

Solution to the Human Suffering and Social Cost of Autism

An Information Brief to Members of Parliament

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Solution to the Human Suffering of Autism

A Two-Tiered Health Care System for Autism Treatment

- **Private, Parallel Health Care in Canada** A two-tiered health care system has developed for autism treatment due to the absence of government involvement in funding autism treatment for children and education for treatment professionals. Those with the financial resources are putting effective autism treatment programs into place. Those without the resources are now outside the “new” health care system with grave consequences for their families and affected children.
- **This new autism reality runs contrary to the rights of Canadians**
The right to medicare, as one of the defining features of Canadian Nationhood, must extend to medically necessary autism treatment for all children who require it. It is fundamental that an autistic child’s access to medically necessary autism treatment be solely based on need and not individual ability to pay. Universality and Comprehensiveness, as guiding principles of the health care system of Canada and the Provinces, must apply to medically necessary autism treatment for children.

Effective Autism Treatment Exists

- **Effective treatment exists** Lovaas treatment has been proven effective in treating young children with autism and is considered to be medically necessary by a significant number of B.C. psychiatrists. In a landmark study done by Lovaas 1987, 47 percent of children who began this treatment before the age of four lost the diagnosis. This form of treatment consists of much more than speech and language therapy. The therapy teaches a child how to learn. The method is designed to break down a task into its smallest components. The child is immediately rewarded for successfully completing each component of the program. Tasks learned are continually reinforced. Through this form of treatment, the child learns appropriate language, behaviour and reasoning. (See Appendix A for a summary of scientific evidence).

The 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.

- **What do B.C. physicians and scientists think about Lovaas treatment?** Sixty (60) licensed psychiatrists in the province of British Columbia have formally endorsed Lovaas Autism treatment as the most effective treatment method for autism spectrum disorders and deem it to be **MEDICALLY NECESSARY** treatment that should be funded under the Canadian health care system. The psychiatrists each signed the following endorsement:

“I agree that Lovaas-type behavioural autism treatment, a form of Applied Behaviour Analysis, is a highly effective treatment of 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.”

In the words of Dr. Jane Garland, M.D., F.R.C.P.(C), Associate Professor, Department of Psychiatry at the University of British Columbia, and Child Psychiatrist at the Department of Psychiatry, B.C. Children’s Hospital:

“Applied Behavioural Analysis is [an autism] treatment based on sound scientific principles, and studied over more than a decade with systematic research. ...this treatment approach... appears to produce remarkable outcomes. I reviewed the research literature systematically evaluating this treatment method, and it clearly demonstrates the effectiveness of this approach. As a result of this intensive early intervention, many children make exceptional gains [and] as a result of this program, children could reach school age with normal language and social development, able to participate in an integrated regular school. While the initial costs and expert human resources of a program requiring 40 hours per week of expert therapy in the toddler and early preschool years may sound unaffordable, in fact the costs for continued one-to-one support in the schools and community mount year after year for these children when they do not have this intervention and lack communication skills or basic daily living skills. After reviewing this literature and observing the program in action, it is my opinion that it is unacceptable to withhold funding for intensive early intervention with a program which clearly works **when we do not have any other effective treatment for Autistic Disorder. This is the same as funding treatment with medications, surgery or rehabilitation services for any other medical disorder** (emphasis F.E.A.T. of B.C.). At present, the only families receiving this treatment are those with the financial resources to do so, which is clearly unfair and does not provide equal access for all children. [Dr. E.J. Garland concludes that] ...effective early intervention could make the difference between a life of dependency and a developmentally capable child.” Dr. E.J. Garland, November 13, 1996. (See Appendix B for a copy of the letter).

- **What is happening in the rest of Canada?** The only province that covers Lovaas Behavioural treatment is Alberta. This occurred after the judiciary ordered the provincial government to cover the cost of autism treatment. In reference to Lovaas autism therapy, the judge ruled that this treatment is the “responsibility of the state.” In the words of Judge Deyell:

“**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.**” (emphases F.E.A.T. of B.C.). C.R. v. Alberta (Director of Child Welfare). (See appendix C).

- **What is happening in the United States?** Throughout the United States, Lovaas-type autism treatment programs are paid for by many state governments resulting from court decisions and legislation supporting the disabled (see appendix C). The governor of the state of Massachusetts, William F. Weld, proclaimed the month of March as Applied Behaviour Analysis Month.

Key points from Governor Weld’s proclamation:

“Whereas: ABA is supported by the most scientific evidence of effectiveness for producing comprehensive, lasting improvements ... in at least 250 scientific studies..., and
Whereas: Early, comprehensive, intensive application of ABA methods has been shown to have dramatic effects for treating children with autism, and most children with autism who receive early, intensive behavioral treatment require substantially less support later in life than they would otherwise ...
I, Governor William F. Weld of Massachusetts, proclaim the month of March, 1997 to be Applied Behaviour Analysis Month” (see Appendix D for full transcript).

- **New York State** Excerpts from the judgment of *Malkentos vs. the New York State Dept. of Health & New York City Department of Mental Health, Mental Retardation, and Alcoholism Services* in favour of the plaintiff. In this decision, the judge found that:

“Autistic individuals are unlike other developmentally disabled individuals in that they lack the skills to begin rudimentary forms of learning. However, with intensive one-on-one early intervention, autistic children are educable. It is therefore essential that autistic children receive appropriate education as soon as possible, ideally, upon diagnosis as infants.”

The judge based this finding of fact upon expert testimony regarding Lovaas-type one-on-one behavioural treatment:

“There are numerous articles that have been published in peer reviewed journals that have shown the effects of this treatment. Forty-five (45) to 50% of children who have received this kind of instruction are currently mainstreamed in normal education settings. This has not been shown in any other treatment modality.”

How Canada Will Benefit from Implementation of Effective Autism Treatment

- **Remove autistic individuals from government programs** When fully implemented, the Lovaas Autism treatment program, as the only highly effective treatment for autistic disorder, will dramatically reduce the number of autistic individuals in Government programs. None of the current programs for autistic children are designed to reduce the number of program recipients, despite significant government expenditures on “support” based programs. If the emphasis is shifted from “support” based programs to intensive “one-on-one treatment”, government dollars will be best targeted for long term savings (See appendix E for a summary of the cost/benefit analysis)
- **Families stay in tact** Families of autistic children have a higher than average rate of breakup due to the tremendous stresses of life with an untreated autistic child. The benefit of Lovaas Autism treatment programs in Canada will be a decrease in single mother families, a decrease in family violence, and foster care costs. Social Services costs of respite care will also decrease as autistic children show improvement with effective treatment. In short, effective, scientifically based intervention keeps the family in tact and the kids can be kept at home rather than given up to the state.
- **Special education expenditures decreased** Since autistic children are highly “mainstreamable” with Lovaas autism treatment, government educational dollars for aides, special education teachers, segregated classrooms and other special support programs will be greatly reduced.
- **Psychiatric hospitalization reduced** Untreated autistic children become costly autistic adults. Lack of effective early intervention leads to the tragic results of long term institutional care in a wide range of government funded facilities. Independent, self-sustaining autistic adults will save millions in social/medical spending and add to the population of productive tax payers.
- **Social costs lessened** Untreated autistic children, as adults, often join the ranks of the homeless when released from the downsized psychiatric infrastructure. Effective treatment of autistic children can be expected to significantly reduce the number of autistic homeless adults over the long run. This will yield a concomitant reduction in the costs of 911 emergency calls, police and medical costs stemming from street violence against the homeless.

Obstacles to Change

- **The Provincial Government Bureaucracy** At present, Lovaas autism treatment has not been incorporated into, or even formally evaluated by, Ministry of Health, Ministry of Education or Ministry of Social Services departments. In the Ministry of Education, all special education personnel currently lack appropriate training for effective autism intervention. They rely on B.C. autism consultants who are not qualified to administer, and are not focussed on, Lovaas autism intervention. Despite the scientific evidence supporting Lovaas Autism Treatment, and years of in-the-field success with the program, autism programs for children in Canada remain “support-based” rather than intervention focussed. Families currently apply for wait listed support programs to help reimburse the cost of treatment but are usually refused since they do not meet the criteria for family distress when the autistic child is very young. Social worker discretion is currently the determinant for reimbursement

of privately funded treatment costs. The result is an inconsistent patchwork of “workarounds” with most families going it alone. Still operating as though autism is “untreatable”, B.C. government autism programs for children remain primarily in the jurisdiction of the Ministry of Children and Families (formerly the Ministry of Social Services). Government policies and programs still reflect the reality of the past - where the absence of effective treatment for autism means the agency of last resort, Social Services, only comes in to help “pick up the pieces” of family distress and break up resultant of autistic disorder. Although support programs do serve an important purpose, they cannot substitute for, or fill the urgent need for intensive treatment of young autistic children. They do not help preempt the problems of autism. In the era before effective treatment, the current government structure made sense. It is outmoded today and diverts funds away from the creation of new government programs that are specifically targeted at autism treatment for children. Social workers are not qualified to diagnose or evaluate treatment options. New government treatment programs must be overseen by psychologists or psychiatrists who are trained in Lovaas-type autism treatment.

- ***The Ministry of Health***

The Ministry of Health funds the services of speech and language pathologists. The current speech pathology staff is not trained in Lovaas autism treatment and is ineffective in the treatment of autism spectrum disorders. When autistic children become adults, they cross over from Ministry of Children and Families jurisdiction into the Health Ministry. Although the Ministry of Health spends significant dollars for institutional care of autistic adults, they have not developed any effective early intervention treatment programs -- nor do they reimburse the costs for existing, home-based private programs that will eventually reduce the number of autistic adults. In addition, there are no broadly based, **timely**, diagnostic services covered by the Medical Services Plan. The current system of centralized diagnostic services for autism has children waiting from 6 to 24 months for a diagnosis of autism. This compromises the precious potential of **early** Lovaas treatment that is most effective when started at infancy.

- ***The existing autism industry*** The existing autism industry originally developed in a treatment-free environment. Consultation the industry provides under government contract does not include effective Lovaas autism treatment, but rather is support-based and operates in an environment where no objective standards exist to measure improvement of autistic children in costly government programs. The status quo assumes that autism is untreatable so government support services have no outcome criteria. The industry’s personnel lack the qualifications to design and administer autism treatment programs. Therefore, private agencies under government contract for autism support services do not advocate implementation of treatment programs for autistic children since they would need to “retool” to deliver the treatment. In the existing autism industry, where there are no expectations for improvement in the autistic child, there is an incentive to maintain the status quo and protect government contracts.

- ***Lack of knowledge regarding modern treatment*** Lovaas autism treatment has not been widely accessible until recently, although many in the psychiatric community have been supportive of this treatment method for years. In addition, there is a severe lack of knowledge in government, amongst educators and the public regarding the efficacy of this treatment. The Autism Society of British Columbia, for example, until very recently, was completely ignorant regarding the legitimacy of Lovaas treatment. This unfortunately is also true of many autism professionals. Their knowledge of the method, if any, is often limited to outdated work done by Lovaas in the early 1970’s when this research project was in its infancy. The effectiveness of modern autism treatment for children remains largely unrecognized. However, parents of children with autism are highly motivated to find and implement the only method that works. There are currently over 100 families in B.C. that have bypassed government and the autism industry to obtain scientifically backed treatment for their children. Unfortunately, this is only possible for those who can afford the expense or can borrow heavily.

What needs to be done to save the children

- ***Autism Policy Task force*** A federal task force must be established as soon as possible to evaluate current autism policies and verify the tremendous potential of effective autism treatment for children. The task force must be comprised of preeminent psychologists, psychiatrists and pediatricians to evaluate the best options for autism treatment, and Canada Health Act experts to determine the most effective ways to deliver treatment in a universal and comprehensive manner.

The goal of the task force must be to confirm the best treatment modality for autism and submit recommendations to government on optimal implementation of autism treatment under the Canada Health Act.

- ***Federal Guidelines***

Federal guidelines must be established for the provincial certification and regulation of a new class of therapists, specifically trained in Lovaas Behaviour Analysis (the treatment of autism). Detailed guidelines must include authorization for professional organization and the review process for applications for certification.* In addition, specific federal policies must be drafted under Canada Health Act Authority, specifying the conditions that must be met by the provinces, vis ‘a vis **universal, comprehensive** autism treatment, before full federal cash contributions to provincial medicare programs can be made. In short, Federal guidelines are vital to ensure that quality, scientifically based autism treatment is available on a consistent basis **nationwide**, and that access to such treatment is timely and not income based.

- ***Professionalization of the autism treatment field***

- University programs - the Autism Education Society (a charitable society) is spearheading the movement to establish a permanent academic chair at the University of British Columbia to train a new class of quality, behavioural autism treatment professionals in Canada. Government funding will dramatically reduce the time frame for the establishment of the new education priority of establishing a Canadian based autism treatment capability. Advanced consultation and treatment is currently provided by U.S. professionals.
- Autism Rapid Response Teams - In the ideal and most refined state of development, the Canadian autism treatment approach will have a nationwide, standardized program of intervention. Since autism treatment must be done at the **earliest** age possible, highly trained 4-5 person autism rapid response teams of Lovaas treatment professionals must begin intensive one-on-one, home based Lovaas treatment programs **from the moment** of diagnosis. This is now being done privately in Canada with a great deal of success. The challenge to the Canadian system of national health care is to weave quality autism treatment into medicare as quickly as possible to include **all** Canadians.

*Refer to California Bill SB 958 Behaviour Analysis (Feb. 2. 1997) for example of certification of autism therapists.

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, Beer 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. Researcher's 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.

November 13, 1996
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Vancouver, B.C. V6H 3Y4
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RE: Intensive Behavioral Treatment for Children with Autistic Disorder

I am writing on behalf of children with Autistic Disorder and their families to strongly support the funding of Applied Behavioral Analysis of the type provided in the programs developed by Dr. O.I. Lovaas and colleagues at the University of California at Los Angeles.

As a child psychiatrist at BC's Children's Hospital, I assess and treat children with Autistic Disorder and related severe Pervasive Developmental Disorders, and consult to the community, schools and families where these children are managed. I am fully aware of the many times that hopes are raised about potential new treatments for this devastating condition and the disappointments when research does not support the hopeful initial results. Applied Behavioral Analysis is a treatment based on sound scientific principles, and studied over more than a decade with systematic research. I have had the opportunity to follow two children who were fortunate to have had several years of early intensive intervention with the Lovaas method and I am impressed with the progress they have made compared to the outcome that their early symptomatology would have predicted. This had led me to critically look at this treatment approach which appears to produce remarkable outcomes.

Recently, I reviewed the research literature systematically evaluating this treatment method, and it clearly demonstrates the effectiveness of this approach. As a result of this intensive early intervention, many children make exceptional gains in language, socialization and intellect compared to children managed with a standard less intensive (but by our BC standards quite generous) intervention program. The principles involved in this form of intensive behavior therapy make sense in terms of our understanding of the pathology of Autism. Children with Autism are unable to learn language and socialization due to abnormal brain development. As a result, they fall farther and farther behind their peers in development, and may by school age lack any meaningful communication or socialization. With the intensive behavioral program they are systematically taught what other children learn intuitively from their families and peers. As a result of this program, children could reach school age with normal language and social development, able to participate in an integrated regular school.

While the initial costs and expert human resources of a program requiring 40 hours per week of expert therapy in the toddler and early preschool years may sound unaffordable, in fact the costs for continued one-to-one support in the schools and community mount year after year for these children when they do not have this intervention and lack communication skills or basic daily living skills. We do provide through the Ministry of Social Services (now Ministry of Children and Families) financial support for non-expert workers and other resources simply to enable families to cope with the intensive complex demands of an autistic child in the home. However, we do not fund treatment resources, with exception of a small amount of expert consultation for low intensity behavioral programs to target problem behaviors such as aggression or lack of toileting skills.

After reviewing this literature and observing the program in action, it is my opinion that it is unacceptable to withhold funding for intensive early intervention with a program which clearly works when we do not have any other effective treatment for Autistic Disorder. This is the same as funding treatment with medications, surgery or rehabilitation services for any other medical disorder. At present, the only families receiving this treatment are those with the financial resources to do so, which is clearly unfair and does not provide equal access for all children. As the rate of Autistic disorder in the population is very low, we are not talking about a large number of children, but for those children and as a result for our community as a whole, effective early intervention could make the difference between a life of dependency and a developmentally capable child.



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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 Pane 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)

Appendix D:

The Commonwealth of Massachusetts
A Proclamation
By His Excellency
GOVERNOR WILLIAM F. WELD
1997

WHEREAS: Applied Behavior Analysis (ABA) is a scientifically-derived treatment method for children with autism that builds useful repertoires by emphasizing the individual learner, positive reinforcement? and objective documentation of treatment effectiveness; and

WHEREAS: Of the available treatments and therapies for autism, ABA is supported by the most scientific evidence of effectiveness for producing comprehensive, lasting improvements, and ABA's effectiveness for teaching children, youths, and adults with autism has been documented in at least 250 scientific studies published in peer-reviewed journals since 1980 and many others dating back to the 1960's; and

WHEREAS: Behavioral methods have proved effective for teaching a vast range of skills to people with and without disabilities, including people of all ages with autism; and

WHEREAS: Early comprehensive? intensive application of ABA methods has been shown to have dramatic effects for treating children with autism, and most children with autism who receive early, intensive behavioral treatment require substantially less support later in life than they would otherwise; and

WHEREAS A lack of public awareness and widespread misconceptions about this approach have made it difficult for many Massachusetts children with autism to receive ABA treatment; and

WHEREAS: Since its founding in 1975, the New England Center for Children in Southborough, Massachusetts, has provided comprehensive programming for children and young adults with autism using the principles of ABA, and has offered a full range of educational and treatment programs to help children with autism and related disorders to reach their full potential; and

WHEREAS: The Autism Partnership for Applied Behavior Analysis (TAP) is a non-profit organization of Massachusetts parents and professionals dedicated to making effective services available to children with autism and related disorders, providing resources and support for families who seek behavioral intervention, and promoting sound scientific research on causes and treatments for autism

NOW, THEREFORE, I WILLIAM F. WELD, Governor of the Commonwealth of Massachusetts, do hereby proclaim the month of March, 1997 to be

APPLIED BEHAVIOR ANALYSIS MONTH

and urge all citizens of the commonwealth to take cognizance of this event and participate fittingly in its observance.

Given at the Executive Chamber in Boston, this eleventh day of March, in the year of our Lord one thousand nine hundred and ninety-seven, and of the Independence of the United States of America, the two hundred and twenty-first.

By His Excellency the Governor <signature> WILLIAM F. WELD

<signature> WILLIAM F. GALVIN Secretary of the Commonwealth

GOD SAVE THE COMMONWEALTH OF MASSACHUSETTS

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.