to assess the overall impact of the initiative in the longer term. Results will be used to modify the program and ensure that families receive the best possible services (Heather Martin, Director, Ministry of Community and Social Services and Ministry of Health and Long Term Care, Toronto: personal communication, 2001 Apr 11).

Two legal actions have been initiated against the Ontario government for alleged failure to provide adequate services for children with autism. The Ontario government is currently defending itself in these actions (Heather Martin, Director, Ministry of Community and Social Services and Ministry of Health and Long Term Care, Toronto: personal communication, 2001 Apr 11).

**Quebec:** In 1999, the Ministry of Health and Social Services published an orientation guide for services for children with autism and their families.<sup>77</sup> Eighteen regions in Quebec were to develop an action plan for specific services for individuals with autism based on the unique needs of each region. As of the year 2000, most regions have prepared a plan of action, but no specific budgets have been allocated for autism. The Ministry provides global funding and orientation to 18 regional boards that decide how best to administer programming for children with autism.<sup>78</sup> Each of the 18 health regions receives a global operating budget and uses it to its discretion (Peter Zwack, Professor, University of Quebec at Montreal: personal communication, 2001 Mar 29). Hospitals and Intellectual Deficiency Rehabilitation Centres then provide

services to individuals with autism. No direct funding is provided specifically for behavioural interventions.

At the Montreal Children's Hospital, 10 new cases of autism spectrum disorder are diagnosed per month, and in most cases the child was diagnosed at less than three years of age (Charles Larson, Director, Developmental and Behavioural Paediatric Services, Montreal Children's Hospital, Montreal: personal communication, 2001 Jan 5). A recent survey of the 18 health regions found that only about 1,400 people in Quebec have been formally diagnosed as having autism. This number represents approximately 10-20% of the number of cases expected based on accepted prevalence studies. Under identification of cases, as noted in the orientation guide, this suggests the need for information and training in the area. Existing waiting lists for diagnostics range from a few months to more than one year in some cases. Since 1997, the Quebec Society for Autism and its affiliated regional societies have organized conferences and workshops throughout the province to provide parents and professionals with information toward the development of programs for screening and diagnosis of autism (Peter Zwack, Professor, University of Quebec at Montreal: personal communication, 2001 Mar 29).

Several types of establishments offer the majority of services to individuals with autism; hospitals, local health centres, rehabilitation centres and schools. In addition, regional societies also provide some services in Quebec. The wait-list for intervention programs can often range up to one year or more after the wait for diagnosis (Peter Zwack, Professor, University of Quebec at Montreal: personal communication, 2001 Mar 29). Most services are running at full capacity (Charles Larson, Director, Developmental and Behavioural Paediatric Services, Montreal Children's Hospital, Montreal: personal communication, 2001 Jan 5).

The health and social service network is the major service provider for children from birth to four years of age. Between the ages of four to 21 years, the responsibility for service is divided between the health and social service network and the school system. Generally, the hospitals are responsible for formal diagnosis and may also do functional assessments. Some hospitals also offer short-term treatment programs based on a variety of treatment models ranging from psychotherapy and play therapy to structured teaching and behavioural methods. Rehabilitation centres also provide functional assessments and family support and respite. Some rehabilitation centres are in the process of organizing programs. Local health centres are responsible for family support and respite, but also provide rehabilitation services based on a variety of models. The Quebec Society for Autism and its affiliated regional associations also offer emergency support and respite services (Peter Zwack, Professor, University of Quebec at Montreal: personal communication, 2001 Mar 29).

In most of the new regional action plans, which have been adopted in a majority of the 18 regions, both the TEACCH and Lovaas type ABA programs were mentioned as treatments of choice. The latter was mentioned for intensive early intervention. One of the regions is organizing a pilot project to replicate the Lovaas early intervention model which follows up on very limited pilot projects on TEACCH and Lovaas type ABA model that were run in Montreal in 1998. However, all centres have experienced difficulty in hiring qualified professionals for new programs. A number of school boards have begun to provide educational programs specifically for autism based primarily on the TEACCH model. Since 1998, the Quebec Society for Autism in collaboration with the Université du Québec in Trois-Rivières has been offering

continuing educational short courses on a variety of areas including diagnosis, behavioural intervention, the TEACCH model, and behaviour management (Peter Zwack, Professor, University of Quebec at Montreal: personal communication, 2001 Mar 29).

Within the Montreal region, six hospitals and five rehabilitation centres work with children with autism. The two paediatric tertiary care hospitals are very much limited to diagnostic and functional assessments. At the Montreal Children's Hospital, the Department of Psychology offers an early autism intervention program for children below 42 months of age and who have been assessed to have potential for normal cognitive development. This is a parent implemented, information processing intervention that lasts for two years. Approximately 20 children are enrolled in the program (Charles Larson, Director, Developmental and Behavioural Paediatric Services, Montreal Children's Hospital, Montreal: personal communication, 2001 Mar 14). Two other hospital centres, Douglas and Rivière des Prairies, provide short-term programs with parental involvement. Support is also provided through the Montreal Autism Society and the Quebec Autism Society (Charles Larson, Director, Developmental and Behavioural Paediatric Services, Montreal Children's Hospital, Montreal: personal communication, 2001 Jan 5).

The pilot project in the Montreal region, "Projet d'intervention comparémentale et intensive pour jeunes enfants autistes dans la région de Montréal," involves Lovaas therapy. In September 1998, Régie régionale de la santé et des services sociaux de Montréal-Centre (RRSSSMC), completed a pilot project where nine children diagnosed with autism were treated with 13 weeks of Lovaas therapy. Two goals identified in the pilot project were to experiment with an organizational model for treating autistic children based on Lovaas therapy, and to train a team of therapists comprised of parents, volunteers, and workers in the centres, based on research of psychologists in Australia.<sup>78</sup> Recommendations included recruitment of students to offer 30-40 hours of therapy per week with the possibility of remuneration following training of hours in duration; training of a team of therapists; an educator to inform parents about the nature and implications of treatment and the use of consent forms; creation of a support group for parents and to rapidly identify the needs of parents before and after three months of treatment.

Following another pilot project of the TEACCH program, recommendations were made for an integrated network of services for developmentally challenged people. This network is being implemented to harmonize a diversity of services offered by various providers.<sup>78</sup>

**Newfoundland:** The Department of Health and Community Services, Government of Newfoundland and Labrador, is offering a two-year pilot project for 20 children aged 18-42 months and 15 children aged 43-60 months with a diagnosis of autism/PDD.<sup>79</sup> The project is funded through the National Child Benefit Fund.<sup>73</sup> Approximately \$975,000 is required to provide two years of therapy for 35 children.<sup>73</sup> The pilot consists of two treatment groups: one parent implemented, cognitive developmental treatment, and the other an intensive, discrete trial treatment.<sup>79</sup> Ten children, in the 18-42 month age group have been selected for each treatment based on spaces available for treatment and parent preference. The final decision for a particular treatment was that of the parents. The only treatment option available to children aged 43-60 months is intensive ABA based on Lovaas methodology. Ten additional families contract for Lovaas therapy privately and receive funding for consultation expenses.<sup>73</sup>

Children selected for cognitive developmental treatment will undergo assessment and treatment at Montreal Children's Hospital.<sup>79</sup> Parents will be trained on how to provide this therapy to their child under the consultant's direction for a minimum of one 12-minute therapy session per day, five to seven days per week. In addition, the specialist provides programming direction and discussion to parents via bi-weekly videoconference consultations. Therapy with this program consists of daily compliance and natural play sessions as well as 12-minute therapy sessions overseen by the consultant. Costs associated with travel to Montreal are covered by funding allocated for the pilot project. Children selected for intensive, discrete trial treatment receive 30 hours of "hands on" intervention by trained home therapists. Funding for home therapists, at 30 hours per week, for families in the pilot project will be covered within the cost of the pilot for the duration of the two-year study. Assessments are required to evaluate the effectiveness of treatments, child progress and family response to treatment, and to identify implementation issues pertaining to the delivery of treatment options. The results of the study will include the effectiveness of treatments and recommendations for further direction in early intervention for children with autism.<sup>79</sup>

**New Brunswick:** New Brunswick does not have a government program that deals specifically with children with autism. Children with autism have access to services such as speech-language pathology, occupational therapy, and psychological counselling through the same programs children with other disabilities access services. There are no formal organizations trained to provide ABA therapy. The Autism Society of New Brunswick has hosted events to raise awareness among professionals and the general public regarding the disorder. There are approximately four parent-centred community resource programs that provide parent support and access to resources. Parents are using available services to the fullest capacity. In October 2000, the government formed an interdepartmental committee with community partnership to determine what services are available in the province and to draft recommendations for June 2001 (Gina Atkinson, Program Consultant, Support and Maintenance Unit for Family and Community Services, Fredericton: personal communication, 2000 Dec 18).

**Nova Scotia:** In response to parents' requests for increased services for children with autism, the Child and Youth Action Committee (CAYAC) of the government of Nova Scotia established a subcommittee to develop a plan to enhance services to children from birth to six years of age. The main focus of the Early Identification and Intervention Services Sub-committee's (EISS) work was the early identification and timely service intervention of children under six years of age with special needs conditions such as autism spectrum disorders. EISS comprises members from the Departments of Health, Education and Community Services and the Izaak Walton Killam Health Centre for Children, Women and Families (Linda Smith, Director, Child and Youth Health Services, Halifax: personal communication, 2001 Apr 11).

The Early Identification and Intervention Services model was released by the Minister of Health in April, 2000 in a document entitled *A CAYAC Model for Enhancing Services in Nova Scotia for Children Under Six Years of Age With Special Needs*.<sup>80</sup> Four strategic directions identified in the report were: "evidence-based" screening; coordinated assessment and diagnosis; regional, coordinated service delivery of interventions; and "evidence-based" awareness and training for health professionals, service providers and families.<sup>80</sup> This model was developed with active stakeholder and parent input. The EISS initiative has progressed to the stage where each of four provincial regions have been asked to prepare region specific proposals on how to enhance

services to children until the age of six years (Sarah Shea, Director, Developmental Clinic, Grace Health Centre for Children Women and Families, Halifax: personal communication, 2001 Mar 19). The Nova Scotia government has allocated \$2 million per year for this service enhancement. The money will be dispersed to the regions following approval of proposals by a subcommittee of the provincial CAYAC (Sarah Shea, Director, Developmental Clinic, Grace Health Centre for Children Women and Families, Halifax: personal communication, 2001 Mar 19).

ABA is not recommended as a stand-alone therapy within the model. Rather, the focus is on the use of behavioural techniques within all interventions tailored uniquely to the individual child's needs. While the amount of time a child is seen by a service provider varies and there is no prescribed minimum intensity for programming, children will receive individualized intensive interventions to promote greater improvements in outcomes.<sup>80</sup> Individual Family Service Plans (IFSP) will be developed by a multi-service team within each region or district.

Within the province, previous work has been done on ABA and other teaching strategies for children with autism. As part of the newly developed EI/ISS model, an additional \$2 million in grant funding has been made available to regions to prioritise the means by which services can best be enhanced to meet needs. Within the model, there is also funding for provincial training. Training events in the near future include: ADOS training for diagnosticians; and TEACCH training for primary school teachers and early interventionists (Linda Smith, Director, Child and Youth Health Services, Halifax: personal communication, 2001 Apr 11). Through the Department of Community Services, parents are able to receive funding for specialized day care seats for respite services.

A study involving three preschool children is being conducted through Mount St. Vincent University, based on a variety of teaching strategies as recommended by the Bancroft and May Institutes in the United States. Approximately \$70,000 per year provides about one third of the true cost of therapy for the three children in the study, the cost of which is supplemented through fund-raising by parents and the university.<sup>73</sup> The government has not yet costed out expansion of the pilot and the costs associated with serving all eligible children in the province. The Department of Paediatrics at Dalhousie University has been the beneficiary of a donation to establish the Craig Chair in Autism Research, the focus of which will be clinical research with emphasis on improving outcome for children with autistic spectrum disorder (Sarah Shea, Director, Developmental Clinic, Grace Health Centre for Children Women and Families, Halifax: personal communication, 2001 Mar 19).

**Prince Edward Island (PEI):** There are approximately 70 children and youth diagnosed with autism spectrum disorder living in Prince Edward Island, 23 of whom are under six years of age.<sup>81</sup> Approximately four to seven new cases of autism spectrum disorder will be diagnosed each year, according to present incidence figures. The Autism Integration Project was jointly sponsored by the Paediatric Clinic of the Queen Elizabeth Hospital, Charlottetown, and the Child, Family and Community Services Division of the provincial Department of Health and Social Services.<sup>81</sup> The goals of the Autism Integration Project are to: improve the level of integrated service delivery; reduce dependency on out-of-province agencies; reduce the need for long-term, expensive interventions and services and reduce family stress. The Departments of Health and Social Services and Education are partnering with the provincial Autism Society to

complete a business plan to assess the feasibility of establishing a Behaviour Based Training Institute for the province. The Department of Health and Social Services is currently funding visits to PEI for consultants from Bancroft Neuro Health in Maine. Regional health authorities provide funding for in-home workers to implement an intensive behaviour based program up to a maximum of 20 hours per week at \$10 per hour. The Department of Health and Social Services provides special needs grants to licensed early childhood centres to support inclusion of children with autism in preschool programs. The planning process for a provincial policy plan began January 2001.<sup>81</sup>

**Yukon, Northwest Territories, and Nunavut:** There do not appear to be any specific behavioural therapy programs for children with autism living in the Yukon (Anne Westcott, Director, Family and Children's Services, Whitehorse: personal communication, 2001 July 16).<sup>61</sup> The Government of the Northwest Territories does not have any specific programs dedicated for persons with autism (Debra Dechief, Consultant for Children's Services, Children and Family Services-Community Programs and Services, Yellowknife: personal communication, 2001 Jan 10). Children with autism and their families are provided service through access to a variety of government and non-government programs. Each case is evaluated and the family's program of services evolves based on their unique circumstances and needs. Services may include but are not limited to: home care, counselling, school aids, assessment services, and medical services and equipment (Debra Dechief, Consultant for Children's Services, Children and Family Services-Community Programs and Services, Yellowknife: personal communication, 2001 Jan 10).

In Nunavut, there are no specific autism services offered by either the Department of Health and Social Services or the Department of Education (Marie Irniq, Department of Health and Social Services, Iqaluit: personal communication, 2001 Mar 19). Health Services offer access to medical assessments and other medical support services as required. Social Services offers support and respite through home care, counselling for parents, and as required, accommodation in a foster or group home. Attempts are made to individualize a program for specific children. Where further required, referral to placement out of Nunavut is made. Children are usually referred to Edmonton, Winnipeg, Ottawa or Montreal for assessment. Placement is made where the needs of the child are best met combined with availability of space, residence of parents and other factors. The Nunavut Government provides funding for such placements; and where able, parents contribute financially to assist in obtaining these services (Marie Irniq, Department of Health and Social Services, Iqaluit: personal communication, 2001 Mar 19).

There is a student support consultant with a specialty in autism who can assist in programming for students with special needs (Margaret Joyce, Department of Education, Arviat (NU): personal communication, 2000 Dec 21). The Department of Education funds school programs while the Department of Health and Social Services pays for residential care, medical assessments, travel and educational programs when children are placed outside of Nunavut. All aspects of the delivery of services are major challenges and no new initiatives are taking place in the area of autism. The area of special needs for children prior to school and in school is receiving review by the Department of Education.



## 5. ANALYSIS OF LEGAL CASES

### 5.1 Introduction

This chapter is designed to present an overview of outcomes of cases that courts of law have resolved. It identifies legal arguments that trial courts have found persuasive, and how judges have approached the claims of parties arguing that governmental provisions for treatment of autistic children have fallen short of satisfying rights secured under the Canadian Charter of Rights and Freedoms. The key issue is to what extent courts of law may be prepared to require governments to allocate resources to the treatment of autism.

Where legislation has appointed administrative bodies or panels to make resource allocation or service decisions, courts have a supervisory role to ensure that such decisions are made in accordance with the law. The courts are not deciding what resources or services those claiming entitlements should receive, but rather whether decisions that the administrative bodies or panels reached were correctly made; that is, whether the bodies or panels proceeded correctly, in accordance with rules of law and evidence. If judicial findings are that they did not, courts will find their decisions void, and require them to reconsider the issues and to do properly what the courts found they had done improperly. The courts themselves, however, will not displace those bodies or panels and say what outcome the judges consider appropriate, because legislation has given decision-making authority to the bodies or panels and not to the courts. This reflects the constitutional doctrine of the Separation of Powers in that the role of the judiciary is to ensure that the administrative branch of government complies with requirements imposed by the legislature, but not itself to supersede the administration and exercise executive powers.<sup>i</sup>

### 5.2 Background

Canadian judgments in cases of parents claiming appropriate treatment for autistic children have not yet reached a level constituting legal precedent in any province; that is, no provincial Court of Appeal has decided a “landmark” case. Trial court decisions, not binding on any other court, go in both directions, some being sympathetic to and upholding parents’ claims to provincial funding of services, and others, despite judges’ declared understanding of parents’ justifiable concerns, not being prepared to direct provincial ministries on allocation of their budgets. Nevertheless, judgments show some judicial willingness to apply the Supreme Court of Canada’s 1997 unanimous decision in *Eldridge v. British Columbia (Attorney General)*,<sup>ii</sup> to overcome conventional judicial deference to governmental budgetary discretions by applying the Canadian Charter of Rights and Freedoms.

The conventional judicial restraint was represented in the Nova Scotia Court of Appeal in 1999, rejecting a claim that governmental refusal to fund a reproductive technology violated patients’ Charter entitlements. Justice Chipman, speaking for the Court’s majority, noted “the extremely difficult task confronting those who must allocate the resources among a vast array of competing claims,”<sup>iii</sup> and observed of governmental health department officers that:

In the face of the tremendous pressures upon them, they must be ‘accorded some flexibility’ in apportioning social benefits among the vast number of competing procedures and the conditions of patients that call for them.

The policy makers require latitude in balancing competing interests in the constrained financial environment. We are simply not equipped to sort out the priorities. We should not second guess them, except in clear cases of failure on their part to properly balance the *Charter* rights of individuals against the overall pressing objectives of the scheme under the [provincial health legislation].<sup>iv</sup>

The exception for balancing Charter rights provides judges with an opportunity to advance the interests of parents on behalf of their autistic children, but judicial determination of violation of Charter rights, such as by discrimination, involves a two-stage analysis.

### 5.3 Discrimination

Accepting that children diagnosed as autistic are within the Charter definition of suffering from “mental or physical disability” under section 15(1), parents must show, as the first stage of the analysis, that denying children the care that their parents demand constitutes unlawful discrimination against them. There are several legal definitions of discrimination, which basically amounts to governmental action that places individuals at disadvantage, deliberately or in its effect, by virtue of their disability. In a widely cited observation, McIntyre J. in *Andrews v. The Law Society*<sup>v</sup> described “discrimination” as:

a distinction, whether intentional or not but based on grounds relating to personal characteristics of the individual or group, which has the effect of imposing burdens, obligations or disadvantages on such individual or group not imposed on others, or which withholds or limits access to opportunities, benefits, and advantages available to other members of society.

In *Eldridge*, for instance, acts performed by hospitals delegated to them by provincial governments for discharge of provincial responsibilities for health services were held to be governmental acts, and failing to provide funding for sign-language interpretation that would equip hearing-impaired patients to communicate with health service providers in the same way that unimpaired patients can was held to constitute discrimination. This set the scene for the second stage of the analysis.

Where an applicant for judicial remedy shows discrimination on the basis of disability, the government responsible then bears the burden of showing, in accordance with section 1 of the Charter, that the discrimination “can be demonstrably justified in a free and democratic society.” The Supreme Court of Canada has accepted, for instance, that mandatory retirement laws for employees who have held privileged or protected rights of employment may be so justified.<sup>vi</sup> The discrimination in *Eldridge*, where the cost of providing the denied services was considered relatively minor, was found unjustifiable. However, the court in the *Cameron* case, concerning *in vitro* fertilization and intracytoplasmic sperm injection (ICSI), gave considerable attention to the incidence of infertility, the costs of the treatments for which funding was sought, and comparative costs of treatments for other conditions. The court, “[h]aving regard to the costs, the limited success rate and the risks,”<sup>vii</sup> found that the government had proven that any discrimination due to non-funding was demonstrably justified, within section 1 of the Charter. The denial of funding was accordingly found to be discriminatory, but not in violation of the Charter.

## 5.4 Autism Trial Decisions

A 1996 case in which parents of an autistic child obtained a favourable judicial order was of a technical jurisdictional nature, and did not involve Charter concerns. In *C.R. v. Alberta (Director of Child Welfare)*,<sup>viii</sup> an Appeal Panel under Alberta's Child Welfare Act denied parents' appeal against the decision of the provincial Director of Child Welfare not to cover costs of Lovaas-type treatment. The Appeal Panel's decision upholding funding refusal was based on the ground that the child was of school age, and that education of school-age children was within the exclusive jurisdiction of school boards acting under the provincial School Act, and so outside the Director's and Appeal Panel's control.

The parents' claim before the Alberta Court of Queen's Bench was that the Appeal Panel erred in law, since the treatment was not exclusively educational but concerned the child's general welfare, and was accordingly within the legal jurisdiction of the Director and Appeal Panel. The trial judge ruled that the parents' claim was correct in law, and accepted that the treatment's development of the child's speech and vocabulary included but transcended his capacity for schooling, touching most if not all areas of his life. The Court ordered the Director of Child Welfare to enter into an arrangement with the school board to ensure the child's appropriate support and future education, and to fund 90% of the costs for the year 1996, amounting to a little under \$32,000.

A more recent Alberta Court of Queen's Bench decision, of July 1999, has disagreed with the decision in the earlier case of *C.R.*, on two grounds. In *D.J.N. v. Alberta (Child Welfare Appeal Panel)*,<sup>ix</sup> the judge addressed Charter issues, finding no violation, and found the Appeal Panel's decision that it lacked jurisdiction to provide the requested services not to be legally erroneous. Second, the Court found that, if it was itself incorrect in that finding of law, the remedy was not for the Court to direct payments, but to send the case back to the Appeal Panel or to the provincial Director for determination and assessment of critical facts. The Director's and Appeal Panel's conclusion that they had no jurisdiction in law to make a decision left unresolved the contending parties' arguments of fact. In the absence of findings of critical facts, the judge in the Court of Queen's Bench found it inappropriate to order payments, as the earlier judge had done, on the basis only that the Director and Appeal Panel had incorrectly concluded that they lacked power in law to decide whether or not payments were appropriate. The appropriateness of the Court ordering payments depended on determinations of facts, which had not been made.

The case of *D.J.N.* involved an autistic boy whose parents were receiving financial family support, but whose various health programmes would not offer the level of occupational therapy or motivation for social skills that his parents claimed he needed. In addition, other school-based services, such as speech therapy, were claimed to be inadequate. The Director of Child Welfare and the Appeal Panel ruled that they lacked jurisdiction to hear the parents' claim or to make a decision, because the claims were exclusively governed by the provincial School Act. This was the same legal argument that was made to the Court in the *C.R.* case, but its rejection there did not constitute a precedent binding any other court, and the judge in *D.J.N.* was free to accept the argument as legally correct. The parents had not applied for assistance under the School Act for funding for the boy's speech therapy, occupational therapy, computer language training, or social skills or reading skills training, but the research and analysis undertaken by the judge indicated that the Act covered such services, even if inadequately.

The parents claimed that the Director had previously funded such services under the Child Welfare Act, and invoked the *Eldridge* judgment, showing applicability of the Charter, to allege that the inconsistency was discrimination, contrary to section 15(1). The judge found the evidence of inconsistency inconclusive, that inconsistency is suspect only when cases are closely alike, which is improbable in light of the wide range of disabilities that affect autistic children, and that, in any event, the changing budgetary constraints on the Director's funding power are unavoidably liable to provide an appearance of inconsistency. The judge found no legal obligation on the Director to provide financial assistance for the types of programmes the parents requested. The judge further found that, if that finding is incorrect, there is an accumulation of precedent from the Supreme Court of Canada, which the judge extensively reviewed, that the Director is equipped, but the Court itself is not, to entertain the merits of the parents' monetary requests. The judge found that:

it would be wrong for a Court to venture into whether the Director or the [Appeal] Panel or a School Board should or should not pay some, none or all of these kinds of requests. Courts are not privy to the policies, budgets or principles that determine access to the public purse ... I accept that the services for handicapped children may be stretched to the limit and may not provide adequate attention to a great number. That conclusion, however, does not entitle the Court to order those services to be provided and paid for by either or any department of the government.<sup>x</sup>

This finding closely reflects the conventional deference to the judgment of governmental resource-allocation agencies illustrated in the *Cameron* case, above.<sup>xi</sup> The power of courts reviewing decisions of administrative officers and tribunals is limited to errors of fact or of law. Insufficiency of funding does not constitute such an error, and a court exercising its jurisdiction to review decisions of lower officers or tribunals has no corrective powers, which are available only to the executive or legislative branches of government. The judge explained that the different decision in the 1996 case of *C.R.*, seeking to provide funding under child welfare legislation that was found not to be available under legislation governing schools, was reached before the judge had access to the Supreme Court of Canada's decision in *Adler v. Ontario*,<sup>xii</sup> which indicated the considerable breadth of services to be delivered in public schools. The provincial School Act dealt with the services requested for the autistic boy more specifically than the general terms of the Child Welfare Act, and if the two Acts overlapped, which the judge found they did not, the former prevailed.

The British Columbia Supreme Court addressed somewhat different legislation in its July 2000 judgment in *Auton (Guardian ad litem of) v. British Columbia (Attorney General)*,<sup>xiii</sup> but was asked to consider defence arguments that were found comparable to those presented before, and rejected by, the Supreme Court of Canada in the *Eldridge* case. The trial judge was critical of the defendant government's reliance on these failed arguments. The petitioners were autistic children and their parents, acting as individuals since the judge had refused certification of the proceedings as a class action, claiming relief under the Charter against denials of funding for Lovaas Autism Treatment. The provincial government denied the alleged discrimination, and claimed in the alternative that any proven discrimination was justified under section 1 of the Charter.

The trial judge accepted evidence that children whose parents had incurred the considerable costs of providing Lovaas Autism Treatment for them had made significant gains, although the treatment was not, and was found not to claim to be, a “cure” for autism. The judge dismissed defence arguments that the Lovaas treatment was not a “medically necessary service,” that it was of unproven efficacy and experimental, and that treatments and services presently provided for families of autistic children and the children themselves, which the judge compared unfavourably with care provided in other provinces, were adequate.

The judge approached governmental responsibility through that of the provincial Ministry of Health rather than of, for instance, the Ministry of Education, in part because some children concerned were below age for school attendance. The judge took this approach even though many of the requested services are delivered by non-medical therapists. By regulations implementing the provincial Medicare Protection Act, such therapists could be “health care practitioners” whose services are “benefits.” Those covered by the Act are entitled to “reasonable access” to benefits rendered by health care practitioners. In light of the services provided for autistic children in the province and the judge’s review of the applicable jurisprudence, a governmental failure was found to make appropriate accommodation for the health care needs of such children, constituting discrimination against them contrary to section 15(1) of the Charter. The judge found that “In comparison to both non-autistic children and mentally disabled adults, the infant petitioners are subject to differential treatment based on the ... ground of mental disability. Indeed, as children and mentally disabled, they are doubly vulnerable.”<sup>xiv</sup>

Citing the Supreme Court of Canada’s judgment in *Eldridge* at several points, the judge similarly dismissed the defence alternative claim that any discrimination was demonstrably justified according to section 1 of the Charter, on the ground of expense. The judge invoked the observation of the Supreme Court’s Madam Justice (now Chief Justice) McLachlin, formerly Chief Justice of British Columbia, in the case of *British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights)*,<sup>xv</sup> that:

[w]hile in some circumstances excessive cost may justify a refusal to accommodate those with disabilities, one must be wary of putting too low a value on accommodating the disabled. It is all too easy to cite increased cost as a reason for refusing to accord the disabled equal treatment ... I do not assert that cost is always irrelevant to accommodation. I do assert, however, that impressionistic evidence of increased expense will not generally suffice. Government agencies perform many expensive services for the public that they serve.<sup>xvi</sup>

The judge was unable to estimate additional immediate costs of a treatment programme for autistic children and any resulting long-term savings. It was noted, however, that the petitioners did not seek full funding for treatment, or treatment of all autistic children. The judge concluded that the government was, as the petitioners claimed, in breach of their Charter obligations of non-discrimination, and so declared.

The judge had earlier recognized limits to the judicial order that could be made, observing that “the Court cannot direct the Crown [the defendant] to specifically provide Lovaas Autism Treatment regardless of the outcome of these proceedings.”<sup>xvii</sup> In the *Eldridge* case, where the Supreme Court of Canada declared the government to be in violation of the Charter, the Court

required the government to submit a proposal for compliance. In the present case, the parties had agreed to address any appropriate remedy of a Charter violation at a subsequent hearing, at which further submissions would be made as to what the Court might direct. Section 24(1) of the Charter empowers a court to provide “such remedy as the court considers appropriate and just in the circumstances.”

The subsequent hearing, conducted in mid-November 2000, resulted in a judgment delivered on February 6, 2001.<sup>xviii</sup> The judge repeated the declaration made at the preceding hearing that the failure of the defendant government to provide the infant petitioners with effective treatment constitutes an unjustified denial of their rights to non-discrimination under section 15(1) of the Charter. The judge recalled that, at the outset of the proceedings permission was denied to conduct them as a class action on behalf of all autistic children and their families who had requested and been denied government funding for Lovaas Autism Treatment. The Crown, while opposing a class action, acknowledged that a finding of breach of the government’s obligations to the petitioners would mean the same breach to other autistic children in general. In making the concluding declaration, the judge noted its significance to the Charter rights of autistic children beyond the petitioners in the case.

The February 6, 2001 judgment also directed that the Crown fund early intensive behavioural therapy for children with autism, including autism spectrum disorder. The judge declined the petitioners’ request to issue a mandatory order, accepting that the government was acting in good faith to implement an effective treatment programme for autistic children between two and six years of age (that is, below school age) through the newly created Provincial Centre for Autism and Related Disorders. The judge concluded that the *bona fides* and efficacy of the proposed treatment programme could not yet be assessed, and that it was premature to make a judicial order mandating a programme of any general scope or content. The judge balanced conventional judicial deference to governmental policy-making on discharge of legal duties against the limited time during which courts can tolerate governmental failure to remedy breaches of the Charter’s antidiscrimination guarantee, and implied that, upon subsequent proof of failure, compliance with the Court’s directive could be mandated. However, the judge observed that “the Court cannot direct the Government to fund or provide Lovaas Autism Treatment, the specific treatment desired by the petitioners,” because “it remains within the competence of Government, not this Court, to determine, upon appropriate professional advice, the nature and extent of the Early IBI [early intensive behavioural intervention treatment] it will provide”<sup>xix</sup> to satisfy its duties.

Finally, the judge recognized the wrong done to each of the adult petitioners, including the financial and emotional burdens they had been required to bear, by awarding each of them \$20,000 in monetary damages. This was estimated not as financial restitution or compensation, since there was evidence that the family of one affected child had spent over \$240,000 on Lovaas Autism Treatment, but as a now conventional modest symbolic or token recognition that “the petitioners have achieved a real victory on behalf of all autistic children whose rights were infringed.”<sup>xx</sup>

The government of British Columbia filed notice to appeal against the judgment, which permitted but did not compel it to take the case further. An appeal became unlikely, however, when the government stated, in the mid-November 2000 hearing, that it was moving swiftly and

in good faith to implement an effective programme that complies with the earlier judgment. An issue in any subsequent hearing, and possibly on appeal, would probably be the financial costs of providing the requested treatment. The contrast may be made with the *Eldridge* case, where “[t]he cost of the proposed program, which would have extended throughout the province, was estimated to be \$150,000 per year.”<sup>xxi</sup> The government in the *Auton* case stated that the provincial Children and Families Ministry serves about 12,000 children with special needs, of whom 1,273 are autistic. The Ministry’s 1999/2000 budget for children and families was about \$62 million with an additional \$28 million for special needs daycare, a total annual budget of \$90 million.<sup>xxii</sup> Lovaas Autism Treatment costs between \$45,000 and \$60,000 a year per child.<sup>xxiii</sup> Accordingly, the full costs of treating the 1,273 autistic children in the province would range from over \$57 million to over \$76 million per year.

The successful petitioners did not require funding for treating every autistic child, nor full support of those whose treatment was funded. Nevertheless, the costs appear to be significantly greater than in *Eldridge*, where “the cost of accommodation was shown to be modest”<sup>xxiv</sup> at \$150,000 per year. In *Cameron*, the Nova Scotia Court of Appeal gave detailed attention to the costs of the treatments for which funding was requested, and concluded largely by reference to them that the defendant government had discharged its burden of showing that its refusal of funding satisfied the Charter section 1 test of being demonstrably justified. The Court of Appeal’s observation that a transfer of funds to provide the requested services would deny funding of services to other claimants in Nova Scotia, whose complaints of governmental discrimination against them would be as valid as those of the complainants then before the Court, could apply equally to actual and potential service recipients in British Columbia.

As against this, however, at the time of the claim in *Eldridge*, the annual health care budget of British Columbia was estimated at about \$6 billion, permitting the Supreme Court of Canada to observe that:

the estimated cost of providing sign language interpretation for the whole of British Columbia was only \$150,000, or approximately 0.0025 per cent of the provincial health care budget at the time.<sup>xxv</sup>

If the funds involved in giving effect to a petition comparable to that leading to the *Auton* judgment were capable of a similarly reductive assessment and a comparably beneficial effect, a court might have the confidence to be more directive than the judge in *Auton* in mandating their expenditure.

In the February 2001 decision, the judge took the opportunity to situate the case in its wider constitutional frame of reference. She observed that

This case raises significant public policy issues as to the respective roles of the judiciary and the legislature. The issues raised by the petitioners underscore the difficulties inherent in a process where the Court’s finding of unconstitutionality is designed to change governmental behaviour. The effective treatment of autistic children must be delivered within a framework that is necessarily constrained by the resources available and the need to allocate those resources equitably in response to competing demands. ... While the Government’s programmes and policies are subject to review by the Courts to

ensure constitutional compliance, the judiciary cannot dictate what treatment programmes should or should not be implemented, nor can it dictate how limited financial resources should be allocated. It is not the role of the Courts to undertake the nature and degree of supervision of the delivery of Early IBI treatment suggested by the petitioners. An overly robust judicial approach may interfere with legitimate policy making choices.<sup>xxvi</sup>

This shows that, while the government bears constitutional obligations that the courts will require to be observed, there are constitutional limits on the powers that courts of law can exercise.

## 5.5 Decisions of Other Courts

Decisions of other courts offer little guidance on how Canadian courts of authority, meaning courts above the trial court level, are likely to resolve claims for provincial funding of services for autistic children. An August 1998 preliminary ruling of the Saskatchewan Court of Queen's Bench declined the governmental defendant's request to strike out the plaintiff's statement of claim for disclosing no reasonable cause of action because, although the statement was overly vague and lacked significant details, it had been amended to raise Charter issues.<sup>xxvii</sup> The *Eldridge* decision made Charter issues plausible, and, although they were undeveloped in the amended statement of claim, the judge considered that an opportunity for their elaboration by argument and evidence should be preserved. The judge observed that

[w]hile the defendants in the case at bar do not deny the plaintiffs' statutory right to appropriate educational service, the effect of *Eldridge* is to elevate this statutory right to a constitutional entitlement. The distinction is highly significant in the context of the defendants' central contention, that the quality of educational services provided is, by statute, a matter of discretion which ... is accorded to the Minister, and, in relation to specific programming, is accorded to local school boards.<sup>xxviii</sup>

Dismissing the preliminary motion to strike out the proceedings, the judge ruled that, in light of the Charter, there could be a genuine issue to be resolved in a trial.

No Charter issues were raised at a trial decided in July, 2000 in the Ontario Superior Court of Justice in which a guardian of an autistic adult requested judicial review of a refusal by the provincial Ministry of Community and Social Services to grant additional funds for residential placement.<sup>xxix</sup> The case centred on details of provincial legislation and technicalities of the Court's review jurisdiction. On wider issues, however, the judge reflected on the background law and observed that:

Similarly in the case at bar, the Ministry's funding decision is a question of allocation of scarce resources among the developmentally handicapped persons in the region. It is not a decision which is amenable to judicial review. Therefore the claim for declaratory relief must be dismissed.<sup>xxx</sup>

The judge added that:

In my view "lack of resources available" is an appropriate reason to refuse an increase in funding under the Developmental Services Act as is a decision based on doubt as to



whether the plan is working as expected. There is a difference between looking at a decision as to whether it is in keeping with the statutory purpose of the statute under which it is made and reviewing the reasonableness of the decision. The latter is not a function of a court on an application for judicial review.<sup>xxx1</sup>

It is interesting to speculate whether the Court might have moved beyond its conventional deference to administrative discretion, and become more engaged with the merits of the case, had the claim raised the Charter issue of discrimination, and thereby achieved the constitutional significance that kept the 1998 Saskatchewan action viable.

The considerable volume of case law in the U.S. concerning parental claims to funding of services for their autistic children may include cases of precedential authority in the U.S., but has little if any influence on Canadian courts. The claims turn on U.S. federal and state legislation and regulations, particularly under the federal Individuals with Disabilities Education Act, the Americans with Disabilities Act and the Rehabilitation Act. These enactments fit within the distinctive U.S. constitutional framework and tradition of adjudication, but have no equivalent in Canada. Further, governmental funding of health care, educational and social services in the U.S. is so different from that in Canada that none of the Canadian cases has benefitted from or been relevantly influenced by the U.S. experience. The volume of U.S. litigation in contrast to the paucity of Canadian cases also reflects the different approaches to due process in administrative decision-making, and the different traditions between the countries on costs rules in litigation. Canadian courts follow the principle that unsuccessful claimants may be required to repay part at least of the legal costs of successful defendants, while parents who are unsuccessful litigants in the U.S. will not be required to pay defendants' costs, nor their own lawyers who act on a contingency fee basis.

Canadian courts have tended to be much more responsive to judgments of high courts in the United Kingdom, but these have provided no relevant guidance on funding of services for autistic children. Judicial decisions under the Disability Discrimination Act 1995, for instance, have provided no clear leadership, because of recognition that “[t]he State’s duty ... is owed equally to all individuals within its community and thus it cannot legitimately promote one person’s rights at the expense of another’s.”<sup>xxxii</sup> On the contrary, the U.K. legal systems have lagged behind Canadian law on implementation of such rights as are contained in the Charter. From October 2000, however, the U.K. Human Rights Act 1998 has been in force, and this may introduce into U.K. jurisprudence the type of reasoning developed by the Supreme Court of Canada since 1982. A recent U.K. commentator has observed that:

[g]iven the English judiciary’s reluctance to consider the merits of resource allocation decisions it is likely that scarce resources will be considered a justifiable constraint on the State’s positive duty. However, under the Human Rights Act, these resource allocation decisions will need to be more transparent and the judiciary should look at both the process and, more importantly, the merits of the decision. This should make it easier for plaintiffs to challenge these decisions.<sup>xxxiii</sup>

If this proves correct, laws in the U.K. and Canada on rights to treatment for autistic children may become more interactive and cross-fertilizing. At present, however, it may be that the U.K.

courts have more to learn on judicial containment of administrative discrimination from the Canadian courts than vice versa.

- i See generally K. Cherniawsky, "Enforcement of Health Care Rights and Administrative Law" 4 *Health Law Journal* (1996) 35-61.
- ii (1997), 151 D.L.R. (4<sup>th</sup>) 577 (Sup. Ct. Can.).
- iii *Cameron v. Nova Scotia (Attorney General)* (1999), 177 D.L.R. (4<sup>th</sup>) 611 at p. 667 (Nova Scotia Ct. of Appeal).
- iv *Ibid.*
- v [1989] 1 S.C.R. 143, at pp. 174-5 (Sup. Ct. Can.).
- vi *Stoffman v. Vancouver General Hospital* (1990), 76 D.L.R. (4<sup>th</sup>) 700, (Sup. Ct. Can.).
- vii Note iii above, at p. 668.
- viii (1996), 43 Alta. L.R. (3d) 179 (Q.B.), September 4, 1996.
- ix Indexed as *N. (D.J.) v. Alberta (Child Welfare Appeal Panel)* (1999), 76 Alta. L.R. (3d) 69 (Q.B.), July 15, 1999.
- x *Ibid.* at p. 81.
- xi Note iii above.
- xii (1996), 140 D.L.R. (4<sup>th</sup>) 385 (Sup. Ct. Can.).
- xiii (2000) 78 B.C.L.R. (3d) 55 (B.C. Sup. Ct.).
- xiv *Ibid.* at p. 80.
- xv [1999] 3 S.C.R. 868 (Sup. Ct. Can.).
- xvi *Ibid.* at para. 41.
- xvii Note xiii above, at p. 67.
- xviii *Auton (Guardian ad litem of) v. British Columbia (Attorney-General)* (2001), 84 B.C.L.R. (3d) 259 (B.C. Sup. Ct.).
- xix *Ibid.* at p. 268.
- xx *Ibid.* at p. 275.
- xxi Note ii above, at p. 588.
- xxii Note xiii above, at p. 56.
- xxiii *Ibid.* at p. 61.
- xxiv McLachlin J. (as she then was), note xv above, at para. 41.
- xxv Note ii above, at p. 628.
- xxvi *Ibid.* at p. 268.

- xxvii *Concerned Parents for Children with Learning Disabilities Inc. v. Saskatchewan (Minister of Education)*, (1998), 170 Sask. R. 200 (Q.B.).
- xxviii *Ibid.* at p. 220.
- xxix *Shah v. Ontario*, [2000] O.J. No. 2843, Court File No. 00/1128.
- xxx *Ibid.* at para. 15.
- xxxi *Ibid.* at para. 18.
- xxxii A.R. Maclean, “The Human Rights Act 1998 and the Individual’s Right to Treatment,” 4 *Medical Law International* (2000), 245-276 at p. 254.
- xxxiii *Ibid.* at p. 261.

## 6. EVOLUTION OF SERVICES IN CANADA

In addition to advances in scientific knowledge, advances in government policy have shaped the care of children with autism in Canada. The first influence to profoundly change the care of children with autism was the introduction of universal healthcare to Canada. The public health care system was designed to provide comprehensive, accessible and universally available medical services to all citizens regardless of income. This arrangement ensured that all Canadian families with an autistic child, regardless of income, had access to diagnostic and treatment services.<sup>8</sup> Currently, however, this aim is tested in the length of time required for assessment and treatment services.

The second major influence to affect service provision to children with autism was a shift in the development of treatment programs from general psychiatric hospitals to community mental health clinics. While diagnostic and assessment services generally occurred in a children's hospital with the assistance of paediatricians and child psychiatrists, treatment programs often took place in community settings or schools. Few hospital-based treatment centres provided residential or day programs; instead, large, rural-based institutions were established to service developmentally disabled children and adults. As a result of recent changes, many of these institutions have closed or provide service for fewer severely disabled adults whose needs cannot be met in a community setting.<sup>8</sup> There may be a lack of synchronization between educators and health professionals in identifying and assessing and meeting the needs of a child. Because provincial systems of health and education vary regarding provision of these services, there are often impediments in the systematic identification of need, diagnosis, related assessment and effective treatment and program delivery.

The third major influence to affect the delivery of services for children with autism was the emphasis on integration of disabled children within community settings. Parent organizations have played an influential role throughout these developments. Emphasis on integration has arisen, in part, from a shift in the use of hospital-based residential services, advocacy movements and developments in integration by school boards. Many school boards across Canada have taken an active role in integrating developmentally delayed children into the regular school system with the assistance of specialized support services. However, the resources necessary to sustain the integration of children with autism appear to be diminishing in some jurisdictions.<sup>8</sup> Many students with autism and related conditions in Canada do not have a comprehensive education plan comparable to those used in autism treatment programs. A number of families are using home-based schooling as a means of assisting a child with autism spectrum disorder. However, there are challenges in accessing specialized services, such as speech therapy, for students with autism when receiving their education in a home-based setting.

Once a child has an identified need for special education and related services, evaluations are conducted in all developmental domains. Children with special needs are issued a written individualized educational program that includes statements of: the child's current levels of performance; annual educational goals and measurable short-term instructional objectives; the specific kind and amount of educational services to be provided to the child, and; the extent to which the child will participate in regular educational programs and needed transitional services.

In a qualitative research study to compare segregated and inclusive schooling in 22 schools in two different local educational authorities in London, England, difficulties associated with diagnosing autism were noted.<sup>82</sup> It is not clear what the unique educational difficulties associated with autism spectrum disorder are, the specific educational expertise pupils with autism require, precisely what unique needs they have in common to justify separate provision, and how any benefits offered justify financial, educational, emotional and social costs.<sup>82</sup> Autistic tendencies of isolation and self-absorption are more noticeable in the segregated education system.<sup>82</sup>

The fourth key influence on service provision to children with autism was the evolution of the classification system for diagnosis. The primary purpose of classification is to enhance communication and allow disorders to be differentiated in significant ways, however, classification may exclude some children with co-morbid diseases. For clinicians and educators, classification may guide the selection and assist with the evaluation of an intervention for individuals with shared characteristics. For the legal system, government regulation, insurance programs and advocates, classification defines individuals with special entitlements. In order to be effective in varied domains, classification must be clear, broadly accepted, and relatively easy to use.<sup>8</sup> With the introduction of the DSM-III in 1980, specific diagnostic criteria for autism were available for easy application but may have resulted in a late average age for diagnosis. In addition, PDD was introduced to identify a spectrum of conditions with similar characteristics. The number of children diagnosed with autism increased and little distinction was made between autism and PDD in terms of access to services.

With the broadening of the criteria for diagnosis of autism with the DSM-III-R in 1987, the number of children diagnosed with autism increased substantially as did those who received a diagnosis of PDD-NOS. However, these children were often classified under the diagnostic category as having a PDD, and autism and PDD were perceived as mutually exclusive terms by lay and professional bodies. This confusion may have improved with the publication of the DSM-IV in 1994. As a result of these numerous changes in criteria for diagnosis and classification there has been a substantial increase in the number of children with classical autism, autistic spectrum disorder and other forms of PDD. There is greater awareness of the disorder among service providers. The demand for services for children with PDD has grown but available treatment centres are facing critical difficulties meeting this increasing demand.<sup>8</sup>

Since diagnostic systems lose their value if they evolve to become either too broad or narrow, a fine balance is required. The limitations of behavioural classification of medical conditions have been recognized by the scientific community, which are now conducting research to identify and clarify specific medical indicators of autism and related conditions. Conflicts may arise between clinical needs for classification and the impact of definitions on policy. For example, narrowly defined categorical diagnosis may be of benefit to researchers and clinicians to facilitate the selection and assessment of interventions and the sharing of knowledge between investigators. A broader diagnostic concept, however, may be most appropriate in terms of service provision. Classification systems may have important implications in terms of legal mandates for services that can result in an inappropriate emphasis on the diagnostic label rather than the process of diagnosis. Categorical diagnosis may be misused when there is potential for stigmatisation, confusion between the person and the diagnostic label, or used to obscure a lack of knowledge.<sup>8</sup>

In selecting interventions and treatments for children with autism it is important to consider what outcomes are anticipated from the program option; the potential risks associated with the program; how the program will be evaluated; what evidence is available regarding program effectiveness, and what other program options would be excluded if this option was chosen.<sup>83</sup>

In Canada, several initiatives are underway to provide treatment services and support to children with autism and their families. Pilot projects to explore the implementation of intensive early behavioural intervention based on previously demonstrated success-based characteristics for children with autism spectrum disorder are under development to varying degrees in several provinces. Only some pilot projects are using ABA or behaviourally based interventions. Advantages associated with IBI include the ability to monitor progress for program evaluation and planning purposes; application across a variety of settings, situations and therapists; parental involvement and training, and the ability to combine behavioural interventions with other methods. The limitations associated with intensive behavioural programs include the need for several well-trained individuals to administer the intervention; the high degree of coordination and consistency required among individuals administering the therapy and demands in time and cost to deliver therapy. The direct costs for an IBI program are dependent primarily on the cost of staff time required by professionals and coordinators and for materials and facilities for centre-based programs. Additional direct costs include service providers from various disciplines, including: occupational therapy; speech, language and communication therapy; child psychology; specialized educators; family support professionals, child psychiatrists and other medical professionals. The indirect costs for a program include time spent by family members in participating in the intervention program.

In November 2000, CAIRN held a forum at the Sunnybrook Hospital in Toronto to assist in developing a research agenda for early intervention. Focus groups were held involving community representatives from parent groups, clinicians, experts, researchers and policy makers in order to identify the gaps in existing evidence and to formulate these gaps into workable research questions. While randomised controlled trials are the gold standard of design for studies, it is difficult to maintain control conditions when evaluating behavioural interventions especially when there are large differences in outcome within experimental groups and success is highly dependent on context. A need has been identified for research into all aspects of autism and related conditions along with international communication and collaboration to maximize research knowledge, prevent non-organized duplication, increase discovery, make better use of research data and materials, and provide controlled replication of studies.

Characteristics leading to the success of an early intervention program in the community include: equity; high intensity; practicality and evidence base with measurable outcomes by blinded evaluators; parental involvement that is community and interdisciplinary integrated with professionally trained staff with ongoing training and supervision. National standards regarding identification and service delivery may facilitate provision of appropriate intervention to those who need it. It was recommended that ABA programming be directed by a qualified behaviour analyst. Autism treatment professionals' organization and system of accreditation can indicate the calibre of professionals in a particular autism treatment genre. ABA professionals can pursue degrees in behaviour studies to the Doctoral level. In the United States, there is national certification of therapists where behavioural analysis is grouped under behavioural psychology

by the American Psychological Association. Group discussion resulted in the following priorities for action: earlier diagnosis; intervention for children diagnosed with autism; provision of a continuum of services with communication between service providers; provincial sharing of previously demonstrated success-based characteristics; raising awareness in the community and more focussed research to answer the question of how much of which intervention works best in which subset of children with autism (CAIRN Forum, Sunnybrook Hospital, Toronto: personal notes, 2000 Nov12). Tenets of best practice include: individualized intervention approaches to match a child's developmental level and learning style; intervention based on current knowledge of child development; intervention that directly addresses the core characteristics of autistic spectrum disorder; approaches that demonstrate a logical consistency between long-term goals and teaching protocols, and approaches derived from a range of sources.<sup>48</sup>

Systems issues in the treatment of children with autism include a broad range of concerns including: systems delivery models and issues related to cost of service, implementation of intervention and training; integration of interventions; provision of treatment to those who need it within the confines of resources; cost and cost-benefit analyses; education of professionals in the area and gaps between research and practice.<sup>84</sup> Considerations for administrators in the design of service options for children with autism include quality inclusion of children with autism to interact with typical age-peers; careful planning, execution and evaluation of children with autism; a level of intervention that matches individual needs; service delivery across different contexts; a scope and sequence of instruction that covers all areas of developmental needs; intervention service provision as early as possible and the management of challenging behaviour through positive, proactive strategies.<sup>85</sup> There is a need for continuous evolution in policy and programming as new evidence develops based on outcome evaluation of current programs (CAIRN Forum, Sunnybrook Hospital, Toronto: personal notes, 2000 Nov12).<sup>86</sup>

## 7. DISCUSSION

In interpreting the findings of this report, it is worth noting that while autism remains behaviourally based, the diagnostic classification and criteria for autism have changed over time.<sup>13,14</sup> Additional validation of the diagnostic instruments, rating scales and checklists has been suggested in order to assess their sensitivity and specificity across populations.<sup>16</sup>

Three groups have published a summary of recommendations as guidelines for implementation of behavioural intervention programs based on clinical opinion and experience.<sup>18,41,63</sup> These groups were discussed in subsection 4.1 of this paper. The working groups recommend that programs be founded on current research and effective practices; inclusive of a variety of methods and approaches consistently applied in a variety of settings; based on comprehensive assessment results; determined by a multidisciplinary team; reflective of an individual's needs; outcome based; provided by trained personnel, inclusive of entrance and exit criteria and; based on an integration of health and education programs, with continuity from pre-school to school and home programming.

Based primarily on expert opinion and experience independent panels of professionals and parents recommend that principles of ABA and behavioural strategies be included in any intervention program for young children with autism.<sup>18,63</sup> It was recommended that intensive behaviour programs include a minimum of approximately 20 hours per week of individualized behavioural intervention using ABA techniques. However, the precise number of hours would be determined on an individualized basis depending on child and family characteristics, including age, severity of symptoms, rate of progress, other health considerations, tolerance for the intervention, and family participation. It was recommended that the number of hours of IBI be periodically reviewed and revised while monitoring the child's progress and that the intervention plan be revised according to the child's progress. Parent involvement and training is important to ensure that the behavioural outcomes, goals and strategies most important to the family are incorporated in the intervention and behavioural techniques are incorporated into daily routines of the child.<sup>18,63</sup> Based on a study by Jacobson, Mulick & Green (1996), the Maine Administrators of Services for Children with Disabilities suggested that competently-delivered, early, IBI can offer unprecedented gains for children and taxpayers, quoting an estimated savings per child to age 22 years of US \$200,000; to age 55 years, US \$1,000,000.<sup>41</sup>

Five previously conducted assessments or critical reviews involving behavioural interventions for children with autism were identified:

### **1. L'Agence Nationale d'Accreditation d'Evaluation en Sante (ANAES)**

ANAES evaluated medical treatments and behavioural and educational programs for autism in 1994.<sup>64</sup> The review of behavioural therapies suggested that the symptoms associated with autism are ameliorated by IBI, but a certain level of intensity is required for therapy to be effective.<sup>64</sup>

### **2. Emergency Care Research Institute (ECRI)**

ECRI reviewed comprehensive treatment approaches that attempt to simultaneously address most or all of the symptoms that characterize autism.<sup>51</sup> Assessed behavioural approaches, all emphasizing early intervention, included Lovaas, Rutgers Autism Program, LEAP, and Autism Preschool Program. The Lovaas analysis provided evidence that improvements occurred in



functional parameters, including a reduction in maladaptive behaviours, severity of symptoms and an increase in socialization. However, ECRI emphasized that the available evidence is only suggestive of treatment effectiveness. ECRI concluded that based on fatal flaws in study design, the results of the study of the Rutgers Autism Program could not be interpreted in terms of effectiveness. ECRI concluded that the small sample size, and confounding effects of maturation, and poor generalizability of the children included in the study to the general population of children with autism precludes the use of the LEAP study in determining effectiveness. ECRI did conclude that language development in the treatment group receiving the Autism Preschool Program showed significant improvement compared to the control group.

### **3. British Columbia Office of Health Technology Assessment (BCOHTA)**

BCOHTA published a critical appraisal of the effectiveness of Lovaas therapy in July 2000.<sup>67</sup> Based on critical appraisal, BCOHTA concluded that while many forms of behavioural therapy clearly benefit children with autism, there is insufficient scientifically valid effectiveness evidence to establish a causal relationship between a particular program of intensive behavioural treatment and the achievement of normal functioning. This outcome measure may not be appropriate for this population, as most children with autism do not achieve normal functioning. BCOHTA's primary concern regarding the Lovaas study was that without randomization, one cannot tell whether or not the number of children achieving normal functioning is due to selection bias by possibly selecting higher functioning children for the 40 hour intervention group.<sup>67</sup>

### **4. Smith**

A review by Smith<sup>68</sup> suggested that the most favourable outcomes occurred in programs that provide the most intensive services. No further clear correlations were evident among treatment intensity, treatment model and outcome.

### **5. Alberta Heritage Foundation for Medical Research (AHFMR)**

An information paper by AHFMR suggests that while children that receive behavioural intervention exhibit functional improvement, it is not clear that any single program is more effective than another.<sup>69</sup> The most common outcome measure included in the studies was that of IQ; however, social interaction and communication are also important outcome measures for assessment.

Reviews in the area suggest that most primary studies regarding the efficacy of behavioural intervention have methodological flaws that make interpretation of results difficult. Study design in this area could benefit from the inclusion of an adequate control group and the application of a consistent outcome measure used for all children enrolled in a study, administered by the same, blinded assessor at the beginning and end of the study. Evidence is limited, for example, the application of ABA for a relatively short period of time followed by observation of school performance. Though limited, existing study findings suggest that preschool children with autism receiving behavioural intervention exhibit cognitive and functional improvement. It is not clear, however, which subset of children with autism derive the most benefit, which components of therapy are integral to positive outcomes, whether similar results would be observed in older children with autism, whether there are definable long term functional benefits, or whether reported gains in IQ translate into happier people with greater

function in the community. Little guidance is provided regarding cessation or modulation of the level of intensity for behavioural therapy.

Generally, research on IBI is weak regarding documentation of responder characteristics. The majority of children diagnosed with autism meet criteria for some degree of mental retardation, which lends importance to performing some form of pre-treatment measure of IQ. However, pre-treatment IQ is not consistently measured in the studies that have been conducted based on the assumption that initial IQ cannot be validly measured. Proxy measures can be found in exploration, play and language in the child not amenable to direct formal assessment. Whether the changes in IQ scores observed in the first few months of early intensive behavioural intervention can be regarded as amelioration of IQ deficits, or whether changes in compliance and attention attribute to increases in instructional control make the child more amenable to direct formal assessment of valid IQ. If this is the case, perhaps further research needs take into consideration multiple baselines for IQ if IQ is to be studied as a pre-treatment measure.

Measures like the development of verbal imitation in the initial months of early IBI may be of assistance in predicting later outcome, as may observational measures such as developmental level of play and curiosity, diagnosis of PDD versus autistic disorder, and scores of autism symptom severity measures. Co-morbidity of disorders other than mental retardation, especially motor and sensory handicaps, is likely to affect the outcome of behavioural intervention and should be considered in research designs to examine pre-treatment responder characteristics. The information regarding the correspondence of pre-treatment responder characteristics and successful candidate characteristics would be useful to clinicians challenged with resource and case management for behavioural intervention. While no firm conclusion regarding which types of interventions work best for different children, such issues could be addressed by meta-analysis if researchers used similar methods to characterize individual differences in children and to quantify progress.<sup>50</sup> Empirical designs that take into consideration the inclusion of appropriate control groups; well-chosen, well-specified populations; comprehensive assessment of study populations; appropriately randomised assignment or matching of research participants; assessment of the accuracy of implementation of the intervention and the assessment measurable, meaningful outcomes will provide more meaningful insight into the effectiveness of interventions.<sup>87</sup> It may not be possible to address all of these research issues ethically in a trial.

A concern regarding the interpretation of any outcome research on early IBI is that of characterizing the intervention itself. Not all behavioural interventions use ABA methods and one must be aware of the basis of each individual program before making comparisons. To characterize the intervention adequately, two main components of early IBI, methodology and curriculum content, need to be considered separately. Under methodology, consideration would be given as to the use of discrete trials, the types of reinforcement strategies, the amount of intervention, individualization of the intervention and the site at which the intervention took place. Consideration would be given to whether the curriculum focuses on development of learning readiness skills such as compliance, attention or imitation; teaching of receptive language, teaching of expressive language, non-verbal problem-solving, and whether the material taught is developmentally-taxonimized or empirically-selected. Any of these methodological or curriculum content measures may mediate overall outcome. Representative measures of these variables need development within an outcomes research model in order to identify key factors of therapy.

Program fidelity is likely to be affected by variables such as the level of training and supervision of those carrying out the treatment. The demand for service has resulted in a range of individuals, from those with certification in applied behavioural analysis to those recruited from outside the area, providing therapy that lends variation in program fidelity as a function of the service providers.

Several initiatives, at different stages of development, are underway in Canada to provide treatment services and support to children with autism and their families. Pilot projects to explore the implementation of intensive early behavioural intervention for children with autism spectrum disorders are underway or under development in the provinces of Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Newfoundland, Nova Scotia and Prince Edward Island.

A new provincial program is a joint effort by the Ministries of Education, Health, and Children and Families in British Columbia. The Program is designed to provide effective early IBI based on scientific research and previously demonstrated success-based characteristics for children with autism below six years of age. Community-based, the Program will provide services, including a minimum of 20 hours per week of early intensive behavioural intervention. The Program aspires to provide therapy to all autistic children below six years of age, who have been diagnosed and assessed by a multi-disciplinary team, in 2003.<sup>71</sup> A Co-ordinating Centre for the Program will provide links between diagnosis and assessment; treatment intervention and implementation for community based programs; training, and research and evaluation.

In the province of Alberta, Handicapped Children's Services will provide funding to assist with the cost of individual intensive behavioural intervention programs as early intervention only for children with a confirmed diagnosis of autism, PDD, PDD-NOS, or atypical autism as made by a medical practitioner in Alberta. However, there are difficulties in diagnosing autism spectrum disorder and efforts are underway to create a greater awareness regarding the signs and symptoms of autism. A maximum of 40 hours of one-to-one IBI per week inclusive of all funding sources, may be provided to preschool children<sup>72</sup> The pilot study in Saskatchewan is in its first year and is currently serving a second group of four children with autism.<sup>75</sup>

The province of Manitoba, Department of Family Services funds an ABA pilot project through the Healthy Child Initiative. The project serves approximately 15 preschool and school aged children. The St. Amant Centre and Manitoba Families for Effective Autism Treatment make key decisions about the implementation of the project jointly through a Working Committee.<sup>76</sup> In Ontario, a new program funded by the Ministry for Community Social Services (MCSS) is underway. Nine agencies have been chosen to deliver behavioural interventions, based on best practice, to children in Ontario two to five years of age with a clinical assessment of severe autism. Regional programs provide between 20 to 40 hours per week of IBI based on the clinical assessment to determine what is most appropriate for the child.<sup>88</sup>

In the province of Quebec pilot projects are underway regarding both Lovaas therapy and TEACCH.<sup>78</sup> The Department of Health and Community Services, Government of Newfoundland and Labrador, offers a two-year pilot project for 20 children aged 18-42 months and 15 children aged 43-60 months with a diagnosis of autism/PDD. The pilot involves one parent implemented, cognitive developmental treatment group and an intensive discrete trial treatment group.<sup>79</sup>

The Early Identification and Intervention Services Sub-committee (EISS) recently prepared a model for enhancing services for children under six years of age with special needs for the Nova Scotia Children and Youth Action Committee (CAYAC) Deputy Ministers.<sup>80</sup> A pilot study involving three preschool children is being conducted through Mount St. Vincent University, based on a variety of teaching strategies as recommended by the Bancroft and May Institutes in the United States.

The province of PEI recently started the Autism Integration Project, jointly sponsored by the Paediatric Clinic of the Queen Elizabeth Hospital, Charlottetown, PEI, and the Child, Family and Community Services Division of the PEI Department of Health and Social Services.<sup>81</sup> The Departments of Health and Social Services and Education are partnering with the PEI Autism Society to complete a business plan to assess the feasibility of establishing a Behaviour Based Training Institute for PEI. The Department of Health and Social Services is currently funding visits to PEI for consultants from Bancroft Neuro Health in New Jersey.<sup>81</sup>

While there are no formal organizations trained to provide applied behavioural analysis in New Brunswick, children with autism have access to services such as speech language pathology, occupational therapy, and psychological counselling through the same programs that children with other disabilities access services. There do not appear to be any specific behavioural therapy programs for children with autism living in Yukon. The Government of the Northwest Territories does not have any specific programs dedicated for persons with autism; however, individualized service is provided through access to a variety of government and non-government programs. There are no specific autism services available in Nunavut. Department of Health Services offers access to medical assessments and support services as required. Where further services are required, referral to placement out of Nunavut is made.

Most Canadian programs used by children with autism have not been subject to objective evaluation or reviewed for therapeutic efficacy. Many programs in Canada are beginning to retrieve this data. An important issue regarding pilot studies is whether data should be collected from ongoing pilots that can be later used to determine continuation criteria. Having an ongoing measure of what constitutes treatment is essential to meaningful interpretation of outcome research. Assuming that pilot programs are of a described and assured fidelity, it is important to consider whether post-hoc analysis of interim outcome measures from these pilots can serve as early outcome predictors for those who can be classified as high, medium, and low responders to behavioural intervention at the end of a defined treatment period.

This approach was taken in the state of California following development of an early IBI decision-tree as part of the California autism task force efforts. The decision-tree was based on three-monthly description of milestones in behavioural intervention curriculum objective that could be expected following inception of an early IBI in children who would be considered high responders. Children showing a weak response to behavioural intervention would be tried on other treatments if progress was not better than expected for growth based on initial developmental level or degree of mental retardation. The decision tree continues to be used by some schools as a means of developing a contract with parents for on-going support or discontinuation of behavioural intervention based on the child's demonstrated ability to respond to therapy.

Dynamic reassessment of on-going early IBI programs serves three purposes. Reassessment serves as a quality assurance that the therapy is actually as it was intended, an assurance that the quality of the therapy remains consistent over time, and if there are repeated measures of child responses, measures that can be used to predict later outcome, and are useful in re-evaluating the on-going appropriateness of the therapy. While only one pilot project, underway in the province of Quebec, was aimed at undertaking a comparison of treatment methods measuring treatment fidelity and responder characteristics, this would be an important consideration regarding study design and development. It is important to consider other treatments, as they, under various conditions may be equally effective but less costly and allow receipt of therapy by a greater number of children. Other factors such as parent training, informal teaching experience, overall hours of treatment, amounts of one-to-one teaching, and developmental appropriateness of curriculum need consideration when comparing methodologies in any program evaluation.

While there are no published direct comparison studies of the therapeutic effectiveness of different programs, effort has been made to combine information across programs to provide a general view of the overall progress of 150 children who received early intervention through eight early intervention programs.<sup>50</sup> It was concluded that, despite the diversity in intervention strategies and philosophical approaches, all programs were effective in fostering positive school placements. Most children participating in the programs had some level of mental retardation at the beginning of the intervention and approximately half of the children made cognitive gains. To date, no studies have been conducted with entirely random assignment to different intervention groups and outcome assessment conducted by people blinded to intervention status. Common elements of the early intervention programs reviewed in this study included: curriculum content emphasizing skill domains; highly supportive teaching environments and generalization strategies; predictability and routine; a functional approach to problem behaviours; transition from the preschool classroom, and family involvement.<sup>50</sup> All but one of the eight programs for children with autism in the United States involved at least 20 hours per week of school-based intervention. However, it is not possible to define from these data what the sufficient number of hours per week of intervention are required for a positive outcome.

Canadian judgments in cases of parents claiming appropriate treatment for autistic children have not yet reached a level constituting legal precedent in any province. In a legal case in British Columbia, where parents have sought funding for therapy for their children with autism, a proposed model of early intervention was accepted as an effective treatment for autism spectrum disorder for children below six years of age. Decisions made in other jurisdictions offer little guidance on how Canadian courts of authority are likely to resolve claims for provincial funding of services.

In addition to advances in scientific knowledge, advances in governmental policy have shaped the care of children with autism in Canada. Delivery of services to children with autism have been influenced by the introduction of universal healthcare to Canada, the shift to community-based programming and integration as well as the evolution of the classification system designed to enhance communication and allow differentiation of disorders in significant ways. There is a need for continuous evolution in policy and programming as new evidence develops based on the results of current pilot projects and newly developed programs.

While autism can be recognized accurately by or before the age of three, autism often remains unrecognized and undiagnosed until or after late preschool age. Efforts are now underway to increase awareness of the early signs of the disorder and to strive towards earlier accurate diagnosis. There is a need for timely access to assessment and training of personnel both in the diagnosis of autism and the provision of early intervention. Early diagnosis and early intervention facilitates educational planning, provision for family supports and education, management of family stress and the delivery of appropriate medical care and treatment. If many children are not identified until five to six years of age or later, the prevalence of autism in the preschool population will appear to be lower than the actual prevalence. Controversy exists as to whether the higher rates reflect a real increase in prevalence and/or changes over time in diagnostic criteria for autism as well as greater awareness of the variability in expression of the disorder. Comparative studies conducted within the same regions in which the same methods of ascertainment and the same diagnostic criteria are used at different points in time may be helpful in answering this question. Autism seems to be associated with environmental factors interacting with a genetic predisposition, as yet unidentified broadly as autistic syndrome. Further epidemiological research is needed to investigate the etiology of this disorder. If causation cannot be found there will be cost implications both for the departments of health and education, for treatment to begin in the very young for every child who exhibits autistic characteristics.

Standard measures for assessment, evaluation of progress, and long term functional outcomes are required in future study design in order to gather more reliable evidence regarding therapeutic effectiveness, and to assist in the planning of individualized treatment programs aimed at more successful outcomes. Criteria are needed regarding program entry, evaluation, intensity and duration of therapy. It is important for policy makers, program developers and clinical researchers to consider the identification of pre-treatment characteristics of those receiving treatment, the measurement of treatment fidelity, on-going progress in treatment to determine whether treatment is or continues to be of benefit, and the comparative value of early intensive behavioural treatment compared to other early interventions for autism.

## 8. CONCLUSIONS

The heterogeneity associated with autism may explain the variability in the effectiveness of therapies. While early identification and early behavioural intervention are important factors in effective treatment, specific components of treatment may be more suitable for children with specific characteristics. Certain communication deficits may be more or less responsive to certain behavioural procedures.<sup>8</sup> The heterogeneity associated with autism leads to the practical difficulty of implementing programs and communicating the varying needs for service to families of these children. Although individualized case management and programming would be ideal, implementation can prove challenging.

It is important for policy makers, program developers and clinical researchers to consider identifying pre-treatment characteristics of those receiving treatment, measuring treatment fidelity, evaluating ongoing progress in treatment to determine whether therapy is or continues to be of benefit, and comparing the value of early IBI to other early interventions for autism.

The field of behavioural intervention faces challenges in proving therapeutic effectiveness through methodologically sound science; the development of procedures that are acceptable to practitioners and society; and accurate, clear, broad dissemination of information about this therapy to those who need it. Aims for further research include:

- the use of standard measures for assessing progress and research designs;
- an independent evaluation of progress and programs;
- the comparison of therapies using sound study design;
- parental participation in therapy and focussed research to define which therapy at what level of intensity works best for which subset of children with autism.

Study design in this field could benefit from the use of an adequate control group, a consistent outcome measure used for all children enrolled in a study administered by the same, blinded assessor at the beginning and end of the study, and exploration of the determinants of long term functional outcomes.

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## APPENDIX I: DIAGNOSTIC CRITERIA

**Table 1: DSM-IV Diagnostic Criteria for Autistic Disorder**

A diagnosis of autism is based on the presence of a total of six or more items from criterions 1, 2, and 3, with at least two from criterion 1 and one each from criterions 2 and 3.	
Criterion 1 (n ≥ 2)	Qualitative impairment in social interaction: <ul style="list-style-type: none"> <li>a) Marked impairment in the use of multiple nonverbal behaviours;</li> <li>b) Failure to develop peer relationships appropriate to developmental level;</li> <li>c) Lack of spontaneous seeking to share enjoyment and interests with others; and</li> <li>d) Lack of social or emotional reciprocity.</li> </ul>
Criterion 2 (n ≥ 1)	Qualitative impairments in communication: <ul style="list-style-type: none"> <li>a) Delayed or lack of development of spoken language;</li> <li>b) Marked impairment in the ability to initiate or sustain conversation with others;</li> <li>c) Stereotyped or repetitive use of language or idiosyncratic language; and</li> <li>d) Lack of varied, spontaneous make-believe or imitative play appropriate to developmental level.</li> </ul>
Criterion 3 (n ≥ 1)	Restricted, repetitive and stereotyped patterns of behaviour, interests and activities: <ul style="list-style-type: none"> <li>a) Preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in intensity or focus;</li> <li>b) Inflexible adherence to specific, non-functional routines or rituals;</li> <li>c) Stereotyped and repetitive motor mannerisms; and</li> <li>d) Persistent preoccupation with parts of objects.</li> </ul>
Criterion 4 (n ≥ 1)	Delays or abnormal functioning in the following prior to age 3 years: <ul style="list-style-type: none"> <li>a) Social interaction;</li> <li>b) Language as used in social communication; and</li> <li>c) Symbolic or imaginative play.</li> </ul>
Criterion 5	The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

Adapted from DSM-IV.<sup>11</sup>

**Table 2: DSM-IV Diagnostic Criteria for Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)**

A diagnosis of PDD-NOS is based on the presence of criterion 1 or 2.	
Criterion 1	Severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills.
Criterion 2	Presence of stereotyped behaviour, interests and activities but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder or avoidant personality disorder This category includes atypical autism where presentations do not meet the criteria for autistic disorder due to late age at onset, atypical symptomatology, sub-threshold symptomatology, or all of these.

Adapted from DSM-IV.<sup>11</sup>

## APPENDIX II: DATABASES AND SEARCH STRATEGIES

DATABASES	LIMITS	KEYWORDS
DIALOG <i>OneSearch</i> <sup>®</sup>  EMBASE <sup>®</sup>	1995-2000	<p>autism!/de OR autism OR autistic OR asperger? OR kanner?</p> <p>AND</p> <p>psychotherapy!/de OR behavior?(w)therap? OR applied(w)behavior?(w)analys? OR ABA OR intensive(w)behavior?(w)intervention? OR IBI OR early(w)intervention? OR Iovaas? OR Rutgers(w)autism OR Princeton(w)child(w) development OR TEACCH OR Denver(w)model? OR LEAP OR autism(w)preschool OR auditory(w)integration OR facilitated(w)communication OR music(w)therap? OR daily(w)life(w)therap? OR higashi OR sensory(w)integration OR option(w)method? OR gentle(w)teaching OR doman(w)delacato(w)method? OR pyramid(w)approach? OR development?(w)individual(w)difference? OR DIR OR miller(w)method? OR greenspan</p> <p>AND</p> <p>clinical study!/de OR controlled study!/de OR evidence based medicine!/de OR random? OR double(w)blind? OR double(w)dumm? OR meta(w)analy? OR metaanaly? OR multicent?(w)stud? OR multi-cent?(w)stud? OR multicent(w)trial? OR multi-cent(w)trial? OR evaluat?(w) stud? OR compar?(w)stud? OR control?(w)stud? OR control?(w)trial? OR uncontrol?(w)stud? OR uncontrol?(w)trial? OR non-control?(w)stud? OR non-control?(w)trial? OR noncontrol?(w)stud? OR noncontrol?(w)trial? OR longitudinal(w)stud? OR follow-up(w)stud? OR observation?(w)stud? OR prospective(w)stud? OR retrospective(w)stud? OR cross-section?(w)stud? OR cohort? OR program?(w)evaluation? OR quantitative?(w)review? OR quantitative(w)overview? OR systematic(w)review? OR systematic(w)overview? OR methodologic?(w)review? OR methodologic?(w) overview? OR collaborative(w)review? OR collaborative(w)overview? OR integrative(w) research(w)review? OR integrative(w)research(w) overview? OR dt=review OR dt=short survey</p> <p>AND</p> <p>infant/de OR child/de OR preschool child/de OR infant OR infants OR toddler? OR child OR children OR preschool? OR pre-school?</p> <p>67 unique records</p>
ERIC		<p>autism/de</p> <p>AND</p> <p>early intervention/de OR special education/de OR special needs students/de OR psychotherapy/de OR behavior modification/de OR sensory integration/de OR social integration/de</p> <p>AND</p> <p>program evaluation/de</p> <p>AND</p> <p>Infants/de OR children/de OR preschool children/de OR toddlers/de</p>



DATABASES	LIMITS	KEYWORDS
		Same keywords as per EMBASE <sup>®</sup> 5 unique records
HealthSTAR <sup>®</sup> MEDLINE <sup>®</sup>		autistic disorder!/de OR asperger syndrome/de AND psychotherapy!/de OR early intervention (education)!/de AND program evaluation!/de OR evaluation studies!/de OR clinical trials!/de OR comparative study!/de OR epidemiologic research design!/de OR epidemiologic study characteristics!/de OR dt= review OR dt=meta- analysis OR dt=multicenter study OR dt=randomized controlled trial OR dt=clinical trial, phase II OR dt=clinical trial, phase III OR dt=clinical trial, phase IV OR dt=controlled clinical trial AND Infant/de OR Child, Preschool/de OR Child/de Same keywords as per EMBASE <sup>®</sup> MEDLINE <sup>®</sup> = 57 unique records HealthSTAR <sup>®</sup> = 0 unique records
PsycINFO <sup>®</sup>		autism/de OR early infantile autism/de OR autistic children/de OR aspergers syndrome/de AND early intervention/de OR special education/de OR special needs/de OR behavior therapy/de OR augmentative communication/de OR sensory integration/de OR social integration/de OR social skills training/de OR creative arts therapy!/de AND program evaluation/de OR educational program evaluation/de AND Infants/de OR children/de OR preschool age children/de OR preschool students/de Same keywords as per EMBASE <sup>®</sup> 13 unique records
Cinahl Information Systems CINAHLdirect <sup>®</sup>		autism! AND psychotherapy! OR early intervention, childhood! OR child development disorders/therapy AND program evaluation OR research studies! (non-cinahl) AND infant OR child OR child, preschool

DATABASES	LIMITS	KEYWORDS
<p>The Cochrane Collaboration &amp; Update Software Ltd.</p> <p>The Cochrane Library, Issue 4, 2000</p>		<p>43 records</p> <p>autism!/de OR asperger syndrome? OR autism OR autistic OR asperger? OR kanner?</p> <p>AND</p> <p>psychotherapy!/de OR early intervention (education)!/de OR behavior therap? OR behaviour therap? OR applied behavior analys? OR applied behaviour analys? OR ABA OR intensive behavio? intervention? OR IBI OR early intervention? OR Iovaas? OR Rutgers autis? OR Princeton child development OR TEACCH OR Denver model? OR LEAP/ti,ab OR Higashi/ti,ab OR autism preschool? OR auditory integration? OR facilitated communication? OR music therap? OR daily life therap? OR sensory integration? OR option method? OR gentle teaching? OR Doman Delacato? pyramid approach? OR development? individual difference? OR DIR/ti,ab OR Miller method? OR Greenspan/ti,ab</p> <p>AND</p> <p>infant!/de OR child/de OR child-preschool/de OR infant OR infants OR toddler? OR child OR children OR preschool? OR pre-school?</p> <p>The Cochrane Database of Systematic Reviews = 7;  The Database of Abstracts of Reviews of Effectiveness = 4 references;  The Cochrane Controlled Trials Register = 124 references; Health Technology Assessment Database = 1 abstract by INAHTA and other healthcare technology assessment agencies</p>
<p>DIALOG Alerts: Current Contents Search<sup>®</sup></p>	<p>weekly</p>	<p>Same strategy and keywords as per DIALOG OneSearch<sup>®</sup></p>
<p>EMBASE<sup>®</sup> Alert</p>	<p>weekly</p>	<p>autism!(l)therapy/de</p> <p>AND</p> <p>psychotherapy!/de</p> <p>AND</p> <p>clinical study!/de OR controlled study!/de OR evidence based medicine!/de OR dt=review OR dt=meta-analysis OR dt=multicenter study OR dt=randomized controlled trial OR dt=short survey</p> <p>AND</p> <p>infant/de OR child/de OR preschool child/de</p> <p>Same keywords as per DIALOG OneSearch<sup>®</sup></p>

DATABASES	LIMITS	KEYWORDS
ERIC	monthly	autism/de AND early intervention/de OR special education/de OR special needs students/de OR psychotherapy/de OR behavior modification/de OR sensory integration/de OR social integration/de AND program evaluation/de OR dt=controlled clinical trial OR dt=short survey AND infants/de OR children/de OR preschool children/de OR toddlers/de Same keywords as per DIALOG OneSearch®
MEDLINE®	weekly	autistic disorder!(1)therapy/de OR asperger syndrome(1)therapy/de AND psychotherapy!/de OR early intervention (education)!/de AND program evaluation!/de OR evaluation studies!/de OR clinical trials!/de OR comparative study!/de OR epidemiologic research design!/de OR epidemiologic study characteristics!/de OR dt=review OR dt=meta-analysis OR dt=multicenter study OR dt=randomized controlled trial OR dt=clinical trial, phase II OR dt=clinical trial, phase III OR dt=clinical trial, phase IV OR dt=controlled clinical trial AND infant/de OR child, preschool/de OR child/de Same keywords as per DIALOG OneSearch®
PsycINFO®	weekly	autism/de OR early infantile autism/de OR autistic children/de OR aspergers syndrome/de AND early intervention/de OR special education/de OR special needs/de OR behavior therapy/de OR augmentative communication/de OR sensory integration/de OR social integration/de OR social skills training/de OR creative arts therapy!/de AND program evaluation/de OR educational program evaluation/de AND infants/de OR children/de OR preschool age children/de OR preschool students/de Same keywords as per DIALOG OneSearch®

## APPENDIX III: SAMPLE LETTER OF REQUEST

December 23, 1999

Dr. John Doe  
President of National Organization/Association  
Organization/Association  
Street Address  
City, Province, Postal Code

Dear Dr. Doe,

The Canadian Coordinating Office for Health Technology Assessment (CCOHTA), established in 1989 by the federal, provincial and territorial governments, analyses, synthesizes, and distributes information on health technologies. Please refer to the attached annual report or our website ([www.ccohta.ca](http://www.ccohta.ca)) for more details. CCOHTA's mandate is to assess technology and produce reports that are of use to decision and policy makers in the health care system.

CCOHTA was asked to consider preparing a report in the area of treatment and support for children with autism in Canada by CCOHTA's Board of Directors and Scientific Advisory Panel. This assessment may be a collaborative study with the British Columbia Office of Health Technology Assessment, which is conducting a systematic review of the efficacy and effectiveness of behavioural interventions.

I am asking for your feedback regarding issues of interest to your organisation in the area of autism, which have realistic impact on policy decisions and standards of practice at the national level. A number of non-drug interventions have been identified as candidates for assessment (please refer to attached list); additional suggestions are also welcome. Your comments, most appreciated, would hold greatest impact if received by January 17, 2000. Please do not hesitate to contact me at the numbers stated below or by email at ([lyndam@ccohta.ca](mailto:lyndam@ccohta.ca)) for further details.

For your information, I am attaching two published reports as examples of the technology assessments we undertake. These evaluations are conducted either solely in-house, or in collaboration with other parties in related disciplines.

Thank you for your kind consideration.  
Sincerely,

Lynda McGahan, MSc  
Research Associate

Cc: Dr. Jill Sanders, President, CCOHTA;  
Dr. Ken Bassett, Research Consultant, BCOHTA

Potential Non-Drug Interventions for Assessment:

1. Auditory Integration Training
2. Behaviour Modification Therapy
3. Facilitated Communication
4. Functional Communication Training
5. Picture Exchange Communication
6. Psychotherapy
7. Sensory Integration Therapy
8. Treatment & Education of Autistic & Related Communications Handicapped Children
9. Visual Integration Therapy
10. Other: IBM Speech Viewer, Sign Communication, Social Skills Training.

# APPENDIX IV: CONSULTED ASSOCIATIONS AND ORGANIZATIONS

## **AUTISM TREATMENT SERVICES OF CANADA**

404 94<sup>th</sup> Ave. SE; Calgary, AB T2J 0E8  
Tel: (403) 253-6961 Fax: (403) 253-6974 Email: [atsc@autism.ca](mailto:atsc@autism.ca)

## **AUTISM SOCIETY OF CANADA**

202, 129 Yorkville Avenue, Toronto, ON M5R 1C4  
Tel: (416) 922-0302 Fax: (416) 922-1032

## **CANADIAN ACADEMY OF CHILD PSYCHIATRY**

12638 Coventry Hills Way NE, Calgary AB, T3K 4Z7  
Tel: 403-226-5735 Fax:

## **CANADIAN ASSOCIATION OF CHILD NEUROLOGY**

810, 906-12 Avenue SW, Calgary, AB T2R 1K7  
Tel: (403) 219-9575

## **CANADIAN ASSOCIATION OF SPEECH LANGUAGE PATHOLOGISTS AND AUDIOLOGISTS**

2006-130 Albert Street, Ottawa, ON K1P 5G4  
Tel: (613) 567-9968 Fax: (613) 567-2859

## **CANADIAN INSTITUTE OF CHILD HEALTH**

885 Meadowlands Dr. East, Suite 512, Ottawa, ON K2C 3N2  
Tel: (613) 224-4144 Fax: (613) 224-4145

## **CANADIAN PAEDIATRIC SOCIETY**

2204 Walkley Road, Suite 100, Ottawa, ON K1G 4G8  
Tel: (613) 526-9397 Fax: (613) 526-3332

## **CANADIAN PSYCHIATRIC ASSOCIATION**

441 MacLaren Street, Suite 260 Ottawa, ON K2P 2H3  
Tel: (613) 234-2815 Fax: (613) 234-9857

## **CANADIAN PSYCHOLOGICAL ASSOCIATION CHILD DEVELOPMENT SERVICE**

151 Slater Street, Suite 205, Ottawa, ON K1P 5H3  
Tel: (613) 237-2144 Fax: (613) 237-1674

## **LEARNING DISABILITIES ASSOCIATION OF CANADA**

#200, 323 Chapel Street, Ottawa, ON K1N 7Z2  
Tel: (613) 238-5721 Fax: (613) 235-5391

## **INTERNATIONAL SOCIETY FOR AUGMENTATIVE AND ALTERNATIVE COMMUNICATION**

#308, 49 The Donway West, Toronto, ON M3C 3M9  
Tel: (416) 385-0351 Fax: (416) 385-03352

# APPENDIX V: CONTACT INFORMATION BY JURISDICTION

## ALBERTA

**Helen Stacey**, Manager, Resources for Children with Disabilities; Government of Alberta; 10030 - 107th Street, 9th Floor- Seventh Street Plaza; Edmonton, AB T5J 3E4  
Tel: (780) 427-3981 Fax: (780) 427-3297 Email: [Helen.Stacey@gov.ab.ca](mailto:Helen.Stacey@gov.ab.ca)

**Fern Miller**, Project Team Leader, Population Health Strategies; Alberta Health & Wellness; 10025 Jasper Ave, 23rd Floor, Telus Plaza North Tower; Edmonton, AB T5J 2N3  
Tel: (780) 422-7071 Fax: (780) 422-5474 Email: [fern.miller@gov.ab.ca](mailto:fern.miller@gov.ab.ca)

**Tony McClellan**, Manager, Special Programs Branch; Alberta Learning; 10<sup>th</sup> Floor, East Devonian Building, 11160 Jasper Ave, Edmonton, AB T5K 0L2  
Tel: (780) 422-6528 Fax: (780) 422-2039 Email: [tony.mcclellan@gov.ab.ca](mailto:tony.mcclellan@gov.ab.ca)

**Kim Ward**, Clinical Psychologist; Autism Treatment Services of Canada; 404 94<sup>th</sup> Ave. SE; Calgary, AB T2V 0E8  
Tel: (403) 258-5518 Fax: (403) 253-6974 Email: [atsc@autism.ca](mailto:atsc@autism.ca)

## BRITISH COLUMBIA

**Randi Mjolsness**, Special Needs Consultant; Policy Division, XPK; Child/Family Community Services Branch; Government of British Columbia; P.O. Box 9719 - STN PROV GOV; Victoria, BC V8W 9S1  
Tel: (250) 387-9489 Fax: (250) 952-6151 Email: [Randi.Mjolsness@gems8.gov.bc.ca](mailto:Randi.Mjolsness@gems8.gov.bc.ca)

## MANITOBA

**Eleanor Chornoboy**, Director, Children's Special Services; Family Services and Housing ;Government of Manitoba; 219 - 114 Gary Street; Winnipeg, MB R3C 4V6  
Tel: (204) 945-3251 Fax: (204) 948-4656 Email: [echornoboy@fs.gov.mb.ca](mailto:echornoboy@fs.gov.mb.ca)

## NEWFOUNDLAND

**Paula Burry**, Consultant; Intervention Services and Autism Pilot; Department of Health and Community Services; Child, Youth & Family Services; Government of Newfoundland and Labrador; P.O. Box 8700; St. John's, NF A1B 4J6  
Tel: (709) 729-3550 Fax: (709) 729-5824 Email: [pburry@mail.gov.nf.ca](mailto:pburry@mail.gov.nf.ca)

## NEW BRUNSWICK

**Gina Atkinson**, Program Consultant; Support and Maintenance Unit; Family and Community Social Services Division; Department of Family and Community Services; Government of New Brunswick; 520 King Street; P.O. Box 6000; Fredericton, NB E3B 5H1  
Tel: (506) 453-8777 Fax: (506) 453-2082 Email: [gina.atkinson@gnb.ca](mailto:gina.atkinson@gnb.ca)

## NORTHWEST TERRITORIES

**Deborah Dechief**, Consultant; Children's Services; Children and Family Services - Community Programs and Services; Government of Northwest Territories / Dept. of Health and Social Services; Box 1320, CS-6; Yellowknife, NT X1A 2L9  
Tel: (867) 873-7068 Fax: (867) 873-7706 Email: [Debra\\_Dechief@gov.nt.ca](mailto:Debra_Dechief@gov.nt.ca)

## NOVA SCOTIA

**Linda Smith**, Director, Child and Youth Health Services; Nova Scotia Department of Health, P.O. Box 488, Halifax, NS, B3J 2R8  
Tel: (902) 424-7934 Fax: (902) 424-0647 Email: [smithlj@gov.ns.ca](mailto:smithlj@gov.ns.ca)

## NUNAVUT

**Marie Imiq**; Department of Health and Social Services; Government of Nunavut; Box 1000, Stn 1000; Iqaluit, NU X0Z 0H0  
Tel: (867) 975-5750 Fax: (867) 975-5722 Email: [Mmiq@gov.nu.ca](mailto:Mmiq@gov.nu.ca)

**Margaret Joyce**; Department of Education; Government of Nunavut; Bag 8000, Arviat, NU X0C 0E0  
Tel: (867) 857-3050 Fax: (867) 857-3090 Email: [Mjoyce@gov.nu.ca](mailto:Mjoyce@gov.nu.ca)

## ONTARIO

**Heather Martin**, Director, Children with Special Needs Branch; Integrated Services for Children Div., Ministry of Health and Long-Term Care; 4<sup>th</sup> Floor, Hepburn Block, 80 Grosvenor Street, Toronto, M7A 2B7  
Tel: (416) 326-8275 Fax: (416) 325-5349 Email: [heather.martin@mcscs.gov.on.ca](mailto:heather.martin@mcscs.gov.on.ca)

## PRINCE EDWARD ISLAND

**Andrea Noonan**, Autism Coordinator; Health and Social Services; Government of Prince Edward Island; 16 Garfield Street, P.O. Box 2000; Charlottetown, PE C1A 7N8  
Tel: (902) 368-6146 Fax: (902) 368-6136 Email: [alnoonan@ihis.org](mailto:alnoonan@ihis.org)

## QUEBEC

**Charles Larson**, Director; Developmental and Behavioural Pediatric Services; Montreal Children's Hospital; 2300 Tupper, Montreal, PQ H3H 1P3  
Tel: (514) 398-7424 Fax: (514) 398-4503 Email: [charles.larson@muhc.mcgill.ca](mailto:charles.larson@muhc.mcgill.ca)

**Peter Zwack**, Professor; Department of Earth and Atmospheric Sciences; University of Quebec at Montreal; 201 President Kennedy West, Room PK-6151; Montreal, PQ H3C 1B4  
Tel: (514) 987-3000 ext3304 Fax: (514) 987-7749 Email: [zwack.peter@uqam.ca](mailto:zwack.peter@uqam.ca)

## SASKATCHEWAN

**Joseph Kluger**; HEPDU - Program Dev. Unit; Saskatchewan Health; 3475 Albert Street; Regina, SK S4S 6X6  
Tel: (306) 787-3298 Fax: (306) 787-7095 Email: [jkluger@health.gov.sk.ca](mailto:jkluger@health.gov.sk.ca)

## YUKON

**Anne Westcott**, Director, Family and Children's Services (H-10); Department of Health and Social Services; Government of Yukon; Box 2703; Whitehorse, YK Y1A 2C6  
Tel: (867) 667-8117 Fax: (867) 393-6204 Email: [anne.westcott@gov.yk.ca](mailto:anne.westcott@gov.yk.ca)

# APPENDIX VI: SUMMARY OF EVIDENCE

TABLE 1: RECOMMENDATIONS BY WORKING GROUPS (Level III Evidence)

Source	Primary Research Reviewed	Primary Study Characteristics and Results	Primary Outcome and Observations	Advantages and Limitations of Therapy as Identified by Secondary Research Group	Overall Recommendations of Secondary Research Group
Panel sponsored by the New York State Department of Health, Early Intervention Program [1999] <sup>18</sup>	5 studies (4 regarding efficacy) Lovaas, 1987 McEachin et al., 1993 Brinbrauer & Leach, 1993 Smith et al., 1997 Sheinkopf & Siegel, 1998	<ul style="list-style-type: none"> <li>• Non-random assignment of subjects but no apparent bias in assignment, equivalent subject characteristics</li> <li>• ABA techniques used 18-40 h/week by a therapist</li> <li>• Behavioural interventions were part of a comprehensive program</li> </ul>	<ul style="list-style-type: none"> <li>• IBI recipients showed consistent significant functional improvement compared to controls</li> </ul>	<p><u>Advantages:</u></p> <ul style="list-style-type: none"> <li>• Positive gains in young children</li> <li>• Scientifically founded on validated principles of behaviour and learning</li> <li>• Monitored assessment</li> <li>• Across settings application</li> <li>• Across persons training</li> <li>• Parental involvement</li> <li>• Combined with other methods</li> </ul> <p><u>Limitations:</u></p> <ul style="list-style-type: none"> <li>• Requires many trained individuals</li> <li>• High coordination of therapists</li> <li>• Disruptive to family</li> <li>• Expensive</li> </ul>	<ul style="list-style-type: none"> <li>• IBI programs include <math>\geq 20</math> h/week of individualized behavioural intervention using ABA techniques depending on child and family characteristics.</li> <li>• Periodic review of intensity and frequency of intervention based on child's progress</li> <li>• Therapist supervision by a qualified professional with expertise in applied behavioural approaches</li> <li>• Parental involvement and ongoing training in consultation with a qualified professional</li> <li>• No physical aversives</li> </ul>
Collaborative Work Group on Autistic Spectrum Disorders sponsored by the California Departments of Education & Developmental Services [1997] <sup>63</sup>	5 studies Lovaas & Smith, 1988 Anderson et al., 1987 Lovaas, 1977 Koegel, 1982 Shienkopf & Siegel, 1998	<ul style="list-style-type: none"> <li>• 37-40 h/week programs are effective</li> <li>• 10 h/week programs are inadequate</li> <li>• Significant improvements with 20 h/week</li> <li>• Children with autism learn only in 1:1 situations for 1-6 months of therapy</li> </ul>	<ul style="list-style-type: none"> <li>• While formally conducted IBI programs provide 37-40 h/week of structured learning, evidence indicates significant improvements occur with 20 h/week</li> </ul>	<p><u>Advantages:</u></p> <ul style="list-style-type: none"> <li>• Skill development</li> <li>• Reduces maladaptive behaviours</li> <li>• Founded on effective practices</li> <li>• Inclusive of parents</li> </ul> <p><u>Limitations:</u></p> <ul style="list-style-type: none"> <li>• Most communities lack the resources</li> <li>• Families experience limitations that prevent delivery of services as intense as those of Lovaas</li> <li>• Quality of teaching expertise, creativity, and use of research-based techniques may be as important as intensity</li> </ul>	<ul style="list-style-type: none"> <li>• ABA assists skills acquisition and reduces negative behaviours</li> <li>• Focus on early intervention</li> <li>• Various methods consistently applied in a variety of settings</li> <li>• Based on comprehensive assessment results</li> <li>• Therapy be determined by a multidisciplinary team</li> <li>• Needs and outcome based</li> <li>• Provided by trained personnel</li> <li>• Parent training</li> <li>• Entrance and exit criteria</li> </ul>



Source	Primary Research Reviewed	Primary Study Characteristics and Results	Primary Outcome and Observations	Advantages and Limitations of Therapy as Identified by Secondary Research Group	Overall Recommendations of Secondary Research Group
Maine Administrators of Services for Children with Disabilities[2000]	<p>10 studies reviews:</p> <p>Hingtgen &amp; Bryson, 1972</p> <p>Hingtgen &amp; Jackson, 1981</p> <p>Baglio et al., 1996</p> <p>Efficacy studies:</p> <p>Fenske et al., 1985</p> <p>Lovaas, 1987</p> <p>McEachin et al., 1993</p> <p>Anderson et al., 1987</p> <p>Birnbrauer &amp; Leach, 1993</p> <p>Sheinkopf &amp; Seigel, 1998</p> <p>Cost-benefit analysis:</p> <p>Jacobson, Mulick &amp; Green, 1996</p>	<p>Little description of study detail provided</p> <ul style="list-style-type: none"> <li>• 40 h/week of Lovaas therapy</li> <li>• Cost-benefit analysis</li> </ul>	<ul style="list-style-type: none"> <li>• Reviews concluded that behaviourally-based interventions demonstrated consistent results and expanded a child's behavioural repertoire</li> <li>• 47% of children receiving 40 h/week of Lovaas therapy reported as having passed first grade with average IQ</li> <li>• Cost-benefit analysis reported estimated savings per child to age 22 of \$200,000; to age 55, \$1,000,000.</li> </ul>	<p><u>Advantages:</u></p> <ul style="list-style-type: none"> <li>• Improve and sustain socially significant behaviours</li> <li>• Outcomes include social skills, communication skills academic performance and cognitive function</li> <li>• Substantial cost/benefit</li> </ul> <p><u>Limitations:</u></p> <ul style="list-style-type: none"> <li>• Studies varied in magnitude of gains</li> <li>• Questionable whether a representative sample of children with autism was depicted in the Lovaas study</li> </ul>	<ul style="list-style-type: none"> <li>• Peer reviewed studies support the efficacy of ABA methods to improve and sustain socially significant behaviours in individuals with autism</li> <li>• Methods of ABA should be considered to evaluate the effectiveness of any intervention used to help individuals with autism</li> <li>• Researchers should continue to investigate behavioural intervention as an area of research and treatment</li> </ul>

## APPENDIX VI: SUMMARY OF EVIDENCE

TABLE 2: EVALUATIONS OF EFFICACY EVIDENCE BY SECONDARY REVIEW

Source	Research Reviewed	Study	Outcomes and Observations	Advantages and Limitations of Therapy	Conclusions of Source
ANAES, [1994] <sup>64</sup>	Lovaas, 1987 McEachin et al. 1993 Schopler, 1989 Howlin, 1987	Review of medical treatments & behavioural & educational approaches	<ul style="list-style-type: none"> <li>• IBI ameliorates symptoms of autism in 47% of children</li> <li>• High intensity is required for effective treatment</li> <li>• Improvement noted after 18 months of therapy</li> </ul>	<p><u>Advantages:</u></p> <ul style="list-style-type: none"> <li>• Cognitive improvement</li> <li>• Functional improvement</li> <li>• Advancement in social &amp; communication skills</li> </ul> <p><u>Limitations:</u></p> <ul style="list-style-type: none"> <li>• Subject selection bias</li> <li>• No long-term outcomes data</li> </ul>	<ul style="list-style-type: none"> <li>• No single cure</li> <li>• Several therapies, including IBI reduce certain symptoms associated with autism</li> <li>• Comparison of treatment modalities proves difficult</li> </ul>
ECRI [1999] <sup>51</sup>	<p><u>Lovaas:</u></p> <p>Lovaas, 1987 McEachin et al. 1993 Anderson et al. 1987 Birnbrauer &amp; Leach, 1993 Sheinkopf &amp; Seigel, 1998</p> <p><u>Rutgers Autism Program:</u> Weiss, 1999</p> <p><u>LEAP:</u> Hoyson et al. 1984</p> <p><u>Autism Preschool Program:</u> Jocelyn et al. 1998</p>	<p>Review of comprehensive treatment programs including:</p> <ul style="list-style-type: none"> <li>• Lovaas</li> <li>• Rutgers autism program</li> <li>• LEAP</li> <li>• Autism preschool program as behavioural approaches</li> </ul>	<p><u>Lovaas:</u></p> <ul style="list-style-type: none"> <li>• Recipients of <math>\geq 40</math> h /week of intervention demonstrated moderate, sustained increases in mean IQ compared to controls that received approx 10 h/week</li> <li>• Improvements in IQ could be achieved at a program intensity of approximately 20 h/week</li> </ul> <p><u>Rutgers Autism Program:</u></p> <ul style="list-style-type: none"> <li>• Extraneous events that may have influenced outcome were not reported</li> <li>• Children taking pharmaceuticals were included</li> </ul> <p><u>LEAP:</u></p> <ul style="list-style-type: none"> <li>• Extraneous events that may have influenced outcome were not reported</li> <li>• Children taking pharmaceuticals were included</li> </ul>	<p><u>Advantages of Lovaas:</u></p> <ul style="list-style-type: none"> <li>• Cognitive improvement</li> <li>• Functional improvement</li> <li>• Reduced maladaptive behaviours</li> <li>• Decreased severity of symptoms</li> <li>• Increased socialization</li> </ul> <p><u>Limitations of Lovaas:</u></p> <ul style="list-style-type: none"> <li>• Institute-trained therapist required</li> <li>• Limit to generalization</li> <li>• Non-randomized study design</li> <li>• Poor replication fidelity</li> </ul> <p><u>Advantages of Rutgers:</u></p> <ul style="list-style-type: none"> <li>• Early intensive</li> <li>• Family and therapist training</li> </ul> <p><u>Limitations of Rutgers:</u></p> <ul style="list-style-type: none"> <li>• Study validity poor</li> <li>• Possible maturation bias</li> <li>• Instrument bias</li> </ul> <p><u>Advantages of LEAP:</u></p> <ul style="list-style-type: none"> <li>• Comprehensive</li> <li>• Parental involvement &amp; training</li> </ul>	<ul style="list-style-type: none"> <li>• Recipients of Lovaas therapy showed improvements in IQ &amp; functional parameters even at intensities &lt;40 h/week; however, available evidence is only suggestive of treatment effectiveness</li> <li>• Due to fatal flaws in study design, the results of the Rutgers Autism Program study could not be interpreted regarding effectiveness</li> <li>• Due to fatal flaws in study design, the results on LEAP could not be interpreted regarding effectiveness</li> <li>• Results of a randomized controlled trial on the effectiveness of the Autism Preschool Program demonstrate language development in the treatment group showed significant improvement compared to the control group</li> <li>• One study of TEACCH found significant improvements in imitation, perception, motor skills and cognitive performance; however, the functioning in children in the control &amp; experimental groups was not significantly different before or after the program</li> </ul>

Source	Research Reviewed	Study	Outcomes and Observations	Advantages and Limitations of Therapy	Conclusions of Source
			<u>AutismPreschool Program:</u> <ul style="list-style-type: none"> <li>• Language improvement in treatment recipients</li> </ul>	<u>Disadvantages ofLEAP:</u> <ul style="list-style-type: none"> <li>• Small sample size</li> <li>• Maturation bias</li> <li>• Poor generalizability</li> <li>• Weak validity</li> <li>• Missing data</li> </ul> <u>Advantages ofAutismPreschool:</u> <ul style="list-style-type: none"> <li>• Improved language skills</li> <li>• Gold standard study design</li> <li>• Children generalizable to population</li> </ul> <u>Limitations ofAutismPreschool:</u> <ul style="list-style-type: none"> <li>• Small effect of drop-out bias</li> </ul>	
BCOHTA [2000] <sup>67</sup>	<u>Lovaas:</u> Lovaas, 1987 McEachin et al., 1993 Birnbrauer & Leach, 1993 Sheinkopf & Seigel, 1998  <u>TEACCH:</u> Ozonoff & Cathcart, 1998	Critical appraisal of Lovaas therapy & one study on TEACCH	<u>Lovaas:</u> <ul style="list-style-type: none"> <li>• 25-30 point increase in IQ in treatment group versus control</li> <li>• 47% of recipients function well in first grade</li> </ul> <u>TEACCH:</u> <ul style="list-style-type: none"> <li>• Auxiliary home interventions increase developmental functioning</li> </ul>	<u>Advantages ofLovaas:</u> <ul style="list-style-type: none"> <li>• Cognitive improvement</li> <li>• Functional improvement</li> </ul> <u>Limitations ofLovaas:</u> <ul style="list-style-type: none"> <li>• No direct comparison with other approaches</li> <li>• Non-random assignment</li> <li>• Lack of external evaluation</li> <li>• Poor external validity</li> <li>• Use of different assessment tools at baseline &amp; outcome</li> </ul> <u>Advantages ofTEACCH:</u> <ul style="list-style-type: none"> <li>• Prospective controlled trial</li> <li>• Alternative to Lovaas</li> <li>• Used same pre-post test</li> </ul> <u>Limitations of TEACCH:</u> <ul style="list-style-type: none"> <li>• No direct comparison with other approaches</li> <li>• Only 10-12 weeks</li> <li>• Poor external validity</li> <li>• Use of different assessment tools at baseline &amp; outcome</li> </ul>	<ul style="list-style-type: none"> <li>• BCOHTA concluded that while many forms of behavioural therapy clearly benefit children with autism, there is insufficient scientifically-valid effectiveness evidence to establish a causal relationship between a particular program of intensive behavioural treatment &amp; the achievement of normal functioning.[924]</li> </ul>

Source	Research Reviewed	Study	Outcomes and Observations	Advantages and Limitations of Therapy	Conclusions of Source
Smith, [1999] <sup>68</sup>	<p><u>Douglass:</u> Harris, 1990 Handeleman, 1991 Harris, 1991</p> <p><u>LEAP:</u> Hoyson et al., 1984</p> <p><u>May:</u> Anderson et al., 1987</p> <p><u>Murdoch:</u> Birnbrauer &amp; Leach, 1993</p> <p><u>PDCI:</u> Fenske, 1985</p> <p><u>UCLA:</u> Lovaas, 1987 McEachin et al., 1993</p> <p><u>UCSF:</u> Sheinkopf &amp; Siegel, 1998</p>	<p>Reviewed 12 peer-reviewed outcome studies</p> <p>9 studies on behaviour analytic programs:</p> <ul style="list-style-type: none"> <li>• Douglass</li> <li>• LEAP</li> <li>• May</li> <li>• Murdoch</li> <li>• PCDI</li> <li>• UCLA</li> <li>• UCSF</li> </ul>	<ul style="list-style-type: none"> <li>• Intensively treated children averaged 22-31 points higher on tests of intellectual &amp; adaptive functioning</li> <li>• Achieved substantially less restrictive school placements</li> </ul>	<p><u>Advantages:</u></p> <ul style="list-style-type: none"> <li>• Cognitive improvement</li> <li>• Functional improvement</li> <li>• Treatment manual &amp; video to standardize treatment</li> </ul> <p><u>Limitations:</u></p> <ul style="list-style-type: none"> <li>• Non-random assignment</li> <li>• Validity poor</li> <li>• Bias in possible differences between families that succeeded in getting treatment &amp; those that did not</li> <li>• Use of different assessment tools at baseline &amp; outcome</li> <li>• Some children did not meet criteria for autism</li> <li>• Lack of independent assessment</li> <li>• Absence of data regarding long-term effects</li> </ul>	<ul style="list-style-type: none"> <li>• Most studies suffer from weaknesses such as small sample size, employment of therapists with minimal training &amp; experience</li> <li>• 11 of 12 studies did not provide data on children's progress following termination of treatment</li> <li>• While these problems hinder firm conclusions from existing studies, the UCLA study had both the most favourable results &amp; strongest methodology.</li> <li>• Two of three studies conducting partial replications of this study also report favourable results</li> </ul>
AHFMR [2000] <sup>69</sup>	<p>ECRI, 1999</p> <p>BCOHTA, 2000</p> <p>Smith, 1999</p>	<p>Information paper on analyses &amp; a list of outcome measures</p>	<ul style="list-style-type: none"> <li>• ECRI suggests Lovaas increases IQ scores</li> <li>• BCOHTA suggest insufficient evidence treatment &amp; overall outcome</li> <li>• Smith suggests Lovaas studies are favourable</li> </ul>	<p><u>Advantages:</u></p> <ul style="list-style-type: none"> <li>• Children that receive behavioural intervention exhibit functional improvement</li> </ul> <p><u>Limitations:</u></p> <ul style="list-style-type: none"> <li>• Methodologically weak</li> <li>• IQ used as outcome</li> </ul>	<ul style="list-style-type: none"> <li>• Lack efficacy &amp; effectiveness evidence on any single treatment program</li> <li>• Social interaction &amp; communication are also important outcome measures</li> </ul>

## APPENDIX VII: CANADIAN PERSPECTIVE

### BRITISH COLUMBIA:

#### Interventions:

- Family support and developmental services
- Infant development, occupational therapy and/or physiotherapy, speech/language therapy, and behavioural support services

#### Issues:

1. Services are heavily waitlisted
2. Consultant services are expensive
3. The Government of British Columbia has been involved in litigation proceedings regarding therapy and services to children with autism since 1998
4. Need for seamless delivery of services during transition phases

#### Initiatives:

- New funding approved for the implementation of a provincial program for children with autism below six years of age
- Provincial program is a joint ministerial effort by the Ministries of Education, Health, & Children and Families to provide effective early IBI based on scientific research & best practices
- The Community-based program will eventually operate in every region where there is a child below six years of age with autism spectrum disorder
- The Program is based on a minimum of 20 hours per week of one-to-one intervention
- A Co-ordinating Centre for the program will provide links between diagnosis and assessment; treatment intervention and implementation for community based programs; training and research and evaluation

#### Cost:

- \$3.42 million allotted to providing behavioural support such as behavioural techniques & behavioural management plans to children & youth diagnosed as having autism or autistic-like tendencies by a medical practitioner in consultation with families.

### ALBERTA:

#### Interventions:

- Children with autism are eligible for home-based early intervention from birth to 3.5 years of age through the Ministry of Health
- The main component of an IBI program is the intensive one-to-one teaching based on behavioural strategies
- Up to 40 hours per week of aide services for the IBI program may be provided to preschool age children inclusive of all funding sources
- The program may be combined with health therapies, which supplement the behavioural intervention but only if these therapy services are not available through associate services providers, including Alberta Learning, the regional health authority, or the local Student Health Partnership

#### Issues:

1. Lack of evidence as to the comparative effectiveness of ABA
2. Lack of definitive information about the impact of age, intensity, necessary components and duration on the outcomes attributed to IBI

3. Questions of which children with autism or other special needs benefit from increased funding for IBI
4. Awarding funds for children with autism is not within the current budgets

**Initiatives:**

- Currently engaged in a pilot project initiated with 15 children, expanding to 30 children
- Program supplements the ABA program with a speech & language component, occupational therapy, & psychological support to families
- Pilot was developed in response to the government's desire to be more proactive in providing services
- Based on new treatments & experience with Lovaas for autism
- A maximum of 40 hours of one-to-one IBI/week inclusive of all funding sources, may be provided to preschool children
- Handicapped Children's Services may assist with the provision of speech & language service, occupation therapy, & physiotherapy when recommended as an essential component of the IBI program
- The provincial IBI policy indicated that the policy would be reviewed & updated following a literature search, evaluation to be conducted of the IBI Pilot Project & interdepartmental collaboration for IBI service provision. It is expected that these three initiatives will be completed by the fall of 2001

**Cost:**

- At 2.5 years of age, families of eligible children may receive \$20,158 per year from Program Unit Funding for educational programming that may include IBI (Tony McClellan, Manager, Special Programs Branch, Alberta Learning, Edmonton: personal communication, 2001 May 17).
- Handicapped Children's Services will provide funding to assist with the cost of individual IBI programs as early intervention only for children with a diagnosis of autism, PDD, PDD-NOS, or atypical autism made by a medical practitioner in Alberta<sup>72</sup>
- The cost of materials & supplies is fixed at \$600 per year, per child
- The cost of an IBI program can range from \$40-60,000 per year
- The annual expenditure for this program is currently 6 million dollars for 170 children

**SASKATCHEWAN:**

**Interventions:**

- Home, centre & community based pilot project including some behaviour modification features typical of Lovaas

**Issues:**

1. There are no programs that deliver formal, classic Lovaas/ABA provided through public funds

**Initiatives:**

- Currently engaged in first year of an autism pilot project with four preschool children funded by Saskatoon Health District
- The Saskatoon District Health, with support from school divisions in the Saskatoon area, is funding a pilot project to provide intensive early intervention to four preschool children three to four years of age diagnosed with autism or PDD.<sup>75</sup> The disciplines involved in the treatment program are speech-language pathology, occupational therapy, early childhood psychology, & special education
- The Saskatoon District Health, the Autism Treatment Services of Saskatchewan & five Saskatoon School Divisions began a one-year pilot school-based program for children with autism in Fall

2000. In each of the three school settings, a speech language pathologist & an occupational therapist work with six children for a concentrated three-month period. Each child has an individualized program where they receive up to one hour/day twice per week of direct therapy.

- Formed the *Autism Discussion Committee* that made recommendations to the *Office for Disability Issues* regarding priority directions for program & budget development

**Cost:**

- Approximate cost per child per year is \$25,000; \$10,000 of which is funded by the Ministry of Education & \$15,000 is funded by the Ministry of Health<sup>75</sup>
- Total program funding committed to the school-based program that serves six children at a time is approximately \$31,000 from Saskatoon District Health, \$15,000 from Autism Treatment Services of Saskatchewan, & \$11,000 from the five Saskatoon School Divisions<sup>75</sup>

**MANITOBA:**

**Interventions:**

- ABA

**Issues:**

1. There may be a lack of trained professionals to support the program
2. Families have difficulty financing private service when they are not part of the demonstration project

**Initiatives:**

- Currently engaged in the second year of an autism demonstration project
- ABA project to serve 15 children & families, conducted out of the St. Amant Center, paying for a clinical supervisor to train paraprofessional therapists, caregivers & service providers to provide ABA therapy 35-40 hours per week to each preschool & school-aged child. The project pays the salaries of the paraprofessional therapists in the various environments.
- Therapy is provided to children at home, in school and/or in a childcare setting
- The purpose of the project is to demonstrate how an ABA/DTT therapy program could be provided to Manitoba children diagnosed with autism by establishing a framework that includes hiring and supporting a local clinical supervisor to train & support paraprofessional therapists in the delivery of the therapy. It also includes the provision of accountability for the therapy.

**Cost:**

- Families not involved in the demonstration project are using respite funding to help defray costs of ABA they access themselves
- Currently, the Province of Manitoba, Department of Family Services & Housing funds the ABA pilot project through the Healthy Child Manitoba. The St. Amant Centre & Manitoba Families for Effective Autism Treatment make key decisions about the implementation of the project jointly through a Working Committee.<sup>76</sup>

**ONTARIO:**

**Interventions:**

- Children with autism receive range of services from the Ministries of Education & Training, Community & Social Services, & Health<sup>89</sup>
- Province-wide intensive early intervention services based on best practices of ABA for young children with autism

- When approaching Cabinet to get funding for the IBI initiative, an Appendix of services available to children with autism was provided by province. They are wishing to update the Appendix & create awareness in others as it unfolds.<sup>61</sup>

**Issues:**

1. A demand by parent groups to base service receipt on the existence of a diagnosis<sup>89</sup>
2. Concern for transition of adolescents to adults
3. Increased demand for early intervention services<sup>89</sup>
4. Pilot projects on new therapies for children are not receiving government funding presently & rely on resources gained through fund raising
5. The Ontario government is in the midst of two lawsuits regarding treatments for autism, one involves a single family, & the other is a Class Action Suit

**Initiatives:**

- Through a tendering process, the Ministry of Community & Social Services funded nine regional service providers to provide 20-40 hours per week of IBI to young children diagnosed as having an autism spectrum disorder
- The provincial training organization provides training to therapists & a parent training course to staff who provide training to parents
- The Ministry is developing tools to measure the quality of the therapy provided to be used in examining the quality of provincial programs
- Services, training, & materials are available in French

**Cost:**

- The Ontario government has committed \$19 million annualised funding to develop early intervention services for young children with autism
- They fund “best practices of ABA” through the Ministry of Community & Social Services
- Either the Ministry provides IBI directly to families via contracted service providers, or the families can have the funding to find their own service providers

**QUEBEC:**

**Interventions:**

- Behavioural interventions
- Zelazo, a behavioural/developmental treatment
- TEACCH
- Non specific programs

**Issues:**

- The waiting list for diagnostics & intervention programs is months long & services are running at full capacity.
- There is a lack of adequately trained behavioural psychologists to supervise programs.
- Currently, most ABA programs are purchased privately by families.
- A group of parents have undertaken a class action suit to obtain funding for intensive early intervention.

**Initiatives:**

- The province of Quebec has an orientation guide for services for children with autism & their families through the Ministry of Health & Social Services<sup>77</sup>
- Many health regions have developed action plans, most of which mention ABA as a treatment of choice for early intervention



- Several types of establishments offer the majority of services to individuals with autism; hospitals, rehabilitation centres & schools
- Within the Montreal region, six hospitals & five rehabilitation centres work with autistic children
- Many hospitals offer limited short-term intervention
- The Montreal Children's Hospital provides an ABA/Developmental program that requires extensive family involvement
- Support is also provided through regional & provincial Autism Societies
- Plans exist to develop Lovaas-inspired programs in some regions of the province; however, there is a lack of qualified personnel

**Cost:**

- No information was provided

**NEW BRUNSWICK:**

**Interventions:**

- Children with autism receive special needs services through a variety of early intervention services available to children with special needs

**Issues:**

1. Consistent lobbying from parent groups to fund services specific to children with autism by diagnosis & to fund ABA
2. Increasing demand on services without budget increase is resulting in waiting lists
3. Co-ordination of services
4. Necessary to apply & re-apply for different services both between & within ministries
5. No specific behavioural therapy programs for children with autism

**Initiatives:**

- No pilot projects on delivery of service
- Reviewing proposals for the development of a body of knowledge & resources but no finalized plans
- Department of Family & Community Services, Family & Community Social Services Division:
  - Community-Based Services for Children with Special Needs Program (CBSCSN) provides social supports
- Department of Health & Wellness:
  - Extra Mural Program provides rehabilitative services (physiotherapy, speech language pathology, occupational therapy)
- Departments of Health & Wellness, Family & Community Services, Education:
  - Early Childhood Initiative (Global Intervention Program):
    - Pre/post natal screening for high risk/developmental delay:
    - Early intervention services
    - Integrated day care services
    - Nutrition & parenting support
    - Rehabilitation services:
      - Hospital
      - Extra Mural Program

**Cost:**

- No information was provided

## **NOVA SCOTIA:**

### **Interventions:**

- Departments of Health, Education, Community Services & the IWK Health Centre for Children, Women & Families developed a plan to enhance services for children
- Pilot program incorporates a variety of behavioural strategies recommended by the Bancroft & May Institutes in the United States

### **Issues:**

1. Request by parents for available, timely, early intervention, behaviourally-based therapy
2. Lack of coordination of services & programs within & between departments
3. Need for expertise & training opportunities in NS
4. Need for new & enhanced funding for diagnostic/assessment services, therapeutic & early intervention services, public school programming & training

### **Initiatives:**

- Created a *Children & Youth Action Committee* with a permanent sub-committee, termed *Early Identification & Intervention*, the role of which is to oversee & make recommendations for the government on early intervention, public awareness & training, & screening & identification<sup>80</sup>
- Pilot pre-school project involving three children based on ABA at the Mount Saint Vincent University Child Study Center
- Individualized programs for three preschoolers with the goal of full inclusion in the child care program at the centre

### **Cost:**

- \$2 million in grant funding has been made available to regions to prioritise the means by which services can best be enhanced to meet needs
- The Department of Community Services & parent funding supplement the pilot preschool project
- Approximately \$70,000/yr provides one third of the cost of therapy for the three children in the pilot study

## **PRINCE EDWARD ISLAND:**

### **Interventions:**

- Behaviourally-based interventions
- In-home program where a maximum of 10 hours of therapy is provided for preschool children
- In a population of approximately 132,000, there are 70 children diagnosed with autism in PEI

### **Issues:**

1. Service delivery lacks integration
2. Dependency on out-of-province expertise
3. Need for long-term expensive interventions & services
4. Family stress
5. Families are required to find their own therapists
6. Issues are emerging regarding the placement of therapists and/or aids in the school system

### **Initiatives:**

- i. Improve level of integrated service delivery
- ii. Reduce dependency on out-of-province agencies & organizations for expertise
- iii. Reduce need for long-term expensive interventions & services
- iv. Reduce family stress

- Established a Provincial Autism Committee & hired an Autism Consultant to improve coordination of treatment services & availability of resources & support, & to develop training opportunities to build local expertise in behavioural approaches
- The government of PEI also has a contract with the Bancroft Neuro Health Institute (BNI) in New Jersey to train some PEI therapists & parents<sup>81</sup>
- BNI has been contracted to provide temporary support to the Autism Consultant for 12 children

**Cost:**

- Funding from Health Transition Fund for the Autism Integration Project to accomplish initiatives i-iv
- Extra funding to parents of set costs of out-of-province consultants providing training to local professionals & paraprofessionals in behaviourally-based interventions
- Providing funding for a version of ABA for any family whose child is diagnosed with autism

**NEWFOUNDLAND:**

**Interventions:**

- Department of Health & Community Services provide general services for children with special needs
- Community-based early intervention services are available for children with developmental delay & behavioural concerns from birth-5 years of age via the Direct Home Services Program, after which, children are eligible for services from the school system and/or Community Behavioural Services Program

**Issues:**

1. Need for specialized services
2. Families currently leave province to gain access to services with a specific designation such as ABA, or purchase it themselves
3. Zelazo, a developmental treatment, is more controversial because:
  - There is less time spent on one-on-one discrete trial, with a minimum of 12 minutes of treatment that are uninterrupted & focus on language production & compliance activities done in a discrete trial framework, naturalistic focusing on generalization; &
  - It is a less well-known ABA therapy.

**Initiatives:**

- Embarking on a major review of services by Provincial Working Group, based on need for specialized services
- Conducting a pilot to evaluate effectiveness of Lovaas/ABA (30 hours per week, one-on-one) & discrete trial therapy & the Zelazo Method, pioneered in Montreal<sup>79</sup>
- The pilot will also determine regional implementation issues that may affect future programming or funding
- Ten Children aged 18-42 months have been selected into each group, increased funding makes it possible to treat an additional group aged 43-60 months that will receive Lovaas-type treatment

**Cost:**

- Parent groups strongly voicing need for government funding for ABA therapy; presently, government funds respite only with families purchasing ABA therapy themselves
- Approximately \$975,000 is required to provide 2 yrs of therapy for 35 children
- Increased funding for pilot study allows for the additional study of another aged group
- Train-the-trainer component so that the government will not have to purchase costly USA based consultants after a year

## **YUKON TERRITORY:**

### **Interventions:**

- There may be two children in the territory with a diagnosis of autism, but no therapies are being provided that resemble ABA/Lovaas/IBI

### **Issues:**

- No specific behavioural therapy programs for children with autism

### **Initiatives:**

- No initiatives were identified

### **Cost:**

- No reference to funding was mentioned

## **NORTHWEST TERRITORIES:**

### **Interventions:**

- Parent support group for parents with children at home
- Provide OT/PT as needed through the medical system
- Four or five children with autism who live with their families are under behaviour management rather than intensive therapy or behaviour modification

### **Issues:**

- No specific behavioural therapy programs for children with autism

### **Initiatives:**

- Children are referred to Alberta for IBI
- One child from NWT lives in Calgary & is receiving treatment through the Society for Treatment of Autism

### **Cost:**

- Funding was not mentioned

## **NUNAVUT:**

### **Interventions:**

- No specific autism services offered by the Department of Health and Social Services or the Department of Education
- Health Services offer access to medical assessments and other medical support services as required
- Social Services offer support and respite through home care, counselling for parents, accommodation in a foster or group home as required

### **Issues:**

- No specific behavioural therapy programs for children with autism

### **Initiatives:**

- Children are referred to Edmonton, Alberta, Winnipeg, Manitoba, Ottawa, Ontario or Montreal, Quebec for assessment & treatment

### **Cost:**

- The Nunavut Government provides funding for placements out of territory when required, where able, parents contribute financially to assist with obtaining out of territory assessment and placement (Marie Irniq, Department of Health and Social Services, Iqaluit: personal communication, 2001 Mar 19)

