An Information Brief to School Districts in British Columbia

Contents:

Summary and Conclusions

What is Autism?

Effective Autism Treatment Exists

- A discussion regarding effective treatment
- What do B.C. physicians and scientists think about Lovaas treatment?
- Implementation of the Home-based treatment program

The School System - Partner or Problem?

- · Safety
- Integration
- School Assistants and Classroom Assistants
- Access to School by Lovaas Autism Consultants
- Communication
- Individual Education Plan the IEP

Obstacles at School to Teaching Children with Autism

- The District "Autism Team"
 - Lack of Lovaas Training
 - Territoriality
 - Autism Team Members
 - Negative Impact of "Autism Team" on Frontline Education Professionals

School District Autism Policy; Laws and Regulations; Charter of Rights and Freedoms

- · B.C. Laws and Regulations
- The Canadian Charter of Rights and Freedoms

Policy Recommendations

Tables

• 1: B.C. Laws, Regulations and Policies to Protect Children with Special Needs

Appendices

· A: Lovaas autism treatment studies

Summary and Conclusions

There is an effective. Home-based, intensive treatment for autism known as the Loyaas method. It is scientifically backed and medically endorsed. Children in Lovaas treatment programs differ markedly from untreated children insofar as they are better able to integrate and learn in the regular classroom, provided that front line support is seamless and knowledgeable in the Lovaas protocol. Parents of children in Lovaas treatment programs also differ markedly from other parents insofar as they usually are the case managers for the treatment program of the autistic child. In this capacity, they are generally very knowledgable regarding the Lovaas treatment protocol and are often highly motivated. Although it is highly effective, the Home-based Lovaas program is often difficult and costly. Therefore, parents running Lovaas programs must have a high degree of dedication to the long term well being and independence of their autistic child. They expect no less from the School District. The nature of autism and the tremendous effort required to treat the condition demand a high standard of attention and physical supervision at school. There must be constant monitoring of the child in the classroom so any negative behaviours can be quickly identified and eliminated. There must be seamless, adult supervision in all areas of the school, at all times of the school day to ensure the physical safety of the autistic child. In the best interest of children with autism, a new spirit of cooperation is needed between school and parents running Home-based Lovaas autism treatment programs. The District must recognize the merits and necessity of the Home-based Lovaas program and the valuable contributions parents and their autism consultants can make. Terrioriality and a lack of training on the part of school staff and the District Autism Team must be addressed since these are obstacles to the child in a Lovaas autism treatment program.

New policies must be adopted in many areas including Classroom Assistants, Teachers, access to school by Home-based teams, communication methods between home and school, and new standards for Individual Education Plans must be established. New ways of doing things must be adopted to solve the problem of educating children with autism.

What is Autism?

Autism is a neurological disorder which is present in approximately 1 out of 1,000 children. It affects children in various ways, which include difficulties with social relationships, communication, perceptual integration, a difficulty in adapting to changes in their environment and self-stimulatory behaviours such as rocking, flapping, occasionally including self-injury. Autism, although most likely present at birth, usually manifests itself at 18 months of age, many times without any warning. Parents hearts are broken as their seemingly normal, attentive, talkative child disappears before them. It is as if the child they know as their own was stolen in the night. Day by day these children regress and fail to develop normal language, social, behavioural and receptive skills.

Children with autism may never speak, make friends, drive a car, go to college or live on their own. Due to lack of treatment many of these children end up in institutions where ignorance has meant years of abuse. An entire generation of children has been lost due to lack of education in proper and effective treatment. Although there is no known cure, there is a highly effective treatment.

Effective Autism Treatment Exists

• Effective treatment exists Lovaas treatment has been proven safe and effective in treating 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 at the prestigious University of California at Los Angeles (U.C.L.A.) is safe, used widely 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 (63) 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 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, in reference to Lovaas based autism treatment:

"[it is] 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.. 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 ours). [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.

Dr. Melvin I. deLevie, a prominent Pediatrician in Vancouver, BC with a focus on autism, says in reference to Lovaas:

"There is a successful treatment. If it is started early and is comprehensive, excellent results can be achieved."

Dr. Glen Davies, Professional Advisor to the Autism Society of B.C., states that, "We know from the scientific literature on autism that if [the child] begins intensive behavioural treatment prior to 30 months of age, [the child] may well be one of the 50%... who will recover to a degree that s/he can function normally."

- Lovaas Treatment for Older Children Much of the pioneering work for the Lovaas treatment protocol is based on work with young children. However, Lovaas treatment is tremendously beneficial for older children as well. The quality and intensity of the treatment program for the older children is especially important since it must address deficits and reverse negative behaviours that have had many more years to establish themselves.
- Lovaas Implementation Lovaas Autism Treatment is a scientifically proven, powerful treatment for childhood autism. It has been refined over 35 years of research. It is not new and certainly not experimental; rather, it is well documented and highly regarded by the medical profession including many BC psychiatrists and pediatricians. Despite this, there are no provincial programs or funding to treat children with autism utilizing the Lovaas protocol. Parents who want Lovaas treatment for their child must provide and pay for it privately.

Typically, a treatment program is implemented in the following way. The parent chooses a Lovaas Autism Consultant to fly to BC and spend three days setting up a program customized to the individual child, tailored to that child's deficits. At this time, ideally the consultant also trains everyone who is in that child's life, including the therapists who will be working intensively with the child, family members, and school staff who will be interacting with that child. The consultant provides the team with all the programs that must to be implemented. These programs include pre-academic or academic, language-based, self-help, peer interaction, and behavioral programs to tackle the child's particular behavioral issues and other deficits. The Home-based staff work on all these programs until the child has mastered them. At this point, usually six weeks to three months after the initial visit, the consultant returns to evaluate the child's progress and moves the child onto the next level. During the three months between visits, the consultant views videotapes of the child working with therapists, and ideally has weekly telephone consultation to work through any problems the Home-based treatment team has encountered. When the child enters the school system, that child already has done much work to prepare him/her for integration. When parents send the Lovaas-treated child to school, they send a child that comes with an "instruction manual" of sorts. If the school follows that manual the transition to school can be greatly eased. The Lovaas-treated child has been prepared for success at school.

The School System - Partner or Problem?

Lovaas Autism treatment is a Home-based treatment program. The reason the program has evolved into a Home-based protocol is that studies show it to be most effective in the home environment. For progress in Autism Treatment to continue when the child reaches school age, special care must be taken to integrate the treatment protocol with the educational program and front line support the school district provides for children with autism. Areas of concern for successful transition are integration, school assistants, training of special education staff and access to school by Lovaas autism consultants and the Home-based autism therapists.

• Safety A child with autistic disorder is especially vulnerable. Unlike his normally developing peers, he must be continually supervised to protect him from abuse and/or neglect (e.g. straying off-site with resultant physical injury). This constitutes a high standard of care but one that has proven to be easily met with the appointment of full-time, on-site support. Anything less than a full-time assistant and 100% adult supervision -- including recess and lunch --fails to meet the test of due care on the part of the school district. Supervision by other children, known as "the buddy system", courts disaster and is wholly unacceptable.

Ministry of Education regulations are unambiguous and forceful in this regard. Ministerial order number 151/89 directs that, "children with special needs are potential victims of child abuse in equal **or possibly greater** numbers than other children", (emphasis ours). The District must provide a full-time assistant to show evidence of a good faith effort in the discharge of its mandated duty to prevent child abuse and/or neglect. If an incident were to occur in the absence of a full-time assistant, the District would likely be held liable for failing to meet its duty to disabled children with respect to child protection regulations.

Recess and Lunch Since children with autism have severe social deficits and are not aware of danger as are typically developing children, it is crucial an adult assistant be assigned to the child during recess and lunch. In addition to basic safety, the goal of the assistant during this time is to implement the social interaction portion of the I.E.P. and to ensure that the child stays clear of danger. This is why a policy of one adult looking after a playground of children including a child with autism is unacceptable. We strongly oppose the buddy program -- AT ANY TIME -- since it is extremely dangerous to the physical safety of children with autism.

Integration For the Lovaas Autism Treatment protocol to be successful, it is necessary that a Lovaas treated child with autism
be integrated with typically and normally developing peers - children who do not have disabilities. This affords greater
opportunities for modeling of appropriate behaviours and opportunity for social and language development - areas of particular
deficit for children with autism.

The province of British Columbia supports integration for special needs children in Ministerial Orders and Policy Manuals (see table 1). For successful integration, a commitment must be made by the district for appropriately trained, full-time, front line support to enable an equal, quality education and to assure physical safety.

• Classroom Assistants (CA's) and Teachers In practical terms, Lovaas-treated children with autism are highly integratable. A crucial prerequisite to successful integration is the training and availability of school assistants. Parents, as case managers for their child's Lovaas treatment program, must have a choice in Classroom Assistants and a role in the autism training of the CA. Classroom Assistants play a very important role in the success of an autistic child in the integrated classroom. They are on-site to target problems quickly and, ideally, have specialized Lovaas autism training to promote learning for the autistic child. In the absence of a Lovaas-trained, full-time assistant, the nature of an autistic child's disability is such that it blocks access to an "appropriate public education". The school district must ensure that classroom assistants and teachers receive instruction in the Lovaas method of autism education from consultants specially trained in this field. It is critical Teachers, Classroom Assistants and special education staff be trained in the fundamental aspects of the Lovaas protocol as it applies to basic teaching methods for children with autism. This knowledge will enable the child to learn and, of vital importance, will support the Home-based treatment program. Classroom teachers are responsible for the educational program of all students, including those with special needs. Therefore, it is imperative they be familiar with specific aspects of the Lovaas method of education for children with autism. Moreover, a behavioural plan must be developed collaboratively with the Home-based autism treatment program to target problem areas. The schools staff MUST work collaboratively with the Home-based autism consultants and Home-based autism therapists to implement the Individual Education Plan. THE SCHOOL MUST NOT WORK AT CROSS PURPOSES WITH A HOME-BASED, MEDICALLY NECESSARY AUTISM TREATMENT PROGRAM.

In the short term, Classroom Assistants who work with children with autism in Lovaas programs must learn how to implement the Lovaas treatment program and be free to attend the Home-based program with the family's consultant. The school principal or teacher must show flexibility in permitting such educational opportunities. In the alternative, the Home-based Lovaas consultant must be permitted to consult with the classroom assistants at school. Parents must be able to have input in the hiring process and must be able to replace any assistant who is hired to work with the child if that assistant is not able to support the Home-based Lovaas treatment program.

Over the longer term, classroom assistants must be trained in Lovaas autism treatment prior to working with these children. This will ensure a successful integration of the child and a positive experience for the teacher who can delegate many autism related issues that may arise during the school day.

- Duties of Classroom Assistant Consistent with, and in support of, goals set out in the IEP, it is essential the autism Classroom Assistant be assigned to the autistic child -- NOT the teacher. The teacher must not have authority to redeploy the autism Classroom Assistant to do work unrelated to supporting the autistic child e.g. photocopying or stapling artwork to the bulletin board. The primary duty of the autism C.A. is to work with the child. This is essential for continuity in the Lovaas treatment program. A child in a Lovaas treatment program must never be permitted to "do his own thing" since this works against the Lovaas treatment program. Both the teacher and C.A. must understand that autism is different from other disabilities. The effort to treat the condition imposes a far higher standard of attention. There must be constant monitoring of the child in the classroom so any negative behaviours can be quickly identified and eliminated, and positive behaviours can be taught and reinforced. This is the foundation of a successful autism intervention program. Any "gaps" in monitoring and effectively addressing the child's behaviour undermine the efforts of the Lovaas autism treatment program.
- Access to School by Lovaas Autism Consultants Lovaas treatment is highly effective in educating children with autism. For
 continued progress once a child enters the school system, it is necessary that key elements behind the success of the treatment
 program be transferred to the classroom setting. This requires cooperation between the school, the Lovaas Autism consultant
 and the Home-based autism treatment team. With formal advance notice, the Lovaas autism consultant working in the Homebased treatment program must be permitted access to all areas of the school environment to observe the autistic child. This is
 required to help support the child and the school-based team, maintain progress in school and ensure consistency between the

school and home programs.

• Communication A key to consistency and success in educating the Lovaas treated child is good communication between home and school. Daily communication reports must be made available for the Home-based team to evaluate progress at school and quickly target problem areas for the Home-based team to concentrate on. All school and Home-based professionals working with or observing the child, must provide written reports within 5 days of observation to communicate their work to other members of the team(s). Everyone must know where the child is in his/her struggle against autism and have a common understanding regarding the areas of deficit that must be addressed.

In order to ensure a team approach, the child must have a communication book that travels with the child to and from school. With this tool, the Home-based team is able to work on all problems that arise during the school day, including concepts or skills that the child had difficulty with and any unacceptable behaviours that may arise. The goal of the communication book is exclusively to ensure congruency between home and school. It is not intended to evaluate school staff working with the child. The communication book gives concrete tools to those working with the child before behaviours have a chance to become entrenched and the child falls behind in the curriculum.

• *Individual Education Plan* The Individual Education Plan is a document that represents the collaborative strategy of school and the Home-based team. As such, it must have specific, measurable goals for progress in areas of social, academics, behaviour and communication (the language deficit). The IEP must explicitly set out the means by which these goals are to be achieved.

Underlying the Individual Education Plan process is a fundamental tenet: The School District must formally recognize that Lovaas autism treatment is the most effective treatment for autism and the only autism treatment protocol with scientific data and considerable medical opinion supporting it. The IEP can then be drafted with this operating assumption so that parents avoid individual battles of "proving" the merits of their Home-based autism treatment programs and their decision to pursue the Lovaas method of autism intervention for the child.

Periodic IEP meetings must be instituted to evaluate actual progress of the child. The IEP serves an important role to ensure consistency between the school special education program and the Home-based Lovaas treatment program. Therefore, it is necessary that parents approve the IEP in writing before it is implemented. In other words, parents running a Lovaas treatment program must "sign-off" on the education plan of their child. Formal parental approval of the IEP is required to ensure the education plan is not working at cross purposes to the Home-based autism treatment program.

Agreements: The parent must be required to "sign off" on all Individualized Education Plans prior to that plan being implemented by any school staff. Contents: For a child with autism, the IEP must include not only academic goals but also language and social goals. These goals must be measurable and progress must be evaluated. The contents of the IEP must include a statement of the child's present levels of educational performance, including how the child's autistic disorder affects the child's involvement and progress in the general curriculum. The IEP must include measurable annual goals, including benchmarks or short-term objectives. The goals and objectives must be related to meeting the child's needs that result from autistic disorder to enable the child to be involved in and progress in the general curriculum, and to meet the child's other educational needs that result from the child's Autism Spectrum Disorder disability.

The IEP must include a statement of how the child's progress toward the annual goals will be measured and how the child's parents must be regularly informed (by such means as regular report cards), at least as often as parents are informed of their non-disabled children's progress. Parents must be regularly informed of their child's progress toward annual goals and the extent to which that progress is sufficient to enable the child to achieve the goals by the end of the year.

In developing the IEP, the IEP team must consider the strengths of the child and the concerns of the parents and Lovaas consultants for enhancing the education of their child.

In the case of a child whose behaviour impedes his or her learning or that of others, Lovaas interventions, strategies and supports should be used, where appropriate, to address that behaviour.

The IEP team must review the child's IEP periodically but no less than annually to determine whether the annual goals for the child are being achieved. Revisions to the IEP must be made as appropriate to address any lack of expected progress toward the annual goals and in the general curriculum. The regular education teacher, as a member of the IEP team, must participate in the review and revision of the IEP of the child.

Speech and Language Pathologists (SLP)

Speech and language is an area of great deficit for most children with autism. Unfortunately, most Speech and Language Pathologists use a method that is actually counterproductive for teaching children with autism - the Hannan Method. The SLP who works with children with autism should be experienced in the behavioral method in order to make that child's time productive and the parent should have a choice regarding which SLP is assigned to the child.

Obstacles at School to Teaching Children with Autism

- The District "Autism Team"
 - 1. Lack of Lovaas Training Unfortunately, Canadian professionals do not have up-to-date training on the Lovaas protocol since it is not offered at the University of British Columbia or any other Canadian university. Due to the present lack of educational opportunities in BC for Lovaas Autism Treatment, families must regularly bring in experts from the

U.S. to set up and oversee the treatment program. Even the most extensively trained and experienced BC autism professionals have, at best, experience only in Applied Behavior Analysis (ABA). It is important to stress that ABA proficiency is not equivalent to proficiency in Lovaas autism treatment. Many so-called autism experts in BC do not have Lovaas proficiency and they do not even have ABA training -- a prerequisite to behavioral consulting. Sadly, many BC autism professionals fall far below the minimum standards required to set up and maintain the highly effective Lovaas autism treatment program, yet they are retained as consultants by school districts to advise on and formulate education strategy at school for children in Homebased autism treatment programs. Authority without training and experience often results in misguided and ineffective policy and strategy in reference to educating children with autism. It often is a fundamental obstacle to progress for the child with autism.

2. Territoriality - The regrettable lack of training in Lovaas on the part of the district "autism team" tends to create an atmosphere of animosity. Professionals accustomed to doing things "the old way" often feel threatened by "outsiders" with new, innovative and effective approaches. Territoriality and the doctrine of exclusion then set in. The philosophy of a "closed shop" may work well in the trade union movement but it does not serve disabled children well. When school staff, administration and consultants work to block from the school those consultants working in the Home-based autism treatment program, the child's RECOVERY FROM AUTISM IS JEOPARDIZED. No less than the child's future as an independent, self sustaining adult is at risk. The danger and often the net result of territoriality is that incompetent, so-called autism professionals, are able to successfully exclude competent autism professionals from observing the child at school to develop effective strategies to deal with problem behaviours and to maximize educational opportunities. District autism consultants often feel threatened because their expertise does not extend to the only scientifically supported autism treatment method -- the Lovaas method. While we certainly regret the lack of opportunity for these professionals to be retrained in this method, the major concern for parents is to ensure their child's treatment professionals be allowed to interface freely with the school system.

3. Autism Team Members

- Special Education Member of the Team The special education member of the autism team may have, in the best case scenario, experience working with children with autism. Without formal education in the Lovaas method, the Special Education professional does not have the qualifications to adapt and tailor the school program to meet the needs of the Lovaas treated child. Parents generally welcome the special education team member to learn from the Home-based team to better enable consistency at school. It is critically important that the Special Education member be permitted to study the work of the Home-based team if s/he is to have meaningful input in development of the school education strategy for the child with autism.
- Speech and Language Pathologist The formal education Speech and Language Pathologists receive is, for the most part, ineffective in addressing the most vexing problem in autism -- the language deficiency. It is only a small subset of SLP's who have acknowledged that doing things "by the book" is ineffective with this population of disabled children. Although the speech and language pathologist generally does not have the expertise to effectively deal with autistic spectrum disorder, parents welcome his/her input and encourage the SLP to observe the behavioural consultant at Home-based treatment sessions. Such educational opportunities for SLPs who are part of the District Autism Team will be valuable for support of the Home-based treatment program in the school.
- Curriculum Head If the autism team has a curriculum head, that professional can be very helpful to the treatment effort. By explaining the regular curriculum of the school to the Lovaas Consultant, the Home-based team can develop a treatment plan that is carefully tailored to the school curriculum. Much of the "heavy lifting" can then be done in the Home-based program, The net result is a well prepared child that can benefit equally from the curriculum. The Lovaas consultant is uniquely qualified to tailor the curriculum for a child in a Lovaas program -- not the curriculum head of the District Autism Team.
- "Outside" Consultants There are three "outside" consulting agencies in British Columbia that school districts generally contract with. These companies are: CBI, Gateway, and the Laurel Group. All three companies work with children with autism. Some utilize Applied Behavior Analysis while others use an "options" approach. It is important to emphasize that none of the BC autism consulting companies are qualified to set up and maintain Lovaas Autism Treatment programs, The reasons for this stem from fundamental ideological objections and, more practically, a profound lack of knowledge and training in the Lovaas treatment protocol. Although it is the right of every parent to choose to retain the services of one of these consulting agencies, it is an equally fundamental right of parents of autistic children to see that their child receives Lovaas treatment -- the only scientifically backed autism treatment protocol. Every child is an individual and that is why every child is entitled to an Individual Education Plan (IEP).

4. Negative Impact of the District "Autism Team" on Frontline Education Professionals

Despite their lack of qualifications and experience in setting up and running Lovaas treatment programs, the District Autism Team (D.A.T.) wields tremendous influence. Since autism is a "low-incidence" disability, most frontline education professionals have had little training or experience with this population of children. In matters relating to children with autism, school staff and administration understandably defer to the D.A.T. Consequently, when the D.A.T. acts in an exclusionary, "closed shop" manner vis a vis consultants working in the Home-Based autism treatment program, the D.A.T. sends an extremely negative message to the school-based staff resource specialist, teacher and the assistant. They give tacit "expert" approval -- the "green light" -- for school staff and administration to be exclusionary and obstructionist towards efforts of the Home-based autism consultants and their treatment program. In this negative atmosphere, it makes perfect sense for school staff and administration to "just say no" to the parent and Home-based consultant when they request access to the school for purposes of observation and study. By rejecting Lovaas, the D.A.T. gives tacit permission for school staff and administration to oppose and reject the tremendous autism treatment effort parents have undertaken.

Table 1: British Columbia Laws, Regulations and Policies to Protect Children With Special Needs

British Columbia Laws, Regulations and Policies to Protect Children With Special Needs:

- 1. Students with autism are "eligible for 950 hours of instruction immediately upon attaining the age of eligibility for kindergarten." Special Education Services: A Manual of Procedures and Guidelines, For Easy Reference, Full Day
- 2. "A board must provide a student with special needs with an educational program in a classroom where that student is integrated with other students who do not have special needs." Ministerial Order M150/89, Rev. M397/98 Special Needs Student Order.
- 3. "access will be seamless as possible... school-based administrations should ensure... first-line resource support on-site." Special Education Services: A Manual of Procedures and Guidelines, Rules and Responsibilities, School Dis-
- **4.** "meaningful consultation with parents [since] they know their children and can contribute in substantial ways to the design of an appropriate program and services." Special Education Services: A Manual of Procedures, Guidelines, Rules and Responsibilities, School Districts, Program Development and Delivery.
- 5. "parents play a fundamental role in the education of their children. Their knowledge about their children should inform planning for their children's education." Special Education Services: A Manual of Procedures and Guidelines, A Message from the Minister.
- "children with special needs are potential victims of child abuse in equal or possibly greater number than other children." Ministerial Order 151/89.
- 7. The BC Ministry of Education states that in the process of ensuring the education rights of disabled children, our goal is not to add to the work load of teachers, but on the contrary to support their capacity to manage in the classroom." Special Education Services: A Manual of Procedures and Guidelines, A Message from the Minister.
- **8.** Charter 15 of the Canadian Charter of Rights and Freedoms states:
- 15(1) 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. (emphasis ours)
- (2) Subsection (1) does not preclude any law, program or activity that has as its object the amelioration of conditions of disadvantaged because of race, national or ethnic origin, religion, sex, age, or mental or physical disability (emphasis ours).

School District Autism Policy; B.C. and Laws and Regulations; Charter of Rights

 BC Laws and Regulations To provide disabled children with a quality education, in the least restrictive environment, is a fundamental tenet in British Columbia. Ministerial order M150/89; Rev. M397/95 — Special Needs Students Order — stipulates that, "A board must provide a student with special needs with an educational program in a classroom where that student is integrated with other students who do not have special needs..." Professional opinion is that Lovaas treated children must have a full-time assistant to ensure successful integration with students who do not have special needs. In the absence of such support, the stage will be set for failure in "the least restrictive environment" as mandated by Ministerial Order M150/89; Rev. M397/95 (Table 1 - Sec. 2).

Similarly, the Ministry of Education Manual of Policies, Procedures and Guidelines, Special Education Services, is unambiguous in its dictate regarding the rights of disabled children to a quality education. The Ministry manual states that, "access [to special needs programs] will be as seamless as possible" (Table 1 - Sec. 2). To achieve this objective, the Ministry of Education manual states that, "school-based administrators should ensure ... first-line resource support on-site" (Table 1 - Sec.2).

The manual also directs that special education services at the local level must be provided with "meaningful consultation with parents [since] they know their children and can contribute in substantial ways to the design of an **appropriate** programs and services..." (emphasis ours, see Table 1 - Sec. 4)

The Office of the Minister of Education has issued a Statement of Guiding Principles supporting the fundamental tenet of "equitable access to learning" (See Special Education Services: A Manual of Procedures and Guidelines; A message from the Minister). Autistic Disorder poses an insurmountable barrier to "equitable access to learning" without full-time, front line support. The Statement of Guiding Principles states that, "parents play a fundamental role in the education of their children. Their knowledge about their children should inform planning for their children's education." (Table 1 - Sec. 5).

The knowledge of parents running Home-based autism treatment programs, of necessity is considerable. They serve as case manager for their child's treatment program. Parents' role in tailoring the school program to the autistic child must

be recognized as "fundamental" and the Provincial policy in this regard must be enforced at all levels of the School District.

Parent's efforts to "inform planning" on autism strategy must not be viewed by school staff and administration as an intrusion into "professional jurisdiction" by "lay people".

- Canadian Charter of Rights and Freedoms The Charter of Rights and Freedoms and legal precedent are clear in mandating the rights of disabled children. The relevant sections 15 (1) and 15 (2) state,
 - 15. (1) 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**. (emphasis ours)
 - (2) Subsection (1) does not preclude any law, **program** or activity that has as its object the amelioration of conditions of disadvantaged individuals or groups including those that are disadvantaged because of race, national or ethnic origin, colour, religion, sex, age or **mental** or physical **disability.** (emphasis ours)

In practical terms, the Supreme Court of Canada has made clear that persons with special needs must have the necessary resources in order to take full advantage of the benefits that are provided to other persons in the same government system. Government is required to take special measures to ensure that disadvantaged groups, including children with autistic disorder, are able to benefit from government services such as education. (see the Eldridge decision, October 9, 1997).

The School District must not permit de facto discriminatory policy against neurologically handicapped children to persist. The District must not permit an arguably calcified, anachronistic view of autistic children to jeopardize the *enormous* potential -- and right -- of children with autistic disorder to lead happy, normal lives as self sustaining adults.

Policy Recommendations

To protect children with autism and give them the best possible chance for a quality education, the school board must issue a strong and unambiguous policy directive. The directive must give clear direction to the "autism team" in Richmond, resource specialists, teachers and school administration. In simple terms, the message that must be sent out is that, "the Lovaas method of teaching autistic kids *works*, and <u>EVERYONE</u> working with autistic children must get behind it enthusiastically". Political turf wars must stop in the best interests of disabled children.

The School District must recognize what scientific data and BC physicians support as medically necessary for children with autism -- Lovaas autism treatment. To this end, directives must be issued to implement a new, supportive policy at school for children in Home-based Lovaas autism treatment programs.

· Recommendations

- 1. **Statement of Principles** In view of scientific evidence and the medical opinion of BC physicians regarding Lovaas autism treatment, the District must issue a statement of principles to formally endorse the merits and efficacy of Homebased Lovaas autism treatment programs. The unique educational needs of Lovaas-treated autistic children must be recognized and addressed by the District.
- 2. **Cooperation with Home-based team** School staff and administration must cooperate with the medically necessary work being done by the Home-based Lovaas autism treatment team.
- 3. School Access for Lovaas Consultants and Home-based Therapists Specific policy must be drafted to allow access by senior autism therapists and Lovaas consultants, to all areas of the school as necessary for the purpose of periodic observation of the autistic child at school. Such observation is necessary to the development of effective autism treatment programs and to a successful, appropriate education for children with Autistic Spectrum Disorder.
- 4. **Parental Involvement** The School District must ensure that parents running Home-based Lovaas treatment programs are involved in the design, evaluation and, where appropriate, implementation of school-based plans that do not conflict with the Lovaas treatment protocol.
- 5. Individual Education Plans (IEP) The IEP must have specific, measurable goals for progress in areas of social, academics, behaviour and communication (the language deficit). The IEP must explicitly set out the means by which these goals are to be achieved. Periodic IEP meetings -- no less than annually -- must be instituted to evaluate actual progress of the child. The IEP serves an important role to ensure consistency between the school's Special Education program and the Home-based Lovaas treatment program. Agreements: The parent must be required to "sign off" on all Individualized Education Plans prior to that plan being implemented by any school staff. Contents: For a child with autism, the IEP must include not only academic goals but also language and social goals. These goals must be measurable and progress must be evaluated.
- 6. Classroom Assistants Consistent with, and in support of, goals set out in the IEP, it essential the autism Classroom Assistant be assigned to the autistic child -- NOT the teacher. There must be constant monitoring of the child in the

classroom so any negative behaviours can be quickly identified and eliminated, and so that positive behaviours can be taught and reinforced. Parents, as case managers for their child's Lovaas treatment program, must have a choice in Classroom Assistants and a role in the autism training of the CA. Classroom Assistants who work with autistic children who are in Lovaas programs must learn how to implement the Lovaas treatment program and be free to attend the Home-based program to observe the family's consultant. The school principal or teacher must show flexibility in permitting such educational opportunities. In the alternative, the Home-based Lovaas consultant must be permitted to consult with the Classroom Assistant at school. Parents must have input in the hiring process and must be able to replace any CA who is hired to work with the child if that assistant is not able to support the Home-based Lovaas treatment program. Over the longer term, classroom assistants must be trained in Lovaas autism treatment prior to working with Lovaas-treated children.

- 7. **Recess and Lunch** Since children with autism have social deficits and are not aware of danger in the same way as typically developing children, it is mandatory a Classroom Assistant or other adult be assigned to the child during recess and lunch. The goal of the Classroom Assistant during this time is to implement the social interaction portion of the I.E.P. and to ensure that the child stays clear of danger. This is why a policy of one adult looking after a playground of children including a child with autism is unacceptable. We strongly oppose the buddy program -- AT ANY TIME -- since it is highly dangerous to physical safety of children with autism.
- 8. **Communication** The child must have a communication book that travels with the child to and from school. With this tool, the Home-based team will be able to work on all problems that arise during the school day, including concepts or skills that the child had difficulty with and any unacceptable behaviours. All school and Home-based professionals working with or observing the child, must provide written reports within 5 days of observation to communicate their work to other members of the team(s).
- 9. **Professional Development Days** Classroom teachers are responsible for the educational program of all students, including those with special needs. Therefore, it is imperative they be familiar with specific aspects of the Lovaas method of education for children with autism. To this end, "In Service Days" must be sponsored by the school district given by qualified Lovaas Autism professionals endorsed by the U.C.L.A. Young Autism Clinic. Classroom teachers and Classroom Assistants must receive autism education opportunities with Lovaas consultants to better manage and educate this population of children.
- 10. **Speech and Language Pathologists (SLP)** The SLP who works with children with autism should be experienced in the behavioural method in order to make that child's time productive. The parent should have a choice regarding which SLP is assigned to the child.

Sources of Information on the Lovaas Method for Children with Autism

Video Tapes

1. "Behavioral Treatment for Autistic Children", By O. Ivar Lovaas. (The university libraries all have copies).

This is an excellent introduction to the Lovaas Method and its tremendous potential.

2. "The Child Who Couldn't Play", By David Suzuki, from the C.B.C. series "The Nature of Things".

Best Selling Books

1. Maurice, Catherine. Let Me Hear Your Voice. New York: Alfred A. Knopf, 1993.

This is the story of a mother who used the behavioral technique pioneered by Dr. O. Ivar Lovaas at the University of California at Los Angeles (U.C.L.A.) to treat two of her children, both diagnosed with autism. She describes the therapy from the beginning up until the time when both her children were indistinguishable from their peers. Dr. Lovaas has a chapter at the end of the book (page 324) and Appendix II contains many of the drills used. This is the best "light reading" on the method.

2. Johnson, C. and J. Crowder. AUTISM:: From Tragedy To Triumph. Boston, M.A.: Branden Publishing Co. Inc., 1994.

This is another story of a mother who used the Lovaas method (based on Behavioural theory) to treat her son who was diagnosed with Autism. This is a very quick read but does not go into as much depth about the treatment is the Maurice book, listed above.

Technical and Academic Material

1. Technical Teaching Manual of the method

Lovaas, I. O. Teaching Developmentally Disabled Children: The ME Book. Austin, Texas: Pro-Ed, 1981.

This is the detailed instruction manual that is the basis for therapy programs using the Lovaas method.

Maurice, Catherine. Behavioral Intervention for Young Children With Autism. Austin, Texas, Pro-Ed, 1996.

This is a comprehensive book which goes into great detail on how to set up, and administer an intensive early intervention program using the technique pioneered by Lovaas.

2. Samples of Journal Articles based on the method pioneered by Dr. Lovaas.

Smith, T. (1998). Outcome of early intervention for children withautism. <u>Clinical Psychology: Research and Practice.</u> (in (press).

Smith, T. and Svein Eikeseth et. al.. (1997) "Intensive behavioral treatment for preschoolers with severe mental retardation and pervasive developmental disorder," American Journal on Mental Retardation, 102(3), 238-249.

Smith, T. (1994). "Improving membory to promote maintenance of treatment gains in children with autism" <u>The Psychological Record</u>, 44, 459-473.

McEachin, J.J., Smith, T. and Lovaas, O.I. (1993). "Long-term outcome for children with autism who received early intensive behavioral treatment", <u>American Journal on Mental Retardation</u>, 97, 359-372.

Lovaas, O.I., & Smith, T. (1989) "A comprehensive behavioral theory of autistic children: Paradigm for research and treatment", <u>Journal of Behavior Therapy & Experimental Psychiatry</u>, 20, 17-29.

Lovaas, O.I. & Smith T.(1988) "Intensive behavioral treatment for young autistic children". In B.B. Lahey & A.E. Kazdin (Eds.), Advances in Clinical Child Psychology, (Vol. II). New York: Plenum Press. Pp. 285-324.

Lovaas, O.I.(1987). "Behavioral treatment and normal educational and intellectual functioning in young autistic children", <u>Journal of Clinical and Consulting Psychology</u>, 55, 3-9.

Lovaas, O.I., Loegel, R.L., & Schreibman, L (1979). "Stimulus overselectivity in autism: A review of research.." <u>Psychological Bulletin</u> 56, 1236-1254.

Lovaas, O. I. (1977). The Autistic Child: Language Development Through Behavior modification. New York: Irvington.

9