

Autism In Canada

Prepared by Brenda Deskin

Autism is...


- a **disease**, classified as such in the World Health Organization's International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)
- a serious neurological disorder whose etiology is yet unknown
- a pervasive developmental disorder affecting its victims in various ways, including having:
 - an inability to talk, understand others or communicate even basic wants and needs
 - an inability to form social relationships
 - an inability to make eye contact with others
 - an inability to recognize dangerous situations
 - an inability to adapt to changes in the environment or routine
 - an inability to learn skills and language naturally, as typically developing children do
 - a tendency to engage in odd, unusual, or repetitive behaviours such as rocking and hand-flapping
 - a tendency to engage in severe tantrums, injurious and self-injurious behaviours
- more common among boys (75% of afflicted are male)
- **more prevalent** now than ever, currently reaching epidemic levels (1 in 10,000 cases 10 years ago is now replaced by statistics of **1 in 200 children** now being diagnosed)
- ideally diagnosed between the ages of 1 and 3, however resources for diagnoses in Canada are still scarce and many are still getting diagnosed later than this

Without Treatment...

Without treatment, autism is a **lifelong affliction** that results in 90% of afflicted individuals placed in institutions and residential facilities, facing an unfulfilling and bleak existence for both the individual and family members.

Effective treatment, however, DOES EXIST. It used to be thought that people with autism could not learn and were destined to a lifelong sentence of profound impairment. Innovative research conducted by Dr. Ivar Lovaas of UCLA in the 1980s, however, proved that while children with autism indeed do not learn like their typically developing peers, they can learn much given appropriate treatment.

This **treatment** pioneered by Lovaas, widely known as **Intensive Behavioural Intervention (IBI)**, is based on the principles of **Applied Behaviour Analysis (ABA)**. ABA breaks tasks down into smaller, more manageable steps. Each newly achieved or "mastered" task then



serves as a building block for the acquisition of future skills. Children are assisted or "prompted" through this extremely positive therapeutic process with tasks continually and systematically reinforced as prompts are slowly faded and the child gains more independence in his abilities.

Why ABA Treatment?

- In April, 2005, Justice Frances Kiteley of the Ontario Superior Court of Justice ruled that "The absence of ABA means that children with autism are excluded from the opportunity to access learning, with the consequential deprivation of skills, the likelihood of isolation from society and the loss of the ability to exercise the rights and freedoms to which Canadians are entitled".
- **Five Canadian Judges** (from B.C. Supreme Court and B.C. Court of Appeal) have ruled or upheld a decision that **ABA is medically necessary**.
- Over the past 30 years, **several thousand published, peer-reviewed research studies** have not only documented its effectiveness for treating children with autism, but have also proven that **it is the only treatment** that can be validated by rigorous **scientific research**.
- In particular, Lovaas' groundbreaking study (1987) demonstrated that **47%** actually improve to the point that they **lose their diagnosis of autism**.
- Lovaas' study has been successfully replicated several times.
- While research has proven that intervention beginning before the age of six is most effective, **children of all ages** and even **adults**, have been proven to **benefit significantly from ABA therapy**.
- The **New York State Department of Health** conducted a comprehensive study examining all known treatments associated with autism. Its findings led them to **endorse and recommend ABA exclusively** as the treatment of choice for children with autism.
- The **US Surgeon General** cites the efficacy of Lovaas-based therapy for children with autism and **recommends ABA-based treatment** to promote the autistic child's language development and minimize behaviours that interfere with the child's functioning and learning.

The Plight of Canada's Autistic Children

Canada boasts universal healthcare, meaning that we all are entitled to treatment for our ailments and medical disorders. Autism is a disease. ABA is a scientifically bonafide treatment. Yet, **Canada's children who suffer from autism are not getting this treatment they so desperately need that can ameliorate and even obliterate symptoms of their medical conditions.** Instead, they continue to be discriminated against. As a result, these children and their families are paying a horrible price.

- **Treatment for IBI costs upwards of \$70,000 per year.** Families are losing their homes, going into unrecoverable debt and financial hardship to provide what therapy they can for their children.
- Many children's families can afford no treatment, and as a result, these children are left to languish and regress further into the abyss of autism.
- Some provinces now do provide IBI for children with autism, however, most often these programs:
 - impose an unfounded, arbitrary age of six for treatment cut-off, thereby discriminating against these children once more, this time by virtue of their age;
 - only provide IBI treatment to those whom they deem to be more severe, leaving those who are more high functioning but still in need of treatment and perhaps closer to recovery, abandoned;
 - have extremely long waiting lists, leaving many children to age out of the program without getting enough or often any treatment whatsoever;
 - are not of high quality, particularly when rolled into the public school system and incorporated into the Special Education programs which have been proven to be harmful to children with autism. **Children with autism need ABA treatment, NOT generic special education.**
- parents are being forced into costly lawsuits and human rights complaints against the provinces in their attempts to provide this medically necessary treatment to their children. While governments continue to lose these legal battles, they refuse to change their stance and continue making decisions that discriminate against these children, devastating families and closing the doors on children who could otherwise grow up to become productive, functioning members of society.

The Solution: A Canadian Federal Autism Strategy

- 1) **AMEND** provincial healthcare plans to include **IBI**, a medically necessary treatment for children with autism.
- 2) **MAKE** funding for IBI treatment available to all individuals with a diagnosis of autism, **regardless of their age or severity of their affliction.**
- 3) **REDIRECT** funding which is presently allocated in non-efficacious "support" and "special education" services to health-based funding to fund IBI, the only evidence based treatment for autism.
- 4) **CREATE** a federal College or individual provincial **Colleges for licensing, registering and certifying professional Applied Behaviour Analysts**, working closely with the already well-established, internationally recognized Behavior Analysis Certification Board (www.BACB.com) in the United States.
- 5) **RECOGNIZE** these highly trained, college-certified professionals as **healthcare practitioners.**
- 6) **ESTABLISH** Chairs and Departments of Applied Behaviour Analysis at **Canadian universities** to create opportunities for our students to pursue university-level undergraduate and Masters degrees as well as PhDs in Applied Behaviour Analysis, as they already exist at numerous American universities. This will drastically reduce our dependency on the US for senior-level experts in the field.

It is only when these steps are implemented and our most vulnerable members of society are given the treatment that they need and so rightfully deserve, that Canada can truly proclaim herself to be a nation upholding the values of universal healthcare.

Please visit www.canadaautism.com and download the petition, obtain at least 25 signatures and send it to your MP for tabling in the House of Commons. Please help the cause. Your contribution will be immensely appreciated.

Andrew Kavchak and his wife have two boys. The youngest one was diagnosed with autism at the age of two in 2003. They immediately applied to the Ontario Preschool Autism Program for autism treatment for their son and were placed on a waiting list for over a year. During that time they pursued a private treatment program at tremendous expense. Andrew Kavchak has become an advocate for autism treatment for people suffering from this disorder and initiated a national autism treatment petition campaign.

Brenda Deskin and her husband live in Hamilton, Ontario and are the parents of two young boys. Upon receiving a diagnosis of autism for their eldest child around his third birthday, Brenda became a vocal advocate and lobbied for government-funded, evidence-based interventions for children with autism. The Deskins recently won a tremendous legal victory in Ontario which orders the province to fund ABA for children of all ages. The family's battle, however, is far from over as the the Ontario Government has already launched an appeal, which will continue tying up the matter in the courts, thereby further delaying the lives and wellbeing of thousands of children with autism and their families. Ms. Deskin is a recipient of a Community Action Award from Ontario's Ministry of Citizenship in recognition of contributions made toward improving the lives or persons with disabilities in the Province of Ontario. She currently sits on the Board of Directors of the internationally acclaimed Association for Science in Autism Treatment (ASAT).

Ms. Deskin and Mr. Kavchak would be very interested in working hand-in-hand with our nation's politicians and policy-makers toward achieving a solution to our country's autism crisis.

Please contact them at

Andrew Kavchak

613-954-3063

Kavchak.Andrew@ic.gc.ca

Brenda Deskin

289-439-6003

brenda@deskin.ca