Citation: Auton et al. v. AGBC Date: 20000726

2000 BCSC 1142 Docket: C984120

Registry: Vancouver

### IN THE SUPREME COURT OF BRITISH COLUMBIA

BETWEEN:

CONNOR AUTON, an Infant, by his Guardian Ad Litem, MICHELLE AUTON, and the said MICHELLE AUTON in her personal capacity, MICHELLE TAMIR, an Infant, by her Guardian Ad Litem, SABRINA FREEMAN, and the said SABRINA FREEMAN in her personal capacity, JORDON LEFAIVRE, an Infant, by his Guardian Ad Litem, LEIGHTON LEFAIVRE, and the said LEIGHTON LEFAIVRE in his personal capacity, RUSSELL GORDON PEARCE, an Infant, by his Guardian Ad Litem, JANET GORDON PEARCE, and the said JANET GORDON PEARCE in her personal capacity

**PETITIONERS** 

AND:

THE ATTORNEY GENERAL OF BRITISH COLUMBIA and THE MEDICAL SERVICES COMMISSION OF BRITISH COLUMBIA

RESPONDENTS

## REASONS FOR JUDGMENT

#### OF THE

#### HONOURABLE MADAM JUSTICE ALLAN

Counsel for the Petitioners: C.E. Hinkson, Q.C. and

Birgitta Von Krosigk Lisa Mrozinski and

Counsel for the Respondents: Lisa Mrozinski and

Joan M. Young

Date and Place of Hearing: April 10-12, 17-18, 20, and

25-28, 2000

Vancouver, B.C.

What children experience in their early years will shape the rest of their lives. We now know from research in a variety of sectors, that children's early brain development has a profound effect on their ability to learn and on their behaviour, coping skills and health later in life.

Research also indicates that intensive early behavioural intervention with children with autism can make a significant difference in their ability to learn and keep pace with their peers. With the intervention many children with autism will make considerable gains by grade one.

- [1] These words embody the philosophy underlying the Ontario Government's "Intensive Early Intervention Program For Children With Autism" commenced in 1999, and numerous programmes undertaken in other provinces, the United States and several countries. To date, the Government of British Columbia has resisted a similar initiative.
- [2] Autism or autism spectrum disorder (ASD) is a neurobehavioural syndrome caused by a dysfunction in the central nervous system which leads to disordered development. According to the Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition ("DSM-IV"), the onset of autistic symptoms begins within the first three years of life and includes three general categories of behavioural impairment:
  - (a) qualitative impairments in social interaction,
  - (b) qualitative impairments in communication, and

(c) restricted repetitive and stereotyped patterns of behaviour, interest and activities.

- [3] Autism may be viewed as the prototypical form of a spectrum or continuum of autistic disorders that vary in severity but share those core symptoms of behavioural impairment.
- [4] Unless their condition is successfully treated, almost all autistic children are doomed to a life of physical, emotional, social, and intellectual isolation and eventual institutionalization a tragic outcome for the children, their families, and society.
- [5] The four infant petitioners, Connor Auton, Michelle Tamir, Jordan Lefaivre, and Russell Gordon Pearce, were diagnosed with autism or ASD. They have received treatment in the form of intensive early behavioural intervention based on methods developed by Dr. Ivan Lovaas and his colleagues at the University of California ("Lovaas Autism Treatment"). The four adult petitioners, Michelle Auton, Sabrina Freeman, Leighton Lefaivre, and Janet Gordon Pearce, are mothers or fathers of the infants who sue in their own right and as litigation guardians. Happily, Russell Pearce no longer requires Lovaas Autism Treatment; unhappily, Connor Auton's family can no longer bear the expense of the therapy.

[6] The Lovaas Autism Treatment received by the infant petitioners has been funded by their parents. Requests to the Ministries of Health ("MOH"), Education ("MOE"), and Children and Families ("MCF)", have gone largely unheeded. MOH has taken the position that the funding responsibility for children with special needs falls under the jurisdiction of MCF. In a joint letter, dated July 30, 1998, Deputy Ministers of MOE and MCF informed a number of the families that the government was not "in a resource position" to respond to requests for funding. Further, MOE's responsibility for special education programmes and treatments is limited to school age children. Ideally, Lovaas Autism Treatment begins as soon as the child is diagnosed with autism or ASD, usually around age two.

[7] These proceedings were commenced under the Class

Proceedings Act, R.S.B.C. 1996, c. 50, by Connor Auton and his

mother Michelle Auton, on behalf of autistic children and

their families who have requested funding for Lovaas Autism

Treatment from the provincial government and who have been

denied such funding. In Reasons for Judgment dated March 31,

1999, I dismissed the petitioners' application to certify the

proceeding as a class action and ordered that their claims be

dealt with summarily under the Judicial Review Procedure Act,

R.S.B.C. 1996, c. 241. The pleadings have been amended to add additional infant petitioners and their parents and the named respondents have become the Attorney General of British Columbia and the Medical Services Commission of British Columbia (collectively, the "Crown").

- [8] The petitioners claim relief pursuant to the Canadian Charter of Rights and Freedoms (the "Charter"). Specifically, they seek a declaration that the denial of funding for Lovaas Autism Treatment by each of the Ministries violates certain statutes and sections 7 and 15 of the Charter. They also seek an order of mandamus requiring the Crown to pay for the costs of Lovaas Autism Treatment already incurred and the future costs of that treatment. The Crown denies that the petitioners have been discriminated against in a manner that contravenes the Charter. In the alternative, they say that any violation of the petitioners' Charter rights is justifiable pursuant to s. 1.
- [9] Counsel agree that, if the petitioners are successful, the issue of the appropriate remedy under s. 24(1) of the **Charter** is to be adjourned to enable counsel to make further submissions.

What is Autism or Autism Spectrum Disorder ("ASD")?

[10] While the etiology (or medical cause) of autism or ASD is unknown, there is substantial agreement about certain features of the affliction. Autistic disorders are complex neurological conditions affecting between 10 and 15 of every 10,000 children. They are significantly more prevalent among boys than girls. Among children with untreated autism or autism spectrum disorders, about half of all pre-school age children (ages 2 to 6) are non-verbal. Most have limited attachment to caregivers, display little interest in pleasing them, evade eye contact and resist displays of physical affection. In a group of peers, a child with autism is likely to avoid contact and remain isolated from the group. of playing imaginatively with toys, autistic children often engage in repetitive behaviour such as arranging objects into neat rows or flapping their hands in front of their eyes. When these behaviours are interrupted, or when they do not get their way, many autistic children have intense tantrums that may include aggression toward others or self-injurious behaviour such as banging their heads against hard objects.

[11] Without effective treatment, autism is a lifelong affliction that results in the placement of over 90% of untreated children in group homes or other residential

facilities. Only one of 64 children will show any improvement without treatment.

[12] The four infant petitioners began showing signs of lack of appropriate development, or began losing the development they had achieved, between infancy and age 2. Their levels of impairment and the severity of their symptoms covered a range on the spectrum of autistic disorders. However, none of them were able to understand the world around them or to communicate. They either did not develop language at all or lost the few words they had mastered. They would not make eye contact or play appropriately with toys or with peers. They lacked a sense of separation anxiety and had no fear of dangerous objects (e.g., cars, knives, or fire). They needed constant supervision. One of them would run away at any time of the day or night, if given the slightest opportunity, forcing his parents to put multiple locks on all doors and windows.

[13] The children's behaviours ranged from the odd to the self-injurious: hand flapping, obsessing with a particular object or pattern, vocalizing or singing incessantly, screaming, biting, pinching or hitting themselves and people around them, head banging, eating inedible objects (such as sand, gravel, coins, Gyproc), plucking out their eyebrows, or

smearing their faeces. All of the children suffered from severe sleep disruptions, adding to the stress and exhaustion experienced by their families.

- [14] The parents of the infant petitioners have described the effects of Lovaas Autism Treatment as dramatic. Connor Auton made substantial progress in the areas of communication, ability to learn, and development of gross and fine motor skills through his Lovaas programme. Since his therapy was discontinued because his mother can no longer afford it, Connor has maintained some of his gains but ceased to learn new skills.
- [15] Michelle Tamir commenced 35 hours per week of Lovaas

  Autism Treatment in January 1992. By September 1993, she was

  able to enter a mainstream kindergarten with a full time

  aide. She is now successfully mainstreamed in a regular grade

  6 classroom. Her mother reports dramatic changes in her

  language and communication skills.
- [16] Russell Pearce commenced Lovaas Autism Treatment on February 19, 1997 and is now doing well in kindergarten. As a result of his therapy, he made great progress in language and learned age appropriate skills and behaviours.

[17] Jordan Lefaivre has also successfully attended kindergarten with the assistance of a teaching aide and Lovaas treatment at home.

- [18] A number of letters written by the petitioners' doctors, outlining the significant advances made by these children, were attached as exhibits to the affidavits of the parents.

  As the Crown points out, those letters do not constitute admissible evidence. However, I am satisfied on the basis of admissible evidence that the infant petitioners made significant gains as a result of the Lovaas Autism Treatment they received.
- [19] The adult petitioners have incurred substantial expenses both recruiting consultants to develop and revise their children's treatment plans and retaining trained therapists.

  In some cases, their marriages have broken down under the strain of the costly treatment superimposed on the overwhelming physical and emotional stresses of caring for an autistic child.
- [20] The establishment of a Lovaas programme for Connor, Michelle, Russell, and Jordan followed months or years of frustration as their parents attempted to access government services. The adult petitioners describe a litany of woes.

  Services such as respite assistance or pre-school aides were

contingent on a diagnosis of autism and then availability was based on means testing. Social workers were either not available or were unable to explain what services were accessible or the criteria for service eligibility.

Frequently, workers gave information that was misleading or wrong. Benefits were promised yet never delivered or they were given but then abruptly terminated. Some parents were given funding earmarked for respite services on the tacit understanding that they could use the money to fund Lovaas therapy; that avenue was blocked when the MCF declared a "moratorium" on the use of monies for that purpose. Families encountered waiting lists of up to two years for access to facilities that purported to offer any treatment, such as Laurel Group and Gateway Society for Persons with Autism ("Gateway").

[21] The petitioner Sabrina Freeman is the mother of Michelle Tamir. While pursuing her graduate studies at Stanford University in 1991, Ms. Freeman was able to access Lovaas Autism Treatment for her daughter for four years. On her return to Vancouver in 1995, Ms. Freeman began an energetic but unsuccessful campaign to advocate for government support of Lovaas Autism Treatment programmes. In 1996, she and her husband established an advocacy group of parents, Families for

Early Autism Treatment of BC ("FEAT BC"). They obtained the signatures of 63 psychiatrists who were familiar with Lovaas Autism Treatment on a petition endorsing that therapy as a necessary medical treatment that is highly effective in the treatment of autism.

- [22] The Crown objects to the admissibility of the petition as evidence of the opinions of the signatories. Nevertheless, there is independent evidence of medical support for Lovaas Autism Treatment in B.C. For example, Dr. Jane Garland, a psychiatrist and Clinical Associate Professor, has deposed that she was a signatory of that petition and supports early intensive behavioural intervention to improve the functioning of children with autism or ASD.
- [23] Dr. Glen Davies, a clinical child psychologist in B.C., has worked with autistic children since 1984. He has deposed that he knows of approximately 70 families associated with FEAT BC who are privately funding Lovaas type programmes and he estimates that number represents about half of the families who are attempting to develop those programmes.

#### Lovaas Autism Treatment:

[24] Lovaas Autism Treatment is a highly intensive form of one-on-one behavioural therapy administered for up to 40 hours

a week for two to three years. The treatment is expensive, costing between \$45,000 and \$60,000 a year per child.

[25] Dr. Lovaas began his behavioural intervention project in 1970 after observing that autistic children, unlike normal children, do not learn from their everyday environments. He hypothesized that a special, intense and comprehensive learning environment for very young autistic children would allow some of them to catch up with their normal peers by first grade. That treatment should occur in multiple settings (home, school, neighbourhood, etc.) and involve several people including the child's parents, peers, and teachers. In 1987, Dr. Lovaas published the results of his study.

[26] Dr. John McEachin, a clinical psychologist in New York and California, received his graduate training under Dr. Lovaas at UCLA on the Young Autism Project ("YAP") between 1977 and 1987. He described Dr. Lovaas' published study evaluating YAP's programme of intensive behavioural treatment for children with autism. The children were three years of age and younger at the commencement of treatment and received an average of 40 hours a week of intensive one-on-one treatment by a therapist. Dr. Lovaas reported that 17 out of 19 children who received intensive behavioural treatment significantly improved their social and communication skills.

Nine of the 19 children were able to successfully complete first grade in regular education classes without special supports and were indistinguishable from their peers on measures of IQ, adaptive skills, and emotional functioning. A control group of children with similar diagnoses and comparable severity of symptoms, who received no intensive treatment, showed very little improvement. None were able to enter regular education classes.

[27] A follow-up study by McEachin, Smith and Lovaas in 1993 showed that treatment gains were maintained and eight of the nine children continued to progress in regular education classes without support. Dr. McEachin states that the 17 children with superior outcomes in the experimental group showed an average IQ gain of more than 20 points, a result which has not been even remotely approximated by any other treatment methodology in any controlled studies. In fact, Dr. McEachin states that the 1987 Lovaas study and the 1993 follow up study are the only controlled studies that have been undertaken with respect to early intervention programmes for autistic children.

[28] Dr. McEachin described the intensive behavioural modification treatment used in Lovaas therapy as the intensive application of applied behavioural analysis (ABA) techniques

for the amelioration of abnormal behavioural patterns and skills deficits typically found in autistic children. Dr. Mulick, a clinical child psychologist and professor in the Departments of Psychology and Pediatrics at Ohio State University, provided the following definition of ABA:

Applied behavioral analysis, or ABA, teaches children, especially those with neurological conditions, small, measurable units of behaviour, and builds in the child more complex and socially useful skills (e.g. attention, compliance, self-monitoring); it also reduces in the child problematic behaviors (e.g. tantrums, withdrawal, and aggression).

small, measurable units These are typically by providing an emphasized cue, although these are faded to be as normal as possible as soon If the child responds appropriately, as possible. child's the response is reinforced consequence that has been determined to function well for the child (e.g., if a child likes music it singing a song). be bу Inappropriate responses specifically are not reinforced; contrary to the characterization by some critics of the ABA approach, children are not punished or disciplined for inappropriate responses as a primary strategy or intent of ABA; instead preference is typically used to guide the child to an appropriate response with sufficient environmental structure and behavioral support so as to prevent inappropriate responding of any kind altogether. Making the program fun for the child is a high priority in ABA and is the only way the program will be successful; indeed, the logic of behavior analysis clearly requires that new behavior elaborated from the child's cannot be repertoire bу any means except through reinforcement.

The child's ABA program is entirely individualized to address that child's strengths and deficits. Data is kept which records the child's responses which are evaluated based upon objective

criteria. If a program is not working, it is the responsibility of the behavior analyst to redesign the program until the child performs the skill reliably.

High priority is given in ABA to moving a child into a more typical environment. Accordingly, children practice their new skills in progressively less structured settings with fewer and fewer overt behavioral or environmental supports.

Intensive behavioral treatment is provided only until the child has the skills to function, benefit not be damaged by more and environments such as a regular or special education child classroom. Once а has the necessary attention, compliance, self-regulation, problem solving, information gathering and using, and social interaction skills to be in а more typical environment, he or she should be moved into that setting.

ABA most often represents the literal displacement of abnormal behavior and learning by patterns filling the child's time rehabilitative activity and is rooted, in part, the notion that the child cannot be doing two things The child practices behavior that is incompatible with the child's usual maladaptive patterns and which is designed to increase the child's skills. Research and my own experience show that children (and all of us) quite literally become what they practice (which is part of the explanation as to why children still do better even when the intensive behavioral treatment is withdrawn). time these children become more skilful and these skills become enjoyable to the child; they become maintainable by the actions of average people and familiar typical experiences and educational practices following successful therapy. can happen for these children absent antecedent and effective influence such as ABA.

[29] The petitioners contend that with Lovaas Autism

Treatment, many autistic children make exceptional gains in
language, socialization and intellect. They say that Lovaas

Autism Treatment is a medically necessary service insofar as
it significantly improves the condition of these children.

The Crown questions the proven efficacy of Lovaas Autism

Treatment and rejects it as a "medically necessary service".

## The Controversy surrounding Lovaas Autism Treatment:

- [30] The Crown contends that the studies purporting to demonstrate the effectiveness of Lovaas Autism Treatment have serious flaws and that it is still an experimental therapy.

  Two related criticisms can be dealt with summarily.
- [31] First, it is said, incorrectly, that Lovaas and his followers purport to claim that Lovaas Autism Treatment "cures" autism. In fact, neither Lovaas nor those who support him have ever claimed that Lovaas therapy "cures" autism.

  Further, the fact that many (but not all) autistic children have benefited from Lovaas Autism Treatment and made substantial observable gains without being "cured" is irrefutable.
- [32] Second, it is suggested that advocates of Lovaas Autism

  Treatment claim it is the only appropriate treatment for all

autistic children. The petitioners and their expert witnesses do not make that suggestion. They recognize that, just as the condition of autism spans a spectrum, so do the needs of the autistic children and their responses to treatment.

- [33] Dr. Frank Gresham is a Professor and Director of the School Psychology Program in the School of Education at He was retained by the Crown to provide an opinion U.C.L.A. "regarding the designation of the so-called 'Lovaas Method' of intensive discrete trial training as a medically necessary treatment for children diagnosed with ASD including Autism." (Discrete trial training refers to the process of repetitively teaching a child a skill and reinforcing the child's response.) Dr. Gresham expressed the view that, because intensive discrete trial training is not provided by doctors, it is therefore not a medically necessary treatment for However, he readily conceded that, as he was not a physician, he was not qualified to offer that opinion. Further, he agreed that discrete trial training may be an important component in treatment of autistic children.
- [34] Dr. Gresham expressed the following criticisms of Lovaas Autism Treatment:
  - ... the prescription of this method as a medically necessary treatment to children with autism, on the basis of the scientific evidence presented by Lovaas

and others in support of the treatment, is not recommended because its efficacy or effectiveness has not been empirically demonstrated and replicated using accepted standards of controlled scientific research. Moreover, when the large degree of heterogeneity of the autistic population is combined with the current state of the science around treatments for autism, it is at best misguided and unjustified to claim that one type of treatment is demonstrably more effective or medically necessary.

Contrary to claims made by some, there is no validated, replicated, or empirically documented "cure" for autism; however, the disorder can be managed effectively using a combination of behavioral and educational intervention programs.

- [35] Although Dr. Gresham agreed that ABA is the treatment of choice for autism, he described ABA as much broader than the intensive discrete trial training used in Lovaas Autism

  Treatment. He also agreed that Lovaas Autism Treatment is appropriate for some, but not all, children with autism or ASD. Although he characterized the findings of the Young Autism Project as "very promising", he described the Lovaas study as "quasi-experimental" because it failed to randomly assign the children to the control and experimental groups.
- [36] Further, in Dr. Gresham's opinion, there has been insufficient research to determine whether 40 hours a week of therapy is any more effective than less frequent treatment of autistic children.

[37] The Crown referred extensively to literature criticizing the scientific methodology of the Lovaas study. One criticism is that the children placed in the experimental group may have had high IQs to begin with. Dr. McEachin flatly denies that suggestion. He testified that those children were fully representative of the spectrum of autistic children in the general population and that their IQs were equivalent to those of the children in the control group.

- [38] The most serious methodological criticisms of the Lovaas study focus on the lack of random assignment of the children into the two groups and the failure to replicate that study. The scientific "gold standard" for experimental studies is random assignment.
- [39] The assignment of children to the experimental and control groups resulted from a scarcity of resources. The children referred to the study could not be assigned to the experimental treatment unless there were enough therapists to administer the intensive treatment. Accordingly, the assignment of children into either the experimental group or the control group was based upon a single criterion: whether a therapist was available to work with the child in the experimental group at the time of his or her admission to the programme. While not random in a strictly scientific sense,

Dr. McEachin stated that the assignment was not biased.

Neither was it based on the child's IQ or the perceived ease or difficulty of the child's outcome. Professor Donald Baer, a university professor at University of Kansas has published extensively in the area of developmental psychology and behavioural analysis. In one of his articles, entitled "Quasi-Random Assignment Can Be As Convincing as Random Assignment" in the American Journal on Mental Retardation, he expressed the opinion that the procedures used by the researchers accomplished an essentially, or functionally, random assignment between the two groups.

[40] Dr. Tristam Smith, an Assistant Professor of Psychology at Washington State University and a Director of the Northwest Young Autism Project, listed 15 partial replication sites in the U.S., England, Norway, and Iceland that are implementing treatment based on the Lovaas model. The petitioners agree that there has not been any scientific replication of the original Lovaas study. They submit that such replication would be difficult if not impossible. First, given the known outcome of the treatment, it would be difficult to obtain the consent of well informed parents to place their children in the control group during the period of time when the window of opportunity will likely close. Second, at the time of the

1987 study, the therapists used contingent physical aversives - slapping the child on the thigh and saying "no" loudly - in addition to using positive reinforcement techniques such as praising and hugging the child. There is general agreement that current treatment does not, and should not, include the use of physical aversives.

- [41] Dr. Bassett is a Senior Medical Consultant with the B.C. Office of Health Technology Assessment Centre for Health Services and Policy Research ("BCHOTA") at U.B.C. BCHOTA is funded by the Provincial Government for the purpose of "promoting and encouraging the use of assessment research in policy, planning and utilization decisions by government, health care executives and practitioners." BCHOTA was asked by the Crown to provide "an assessment of the effectiveness evidence" regarding Lovaas Autism Treatment for pre-school children with autism.
- [42] Drs. Bassett, Green, and Kasanjian prepared the report entitled "Autism and Lovaas treatment: A systematic review of effectiveness evidence" (the "BCHOTA Report"). The foreword to that report describes the methodology utilized in BCHOTA projects generally. It states that "reports are reviewed internally, and then sent for external review to experts from a variety of academic or clinical disciplines. Comments and

suggestions are considered before a final document is produced." That statement clearly implies that the BCHOTA Report, which was prepared for the purpose of this litigation, was subjected to external peer review before it was filed as an exhibit in these proceedings. However, Dr. Bassett testified that, as at the date of the hearing, the BCHOTA Report was out for external review and only one response had been received. He described the BCHOTA Report as the final document for these proceedings but not the final document for the purpose of publication.

[43] Dr. Bassett and his colleagues did not consult with any psychiatrists or clinicians who are known to support Lovaas Autism Treatment. They spoke with only one external medical consultant, Dr. Miller, who commented that the incidence of autism might appear higher than it actually is because of a tendency to label a child with autism or ASD to obtain access to services. On the basis of that single anecdotal comment, the BCHOTA Report states:

A more recent problem has emerged in relation to estimates of the incidence of autism. It appears that, at least in the BC context, problems with the diagnosis of autism may not simply be due to problems in the application of validated diagnostic criteria. The possibility arises that children with other pervasive development disorders may nonetheless be diagnosed with autism in order to gain access to services linked to that diagnosis.

[44] The Executive Summary of the BCHOTA Report begins with the following statement:

This systematic review examined whether early intensive behavioural therapy for children with autism results in normal functioning, or essentially a cure. The scientific validity of this curative claim is central both to legal proceedings brought on behalf of several children in British Columbia against the Province seeking an intensive behavioural program; and to cost-benefit analyses and clinical guidelines used for planning autism treatment programs.

- [45] The BCHOTA Report reiterates that Drs. Lovaas and McEachin claim that their treatment "normalized or cured children with autism." As noted earlier, neither Dr. Lovaas nor Dr. McEachin -- nor the petitioners -- assert such a claim.
- [46] The BCHOTA Report criticizes the Lovaas study because it used a small number of children and further suggests that the reported findings of benefits may have been achieved by assembling a high-functioning group of autistic children. Dr. Bassett was unable to suggest how one would assemble a high functioning group and agreed, in cross-examination, that he was unaware of any evidence to contradict Dr. Baer's opinion that such a selection could not be made.

[47] While the BCHOTA Report criticizes the methodology of the Lovaas and McEachin studies and the absence of replication at length, it adds little if anything to the existing debate in the scientific journals on the subject.

- [48] The BCHOTA Report exhibits an obvious bias towards supporting the Crown's position in this litigation. That detracts significantly from its usefulness.
- [49] The BCHOTA Report does acknowledge the fact that behaviour therapy, or ABA, is accepted as a benefit to children with autism. Its authors agree that early intervention with behavioural treatment can help to alleviate autistic symptoms in many if not most autistic children. Dr. Bassett testified that he was unaware of any government-funded programme in B.C. that provided behavioural therapy.
- [50] The parties adduced the evidence of several expert witnesses who were advocates of, or detractors from, Lovaas Autism Treatment. However, as I have concluded that the Court cannot direct the Crown to specifically provide Lovaas Autism Treatment regardless of the outcome of these proceedings, it is unnecessary to descend further into the ongoing debate that appears to have occupied several thousand pages of print in medical and scientific journals.

## The points of agreement with respect to treating autistic children:

[51] There is no dispute that the autistic spectrum of mild to severe disability is a neurological disorder with a very poor prognosis historically. Autism is a mental disorder and early diagnosis and treatment are essential. There is a window of opportunity during which it is possible to treat autism and obtain, in some cases, significant results. The later the intervention, the poorer the prognosis.

[52] Current research has established, with some certainty, the efficacy of early intervention in assisting many children to achieve significant social and educational gains. The expert witnesses agree that the most effective behavioural therapies are those based on principles of ABA. There are no effective competing treatments. As Dr. Gresham stated, "there is no question that ABA is the treatment of choice for children presenting with autistic disorder based on over 35 years of research in the field." He emphasized the fact that although replication of the Lovaas study was necessary, treatment should not be delayed awaiting the outcome.

## What treatment is presently provided for autistic children?

[53] The Crown says that numerous programmes and services provide assistance for families of children with autism or

ASD: infant development, supported child care, at-home respite, respite relief, contracted respite, occupational therapy, physical therapy, speech therapy/language therapy, homemaker and home support services, hearing services, child care workers and specific behavioral support. It is immediately obvious that none of those services except the last, even attempt to <a href="treat">treat</a> the condition of autism. Many of the enumerated programmes fall within the rubric of respite and home-care services or counselling for parents to help them cope with the daily ordeal of managing an autistic child.

[54] Currently, the Ministry of Health provides no treatment for autism although diagnosis of the disability comes under its jurisdiction. The adult petitioners describe waiting periods of up to two and a half years to obtain a referral to Sunny Hill Hospital for Children and a diagnosis.

[55] Until they are of school age, autistic children are not eligible for any educational services provided under the **School Act**, R.S.B.C. 1996, c. 412. All services for preschool children with special needs come within the jurisdiction of the MCF. As the petitioners point out, MCF operates on a social services model that has neither the mandate nor the expertise to deliver treatment. The Crown describes MCF's primary programme areas as child protection

and guardianship, child family and community services, adult services and regional support. Many of the programmes available under the MCF are subject to income testing.

- [56] The Crown says that MCF serves approximately 12,000 children with special needs, of whom 1,273 are children and youth with autism. That Ministry's 1999/2000 budget for children and youth with special needs and their families was \$61,910,000, with an additional \$28,015,498 for special needs day care.
- [57] MCF provides services to autistic children through contracted agencies, some of which apparently employ some behavioural analysis techniques. Generally, the focus is on teaching families those techniques to help them work with their children. Those agencies include CBI Consultants, Laurel Group, Gateway, Giant Steps West Therapeutic Centre for Children ("Giant Steps"), and some smaller contractors throughout the province.
- [58] Dr. Thomas Barnett, who is the child psychiatry representative on the B.C. Psychiatric Association, described the transfer of child and youth mental health programmes from MOH to MCF in 1997 as "an expensive experiment gone wrong." At the community level, he sees no benefits resulting from the transfer, in large part because the individuals who make

policy within MCF and determine what services are available for autistic children lack training in psychiatry, psychology or behavioural intervention.

- [59] Dr. Davies accurately described the fate of autistic children in B.C. whose families seek government services.

  They face long delays before they are diagnosed. They may then be referred to agencies with long wait lists that, when accessed, generally provide services that are supportive rather than therapeutic.
- [60] Dr. Davies described the LEAP Program in Ladner as the only provincially funded behaviourally based early intervention programme. It is loosely modelled after a programme commenced by Dr. Strain in the U.S. It has spaces for only six autistic children and, naturally, a long waiting list. Dr. Davies was initially involved in the creation of the B.C. LEAP programme but left after a few years, frustrated by the lack of resources.
- [61] Dr. Davies is presently associated with the South Fraser Child Development Centre. He says that centre, as well as Laurel Group, CBI Consultants (which was formed by a group of former employees of Laurel Group), and Gateway, base their interventions on methods derived from credible research. However, in each case, the services provided are not

intensive; they are not delivered early enough in the child's development; and they are rarely of sufficient duration to maximize the child's development. Those organizations typically provide consultation services to the parents rather than direct therapy to the child. The frequency of consultation may range from less than an hour to a few hours a week. Dr. Davies describes these interventions as "minimal treatment/minimal outcome." Several parents described dissatisfaction with CBI Consultants and Laurel Group, citing long waiting lists and ineffective treatment that included little, if any, one-to-one therapy.

- [62] Dr. de Levie, who has served as a pediatrician to Laurel Group in the past, described the treatment provided by Laurel Group and CBI Consultants as much less intense and effective than Lovaas Autism Treatment.
- [63] Gateway's stated objective is "to assist families in their attempts to understand and help their child with autism." Its focus is not on treatment, but on assisting families to develop "a behavioural support plan".
- [64] Giant Steps has a day care licence and provides services for approximately 15 children aged 5-12. It is partially funded by MCF and MOE. It offers "speech and occupational therapy, music pre-academic programmes, self-care skill

training and community experiences." Dr. Jill Calder, a medical doctor and mother of an autistic child, described the main component of the treatment offered by Giant Steps as "a sensory-integrative approach." Wanda Bent, the Programme Director for Giant Steps, agreed that the programme includes no applied behavioural therapy.

- [65] Dr. Gresham agreed that facilitated communication, auditory integration training, and sensory integration training are controversial treatments that have little or no empirical support and show no benefit to autistic children. He also agreed that ineffective treatments for autism may be harmful if they supplant effective treatments that might have been utilized. He expressed the opinion that programmes such as LEAP were not well established and they were probably not efficacious treatments for autism.
- [66] It is ironic that the very limited treatment services provided by the Crown not only fail to meet the gold standard of scientific methodology; they are positively discredited by one of the Crown's own expert witnesses.
- [67] Dr. Davies was critical of the Crown's failure to provide treatment to autistic children:

Providing a number of <u>supportive</u> services to a disorder that with treatment we know that half could

recover, is tantamount to withholding treatment and continuing with support and respite services for AIDS patients <u>after</u> a treatment that can cure half of them has been discovered.

[68] In May 1999, MCF announced an Autism Action Plan and an Autism Action Implementation Plan, which acknowledged the importance of early intervention, diagnosis and assessment. Many parents had been initially optimistic that their autistic children would obtain treatment. Their hopes were dashed when they learned of two of the plan's stated constraints: (1) there is no new funding available; and (2) services for autistic children must be balanced with services to children with other special needs. While the plan speaks generally of "early intervention and treatment," it makes no mention of any form of early ABA intervention or comparable treatment. As a result of these funding and policy constraints and the lack of any concrete plan to provide intensive early intervention treatment, the plan offers little hope for future treatment and no hope at all for families whose children are presently young enough to benefit from ABA therapy.

# State-supported intensive behavioural intervention therapy in other jurisdictions:

[69] Several jurisdictions in Canada and elsewhere have instituted intensive early intervention programmes for autistic children. It appears that government action has

resulted from intense lobbying by parental advocacy groups or litigation. Dr. Gresham estimated that about 75% of parents of autistic children who have actively advocated for statesupported Lovaas therapy in the U.S. have been successful.

- [70] In C.R. v. Alberta (Director of Child Welfare) (1996), 43

  Alta. L.R. (3d) 179 (Q.B.), the parents of a 6-year-old

  autistic boy appealed a decision denying their request for

  funding for their child's Lovaas Autism Treatment, which they

  had begun after his diagnosis at age 5. Deyell J. allowed the

  appeal, ordering the Director of Child Welfare to enter into

  an agreement to fund 90% of the cost of the Lovaas Autism

  Treatment and to reimburse 90% of the costs already incurred

  by the parents.
- [71] However, in *D.J.N. v. Alberta* (Child Welfare Appeal Panel), [1999] A.J. No. 798, (Q.L.) (Q.B.), the parents of an autistic child appealed a decision of the Child Welfare Appeal Panel that had refused to provide financial assistance for certain programmes. Rawlins J. held that the programmes requested were within the exclusive jurisdiction of the *School Act* and not the *Child Welfare Act*.
- [72] Rawlins J. also held that the courts should not interfere with the exercise of discretion by the director in deciding whether or not to fund particular services for a particular

child. She commented that Deyell J. ought not to have taken it upon himself in *C.R.*, supra, to order that a certain percentage of the services be funded by the Director. That issue should have been the subject of a separate determination on the merits.

- [73] Several appeals for Lovaas Autism Treatment followed the decision in *C.R.* As a result, the Alberta government instituted a pilot project for treatment of 15 children with a diagnosis of autism or ASD. The project utilizes ABA intervention with a speech and language component, and occupational therapy and physiotherapy, as appropriate.
- [74] Subsequently, Alberta introduced a much broader interim policy on May 27, 1999. The Child and Family Services

  Authority may now provide funding ranging from \$45,000 to \$60,000 per child for in-home, early intensive behavioral intervention ("IBI") programmes for pre-school children aged 2 to 5 with autism or ASD. (The terms IBI and ABA appear to be used interchangeably.)
- [75] To be eligible for IBI treatment, a child must be diagnosed as autistic by a medical practitioner in Alberta. A child may access an IBI programme for a maximum of 40 hours a week, for up to three years. The programme is home-based and its stated intent is "to improve the child's communication,

academic, social and behavioural skills to a level where he/she is able to transition to the community and educational system without IBI programming or intensive support."

- [76] The interim policy and guidelines of the Alberta policy describe who is eligible for the treatment and the qualifications for those who provide IBI treatment. While the procedures are to be developed in collaboration with health and educational departments of government, the IBI services are funded by the Ministry of Children's Services and not through medicare.
- [77] In the spring of 1999, the government of Ontario announced a major initiative to fund intensive behavioural intervention for children with autism aged 2 to 5. The Ontario project recognizes that many children can make considerable gains with IBI in their early years if services (1) begin early, (2) are intensive, and (3) are provided by well-trained therapists.
- [78] An informational brochure distributed by the Office of Integrated Services for Children of the Ministry of Community and Social Services describes the proposed development of individualized service plans to deliver therapy services to autistic children and their families and to develop "much needed expertise" in intensive early intervention services,

"filling a gap in service identified by both parents and professionals." Parents will have the option of engaging in private therapy arrangements funded in accordance with governmental guidelines.

- [79] Previously, IBI therapy was not available through publicly funded agencies in Ontario. Families did have access to other services such as respite, infant development, child care, speech and language, occupational therapy and recreational services. While those services provide families with relief and support, and provide children with treatment for particular problems (e.g. speech and language), they did not include IBI before the 1999 initiative. The Ontario government recognized that families who had been funding IBI themselves incurred considerable expense and had great difficulty in recruiting trained qualified therapists.
- [80] The Ontario programme specifically excludes several unproven or experimental approaches, including sensory integration therapy.
- [81] In Prince Edward Island, the family of a child who is diagnosed with autism receives provincial funding for up to 20 hours per week of home-based Lovaas Autism Treatment.

  Governmental pilot projects currently underway in Newfoundland and Manitoba also deliver Lovaas Autism Treatment or ABA.

[82] In the United States, several jurisdictions provide

Lovaas-based Autism Treatment; some funded by Departments of

Education and some funded by Medicaid programmes. Two recent

publications, the New York State Department Guidelines and the

1999 U.S. Report of the Surgeon General on Mental Health,

recognize early IBI as the treatment of choice.

[83] Litigation in England has also resulted in judicial direction to local councils to fund Lovaas Autism Treatment.

## Has there been a breach of the petitioners' Charter rights?

[84] Section 7 of the *Charter* states:

Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

[85] Section 15(1) of the *Charter* enshrines the principles of equality:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.

[86] McIntyre J. described "discrimination" succinctly in Andrews v. the Law Society, [1989] 1 S.C.R. 143 at 174-5:

I would say then that discrimination may be described as a distinction, whether intentional or 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. Distinctions based on personal characteristics attributed to an individual solely on the basis of association with a will rarely escape the charge discrimination, while those based on an individual's merits and capacities will rarely be so classed.

#### The Legislative Framework

[87] The primary relief sought by the petitioners is an order that the Medical Services Commission ("MSC") and MOH provide Lovaas Autism Treatment as a medical benefit under the province's medicare scheme. They seek to have the Minister of Health establish a tariff for the payment of Lovaas Autism Treatment by approved non-medical therapists. Alternatively, they seek orders compelling either the Minister of Education or the Minister of Children and Families to fund that treatment.

[88] As I consider the issue to be primarily a health issue, I propose to set out only the legislative provisions that relate

to the delivery of medical services. I note, parenthetically, that I do not suggest the Crown is precluded from delivering treatment through a department of government other than MOH.

[89] Section 3 of the Canada Health Act, R.S.C. 1985, Chap. C-6, describes the primary objective of Canadian health care policy as protecting, promoting and restoring the physical and mental well-being of residents of Canada and facilitating reasonable access to health services without financial or other barriers. Pursuant to section 5 of that Act, the federal government makes cash contributions towards the funding of B.C.'s health care system. Those cash contributions are contingent on provincial compliance with the criteria described in sections 8 to 12 of the Act respecting (a) public administration; (b) comprehensiveness; (c) universality; (d) portability; and (e) accessibility.

[90] The preamble to the *Medicare Protection Act*, R.S.B.C.

1996, c. 286 (the "Act") states that "the people and
government of British Columbia believe that medicare is one of
the defining features of Canadian nationhood", and "wish to
confirm and entrench universality, comprehensiveness,
accessibility, portability and public administration as the
guiding principles of the health care system ... and are
committed to the preservation of these principles in

perpetuity". The preamble also refers to the need for "judicious use" of medical services in order to maintain a fiscally sustainable health care system for future generations. Finally, the preamble emphasizes the fundamental value that an individual's access to necessary medical care must be based solely on need and not the individual's ability to pay.

- [91] Section 2 specifically articulates the purpose of the Act: to "preserve a publicly managed and fiscally sustainable health care system for British Columbia in which access to necessary medical care is based on need and not an individual's ability to pay."
- [92] Section 3(3) of the Act describes the function of MSC as the facilitation of "reasonable access, throughout British Columbia, to quality medical care, health care and diagnostic facility services for residents of British Columbia under the Medical Services Plan."
- [93] Section 5(1)(j) of the Act, gives MSC authority to determine whether a service is a benefit or whether any matter is related to the rendering of a benefit. MSC can also determine whether a person is a medical practitioner or a health care practitioner (S. 5(1)(h)).

[94] Section 5(2) requires MSC to act in a manner that satisfies the criteria in section 7 of the *Canada Health Act* in exercising its responsibilities and powers under s. 5(1).

- [95] "Benefits" are defined as medically required services rendered by a medical practitioner who is enrolled under s. 13, as well as:
  - (b) required services prescribed as benefits under section 51 and rendered by a health care practitioner who is enrolled under section 13....
- [96] "Health care practitioners" are defined to include chiropractors, dentists, naturopathic physicians, optometrists, podiatrists, or:
- [97] B.C. Regulation 426/97 to the *Act* effective December 18, 1997 prescribes physical therapists, massage therapists, and nurses (for some purposes) as health care practitioners.
- [98] Additionally, the *Ministry of Health Act*, R.S.B.C. 1996, c. 301, section 3, provides that:
  - s.3 The minister may, for the purposes of any Act under the minister's administration, enter into agreements with any person.

[99] The petitioners submit that the relevant legislation clearly provides the framework for the provision of treatment to autistic children who suffer from a neurological disorder causing severe impairment if left untreated. They suggest there is considerable flexibility within the Act to prescribe services that may be covered under the Medical Services Plan

- [100] The Crown's vigorous opposition to the petitioners' submissions arises from its narrow interpretation of the legislative provisions which ignores the specific ability of MSC to prescribe members of "an occupation" as health care practitioners. The Crown asserts that, because Lovaas Autism Treatment, ABA or IBI are not provided by health service practitioners, they are not medically necessary services and hence do not qualify as benefits provided under the medicare scheme.
- [101] The Crown points out that the medicare scheme does not guarantee funding for all health services and no person in B.C. receives 100% coverage for all of his or her health care needs. They say that the infant petitioners receive the same services under the Medical Services Plan as all other British Columbians.

[102] The Crown's narrow definition of a "medically necessary service" as one that must be provided by a health care practitioner presently scheduled by the MSC precludes delivery of Lovaas Autism Treatment or ABA or any intensive behavioural therapy as a benefit. However, as Dr. Baer suggests, a more accurate definition of medical treatment is whatever cures or ameliorates illness. On the basis of the expert evidence introduced by both parties, I find that early intensive behavioural treatment is a medically necessary service.

- [103] Further, I consider it significant that the definition of "health care practitioners" in the Act expressly contemplates persons who belong to an "occupation" other than a health care profession. Accordingly, it would appear that behavioural therapists could be scheduled as health care professionals.
- [104] Somewhat surprisingly, the Crown's insistence on a restrictive definition of "medical service" for the treatment of children suffering from the mental disability of autism seems incompatible with MOH's recent policy relating to the treatment of adults with mental disorders.
- [105] The 1998 B.C. Mental Health Care Plan (the "Mental Health Care Plan") prepared by MOH sets out the principles of

mental health care for British Columbians. The stated purpose of the Mental Health Care Plan is to assist health authorities to develop mental health care systems "which would help people with mental illness and their support networks access the services they require to restore and maintain optimal functioning and health." Core mental health services include preventative measures such as early identification and psychosocial rehabilitation.

- [106] In the Mental Health Care Plan, MOH sets out a Mental Health Mandate that includes "core mental health services" such as residential services and assistance in accessing housing, income assistance and rehabilitation services and benefits. Those services would seem to fall farther down the spectrum of "medical services" than intensive behavioural therapy.
- [107] MOH proposes to deliver treatment based on a multi-disciplinary model of care "within a bio-psycho-social service model." Multidisciplinary care teams will include physicians, nurses, social workers, occupational therapists, dieticians, and psychologists. It is obvious that many of the members of those care teams will not be scheduled health care practitioners.

[108] The Mental Health Care Plan also recommends the encouragement of early and effective treatment practices and the evaluation of innovative therapies to ensure the promotion of advances in mental health care. Given that autism is defined in DSM-IV as a mental disorder, it is difficult to understand the reluctance of the government to provide ABA treatment that has been widely endorsed by medical practitioners and academics throughout the world.

- [109] Canadians are entitled to expect medical treatment for their physical and mental diseases. This is so, even where a disease cannot be "cured." I conclude that the legislative framework does not preclude the delivery of early intensive ABA treatment to autistic children, where appropriate, within B.C.'s medicare scheme.
- [110] The remaining issue is whether the Crown's failure to provide effective treatment to the infant petitioners violates their *Charter* rights.

## Section 7 analysis:

[111] It is unnecessary to consider the petitioners' arguments relating to s. 7 of the **Charter.** 

### Section 15 analysis:

[112]The jurisprudence since Andrews, supra, has refined the analysis of equality claims under s. 15 of the Charter. For some years, the members of the Supreme Court of Canada expressed divergent views on the appropriate resolution of In Law v. Canada (Minister of Employment and equality issues. Immigration), [1999] 1 S.C.R. 497, a case dealing with age discrimination, the Court established a unified framework for In Granovsky v. Canada (Minister of Employment and analysis. Immigration), 2000 SCC 28, the most recent case dealing with s. 15 equality rights, the Court has cemented that common ground, articulating a three step test for determining whether a claimant's s. 15 rights have been infringed. may be summarized as follows:

- (1) Does the impugned law draw a formal distinction between the claimant and others on the basis of one or more personal characteristics or fail to take into account the claimant's already disadvantaged position within Canadian society resulting in substantively different treatment between the claimant and others on the basis of one or more personal characteristics?
- (2) Was the claimant subject to differential treatment on the basis of one or more of the enumerated and analogous grounds?
- (3) Does the differential treatment discriminate in a substantive sense, bringing into play the purpose of subsection 15(1) of the Charter?

[113] It is true that in Law, the petitioner's claim of discrimination was rejected, even though she had established a legislative distinction based on age, and in Granovsky, the petitioner's claim of discrimination was rejected, even though he had established a legislative distinction based on disability. However, I am unable to agree with the Crown that Granovsky constitutes a retrenchment by the Court from its earlier s. 15 pronouncements.

[114] In *Granovsky*, Binnie J. for the Court described the focus of the s. 15 analysis in disability claims at para. 26:

The true focus of the s. 15(1) disability analysis is not on the impairment as such, nor even any associated functional limitations, but is on the problematic response of the state to either or both of these circumstances. It is the state action that stigmatizes the impairment, or which attributes false or exaggerated importance to the functional limitations (if any), or which fails to take into account the "large remedial component" (Andrews v. Law Society of British Columbia, [cite omitted] at p. 171) or "ameliorative purpose" of s. 15(1) (Eaton v. Brant County Board of Education, [1997] 1 S.C.R. 241, at para. 66, Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624, at para. 65; Law, supra, at para. 72) that creates the legally relevant human rights dimension to what might otherwise be a straightforward biomedical condition.

[115] Binnie J. emphasized, at para. 33, that s. 15 addresses the state's response to the disability, rather than the disability itself:

The Charter is not a magic wand that can eliminate physical or mental impairments, nor is it expected to create the illusion of doing so. can it alleviate or eliminate the functional limitations truly created by the impairment. What s. 15 of the Charter can do, and it is a role of immense importance, is address the way in which the state responds to people with disabilities. 15(1) ensures that governments may not, intentionally or through failure of appropriate accommodation, stigmatize the underlying physical or mental impairment, or attribute functional limitations to the individual that the underlying physical or mental impairment does not entail, or fail to recognize the added burdens which persons with disabilities may encounter in achieving selffulfilment in a world relentlessly oriented to the able-bodied.

### [116] And again, at para. 80:

The "purposive" interpretation of s. 15 puts the focus squarely on the third aspect of disabilities, namely on the state's response to an individual's physical or mental impairment. state's response were, intentionally or through effects produced by oversight, to stigmatize the underlying physical or mental impairment, or to attribute functional limitations to the appellant that his underlying physical or mental impairment did not warrant, or to fail to recognize the added burdens which persons with temporary disabilities may encounter in achieving self-fulfilment, or otherwise to misuse the impairment or its consequences in a discriminatory fashion that engages the purpose of s. 15, an infringement of equality rights would be established.

[117] In *Granovsky*, the claimant was unable to satisfy the third part of the test. He suffered from a temporarily disabling condition of back pain. As a group, people with

back pain have little in common and the group could not be compared to other groups that have attracted s. 15 protection. The exclusion of a more advantaged group (the temporarily disabled) from a benefit extended to less advantaged individuals (the permanently disabled) did not offend the **Charter**. The exclusion was consistent with the ameliorative purpose of the relevant legislation.

[118] In Cameron v. Attorney General of Nova Scotia

(1999), 177 D.L.R. (4<sup>th</sup>) 611 (N.S.C.A.), the claimants were
seeking medically recommended treatments that would ameliorate
their condition of infertility and promote, if not attain,
equality with the fertile. Chipman J.A., for the majority,
stated at p. 654-5:

The government has failed to ameliorate the position of the infertile compared with fertile people. They are unequally treated because they are denied a medically recommended treatment appropriate for them.

[119] The majority of the Court concluded that the government's failure to fund *in vitro* fertilization violated the petitioners' s. 15 rights but that the policy was justified under s. 1. (An application for leave to appeal to the Supreme Court of Canada was dismissed without reasons on June 29, 2000.)

[120] In Eaton v. County Board of Education, [1997] 1

S.C.R. 241, the Court considered a decision of the Ontario

Special Education Tribunal confirming the placement of a

severely disabled child in a special education class contrary

to the wishes of her parents. The Court undertook a useful

analysis of the application of section 15 to disability

claims, although it concluded, on the facts of that case, that

there had been no violation of the child's equality rights.

- [121] Sopinka J. noted, at para. 66, that the purpose of s. 15(1) is not only to prevent discrimination through the attribution of stereotypical characteristics to individuals, "but also to ameliorate the position of groups within Canadian society who have suffered disadvantage by exclusion from mainstream society as has been the case with disabled persons."
- [122] At para. 67, Sopinka J. also described eloquently the essence of the discrimination against the physically or mentally disabled as the government's failure to make reasonable accommodation for them:

The principal object of certain of the prohibited elimination grounds is the discrimination by the attribution of untrue based characteristics on stereotypical attitudes relating to immutable conditions such In the case of disability, as race or sex.

this is one of the objectives. The other equally important objective seeks to take into account the true characteristics of this group which act as headwinds to the enjoyment of society's benefits and to accommodate them. Exclusion from the mainstream of society construction results from the of "mainstream" attributes based solely on which disabled persons will never be able gain access. Whether it is the impossibility of success at a written test for a blind person, or the need for ramp access to library, the discrimination does not lie on the attribution of untrue characteristics to disabled individual. The blind person cannot see and the person in a wheelchair needs a Rather, it is the failure to make reasonable accommodation, to fine-tune society so that its structures and assumptions do not in the relegation and banishment result disabled persons from participation, results in discrimination against them. The discrimination inquiry which uses attribution of stereotypical characteristics" reasoning as commonly understood is inappropriate here. It may be seen rather as a case of reverse stereotyping which, by not allowing for the condition of a disabled individual, ignores his or her disability and forces the individual to sink or swim within It is recognition the mainstream environment. of the actual characteristics, and reasonable accommodation of these characteristics which is the central purpose of s.15(1) in relation to disability.

#### [123] In Eldridge v. British Columbia (Attorney General),

[1997] 3 S.C.R. 624, the Court ordered the British Columbia government to fund deaf interpretation services, where appropriate, to ensure that the deaf claimants had equal access to health care. Because of their physical disability,

deaf persons were unable to communicate with their doctors and thus unable to receive universally available health benefits. The Court held that the government had violated s. 15(1) by failing to recognize the added burdens faced by deaf persons in accessing the core medical services provided to every other user. That failure to accommodate deaf persons constituted adverse effects discrimination.

- [124] It is clear that discrimination may arise from the failure of legislation to take into account the need for accommodation of a particular group in order to ensure access to the same benefits received by others. In **Eaton**, supra, the Court emphasized that the legislation's failure to take into account the true characteristics of a disadvantaged person or group triggers s. 15. Similarly, in **Eldridge** and **Cameron**, supra, the **Charter** was held to apply to government inaction that had the effect of discrimination as well as actual discriminatory action.
- [125] The petitioners complain that by failing to fund effective treatment for autism, the government has misinterpreted its legislative mandate to provide health care services. They say that failure to fund Lovaas Autism Treatment neglects to take into account the disadvantaged position of autistic children and results in substantively

different treatment, placing an additional burden on them which is not suffered by non-autistic children or mentally disordered adults.

[126] The purpose of the legislation is relevant to a determination of whether Charter rights have been breached. Here funding appropriate treatment for autism is entirely consistent with the ameliorative purpose of the heath legislation. The Medical Services Plan is designed to assist people with health care needs. As stated in Eldridge, supra, the values of the health care system are to promote health, prevention and treatment of illness and disease and to realize those values through a publicly funded health care system. Having created a universal medicare system of health benefits, the government is prohibited from conferring those benefits in a discriminatory manner. In the case of children with autism, their primary health care need is, where indicated, early intensive behavioural intervention. In failing to make appropriate accommodation for their health care needs, the Crown has discriminated against them. It is not the medicare legislation that is discriminatory or defective but the Crown's overly narrow interpretation of it.

[127] The absence of treatment programmes for autistic children must consciously or unconsciously be based on the

premise that one cannot effectively treat autistic children. The extensive evidence in this case shows that assumption to be a misconceived stereotype. The stigma attached to mental illness is historical and widespread. Only effective treatment can reduce the marginalization of autistic children and their exclusion from the mainstream of society.

- [128] The Crown seeks to justify its discretion in allocating expenditure among children with special needs by comparing autistic children with other groups of disabled children or comparing differing degrees of disability. That approach, which pits groups of disadvantaged people against each other to determine who is more disadvantaged, was expressly disavowed in *Granovsky*, at para. 67.
- [129] In this case, the appropriate comparative groups are non-autistic children or mentally disabled adults. In comparison to both non-autistic children and mentally disabled adults, the infant petitioners are subject to differential treatment based on the enumerated ground of mental disability. Indeed, as children and mentally disabled, they are doubly vulnerable.
- [130] The petitioners argue that they are victims of adverse affects discrimination as were the deaf petitioners in **Eldridge**, supra. In that case, the Supreme Court of Canada

noted that the medicare system applied equally to the deaf and hearing population. However, because the deaf could not access that system, they suffered from adverse effects discrimination. The adverse effects did not arise from a burden imposed on the deaf petitioners but from the government's failure to ensure that deaf persons benefited equally from a service offered to everyone.

- [131] Here, the petitioners say that because one of the indicia of autism is an inability to communicate, the autistic children are also unable to access health, education and other services available to everyone else. They require appropriate accommodation (by behavioural therapists), in order to communicate and access the government services available to the rest of society.
- [132] In my opinion, there is no need to consider adverse effects discrimination. The petitioners are the victims of the government's failure to accommodate them by failing to provide treatment to ameliorate their mental disability. That failure constitutes direct discrimination. Further, the petitioners' disadvantaged position stems from the government's failure to provide effective health treatment to them, not from the fact that their autistic condition is

characterized, in part, by an inability to communicate effectively or at all.

- [133] Counsel for the Crown seek to distinguish *Eldridge* on the basis that the deaf claimants were denied equal access to core medical services solely because of their inability to communicate. The claimants were not seeking treatment for their condition or "extra" services. Counsel point out that, in contrast, autistic children have access to fully funded core medical services in the event of illness, disease, or accident.
- [134] As one example, the Crown submits that if an autistic child gets cancer, he or she will receive treatment for cancer. That justification is misguided as well as unfortunate. It ignores the fact that autism is a medical disability just as cancer is and that both require treatment. As the petitioners point out, autism is a disability so severe and comprehensive that it affects all aspects of their lives. Their core medical need is for treatment that will permit them to break out of their isolation. They require treatment for that condition, as well as any other conditions that they may be unfortunate enough to incur additionally.
- [135] Autism <u>is</u> the disorder or illness that requires treatment. It is of little assistance to reassure people

suffering from debilitating illnesses that although the state will not provide treatment for that illness, should they break a leg or develop pneumonia, they will be treated for those conditions. While one of the effects of autism may be an inability to communicate and obtain government services which are universally available, the gravamen of the government's omission is its failure to provide treatment for the underlying disability, not its willingness to ensure access to other benefits.

- [136] Similarly, the fact that autism can't be "cured" is no reason to withhold treatment. Often cancer cannot be cured but it is unthinkable that treatment designed to ameliorate or delay its effects would not be forthcoming. Further, the Crown's argument that behavioural therapies will not assist all autistic children to overcome their functional limitations does not justify a failure to provide those therapies to any of them.
- [137] Depression is a mental disability on a spectrum from mildly impairing to life threatening. On diagnosis and referral by a physician to a psychiatrist, treatment is provided through medicare. Numerous other conditions that presently defy a "cure", such as cerebral palsy, are provided with treatment to ameliorate their effects.

[138] The Crown's submissions in this case are reminiscent of their earlier arguments in *Eldridge*. There counsel for the Crown argued that deafness was a condition of the claimants that had nothing to do with the health scheme and that, in refusing sign language interpreters, the health plan treated the deaf and non-deaf on an equal footing. In *Granovsky*, Binnie J. noted that submission had failed in *Eldridge*, together with the Crown's proposition that government was not required to ameliorate disadvantages it had not helped to create or exacerbate.

[139] I find that the petitioners have established that their s. 15 rights have been infringed on the basis of the test set out in Law and Granovsky. The Crown has failed to take into account and accommodate the infant petitioners' already disadvantaged position, resulting in differential treatment. That unequal treatment, which is based on the enumerated ground of mental disability, is discriminatory. Here the only accommodation possible is funding for effective treatment.

# Can the Crown's failure to provide treatment be justified under s. 1 of the Charter?

[140] The Crown submits that a violation of s. 15(1) is, in the context of this case, justifiable under s. 1 of the **Charter**. That section provides as follows:

s.1 The [Charter] guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

- [141] The onus of proving that a limit on a right or freedom guaranteed by the *Charter* is "prescribed by law", is "reasonable", and demonstrably justified in a "free and democratic society" rests on the Crown: *R. v. Oakes*, [1996] 1 S.C.R. 103.
- [142] In *Oakes*, the Court set out the analytical framework for s. 1, which was succinctly restated by Iacobucci J. in *Egan v. Canada*, [1995] 2 S.C.R. 5i3 at para. 182:

First, the objective of the legislation must be pressing and substantial. Second, the means chosen to attain this legislative end must be reasonable and demonstrably justifiable in a free and democratic society. In order to satisfy the second requirement, three criteria must be satisfied: (1) the rights violated must be rationally connected to the aim of the legislation; (2) the impugned provision must minimally impair the Charter guarantee; and (3) there must be a proportionality between the effect of the measure and its objective so that the attainment of the legislative goal is not outweighed by the abridgement of the right. all s. 1 cases the burden is on the government to show on a balance of probabilities that the violation is justifiable.

[143] The Crown is entitled to judicial deference in performing its difficult task of making policy choices and allocating finite resources among myriad vulnerable groups.

However, in M. v. H., [1999] 2 S.C.R. 3 at para. 78, Iacobucci J. emphasized that deference "is not a kind of threshold inquiry under s. 1" and made the following observation:

As a general matter, the role of the legislature demands deference from the courts to those types of policy decisions that the legislature is best placed to make. The simple or general claim that the infringement of a right is justified under s. 1 is not such a decision. As Cory J. stated in **Vriend**, supra, at para. 54 "The notion of judicial deference to legislative choices should not ... be used to completely immunize certain kinds of legislative decisions from Charter scrutiny.

[144] In B.C. (Superintendent of Motor Vehicles) v. B.C. (Council of Human Rights), [1999] 3 S.C.R. 868, the petitioner successfully challenged a policy of the Superintendent which prohibited persons with homonymous hemiaopia ("H.H.") (a condition which eliminates peripheral vision) from holding a driver's licence, regardless how they may have been able to compensate for their disability. McLachlin J. (as she then was) responded to the government's argument that it would be too expensive to assess people with H.H. at para. 41:

While 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. This Court rejected cost-based arguments in Eldridge v. British Columbia (Attorney General), [cite omitted], paras. 87-94, a case where the cost of accommodation was shown to be modest. 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.

- [145] The Crown makes the irrefragable statement that its health care resources are limited and argues that the effect of funding treatment for autistic children would direct resources away from other children with special needs. In response, the petitioners employed an economist to prepare a cost-benefit analysis of Lovaas Treatment for Autism and ASD, and adduced evidence of another cost-benefit analysis conducted in the U.S. In my opinion, it is not possible to estimate accurately either the additional immediate costs of a treatment programme or the inevitable savings in the long run.
- [146] The petitioners also suggest that a great deal of the money spent by the government is misdirected. For example, money spent on BCHOTA's research, which simply reviewed and summarized existing critiques of the Lovaas studies, would have been better spent assessing the efficacy of programmes and services provided in B.C. in comparison to IBI therapies that have implemented in other jurisdictions.

[147] In a broad sense, it is apparent that the costs incurred in paying for effective treatment of autism may well be more than offset by the savings achieved by assisting autistic children to develop their educational and societal potential rather than dooming them to a life of isolation and institutionalization.

- [148] In any event, the petitioners do not seek full funding for Lovaas Autism Treatment for all autistic children. They seek government funded treatment where it has been requested and recommended by the appropriate health care practitioner familiar with the children, their diagnoses, and their needs.
- [149] The Crown also submits that an order constitutionalizing a particular method of treatment will lead to a checkerboard effect in the medicare system. They predict that some services will be de-listed, some new services added and other services will be constitutionally entrenched, regardless of their efficacy relative to other treatments for the same condition. The Crown expressed similar predictions of disaster in *Eldridge*. They suggested the government might have to provide interpreters for all non-official language speakers and predicted that recognition of the appellants'

claims would have a ripple effect throughout the health care field. La Forest J. quoted the Crown's submission:

Virtually everyone in the health care system who is denied a service will either be medically disadvantaged or could argue that a medical disadvantage will arise from the lack of service.

- [150] Those submissions were resoundingly rejected by the Court. As it turns out, accommodation for the deaf has been made without catastrophic results to the health care system.

  In *Eldridge*, as here, if there is a constitutional violation that must be redressed, a remedy can be fashioned without the wholesale destruction of the government's medicare system.
- [151] The exclusion of effective treatment for autistic children undermines the primary objective of the medicare legislation, which is to provide universal health care. The additional stated objective of the statute, to make "judicious use" of limited health care resources, does not justify a violation of the petitioners' section 15 rights. Further, the state's failure to accommodate the petitioners cannot be classified as a minimal impairment of their rights. It follows that the Crown's submissions, which characterize the objective of the medicare legislation as funding core medical services that do not include ABA, cannot withstand the scrutiny of a proportionality analysis.

[152] Accordingly, I conclude that the violation of s.

15(1) cannot be justified under s. 1 of the Charter.

#### Conclusions:

[153] The infant petitioners suffer from a serious mental disability for which effective treatment in the form of ABA is available. The inability of the petitioners to access that treatment is primarily an issue of health care, not education or social services.

[154] The Crown, and specifically the Ministry of Health, provides no effective treatment for the medical disability of autism. The respondents' argument that they are unable to provide effective treatment for autism because of constraints in the legislation governing medicare attempts to erect a false barrier. Early intensive behavioral treatment could be provided by MOH in one of two ways. MSC may determine that behavioural therapy merits funding according to the criteria set out under the Medical Services Plan and add behavioural therapists to the scheduled list of health care providers by regulation. Alternatively, MOH could pay for the treatment through block funding as it has done to pay for interpreters for the deaf to comply with the decision in **Eldridge**, supra. It is for the Crown to determine the measures it will take to comply with its constitutional obligations.

[155] However, it is the government, rather than the Ministry of Health, that has failed to meet its constitutional obligations. Accordingly, it makes no difference if the Crown fulfils its obligations through another ministry as the governments of Alberta and Ontario have done.

- [156] The Crown discriminates against the petitioners contrary to s. 15(1) by failing to accommodate their disadvantaged position by providing effective treatment for autism. It is beyond debate that the appropriate treatment is ABA or early intensive behavioural intervention.
- [157] While the clinical results of Lovaas Autism

  Treatment are impressive, I agree with the Crown that the

  Court has no jurisdiction to specifically order Lovaas therapy

  or to order that MSC list Lovaas behavioural therapists as

  service providers on the MSC tariff.
- [158] The infant petitioners are entitled to a declaration that the Crown has violated their section 15(1) *Charter* rights.
- [159] The petitioners also seek an order of mandamus directing the Crown to pay the costs of past and future Lovaas Autism Treatment. The Crown adamantly opposes any relief in the nature of mandamus on constitutional and administrative

grounds. They note that in *Eldridge*, the Court made a declaration that the Crown's failure to provide interpreters denied the petitioners' s. 15 rights. The Court resisted giving injunctive relief on the basis that there were myriad options available to the Crown to rectify the unconstitutionality of its procedures. However, the declaration included a direction to the Crown to administer its health legislation in a manner consistent with the requirements of s. 15(1).

- [160] In this case, counsel have agreed to address the issue of the petitioners' claim for a remedy under s. 24(1) of the *Charter* at a subsequent hearing. Counsel may then make further submissions as to whether an order of *mandamus* is justified in this case and, if not, whether the declaration should include a direction to the Crown to provide early intensive behavioural treatment, or funding for that treatment, within reasonable parameters when a diagnosis of autism or autism spectrum disorder has been made by a physician and that physician and the child's family have agreed upon a mode of treatment.
- [161] Counsel may set down a further application in chambers to make submissions which I expect will address the following issues:

(a) the specific terms of a declaration and/or an order of mandamus;

- (b) whether the petitioners are entitled to be indemnified for monies expended to date on Lovaas Autism Treatment or for future ABA treatment;
- (c) whether the petitioners are entitled to additional damages;
- (d) costs; and
- (e) any other issues properly arising from these reasons for judgment.

"M.J. Allan, J."
The Honourable Madam Justice M.J. Allan

August 4, 2000 -- Memorandum issued to the Legal Publishers as directed by Madam Justice Allan advising that on Page 48, Paragraph 119, it should state:

".... (An application for leave to appeal to the Supreme Court of Canada was dismissed without reasons on June 29, 2000."