

An Autism Care Pathway:

***The Need for 'Cradle to Grave' Treatment of Children and
Adults with Autism Spectrum Disorders***

A Brief by the ASBC Board of Directors

April 12, 2001

We, the Board of Directors of the Autism Society of British Columbia, are issuing this brief at an important crossroads in the history of autism treatment in British Columbia, on behalf of hundreds of children and adults with Autism Spectrum Disorder across the province. We are calling for government ministries to work together, on an urgent basis, to develop a Care Pathway for people on the Autism Spectrum to ensure effective, rapidly available, and accountable treatment. We fear that without high-level leadership and political commitment from the government of British Columbia, the current situation will dissolve into a series of long-term legal battles that will fail to provide essential treatment for those who require it now and in the future.

In order to avoid this waste of financial and human resources, it is imperative that the government adopt an approach to the challenge of autism that is based on current research and best practices in autism treatment, rather than bureaucratic expediencies. This would be in the spirit of the *Auton* decision which confirms that children with autism have a right to treatment according to the Charter of Rights and Freedoms.

The Background

Autism is a development disability that impairs communication, social skills, and cognition, and is sometimes called “Pervasive Developmental Disorder”(PDD). Other disorders in the PDD family of Autism Spectrum Disorders include Asperger’s syndrome, Rett’s syndrome, Childhood Disintegrative Disorder, and PDD-NOS (pervasive developmental disorder – not otherwise specified). The current studies on the number of children affected are alarming: about 1 in 1,000 children are born with the full symptoms of autism. The number born within the PDD is even higher, at about 1 in 500. autism is a very complex disorder, and the needs of these individuals across the spectrum vary greatly. It is also important to mention that parents and professionals now know that the symptoms of autism are treatable – there are interventions that can make a significant difference in lessening long-term dependency on family and government support.

Over the last decade, ASBC has consistently advised government agencies of the dire need for comprehensive skilled services for children and adults on the Autism Spectrum. Finally, in January 1998 ASBC spearheaded The ***Crisis in Services for People with Autism in British Columbia*** – a brief submitted by the BC Council on Autism. The inter-ministerial ***Autism Action Plan*** that belatedly followed in May 1999 had promise but lacked inter-ministerial will, a proscribed budget, and timeline to be effective in addressing the crisis. In May 2000, a ***Pilot Project for Early Autism Intervention*** was being formulated as court proceedings were ongoing. The purpose of the Pilot Project was not to re-determine that treatment of young children is effective – international research had already done that. The purpose of the Pilot was to determine if there were enough skilled psychologists and other specialists working in teams in BC willing to come forward and provide structured accountable services.

The court proceedings described above were at first a class action petition heard before Madame Justice Allan in 1999. She decided that the children being represented did not fulfill the definition of a class action. The next proceedings were heard by Madame Justice Allan in the Spring and Summer of 2000 in which four representative families petitioned the Supreme Court of BC – “***Auton et al. v. the Attorney General of British Columbia***” (Docket: C984120; Registry: Vancouver). The *Auton* decision was specifically limited to the issue of programs for pre-school children and their families who were privately funding these treatments.

On July 26, 2000 Madame Justice Allan of the B.C. Supreme Court ruled that the Crown discriminated against the infant petitioners contrary to s. 15(1) of the Charter of Rights and Freedoms “by failing to accommodate their disadvantaged position by providing effective treatment for autism.” This landmark decision recognizes the treatment rights of these children. Medical evidence shows that early intervention treatment for children between the ages of two and six has significant benefits within this target group. Of course, it should be recognized that the treatment of autism does not stop at age seven. There is also evidence supporting ongoing individualized treatment as highly effective in increasing the functioning level of those who receive treatment.

The Current Dilemma

The *Auton Decision* has forced a response to address early intervention (Ages 2-6) but B.C. does not have the capacity to treat this target group. As we have not had funding for treatment in the past, we simply do not have a sufficient pool of skilled early intervention specialists to treat the children who now require it. In particular, there is short supply of psychologists with credentials and experience in Applied Behavioural Analysis. We also need Speech Pathologists, Occupational Therapists, and one-to-one therapists/tutors to implement these programs.

A major concern is that the apparent commitment to a centralized program. Leaves out a potential major resource for the children currently in need: the Out-of Province psychologists who currently provide individual treatment programs effective for a number of families who have been funding these programs from their own resources. We believe that some form of individualized funding should be made available to credentialed specialists and monitored in the same fashion as potential in-province providers.

In effect, the fast track response by the Ministry for Children and Families and the Ministry of Health in response to the *Auton Decision* has catapulted the Pilot Project into a full provincial program which we are aware is in the planning phase. We have some of the details of the three agencies providing Early Intensive Behavioural Intervention Programs, that have been recently approved. We are aware from the short experience of planning the Pilot that the vast majority of current B.C. services providers will be challenged to meet a baseline of “best practice” criteria for autism treatment because of the lack of experience with pre-schoolers in B.C.

We are very concerned that our current diagnosis services are overburdened and inefficient. We need diagnosis that includes ongoing medical support for children and adults who live with a severe, though invisible disability. We are concerned about the development of a new Provincial Program that does not include an excellent proposal that was already available and endorsed by our Board for Government consideration that was already available and endorsed by our Board for Government consideration (PADD Pilot – Pervasive/Autistic Developmental Disorder). The proposal for the PADD Pilot appears to be languishing even as waiting lists for diagnosis and assessment continue to grow.. this is a time when we must innovate to meet the diagnostic needs of children entering the new Intensive Early Intervention Programs.

Getting access to speedy diagnosis and treatment is an important issue for many families. At the offices of ASBC in recent months we have been fielding dozens of calls the *Auton Decision*. To most of these families we can only reply that either their child is too old to

qualify for the treatment programs ordered by Madame Justice Allan or that by the time programs are in place in their region, their child may be too old. We estimate that 75 percent of our current membership will not benefit from what we understand of the current restrictions on treatment.

We are encouraged that the Auton decision has positive implications for the very young children currently being diagnosed who until recently had little hope of treatment unless their parents could pay privately. It is our contention that the need for families of children with autism to go to court could have been averted had the Government of the day developed services in step with research developments in autism treatment. Instead it was insisted, in the face of all the evidence of need and efficacy, that they would not fund the provision of any behaviourally – based treatment, specifically those using the methodology of Applied Behaviour Analysis.

While we are encouraged for the young child with autism, in our role as ASBC's Board of Directors, it is our mandate to represent all people with Autism Spectrum Disorders in this province. The Auton decision does not address the lifelong treatment requirements of people with autism; however, it does set a significant legal precedent in determining that autism is a medical condition with the potential to improve significantly with appropriate treatment. Research demonstrates that the benefits of treatment do not stop at age six, and further improvements can reduce total costs in lifelong supports. Moreover, the Charter of Rights and Freedoms does not allow discrimination based on age.

We know, based on the research, that early intervention will only solve half the problem. Many graduates of even the best programs need continuity in transition between home-based programs and school, school to higher education and vocational arenas. What is required is a well thought out inclusive plan for autism treatment across the life-span. Though a future of multiple lawsuits and Human Rights complaints could gradually rectify the global problems, would it not be better to plan proactively based on the literature, research, and input of experts in autism?

We appreciate that the Ministry of Children and Families had committed itself to developing treatment based on a best practices model as directed in the Auton decision, but they need significant community input, and real commitment from other relevant government ministries because of the magnitude of the task. Our families will not accept that only pre-school children will benefit from this commitment to best practices in autism treatment.

The Solutions

The Ministries of Health, Education, and Children and Families each have an essential role to play; we need to meld the good of each and plan for continuity, efficiency, and effectiveness in the delivery of government programs in order to have a proper Care Pathway for people with Autism Spectrum Disorders.

The Ministry of Health:

- Is currently restricted by a medical model that must flex to include traditionally non-medical expertise. The current Mental Health Model must shift away from medication for crisis management to providing treatment in balance with support. It is ethically unacceptable to continue to medicate children and adults with autism because the

behavioural treatment they require is not available to proactively help them, whether it is required in the school system or in a group home for adults. The PADD Pilot should be funded to encourage early diagnosis and the proactive team treatment of people on the Autism Spectrum, to ensure that medications are utilized ethically.

The Ministry of Education:

- Autism treatment must not stop as children move into the school system. Currently, dozens of children on the Autism Spectrum are being medically excluded or withdrawn from B.C. schools because of inappropriate programs and a lack of expertise within schools. We hear from their parents who are desperate for their children to have a meaningful education experience in the public school system.
- To prepare our children to become functioning adults, schools must continue using treatment that worked with pre-schoolers. Too many of our children are being withdrawn from the school system because the Ministry of Education appears unwilling to implement its own policies in local school districts. Home-schooling a child cannot rectify a social-communication disorder. We are particularly disturbed that provincially negotiated collective agreements are interpreted at a local level to the detriment of special needs students. We see no evidence that the recent Special Education Review is having any positive impact on our children in B.C. schools.
- We are particularly disappointed that the Ministry of Education's own under funded Provincial Outreach Program for Autism and Related Disorders, or programs similar to it, have not been expanded despite the frantic requests from parents for help from their consultants. The POPARD has only 4.5 F.T.E. consultants to meet the needs of all the school age children in this province on the Autism Spectrum. This is an appalling under-resourcing of the population and directly contributes to the number of ASD children who are unable to attend school.

The Ministry for Children and Families:

- The social support model of Community Living Services must change its focus from support to treatment of school age children and adults.
- We are encouraged that MCF is preparing to re-evaluate the current Behaviour Support Program for children up until the age of 18. Both the service delivery model and the necessary qualifications of the consultants must be re-evaluated to ensure that the families are properly served. Regular review of programs focusing on outcome measures is a necessity. As is the regular independent assessment of parental satisfaction with this service. The high level of credentials required to run an Early Intensive Behavioural Intervention Program should be reflected in the credentials required to provide Behavioural Support Programs. The objective should be a seamless transition from the Early Intensive Behaviour Intervention Programs to Behaviour Support Programs for school-age children.
- Research demonstrates that there are ongoing improvements if the adult with autism is treated and this leads to cost savings. We are particularly concerned that adults with Autism Spectrum Disorder are being denied treatment largely because of budgetary constraints. Of particular concern are the many instances of the dependent adult in a group home whose needs for a communication/behavioural program is denied, leading to burgeoning behavioural problems often inappropriately managed by medications.

- The more able adults who are denied any treatment/support because their I.Q's are over the arbitrary level of 70 are also a tremendous cause of concern. They remain very vulnerable and dependent on their families. Specialists agreed that I.Q measurements are irrelevant to people with Autism Spectrum Disorder as it is a social/adaptive disability that has little to do with standard measurement intelligence tests.

Recommendations:

When all these ministries and models pull together, adopt and absorb, shift and change, there will be a great savings – both monetary and human. In essence one Ministry must spend for another to save. The taxpayer does not care which, just that the taxpayer spends wisely, and saves on the long-term costs in support of these individuals. We recognize that autism seriously challenges the government to plan outside of the customary boundaries.

In addition to the specific suggestions we have made above, we respectfully propose the following recommendations in order to develop a 'cradle to grave' Autism Care Pathway;

- We need to bring all the appropriate players to a planning table to design a care plan.
- An expert committee/panel should be contracted, and properly remunerated, to credential potential service providers who satisfy "best practice" criteria. This will avoid any potential conflicts of interests for an advisory committee that contains service providers.
- The expert committee/panel should endeavor to review ongoing developments in autism and incorporate these into future criteria.
- A separate system be formed to assess efficacy and efficiency of service providers based on objective parameters in keeping with the same best practice literature.
- After a review of cost effectiveness, and after a credentialing process to meet the same best practice criteria, current parent-funded treatment programs should be maintained and built upon.
- Ministerial and Treasury Board commitment be monitored by the autism care planners.

Respectfully submitted by the Board of Directors of the Autism Society of British Columbia.