

Autism and F.E.A.T. of B.C.

Autism

Autism is a neurological developmental disorder that shows its first signs at approximately eighteen (18) months of age. Although autism is likely present at birth, most often, it is not detected until the child fails to develop communicative language skills. Developmental signs of autism are apparent in various behavioural disorders which include difficulties with social relationships, communication, perceptual integration, and adaptability to changes in their environment. Children with autism have difficulty integrating new experiences or information with prior experiences. As a result, these children “experience” their environment differently than most.

Families for Early Autism Treatment of British Columbia (F.E.A.T. of B.C.)

F.E.A.T. of B.C. is a nonprofit organization of parents, grandparents and concerned professionals working to establish and run treatment programs for autistic children. F.E.A.T. of B.C. is also working for universal access* to effective, scientifically backed autism treatment for all children diagnosed with autism spectrum disorders -- from the moment of diagnosis by a B.C. pediatrician or psychiatrist.

MLA Support

Presently, there are no B.C. laws or regulations that specifically address children with autism and their need for medically necessary treatment. Your support representing the needs of this disabled population of children and will help ensure their future independence as self-sustaining adults. Treatment must begin at the youngest possible age and must be intensive to help children defeat autism.

*Full government funding for medically necessary autism treatment, accessible to all children with autism spectrum disorders.

Summary of Autism Treatment in B.C.

Lovaas Therapy

- Effective, scientifically supported autism treatment exists. This treatment is known as Lovaas-type Applied Behaviour Analysis (Lovaas A.B.A. - see Appendix A for a summary of scientific studies) .
- The most thoroughly documented treatment of autistic children is a fifteen-year research project conducted by Dr. Ivar Lovaas at the University of California at Los Angeles. His studies concluded that through intensive "operant conditioning" or "behavior modification therapy," a significant number of autistic children can recover and function normally if intensive therapy is commenced before age 4.
- Sixty (60) licensed, B.C. Psychiatrists formally endorse this method as **medically necessary** and have signed the following endorsement statement:

"I agree that Lovaas type behavioural autism treatment, a form of Applied Behaviour Analysis, is a highly effective treatment for children with autism and is the most effective treatment currently available for this neurological condition. Insofar as it significantly improves the condition of autistic children, I am of the opinion that it is medically necessary treatment that should be widely available upon diagnosis and funded under the Provincial Medical Services Plan or the Ministry of Health, or both."

(See Appendix B for complete listing of the above referenced psychiatrists)

- This autism treatment method, pioneered by Dr. Ivar Lovaas (U.C.L.A) is now widely used throughout the world and is remarkably successful. In the words of David Suzuki in an episode of "The Nature of Things" regarding this method of autism treatment:

"Once it seemed like a life sentence. Now we know that that sentence can often be commuted, even lifted. Now we know there is hope. As long as we intervene early enough, intensively enough, we can rescue many children from the solitary confinement of autism... Where are other parents to turn -- parents without the resources to hire trained therapists. Somehow, we have to find the money to help children with autism in those crucial preschool years. If we don't the cost to all of us of caring for an untreated adult will be far greater, reaching into the millions. The cost in terms of human suffering is not to be measured." David Suzuki, 1996.

- No B.C. government supported agencies or departments currently offer bona fide Lovaas A.B.A. treatment or designated, universally accessible funding for Lovaas A.B.A. treatment.

Cost vs. Benefit

- Lovaas A.B.A. treatment is highly cost-effective and will save significant sums of government resources over the life of an autistic adult (see Appendix C for a summary of the cost/benefit analyses).

Legal Decisions

- The issues of effective autism treatment and its funding have been debated in many political jurisdictions - over 50 of which have now adopted or support A.B.A. programs for their population. (See Appendix D for a summary of court cases). Notable examples are below:

ACTION AGAINST DEPARTMENT OF CHILD WELFARE:

Alberta Legal Decision - C.R. and H.R. Appellants vs. Child Welfare Appeal Panel and Director of Child Welfare.

Excerpt from judgment in favour of Appellants:

[para36] "The therapy is a "service" and the child is a "handicapped child" within the meaning of s. 72 of the Child Welfare Act. The therapy is of great benefit to the child and to his family. It is addressing some fundamental issues, such as speech and aggression. The appellants have been borrowing heavily to fund the therapy. They cannot afford the expense, **and the expense is the responsibility of the State. (our emphasis).** Judge Deyell, 1996

ACTION AGAINST DEPARTMENT OF HEALTH AND THE NEW YORK DEPARTMENT OF MENTAL HEALTH, MENTAL RETARDATION AND ALCOHOLISM SERVICES:

Excerpts from the judgment in favour of the plaintiff:

"MM's abilities improved as a result of the ABA therapy. Before beginning the program, MM avoided all human contact, had no apparent language comprehension and engaged in "operant vomiting" to avoid contact. Tr. 42-43, 76-79, 81-82. Nine months after the program began, however, MM was able to follow spoken instructions, make eye contact, speak, imitate activities, had a greater attention span, could indicate his needs and be held by his father... We hold that, given the unique facts of this case, it is appropriate to award plaintiff the nominal sum that he has so far expended in providing early intervention services to MM... Defendants will have the option of either providing 40 hours per week of ABA therapy of MM or of reimbursing plaintiff for arranging these services. In addition, defendants will reimburse plaintiff for his proven expenditures to date."

Supporting testimony underlying this action includes the following excerpt to explain why it is critical to offer autistic children A.B.A. therapy at as young an age as possible: "There are numerous articles that have been published in peer review journals that have shown the effects of 45 to 50% of children who have received this kind of instruction are currently in mainstream doing normal education settings. This has not been shown in any other treatment modality."

Statutory Reform

- Several private insurance companies in the U.S. are now covering this medically necessary treatment either of their own accord i.e. Mutual of Omaha, or because several states have passed new legislation mandating that insurance companies include this therapy in the fee for service schedule i.e. Colorado, Indiana, Vermont. Comprehensive parity bills have recently been introduced in Arkansas, Hawaii, Iowa, Vermont, Massachusetts and Oregon to stop discrimination and make developmental/mental disabilities equal to physical disabilities with respect to insurance funding.

Recommendations

- To correct the inadequate standard of autism treatment and funding in B.C., F.E.A.T. of B.C. urges the following reform be implemented immediately:
 - Early, Intensive Lovaas Applied Behaviour Analysis must be funded, universally, from the moment of diagnosis by a pediatrician or psychiatrist
 - Section 5 (2) of the Family, Children and Community Act must be amended to specifically include vital autism treatment, as illustrated below:
 - "The services may include but are not limited to the following:
 - (a) services for children and youth;
 - (b) counselling;
 - (c) in-home support;
 - (d) respite care;
 - (e) parenting programs;
 - (f) services to support children who witness family violence;
 - (g) early, intensive Lovaas-type Behavioural Treatment for all children diagnosed with autism spectrum disorders from the moment of diagnosis.**
 - A Ministerial directive must be handed down to all levels of the Ministry to communicate the urgency of the current situation and the high priority that must be placed on implementation of regulatory reform.
 - New programs to fund Lovaas A.B.A. treatment must be developed expressly for children with autism. This will replace the current "patchwork" of inadequate and inconsistently granted programs.
 - The Ministry of Families and Children must negotiate transfer payments from the Ministry of Health to ensure adequate funding for Lovaas-type autism treatment since the Ministry of Families and Children is acting as the agent of the Ministry of Health in the funding of this medically necessary neuro-cognitive treatment.

A Summary of Scientific Evidence in Support of Early, Intensive, Autism Treatment

The impacts of treating Autism with intensive Early Intervention (IEI) are widely accepted by scientists as being effective, while retaining long lasting benefits.

In a fifteen year study, conducted by Dr. Ivar Lovaas and his colleagues at UCLA, results indicated that after undergoing Intensive Early Intervention (IEI) for Autistic children under age 4, there was considerable progress made in the children's development of language, social skills and IQ. An impressive 47% in the experimental group achieved "Normal functioning" after receiving IEI and were considered to be fully recovered, whereas none of the control group subjects, who received minimal intervention achieved such a favorable outcome. In fact, findings show that the experimental group had a mean IQ which was 30 points greater than that of the control group after treatment. Furthermore, of the experimental group, 47% had average IQ's, attended normal schools, had no visible signs of emotional disturbance, adequate social skills in normal range. Additionally, blind examiners (those unaware of which subjects were autistic) could not distinguish the autistic children from normal peers.

In 1987, McEachin, Smith and Lovaas performed a follow up study based on the same subjects in Lovaas' original research). This follow up attempted to determine the validity of the treatment with respect to regression over time. Results indicated that the recovery from autism based on IEI was long-lasting. A report by the American Journal on Mental Retardation states that the children who reportedly recovered from Autism, "continue to function well and are indistinguishable from average children on tests of intelligence and adaptive behaviour," (McEachin, et al, 1987). Comments on the state of the subjects illustrated that, "the children apparently have no permanent intellectual or behavioural deficits and that their language seems normal," (McEachin et al, 1987).

One common point of debate regarding the original and therefore the follow-up study has been the randomness of the selection of autistic subjects for the experimental group. Children were selected based on the availability of the therapist and some researchers believe that this is not a random enough selection process. However, Baer asserts that this "Quasi-random" assignment is still accurate. He points out that Rutter (1985) found only 1/64 Autistic subjects got better without treatment. Subsequently, "systematically getting that 1 into the experimental group will still not produce the results found by Lovaas and colleagues," (Baer, 1993). McEachin reinforces his results by noting the similar averages scored on psychometrics, including age, IQ, etc., achieved by both the experimental and the control group prior to treatment. Also, Baer points out that the control group was slightly younger than the experimental group which may indicate a slight bias in favour of the control group, as IEI effectiveness increases with earlier intervention.

Several researchers applaud the thorough and extensive methodology used by both the original and the follow up study determining, after examination, that the, "conclusions presented by this study are reliable, correct, and exceptionally important," (Baer, 1993).

Based on other researchers comments, including R.M. Fox and P. Mundy, results of both the original study and the follow up study have been exciting. Consistently, scientists urge that these promising results be duplicated by independent researchers in order to confirm the effect of treatment. Researchers at the Princeton Child Development Institute have attempted to duplicate the findings of Lovaas and reportedly, "continue to achieve outcomes that are comparable," (McClannahan and Krantz, 1992). Similarly, a study conducted by Anderson, et al, at the May Institute concluded that, "the results appear to support the literature indicating the social significance of Early Intervention with severely handicapped and Autistic children."

The seemingly arbitrary nature of the success of IEI leads to the inevitable question, "Why does it work?" and, more importantly, "How are its results most effective?" In animal experiments, it has been shown that, "alterations in neurological structure are quite possible as a result of changes in the environment in the first years of life," (McEachin, et al, 1993). Children under age three are noted to over produce brain cells and their connections, subsequently allowing, "infants and pre-schoolers to compensate for neurological anomalies much more completely than do older children," (McEachin, et al, 1993). The importance in asking "Why" and "How", with respect to these experiments, is apparent when stressing the importance of intervening early. The older age of a child acts as a disadvantage because of the loss of this ability to overcompensate.

As more and more researchers examine the results of IEI, the original results found by Lovaas and his colleagues are confirmed. Its effects on the development and integration of Autistic children are significant and long-lasting.

Doctors and Autism Treatment

Families for Early Autism Treatment of British Columbia

Endorsements Regarding Autism Treatment from the Psychiatric Community

The following statement has been signed by sixty (63) licensed B.C. psychiatrists:

"I agree that Lovaas-type behavioural autism treatment, a form of Applied Behaviour Analysis, is a highly effective treatment for children with autism and is the most effective treatment currently available for this neurological condition. Insofar as it significantly improves the condition of autistic children, I am of the opinion that it is medically necessary treatment that should be widely available upon diagnosis and funded under the Provincial Medical Services Plan or by the Ministry of Health, or both."

Signatures are on file with F.E.A.T. of B.C.

Cost - Benefit Analysis

Families for Early Autism Treatment of British Columbia

A Summary of the Cost - Benefits of Intensive Early Intervention

The "Pennsylvania Model", introduced in the attached material, offers an analysis of the financial costs and savings associated with Intensive Early Intervention (IEI) for children with Autism and PDD. Recent research into the effects of this intervention on the functioning of a child have facilitated accurate estimates of the associated long term financial benefits.

Specifically, results found in research by O. Ivar Lovaas and his colleagues at UCLA indicate that 42% of children who received early, intensive therapy achieved normal functioning levels with long lasting results. Of the remaining children, 47% still required some special education, but showed substantial improvements in both social and language skills, thereby achieving some levels of integration. Only 11% of the children still required intensive special education and care.

The effectiveness of IEI, and its subsequent cost efficiency, is best illustrated when compared with values calculated for UCLA controls (non-intensive intervention) of the same age. Results for the controls showed very different levels of achievement without IEI (See Schedule 9).

In light of these results, the most probable levels of functioning to be expected from IEI have been used to make the calculations. The savings, with reference to "cost-avoidance" are as follows;

At a 30% normal range of functioning, gained as a result of the therapy, net savings are approximately \$1,196,048, per child from age 3 to 45. based on inflated rates.

At a 40% normal range of functioning net savings are \$1,351,290, per child aged 3 to 45 based on inflated rates.

Note: Schedule 2 extrapolates the above information.

Schedule 1 provides a compilation of the numbers used to calculate costs for required services for individuals with Autism, including estimates of average household income and supplementary support. Based on these financial considerations, estimates have been made as a function of a variety of factors (detailed on pages 7, 8, 9 under "Assumptions in Present Analysis"). Schedule 5 indicates that;

Net costs required for differing functioning levels, which vary from normal to minimal due to effects of IEI, ranged from \$385,842 (inflated) for Non Disabled to \$2,941,671 (inflated) for children with Minimal Effects of IEI respectively

Net costs for children with Normal Range Effects and Partial Effects of IEI were \$265,584 and \$2,130,203 respectively.

Schedule 9 illustrates the potential financial benefits from 30-50% of normal range.

The benefits associated with IEI ranged from totals of \$1,196,048 - 1,506,532 per child aged 3 to 45, based on inflated rates.

In contrast with UCLA controls, benefits ranged from \$668,678 - 979,162, based on the 30-50% Normal Range level of benefit.

Information, provided in greater detail within the attached package, includes calculations of costs, savings and again contrasts figures with the UCLA controls. The schedules provide data as a function of different levels of functioning achieved, different age spans, varying initial costs and inflated vs uninflated (1996 dollars) costs.

A Summary of Legal Decisions in Support of Funding for Early, Intensive, Autism Treatment

The use of Intensive Early Intervention (IEI) as education for the young autistic child is a widely accepted, government funded method of providing for and protecting these developmentally disabled children's' right to free education.

The provisions for appropriate intervention begin at diagnosis in order to maximize individual progress and subsequently minimize long term costs of social assistance. In this way, the provision of funds for early childhood education is of great significance to the government of BC as it can be correctly viewed as a cost saving device, by its alleviation and elimination of the need for special education and institutions for autistic adults and young adults.

The demand for government funded IEI is growing amongst parents and families of autistic individuals across Canada. A recent victory in Alberta was won by the parents of an autistic child who were denied funding by the Director of Handicapped Children's Services, a division of Alberta Family and Social Services. **The parents sued the Child Welfare Appeal Panel and Director of Child Welfare and won the right to funding for in-home IEI (Lovaas) therapy and reimbursement for costs incurred for therapy prior to funding. The Court found that the cost of providing this therapy as a service to the family was, "the responsibility of the state."** Since this victory, a number of Alberta families have been awarded the same right to funding based on the legal precedent set by this case.

Similarly, families across the United States have successfully sued and won the right to, not only future funded treatment, but also reimbursement for incurred costs, dating back to the introduction of the treatment.

Such victories include, but are not limited to, the following:

Decisions Against the Department of Child Welfare

- C.R. and H.R. vs. Child Welfare Appeal Panel and Director of Child Welfare
 - The court ordered reimbursement for costs incurred from January 1 1996 to December 31, 1996, in the amount of 90 percent of \$7,404
 - The court ordered the director to fund 90% of the costs of the therapy (\$31,965)

Decisions Against Departments of Health

- Parents vs. New York State Department of Health
 - The court order reimbursement for IEI (Behaviour Modification Therapy)
- Parents vs. New York State Department of Health, New York City Department of Mental Health, Mental Retardation and Alcoholism Services
 - The court ordered reimbursement for incurred expenses of IEI Lovaas or ABA therapy)
- New York State Department of Health (on behalf of child "EM") vs. New York City Department of Mental Health, Mental Retardation and Alcoholism Services, City of New York
 - The court ordered reimbursement for incurred cost of IEI (Applied Behavioural Analysis)
- Malkentzos (on behalf of child "MM") vs. New York City Department of Mental Health, Mental Retardation and Alcoholism Services, New York State Dept. of Health
 - The court ordered reimbursement for incurred cost of IEI (Applied Behavioural Analysis)
 - The court ordered provision of 40 hours per week of IEI (Applied Behavioural Analysis)

Decisions Against Departments of Education

Note: The large number of decisions against school boards is due to a powerful law which is called the Individuals with Disabilities Education Act (IDEA). The guarantees all children the right to an "appropriate education in the least restrictive environment."

Legal Decision continued

- Parents vs. Pitt County School Board
 - The court ordered reimbursement for costs incurred from diagnosis to point of implementation of appropriate education by board, (\$29,403.06)
- Parents vs. Connecticut School Board
 - The court ordered reimbursement for cost of in-home IEI (Lovaas) therapy program
 - The court ordered employment of Consultant to assist in continuation of Lovaas therapy within the home
- Mary Jane W. Vs. Allamakee Community School District
 - The court ordered the school district to provide instructive service and integration opportunities in addition to 1:1 therapy
- Parents vs. Multnomah Education Services District, Columbia Regional Programs, Portland School District, Oregon Department of Education
 - The court ordered reimbursement of in-home IEI therapy for 40 hours per week
- Parents Vs. Inland Reg. Cnt, San Bernardino Cnty Superintendent of Schools
 - The court ordered funding for 40 hours per week of IEI
 - The court ordered reimbursement for costs incurred, including; materials, transportation and meals and lodging for tutors
- Parents vs. High Bridge Board of Education
 - The court ordered reimbursement for in-home IEI (Lovaas) therapy
 - The court ordered continuation of funding of in-home IEI (Lovaas) therapy
- Parents vs. Capistrano Unified School District
 - The court ordered reimbursement for cost of in-home IEI (Lovaas) therapy
 - The court ordered the school district to provide 25 hours per week of 1:1 IEI (Lovaas) therapy throughout school year
- Parents vs. Independent School District No. 318
 - The court ordered reimbursement for costs of in-home IEI (Lovaas) therapy
 - The court ordered the introduction of IEI (Lovaas) therapy into school
- Parents vs. Watertown Public Schools
 - The court ordered the public schools to fund program with both behavioural and in-home components with 6-8 other students
- Parents vs. Columbia Regional Programs and Portland School District
 - The court ordered the school district to fund in-home IEI (Lovaas) therapy for 40 hours per week
 - The court ordered reimbursement for independent evaluation and continued programming
- Parents vs. Cobb County School System
 - The court ordered reimbursement for in-home IEI (Lovaas)
- Parents vs. Frederick County Public Schools
 - The court ordered reimbursement for summer speech and language therapy
 - The court ordered the county to fund implementation of in-home IEI (Lovaas) therapy
 - The court ordered the county to pay for transportation costs for therapy and assessments
- Parents vs. Mill Valley Elementary School District
 - The court ordered reimbursement for speech and language therapy when school out
 - The court ordered the school district to fund participation in integration play therapy group
 - The court ordered the school district to pay for transportation costs for therapy and assessments
- Parents vs. Broward County School Board
 - The court ordered reimbursement for in-home (Lovaas) therapy
 - The court ordered reimbursement for attorney fees
- Parents vs. Delaware County
 - The court ordered reimbursement for all past IEI (Lovaas) expenses
 - The court ordered the county to fund training for IEI (Lovaas) for additional year
 - The court ordered reimbursement for attorney fees
- Parents vs. Voorhees
 - The court ordered the district to fund all costs of in-home IEI therapy (includes experts, aides, materials and transportation)
- Parents vs. East Hanover
 - The court ordered the district to fund costs of in-home counselling and parent training
 - Fund all necessary 1:1 therapy (full-time program)