The Crisis in Services For People with Autism in British Columbia

A Brief by the B.C. Council on Autism

January 15, 1998

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*** in a footnote indicates that the reference is contained in the collection of 'Supporting Documents' for the brief, available from the Autism Society of British Columbia. The books referred to in the brief are available from the ASBC library.*

Endorsements

The membership of the British Columbia Council on Autism, in view of their extreme concern over the deterioration of services to people with autism in British Columbia, requested Deborah Pugh, Program Director of the Autism Society of British Columbia, to develop the following brief. Members of the Council, who include leading professionals in the field of autism, were extensively consulted and provided informed insight and extensive suggestions into this complex area during the development of this paper.

The following members of the Council have had the opportunity to read and have endorsed the brief:

Dr. David Batstone,	**Clinical Child Psychologist, Queen Alexandra Centre for Children's Health, Victoria**
Susan Cambridge,	**Vancouver Island Autistic Homes Society**
Dr. Glen Davies,	**Psychologist, South Fraser Child Development Centre**
Bruce Douglas,	**Director, Giant Steps Vancouver**
Dr. Linda Eaves,	**Psychologist, Sunny Hill Health Centre for Children**
Andrea Emmons,	**Gateway Behavioural Support Services, Northern B.C.**
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Dr. Helena Ho,	**Pediatrician, Sunny Hill Health Centre for Children; Professor of Paediatrics, University of British Columbia**
Karen Hovestad,	**Vancouver Island Coordinator, ASBC**
Susan Mann,	**Executive Director, Gateway Society**
Barbara MacLean,	**Gateway Behavioural Support Services (Lower Mainland)**
Joanne Marshall,	**Delta Association for Child Development; Leap Pre-School**
Chris Rose,	**Program Director, Giant Steps West Therapeutic Society**

Jo-Anne Seip, **Principal, Gateway Provincial Resource Program**

Colin Tisshaw, **Executive Director, Laurel Group**

Other professionals involved in autism endorsing the brief:

Cathy Anthony,	**The Family Support Institute**
Dr. Jackie Baker –Sennet,	**Associate Professor in Educational Psychology and Special Education, University of British Columbia (U.B.C.)**
Dana Brynelsen,	**Provincial Advisor, Infant Development Program**
Dr. Melvin deLevie,	**Pediatrician**
JoAnne DiTommasco,	**Infant Development Consultant**
Dr. Jane Garland,	**Clinical Associate Professor in Psychiatry, U.B.C. Director, Mood and Anxiety Disorders Clinic, British Columbia Children's Hospital**
Leonora Gregory,	**ANCA Consulting Incorporated**
Dr. Keith Marriage,	**Clinical Professor of Psychiatry, U.B.C. Medical Director Adolescent Psychiatric Unit, British Columbia Children's Hospital**
Dr. Pat Mirenda,	**Associate Professor, Department of Educational Psychology and Special Education, U.B.C.**
Dr. Carl Rothschild,	**Child and Family Psychiatrist Alan Cashmore Centre, Vancouver; Co-Chair of Autism Spectrum Agency Partners (ASAP)**

This list is accurate as of March 11, 1998

British Columbia Council on Autism

Vision Statement

In order for children and adults living with autism to reach and maintain their potential, services must be accessible, equitable and appropriate to that individual, wherever a person is in British Columbia, whatever their age.

Services need to be delivered by knowledgeable professionals in a timely fashion. Specialized research programs and training in autism spectrum disorders should be developed at the college and university level for education, medical and social work professionals. The professionals who deliver these programs must have access to ongoing professional development in autism. Professionals must be accountable to families and to taxpayers for providing support that will build independence, to the degree that each individual is capable. People with autism vary dramatically in their abilities; the only practical approach is one that develops individualized programs.

Given what is now known about the efficacy of early intervention for children with autism, early diagnosis is vital in order to ensure that interventions are made available while the brain is still developing rapidly. This is critical to cost-effective outcomes aimed at maximizing a child's potential and minimizing stressful behavioural problems, leading to family break down. The vital contribution that parents can make in choosing an appropriate program for their child needs to be recognized by government and professionals. Ideological commitment to inclusion or to specialized programs should not distract from the primacy of focusing on the needs of the child or adult with autism. Focusing on individual requirements necessitates an integrated approach that includes the family as the person with autism makes the transition from pre-school to school, from school to adulthood.

Executive Summary

When British Columbian policy makers are contacted by concerned parents representing groups within the autism community, whether it is Families for Early Autism Treatment of British Columbia – (F.E.A.T. of B.C), Giant Steps or parents of children using the Gateway facility in Ladner, they often assume that these groups represent completely conflicting positions within the autism[1] community. While these groups have different approaches, in part because they are focusing on the needs of different age groups, they are united by a common thread. They all represent groups of families whose children are not being adequately served by the current system and are desperate to have funding re-directed to programs that will better serve the diverse needs of people with autism.

As the Autism Council of B.C., we represent the professional community involved in the autism field. In recent years, we have found our work increasingly onerous because we have been unable to respond effectively to the needs of people with autism given the limited resources available. Rather than responding pro-actively, we are operating in crisis mode.

Early intervention is recognized as critical to reducing the long-term impairments associated with autism in terms of both cost and the impact on family and community. The current long waiting lists for services, and the insidious thinning of these same services results in the denial of early intervention. Yet, time is critical. The same services delivered at five years of age will not get the same results as if they are delivered at two or three. Thus waiting lists are a terrible waste of financial and human resources.

Ironically, the failure to provide adequately what is required has come at a time of unprecedented international progress in the assessment and treatment of autism spectrum disorders. Many families in B.C. know about specialized intervention programs. They are also aware of the latest research on brain plasticity that proves that it rapidly diminishes with age – if you do not intervene before the age of four, the optimum window of opportunity is lost forever. The unwillingness of government to fund intensive early intervention, insisting that needs can be met by generic services (for example supported child care) leads to wasted resources and tremendous frustration. This is especially the case for the parents of younger children who have been badly impacted by waiting lists. These are the children who could benefit to the greatest degree from the latest developments but they are denied autism specific intervention programs.

Families in British Columbia have no guaranteed access, and no legislated right to therapeutic services. In the United States, where most of the best work has been done on autism treatment, funding has been provided because federal law requires state Departments of Education to implement early intervention programs for all disabled children or federal funding is not forthcoming. Eligibility for full-day early intervention programs begins at the age of two and carries on until the age of 21. Outcomes are closely

[1] For a definition of autism please see p. 11

measured. In addition, American private health insurance companies cover intensive, expensive autism intervention programs. These sources of funding have led to a proliferation of intensive therapeutic programs based on the premise that autism is treatable. Research cited in the attached brief substantiates this premise and indicates that the implementation of early intervention results in significant savings for the taxpayer.

In B.C. the dominant attitude is that autism is incurable, therefore parents who are requesting therapeutic interventions are either cruelly deluded by questionable practitioners or are in denial, refusing to accept the seriousness of the diagnosis. Neither the Ministry of Health nor the Medical Services Plan covers early intervention therapies beyond the skimpy provision of generic speech and occupational therapy.

Historically the Ministry of Social Services, now the Ministry for Children and Families (MCF), has dominated service provision for pre-school children with autism. The Ministry of Social Services was very reluctant to involve itself with therapies. Instead social workers favoured strategies aimed at providing supports that allow a family "to retain its dignity" with the provision of respite services and behaviour consultants. Increasingly, because funding has not kept up with the numbers of children diagnosed, services are not implemented until the family is in crisis and the child's difficult, often dangerous, behaviours are entrenched. While the Ministry for Children and Families has the responsibility for ensuring that all pre-school children with disabilities receive intensive early intervention services, lack of funding is making adequate provision an illusion.

Supported Child Care (SCC), the latest program initiative by MCF, exemplifies the bias of policy makers. They have ignored the vociferous opposition of parents of children on the autism spectrum, who are extremely concerned that the program does not prioritize the need for specialized and highly skilled therapeutic interventions for children being placed in neighbourhood child care facilities. SCC gives secondary status to parental demands for autism specific interventions to enable the autistic child to achieve life-long inclusion in the community. Families have been frustrated at their requests for continued funding for specialized, integrated centres being misconstrued as support for segregated institutions.

A similar dilemma faces parents within the education system. While it is the policy of the Ministry of Education, Skills and Training that special settings with specialized expertise have a place for some children, in practice school boards are limiting options for children with autism in order to save funds. This situation will worsen if funding for special education is de-targeted without province-wide standards being put in place first, as is the plan of the Ministry for the 1998-99 school year.

In some areas the only option is the placement of a child in a regular classroom, in others most are forced into segregated classrooms, regardless of the student's individual needs. Children across British Columbia have benefited dramatically from inclusion. Parents strongly approve of the inclusion philosophy now endorsed by the B.C. Ministry of Education, Skills and Training but they do not believe their children can continue to be successfully educated in regular schools in the absence of sufficient resources and trained personnel - both of which are in short supply in British Columbia's schools because of

funding cuts. In the case of some children who are profoundly affected in the sensory realm by autism, there needs to be recognition that they may require very modified programs before they can be included in regular programs. Without them they are often given medical exclusions and suspended indefinitely. This denies them the education they so vitally need to prepare them for life in the community. The fact that the Ministry for Children and Families does not provide services during school hours puts even greater pressure on families.

We also must not neglect the needs of adults with autism, in particular those making the transition to adulthood. All too often this is done in a confused manner, with various ministries unwilling to cooperate. In particular, we see teenagers and adults deprived of the resources that they need to live and work independently because there are both massive deficits in funding and a lack of programs that are appropriate to the very variable abilities of this group. Many people with autism do not qualify as mentally handicapped but they do require services to address their profound social deficits so that they can live safely and independently. People with Asperger Syndrome are a particular concern. Autism is unique and complex neurological disorder and must be recognized as such.

Both professionals and parents fear generic programs, implemented by large organizations with no specialised knowledge of autism. They believe that the current move to large service providers will mitigate against the provision of programs which can address the individual needs of people with autism, whatever their age. In many cases, individualized funding could insure that families can access the specialized services that they require. Indeed many non-specialist service providers do not want to offer programs to people with autism because they know it is a difficult job requiring expertise.

Great progress has been made for people with autism in British Columbia over the last two decades. No longer are young children with autism taken from their families and placed in institutions for life. The decisions taken this year will be crucial to determining whether this progress will continue or whether the clocks will be turned back. Children and adults with autism need to live with dignity within their communities. Specialized programs built around the differing needs of individuals are the accepted way of making this inclusive philosophy a reality. The surest way of segregating people with autism is leaving them unprepared to live in their communities. When a family goes into crisis because the desperate needs of a family member are not met, taxpayers will eventually pay the price. Families recognize that the cost of supporting a dependent person with autism for life is probably higher than for most other disabilities. They wish the government to recognize that the cost, for a significant percentage of people with autism, can be much less, and the integrity of the family better protected if individual needs are addressed proactively with specialized support from the earliest age.

Recommendations

1. The B.C. Council on Autism recommends that Sunny Hill Health Centre for Children should be strengthened as the provincial centre for excellence in autism, with expanded resources to provide leadership and training for regional autism teams. Sunny Hill's clinical programs should continue to provide services for children with more complex needs. No family anywhere in British Columbia should have to wait longer than three months to have an assessment by an experienced team.

2. The BC Council on Autism recommends that children with Asperger Syndrome should have access to autism services that should be available to all children on the autism spectrum based on need. Sexuality awareness training should be available to all children with autism, appropriate to family circumstances.

3. The B.C. Council on Autism recommends that children on the autism spectrum must have access to full day intensive early intervention programs, regardless of whether both parents are employed. Families must have the option of implementing such a program at home or having access to a competent centre. Baseline assessments and outcome measurements must be made to ensure cost-effectiveness of programs. Given that such programs are a therapeutic necessity resulting from a medical condition, autism, the British Columbia Medical Plan should expand its coverage to fund intensive early intervention program.

4. Autism is a medical condition that often results in severe costs for families. The Autism Council of B.C. recommends that the administrators of the At-Home program reconsider their guidelines so that they do not discriminate against children on the autism spectrum.

5. The BC Council on Autism recommends that specialized teams for people with mental handicaps, and distinct budgets to support them, need to be retained within the MCF. Social workers within these teams must carry out their obligation to inform families of services, however long the waiting lists.

6. In the interests of lessening the potential for miscarriages of justice, the B.C. Council on Autism recommends a province-wide policy ensuring that when a child with a mental disability is to be interviewed by child protection, it should be done in the presence of a social worker from the Community Living stream with experience in autism or another professional with relevant experience. This is already the policy in the Vancouver region. In addition, such an interview should be video recorded. Protection workers need to notify families of existing policies

on family rights, respond to allegations, and follow up with families after investigations. Basic training in autism is warranted for all social workers.

7. The B.C. Council on Autism recommends that the current system be reformed. Families should not be forced to put their child into care at the expense of the tax payer because supports in the home are denied, due to insufficient funding within the Community Living arm of MCF. Families must not be offered foster care instead of in home supports because of MCF budget restrictions. Reform would be both cost effective and more humane.

8. The B.C. Council on Autism recommends that timely and intensive behaviour consultation services be available in conjunction with child care workers and other intervention services. These should be subject to impartial baseline and outcome assessments so that the relative effectiveness of service providers can be gauged. For older children, consultants should be free to consult both with the school and the home, providing seamless cost-effective service.

9. The B.C. Council on Autism recommends the implementation of a province-wide policy to protect families from having services removed or losing their positions on waiting lists, if they move from one region of British Columbia to another. We urge the establishment of a province-wide fund to enable regions to continue to fund services to families who have had to move within British Columbia, without affecting people already on waiting lists in the region accepting new clients.

10. To address the needs of high-needs adolescent children with autism in their communities, the B.C. Council on Autism recommends the establishment of new specialized residential facilities in each region if the Lower Mainland facility is downsized. There should be a reasonable transition plan and appropriate dollars allocated with necessary supports for educational programs provided by the Ministry of Education, Skills and Training. If this cannot be accommodated, the facility needs to remain viable.

11. The Council agrees with the B.C. Teachers' Federation that the targeting system for special education should not be removed until the following five principles are embraced: "Total transparency; Agreed-on best practice; Assessment and identification; Identification leads to resources; Accountability for district, school and classroom support."[2]

12. The B.C. Council on Autism recommends that the Ministry of Education stop the practice of starving special education of funding. It is threatening the successful implementation of its own policy of inclusion. In addition,

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[2] Targeted Funding for Special Education; A BCTF Discussion Paper, May 1997**

administrators and teachers must have further training on autism to improve the effective use of resources.

13. The B.C. Council on Autism recommends that children with autism must not be subjected to the bumping of their Special Education Assistants because of union seniority issues.

14. The B.C. Council on Autism strongly recommends that B.C. maintain its current policy of including children with autism in regular schools. However, the needs of the child for an education must be properly met. Simply physically integrating a child with autism in a regular classroom does not mean that the child is included. To include a child, proper supports must be put into place so that s/he receives an education and benefits from associating with his peers. There must also be recognition that for some children with autism, full-day placement in a regular class room may be too challenging, at least in the short-term. Alternatives must be provided to enable the child to be included gradually. This inclusion should be based on the child's needs and abilities. The practice of medically excluding children with autism must end.

15. The B.C. Council on Autism recommends that High Functioning Autism and Asperger Syndrome should be considered disabilities under B.C. Benefits along with autism, and that more attention be paid to helping people with autism find suitable supported paid employment.

16. The B.C. Council on Autism recommends serious attention be paid to improving professional training in autism in British Columbia.

What is Autism?

Autism is a developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects functioning of the brain, autism and its associated behaviors occur in approximately 15 of every 10,000 individuals.

Autism interferes with the normal development of the brain in the areas of reasoning, social interaction and communication skills. Children and adults with autism typically have deficiencies in verbal and non-verbal communication, social interactions, and leisure or play activities. This disorder makes it hard for them to communicate with others and relate to the outside world. They may exhibit repeated body movements (hands flapping, rocking), unusual responses to people or attachments to objects and resist any changes in routines. In some cases, aggressive and/or self-injurious behavior may be present.

It is conservatively estimated that nearly 400,000 people in the U.S. today have some form of autism. Its prevalence rate now places it as the ***third*** most common developmental disability – more common than Down syndrome. Yet the majority of the public, including many professionals in the medical, educational, and vocational fields are still unaware of how autism affects people and how to effectively work with individuals with autism.

Definition of autism by the Autism Society of America

Introduction

The B.C. Council on Autism would like to bring to the attention of all government ministries dealing with children and adults with autism the deteriorating situation facing these vulnerable individuals. Over the past four years waiting lists have dramatically increased for young children with autism for all services. They have now reached the point where they are "long and unacceptable", according to a public statement by the Minister for Children and Families, The Honourable Penny Priddy.[3] Funding has not been increased to cover the children who have been diagnosed with autism or other disabilities during this period. Services for young people within the education system, and as they make the transition to adulthood, have been weakened, decreasing their effectiveness.

As professionals working in this field, we are deeply concerned that families, especially of pre-school children, are being given little proactive support in dealing with what is recognized as a profound and complex developmental disability. Research has shown that the parents of children with autism have the highest stress levels, even when compared to the parents of children with Down Syndrome and those with psychiatric disorders, largely because of the extremely difficult behaviours associated with autism.[4] It is also an invisible disability causing behaviours that are easily confused with neglect and even sexual abuse. Yet it is a disability where research into early intervention programs, including outcome data, has shown excellent results in minimizing family stress and maximizing the potential of affected children. [5]

People affected by autism spectrum disorders require specialized intervention if they are to make progress and become contributing members of society. Without early diagnosis and intensive early intervention, most will remain severely mentally and socially disabled, necessitating costly maintenance for their life spans, [6] which are of normal length.

Members of the BC Council on Autism recognize that reorganization of services within the Ministries of Health, Education and Children and Families have the potential to

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[3] See: " '*Some impact' on wait-lists by April 1: Priddy's promise*", The Province Newspaper, January 6, 1997 **

[4]Holroyd, J. , & McArthur, D. Mental retardation and stress on the parents: An instrument to measure family response to a handicapped member. *Journal of Community Psychology*, 1974, 2, 92-94; Bristol, M.M. *Maternal coping with autistic children: The effects of child characteristics and interpersonal supports*. Unpublished doctoral dissertation, University of North Carolina, Chapel Hill, North Carolina 1979; Stress and Coping in Families of Autistic Adolescents, from *Autism in Adolescents and Autism*, edited by Schopler, E. & Mesibov, G.B. Plenum Press, New York, 1983

[5] Harris, S.L.& Handleman, J.S. ed. Preschool Education Programs for Children with Autism, Pro-Ed, 1993

[6] Financial Cost and Benefits of Intensive Early Intervention for Young Children with Autism - Pennsylvania Model Achieving Cost Savings - A briefing. Jacobson, J.W. & Mulick, J.A. & Green, G, October, 1996**

improve services to people with autism throughout the province. We do not dispute that there is a need to re-think the way services have been delivered in the past. Methods must be developed to assess program outcomes, in the interests of delivering cost-effective interventions that achieve their objectives. Soliciting of feedback from families on the effectiveness of programs is an important part of this process. However, given that these services are already severely compromised, we are concerned that the needs of this vulnerable population for specialized services from trained individuals are at risk if the specific needs of people with autism are not recognized during reorganization.

The following are areas of concern:

Diagnosis:

Currently in British Columbia, a definitive diagnosis of autism is only required before a child enters school because the Ministry of Education, Skills and Training requires one before they will release adequate special education funds to provide for the range of supports a child will need. For children with autism this usually often includes a Special Education Assistant. Until that time generic services are provided for any child as long as it is acknowledged by a health professional that the child is developmentally delayed. Unfortunately, these generic programs are often waitlisted and ineffective for children with autism. This is wasteful both of public funds and of the tremendous potential of young children with autism to make profound progress - in some cases allowing them to dispense with the support of a school special education assistant. [7]

This practice of delaying a diagnosis is hugely frustrating for many families and informed professionals because they realize that in order to reach their potential, children with suspected autism must be diagnosed at a far younger age. In the United Kingdom, there is impressive research demonstrating that this can be done as early as eighteen months. [8] While there will be some cases in which it is difficult to be definitive so young, families need to know they are dealing with a child on the autism spectrum and not with simply 'global developmental delay'.

There is a related problem. Ignorance in British Columbia of the great strides in autism treatment leaves many pediatricians highly reluctant to use the word autism in diagnosing a child. Frequently they hope that the child will grow out of their symptoms, as does happen in rare cases. Unfortunately, a doctor's reluctance to use the 'A' word to a family (which he or she often believes is tantamount to declaring the child hopeless) often delays intervention by at least a year, if not several. Sometimes children are entering school before the family receives a definitive diagnosis. Then the family begins to mourn deeply and profoundly for the time they have wasted - time in which medical professionals believed they were doing the family a favour by not raising the issue, even

[7] '*Early Intervention Victory*' by Karen Hovestad, Autism BC Newsletter, Feb. 1997 **

[8] Baron-Cohen, S. et al. (1996) *"Psychological markers in the detection of autism in infancy in a large population*", British Journal of Psychiatry, 168: 158-163.**

when the family was frantically looking for an explanation of their child's strange behaviour.[9] In any gathering of families of children with autism, the failure of professionals to mention the word "autism", even when there was overwhelming reason for concern, is a focal point of family anger.

Policy makers must take seriously the latest research on the early development of the brain.[10] There is a critical period before the age of three during which the ability of the brain to re-wire itself is strong. This declines steadily up until the age of eight, after which it is far more difficult to help a child improve their abilities to function normally. These findings are substantiated by the fact that very few non-verbal children with autism learn to speak after the age of six. It is illogical to make one–to-one supports available to children with autism only once they have reached school age, when interventions would have been far more effective if they had begun three years earlier.

When families are helped with early intervention strategies that show results, they are not so overwhelmed by the diagnosis of autism. Lingering for months, if not years, waiting for a conclusive diagnosis from an experienced team as their child's behaviours deteriorate, dramatically increases family stress:

"Because the autistic child appears physically normal and often extraordinarily attractive, whether or not the child is actually handicapped is ambiguous. Until the mother understands that the child's deviant behaviour stems from an inborn disorder of behaviour and communication, she may feel inadequate as a parent because the child is obviously not responding the way she imagined well-raised children should. When such misplaced feelings of guilt are intentionally or unintentionally reinforced by professionals who imply either that there is no problem or that the problem is one of parental mismanagement, the ambiguity of the child's handicap significantly increases the risk of family crisis." [11]

Sunny Hill Health Centre for Children

In 1995, Sunny Hill Health Centre moved to a program management approach for the clinical care of children with a broad range of complex developmental disabilities. This move recognized the need for a broader group of providers to assess a larger number of children, both on site and in the community. In the area of autism, this requires significant resources to be committed to working both at Sunny Hill and across the province to

[9] '*Study recommends listen to Parents!'* Autism Research Review International, Vol. 11, N.2 1997**

[10] Greenspan, S., (1997) The Growth of the Mind , Addison-Wesley; *Fertile Minds,* Time, June 9, 1997 p. 45-54.**

[11] *Family Resources and Successful Adaptation to Autistic Children*, Bristol, M., ** from The Effects of Autism on the Family , Schopler, E. & Mesibov, G.B., Plenum Press, 1984 p.291

support the ongoing training of providers in the assessment of children with autistic disorders.

In addition, Sunny Hill has recognized the need for new knowledge in this important condition and therefore continues to support ongoing research activity in autism. These educational and research commitments have been made by Sunny Hill's Autism Spectrum Resource Team, whose primary role is to be a resource to clinicians and care providers of children with autism spectrum disorders.

Sunny Hill has been using these strategies to ensure that the largest number of children receive a competent assessment, whether in the community or on site. However, there remain significant barriers to meeting the need for timely assessment. These include the increasing number of children with these disorders, due to population growth and increasing awareness of autism. Additional pressures are also created by the demands of the school system for diagnostic categories before they will provide resources.

According to international standards, the optimal approach to diagnosis requires a team (pediatrician, psychologist, speech pathologist, and other disciplines as needed), all with skills and experience in the diagnosis of autism. Such teams are not yet available outside the Lower Mainland and the Capital Region. Many areas of the province are thinly populated, giving local providers few opportunities to develop their skills in autism assessment. A creative approach is needed to ensure optimal use of existing community expertise complemented by resources and training opportunities.

Currently the demand for services at Sunny Hill still overwhelms the available resources with waiting times for assessment ranging from six to twelve months. Given the growing evidence to support the importance of early diagnosis, it will be an ongoing challenge to identify and train committed providers across the province. The B.C. Council on Autism is deeply concerned that until these barriers are resolved, necessitating increased resources for training and assessment, many more children will receive late or inaccurate diagnoses.

Recommendation 1: The BC Council on Autism recommends that Sunny Hill Health Centre for Children should be strengthened as the provincial centre for excellence in autism, with expanded resources to provide leadership and training for regional autism teams. Sunny Hill's clinical programs should continue to provide services for children with more complex needs. No family anywhere in British Columbia should have to wait longer than three months to have an assessment by an experienced team.

Asperger Syndrome/ High Functioning Autism and the issue of the growing numbers of children diagnosed with autism spectrum disorders in B. C.

Unprecedented numbers of children with autism are being diagnosed in British Columbia, according to Ministry of Education officials. Their figures indicate a leap in the number of children with an autism diagnosis (not including Asperger Syndrome) entering the school system, from 650 in the 1996/1997 school year to nearly 750 in 1997/1998.[12] This is a very high figure if the usual incidence figure of 4-5 children per 10,000 is used. However, there is international research to indicate that the figure of 4-5 children per 10,000 is not a realistic projection on which to base services, because it is an academic distinction made by researchers looking at classical autism:

"The [British] National Autistic Society confirms that the incidence of autism is 4 or 5:10,000 for classic cases, and 17:10,000 for closely related conditions which will require similar services. These figures are higher than earlier estimations quoted in the literature. However, more recently still, researchers looking at the full spectrum of autistic disorders have suggested that the incidence may be as high as 23:10,000."[13]

Similar figures are quoted in the Ministry of Health's Training Manual on Autism:
"The syndrome occurs in approximately 20-21 out of every 10,000 births (5 in 10,000 classical diagnosis, 15 autistic-like)"[14]

While the concern expressed within the Ministry of Education, Skills and Training and within the Ministry for Children and Families is that children are being diagnosed inaccurately so that they will be entitled to increased funding, it appears likely that the increase is largely related to a greater awareness of autism in general and 'high functioning autism' or Asperger Syndrome in particular.

It appears that other jurisdictions are also struggling to arrive at a definition of autism spectrum disorders that addresses the practicality of providing services. The North Carolina Department of Public Education has been collaborating on the draft of a new definition of Autism Spectrum Disorders to "more accurately reflect current clinical practice and improve educational options for students with various Autism Spectrum Disorders throughout North Carolina"[15]. It includes:

"Autistic Disorder, Atypical Autism (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder or all

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[12] Source: Ministry of Education, Skills and Training, Special Programs Branch, Special Education Enrollment, Victoria, British Columbia.

[13] Aarons, M.,& Gittens, T. (1992*) The Handbook of Autism, A Guide for Parents and Professionals*, London: Routledge.

[14] The Ministry of Health, British Columbia, M.H. Core Training Autism Module, Compiled by Gateway House Society, January 1992. P.13

[15] '*Autism Spectrum Disorders'* Autism Society of North Carolina, Vol. 13, No. 4 –Fall 1997 p.6

Pervasive Developmental Disorders. These disorders can co-exist with other disorders such as: Mental Retardation, Learning Disabilities, Attention Deficit Disorder, Down Syndrome, Tourette's Disorder. Autism alone, and together with the co-existing conditions, significantly affect educational programming, planning and performance."[16]

Asperger Syndrome and high functioning autism are indistinguishable in a practical sense.[17] Yet, if a child is diagnosed with Asperger Syndrome he or she may be denied services by most but not all regions of the Ministry of Children and Families. Within the Ministry of Education, he or she is like to be classified as 'High Incidence' and may receive little or limited services from a Learning Assistance Teacher, unless they are included within the category of children who have severe behaviour problems.[18] However, if they are diagnosed as having 'high functioning autism', they are entitled to full services.

For some children diagnosed with Asperger Syndrome, fewer supports are appropriate. For many it means that they are denied essential help because although their disability is essentially invisible, they have little innate ability to discriminate socially against those who may try to exploit them. Indeed, their problems in coping socially can be equal to, if not more profound, than a person who is clearly mentally handicapped because people with Asperger's Syndrome usually do not appear disabled.

In an important recent work of the latest research into diagnosis and classification, analysts note that: "Systematic research has failed to show a linear relationship between I.Q. and severity of autism."[19] In other words, a person can be very intelligent and yet so autistic that they need extensive help in coping with the world.

Early intervention is essential because, although a person with Asperger Syndrome may have acquired language normally, they need specialized training to cope socially, even though they have normal or above normal intellectual abilities. Dr. Temple Grandin is a brilliant specialist in animal behaviour, who has autism. She has described herself as feeling like "an anthropologist on Mars"[20] because typical social interaction is so foreign to her. She has learned the non-verbal cues that people give which she needs to understand to cope well in a social situation. This is what all children with autism need to be taught or they risk being shunned by their peers. Many people with high functioning autism can go on to university and into skilled professions if they are taught the social

[16] ibid

[17] See: *Are autism and Asperger syndrome (AS) different labels or different disabilities*? Journal of Autism and Developmental Disorders. Vol.26. No.1 1996 p.109 **

[18] For an excellent analysis of the issues facing students with Asperger Syndrome see: A Delicate Balance (A Brief on Asperger's Syndrome),1996, excerpts in Appended Documents.**

[19] Handbook of Autism and Pervasive Developmental Disorders, 1997 John Wiley & Sons, New York . p.42

[20] Grandin, T. ,Thinking in Pictures, Doubleday, New York, 1995

tools to cope. Recent research is increasingly optimistic about the ability of people with autism to succeed.[21]

Denied supports, these are the children and adults who fall into the hands of unscrupulous individuals, and have serious mental health problems including a high incidence of suicidal behaviour because they are so isolated. A minority even ends up in trouble with the courts, often because they do not understand society's norms over approaching members of the opposite sex.[22]

Denying these people help when they are young may save money in the short-term but over the long-term it is a waste, both of their significant potential and the funds it will take to provide crisis intervention. It is significant that in the American system of providing early intervention programs, all children on the autism spectrum appear to be entitled to services, including those with Asperger's Syndrome and Pervasive Developmental Disorders.[23]

Recommendation 2: The B.C. Council on Autism recommends that children with Asperger Syndrome should have access to autism services that should be available to all children on the autism spectrum based on need. Sexuality awareness training should be available to all children with autism, appropriate to family circumstances.

Pre-School Intervention: intensive therapies must be provided

We must recognize that children with autism have needs as distinctive as those of blind or deaf children. Autism carries with it profound social and sensory deficits, in addition to communication problems. There is no known cause of autism but many scientists believe that autism is a spectrum disorder trigged by "central nervous system problems", "immune system difficulties", "alimentary system abnormalities", and "biochemical peculiarities." [24] In other words, the causation of autism may be different for different children which is why many specialists in autism treatment accept that a wide-range of intervention strategies may be required, in order to see which combination best meets the needs of a particular child:

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[21] Venter, A., Lord, C., Schopler, E. (1992) *A follow-up study of high functioning autistic children.* Journal of Child Psychology, 33, 489-507.

[22] Cohen, D. & Donnellan, A. ed. Handbook of Autism and Pervasive Developmental Disorders, John Wiley & Sons, New York, 1987. P.10.

[23] Harris, S.L.& Handleman, J.S. ed. Preschool Education Programs for Children with Autism, Pro-Ed, 1993

[24] Baker, S.M.& Pangborn, J. (1997) Biomedical Assessment Options for Children with Autism and Related Problems, April 1997 p.2.

“Treatment modalities that encompass various aspects of sensory integration, visual and auditory training, and behavioural modification are all appropriate, especially when combined with educational programs in which teachers are attuned to each child’s individual needs.” [25]

B.J. Freeman, Professor of Child and Adolescent Psychiatry at the UCLA School of Medicine and Neuropsychiatric Institute, one of the world’s foremost authorities on autism, agrees that early intervention is critically important for young children with autism. She writes that best practice for these children includes: “structured treatment utilizing the principles of applied behaviour analysis, parent involvement in home, school and community, early intervention, intensive treatment, programming for generalization, curricula that emphasize development of social and communication skills, and integration with typical peers when possible.” [26]

Supported Child Care Does Not Address the Needs of Children with Autism
Currently in British Columbia, specialized services for pre-school children with autism are minimal, especially outside the large urban centres. The Supported Child Care Initiative[27] now being implemented across the province, does not address the needs of children with autism for therapeutic interventions. Rather the mandate of Supported Child Care is to promote inclusion of children with disabilities into neighbourhood day care centres, if both parents are working, and into pre-school centres if they are not. Research demonstrates that children with autism usually benefit from the consistency and the enrichment of a full-day program with a high ratio of one to one therapy.[28] The availability of such a program should be an entitlement linked with having a disability and not dependent on the working status of the parents.

Access to Speech and Occupational Therapy is Very Limited
In the past, speech and occupational therapies have been provided by the Ministry of Health. It is still unclear as to how this will change with many services for children now encompassed by the Ministry for Children and Families. In theory, generic occupational therapy and speech pathology are available for all children with disabilities but long waiting lists are the reality. When services are available they are increasingly on a consultative basis. This means that children get very little actual therapy from a professional, often only an hour every two weeks. An additional problem is that many

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[25] ibid p.1

[26] Freeman, B.J., Guidelines for Evaluating Intervention Programs for Autistic Children, P. 10, 1996 Pre-publication copy, available from ASBC. Sunny Hill Health Centre has adapted an excellent set of guidelines: ‘What Children with Autism/PDD Need to Learn Before School.’ **

[27] Supported child care: enhancing accessibility: a resource manual for communities, child care settings and child care providers. Co-published by British Columbia, Ministry for Children and Families.

[28] Harris, S.L.& Handleman, J.S. ed. Preschool Education Programs for Children with Autism, Pro-Ed, 1993

speech pathologists and occupational therapists have had no experience or training in working with a child with autism. When they eventually receive services families are frequently disappointed to find that the service provider has little or no experience with autism and that the generic therapies are not effective.

Therapies that Families Find Useful Are Not Covered by Medical Services Plan
Ironically, many of the therapies that families have found to be useful for their children are not funded by any government agency. These include Lovaas type applied behaviour analysis (ABA), vision management therapy, and auditory training, as well as music and speech therapy especially geared for children with autism.

There are a number of scientific papers detailing the effectiveness of the Lovaas type ABA approach.[29] Many B.C. families are finding it effective. Other families favour more of a sensory integration approach, as exemplified by the Giant Steps program which is now only available for school age children in the Kamloops area.

Yet only a small percentage of children with autism in B.C. benefit from any specialized programming. A few families have been forced to move to Kamloops, or even commute weekly from Vancouver, so that their children, floundering in their neighbourhood schools, can attend Giants Steps. Dozens of families in British Columbia are funding, from their own resources, the importation of American consultants to set up an in-home ABA program[30]. Others fly to Toronto paying $6,000 for a course of auditory therapy. Still others pay for private vision therapy. The majority have found these expenditures worthwhile, in terms of the improved functioning of their children, even if they have had to borrow, fund raise, or ask for charity to pay for them.[31] Families involved with FEAT are so frustrated at the lack of public financial support that they have launched a petition requesting the Premier of British Columbia to "include medically necessary autism treatment in the B.C. public health care system."[32]

The Current Situation is Not Equitable
There are many children whose families have no access to money for therapeutic interventions. This is not equitable. A great deal of money goes into funding children in Supported Child Care programs and for generic speech and occupational therapy. Some are suitable placements, yet many concentrate on simply including a child with autism

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[29] '*Intensive and Long Term Behavioural Treatment for Four to Seven Year Old Children with Autism: A One Year Follow-up*,' Preliminary Report Presented at the P.E.A.C.H. Early Intervention Conference, U.K. , September 12-13, 1997 ** and *Intensive Behavioural Intervention with Young Children with Autism* by Ivar Lovaas & G. Buch, from Prevention & Treatment of Severe Behavior Problem. Models and Methods in Developmental Disabilities edited by Singh, N.N., Brooks/Cole Publishing 1997 p.62-86 **

[30] Submission to the B.C. Council on Autism, submitted by F.E.A.T of B.C.**

[31] Based on reports by parents to the staff of Autism B.C., a parent based organization.

[32] Petition, F.E.A.T. of B.C. **

without recognizing that these children require intensive one-to-one therapy if they are to reach their potential for life-long inclusion.

Programs prioritizing inclusion need also to commit to providing every child with an effective program that teaches the skills that the child will need to be independent, productive, and successfully included throughout life.

In many communities, an intensive early intervention program appropriate for a child with autism is not available. In such situations, individualized funding should be made available to the family to allow them to set up their own program at home, until such a time that the child is ready to move into a center. However, for many families, such home based programs are not practical. Centres should be designated in each community to serve as centres of excellence for the provision of intensive early intervention services to children with autism. These centres need not be exclusively for children with special needs but some concentration will allow staff to gain experience and expertise. Not every family should be required to send their child to these centres of excellence, but they should function as training centres where those who will work with children with autism can gain practical experience. As importantly, these centres can provide the support and training to neighbourhood pre-schools, day cares and schools, when the child is ready to make a transition.

Early intervention is cost effective but outcome data must be gathered.
Given the extremely high costs of providing life-long care for people with autism, it is cost effective to allow families to explore the therapeutic approaches best applicable to their child.[33] Individualized funding can enable families to explore those therapeutic approaches applicable to their child, rather than restrict them to the use of ineffective and costly programs because those are all that are available in local child care or health centers.

Cost-effective programming recognizes that pushing all children with autism into the same slot is a waste of resources, both human and financial. It is necessary to gather outcome data on various treatments implemented to gauge the effectiveness of interventions in the community. Neutral assessors should take baseline assessments before programs begin, and after they are finished to provide outcome data. Programs and services that aspire to provide interventions for children with autism should be prepared to chart the child's progress regularly. Not all children with autism have the same potential for progress because of the varying severity of this spectrum disorder. As we do not yet know which children will benefit more from a specific intervention we must

[33] Jacobson, J.W.; Mulick, J.A. & Green, G.(October 1996) Financial Cost and Benefits of Intensive Early Intervention for Young Children with Autism – Pennsylvania Model Achieving Cost Savings Briefing.**

be prepared to innovate and individualize, depending on the age of the child and their responsiveness to various treatments.[34]

The B.C. Council on Autism believes that if investment in these children is to be outcome driven, it behooves policy makers to look at international research. It demonstrates that specialized programs, whether delivered in the home, in regular preschools or day care centres, can result in significant improvements in the child's ability to become independent, lessening the burden on the taxpayer as they mature.[35]

Recommendation 3: The B.C. Council on Autism recommends that children on the autism spectrum must have access to full day intensive early intervention programs, regardless of whether both parents are employed. Families must have the option of implementing such a program at home or having access to a competent centre. Baseline assessments and outcome measurements must be made to ensure cost-effectiveness of programs. Given that such programs are a therapeutic necessity resulting from a medical condition, autism, the British Columbia Medical Plan should expand its coverage to fund intensive early intervention program.

At-Home Program

Up until a few years ago, children with autism qualified for the At-Home Program, run by the Ministry of Health. Increasingly in recent years the vast majority of children with autism have been denied the medical portion of the program, apparently because they have no obvious physical disability. Yet their parents are spending significant sums of money on behavioural, speech, occupational, music, vision, and listening therapies, as well as dental surgery and even diapers, all as a direct consequence of their child's neurological disorder.

Currently, families and the professionals supporting them are told that the criteria for eligibility are being interpreted strictly so that children with autism may not even qualify even for the Respite portion of the At-Home program. Thus if a child can physically pick up a spoon, they will not qualify for At-Home respite, even if they are so tactile defensive that they refuse to eat and must be force fed. Alternatively, a child may be physically

[34] For an interesting discussion of this point see *Intensive Behavioural Intervention with Young Children with Autism* by Ivar Lovaas & G. Buch, from Prevention & Treatment of Severe Behavior Problem. Models and Methods in Developmental Disabilities edited by Singh, N.N., Brooks/Cole Publishing 1997 p.85**

35 '*Intensive and Long Term Behavioural Treatment for Four to Seven Year Old Children with Autism: A One Year Follow-up*,' Preliminary Report Presented at the P.E.A.C.H. Early Intervention Conference, U.K., September 12-13, 1997** and Harris, S.L. & Handleman, J.S. eds, PreSchool Education Programs for Children with Autism, Pro-Ed, 1993.

36 Letter from Autism Society of B.C. to At-Home Coordinator, June 16, 1997**

healthy but if he is obsessed with smearing feces, he cannot be left unsupervised.[36] This tactile defensiveness is a direct result of autism - a medical condition. Responsibility for the At-Home Program has now moved to MCF.

Recommendation 4: Autism is a medical condition that often results in severe costs for families. The Autism Council of B.C. recommends that the administrators of the At-Home program re-consider their guidelines so that they do not discriminate against children on the autism spectrum.

Reorganization of the Ministry for Children and Families

There is deep concern among families and professionals that today's political climate is not attentive to the needs of people with disabilities. There is particular concern that the current preoccupation with child abuse within the new MCF system, and within the media, is undercutting the ability of social workers to deal proactively with the needs of children with disabilities.

The need for distinct MCF teams for children with disabilities

In 1988 the then Ministry of Social Services created specialist teams of social workers who dealt only with people with mental handicaps. This approach has been widely viewed by families and by social workers as a vast improvement over the previous system. Before 1988, when social workers had mixed caseloads, workers were forced to deal with issues of abuse and neglect before attending to the less urgent but equally profound needs of the children on their caseloads who had disabilities.

Currently most of the 20 MCF regions have created multi-disciplinary teams that include social workers who are supposed to specialize in working with children with disabilities. No one is questioning the commitment of MCF to early intervention for all children. However, there is fear, based on experience from the pre-1988 period, that child protection issues will overwhelm the needs of children with disabilities. It should be noted that children with disabilities receive services only when funding is available, they do not have any legislated right to services. In contrast, child protection interventions are mandated. If both programs share the same budget, the potential for neglecting children with disabilities is very great. Child protection issues and the challenges facing families of children with disabilities are distinctly different. The latter requires specialized training and experience, as does the former. It is unrealistic to expect social workers to carry both kinds of cases, especially in urban areas where numbers mean that there is no objective need for this.

A serious issue that must be addressed by the Ministry for Children and Families is that increasingly families are not being told of the various services available to children with

autism by their social workers. It would appear that social workers, aware of long waiting lists, do not want to inform families of services they may not get for a year or two, for fear of parental frustration. In other cases, social workers appear to be unaware that certain specialized services exist. The result is that the level of real need for services is obscured. The Autism Society has detailed information about families who had a diagnosis for a year or two and had never been informed about behavioural support or childcare workers. In one publicized case, a child nearly died because he lacked timely behavioural support.[37]

Recommendation 5: The BC Council on Autism recommends that specialized teams for people with mental handicaps, and distinct budgets to support them, need to be retained within the MCF. Social workers within these teams must carry out their obligation to inform families of services, however long the waiting lists.

Allegations of abuse: A Systemic Problem

When families of older children remember the system that existed prior to the reforms of 1988, they speak of the pain and humiliation of having to deal with social workers who could not differentiate between autism and child abuse. In the current atmosphere of acute concern over abuse, The Autism Society of British Columbia, is already seeing cases of the families of children with autism being mistakenly investigated by child protection workers with limited experience and training in autism. [38]

Families and professionals realize that children with disabilities, especially when they are non-verbal, are very vulnerable to abuse. They agree that allegations must be properly investigated. The concern is that investigations are being triggered by the lack of knowledge of autistic behaviours within the community, even among support workers. There is a dearth of awareness that autism can manifest itself by self-injurious behaviour, constant screaming and inappropriate public sexual behaviour. Families are particularly worried because children with autism frequently echo questions asked of them, possibly leading a protection worker in an interview setting to believe that the child is agreeing with an allegation. An Autism Training Module was developed for the Ministry of Health by Gateway Society in 1992.[39] It would be appropriate if all ministry social workers, including protection workers, completed this training. The module itself would benefit from updating to include information on inappropriate sexual behaviour.

Recommendation 6: In the interests of lessening the potential for miscarriages of justice, the B.C. Council on Autism recommends a province-wide policy ensuring

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[37] See 'BLAKE, 5, COULDN'T GET ON TO THE WAITING LIST FOR GOVERNMENT HELP. UNTIL HE RAN INTO A TRUCK.' The Province Newspaper, January 6, 1997, P. A13**

[38] Letter from Rhonda Garside, Executive Director of the Autism Society of B.C. to the Director of the Child Protection Division, Ministry of Children and Families, British Columbia.**

[39] M.H. Core Training Autism Module, The Ministry of Health, British Columbia, Compiled by Gateway House Society, January 1992.

that when a child with a mental disability is to be interviewed by child protection, it should be done in the presence of a social worker from the Community Living stream with experience in autism or another professional with relevant experience. This is already the policy in the Vancouver region. In addition, such an interview should be video recorded. Protection workers need to notify families of existing policies on family rights, respond to allegations, and follow up with families after investigations. Basic training in autism is warranted for all social workers.

Ministry for Children and Families Respite Funds

Waiting lists for respite for the families of children with autism are one to two years long in most parts of the province because of lack of funding. Yet families are desperate for respite. Many children with autism may only sleep two hours a night. They frequently scream incessantly. They must be supervised constantly in case they jump out of a window, eat their own feces or bite a sibling. The MCF's philosophical statements on early intervention and family support as a guiding principle is contradicted by the widespread MCF practice of placing families on waiting lists and providing minimal support services to those in great need. These practices further isolate families of children with disabilities and renders them unable to cope.

Families Are Given Few Options But Putting Their Child Into Care

Twenty-five years ago most children with autism would have been institutionalized at great cost. Today, families want to keep their children at home, yet they require help. An increasing number are being forced to put their children into care at great cost to the taxpayer because the Ministry for Children and Families can not provide sufficient service to keep the child in the home with the current level of funding. **It is ironic that MCF must provide foster homes to children whose families are unable to cope, but they are not obligated to provide vital services for disabled children to remain in the family home. $10,000 – $20,000 annually for support in the home is far more cost effective than $50,000 - $100,000 for the cost of a placement in care.** The same principle applies to adult children whose families want them to remain at home – there is no help available unless the family agrees to place their child in another residence.

***Recommendation 7: The B.C. Council on Autism recommends that the current system be reformed. Families should not be forced to put their child into care at the expense of the tax payer because supports in the home are denied, due to insufficient funding within the Community Living arm of MCF. Families must not be offered foster care instead of in home supports because of MCF budget restrictions. Reform would be both cost effective and more humane*.**

Behavioural Support

Under the Autism Initiative, children with autism had access to behaviour support consultants who helped families to understand autism and how to improve their child's ability to communicate, thus lessening behavioural problems and family stress. For the past four years, funding has not been increased to deal with the numbers of new children being diagnosed. This thinning out of service often gives poor results as consultants have no time to engage in hands on work. In addition, long waiting lists mean that families do not have the support of child care workers to help implement program suggestions.

There is also an overlap of services with behaviour consultants contracted by the Ministry for Children and Families being restricted from consulting to the schools. The schools have their own behaviour consultation teams who do not advise on issues in the home. This overlap results in wastage of resources. Often families who have no current need for a behaviour consultant do not give up the service, fearing that if they face a crisis they will have to begin at the bottom of the waiting list before they can get help.

Most Families are Exhausted

The reality is that the families of children with autism who receive few services are emotionally and physically exhausted. By the time they begin to receive the services of a consultant they may have been living for several years with a child who is out of control for most of the time. Often they are sleep deprived. Occasional visits from a consultant who has ten to twenty other families on his or her caseload will not allow a break through. Currently few families get quality, intensive behavioural support for their children with autism before school age, thus, putting great strain on their families and increasing the need for respite and even foster services.

Training families and making them part of behavioural intervention programs has been shown to be highly effective at reducing family stress and improving the abilities of children with autism. This can be achieved in a number of ways: individually, through workshops, parent groups and through specialized pre-schools. It should be a priority. The high incidence of marital breakup among families with children with autism, forcing families to go on income support and increasing the burden to the foster care system, should be factored into a cost-benefit analysis of providing adequate behavioural supports before a family reaches such a crisis point.

A good intensive early intervention program that address sensory issues and develops early communication will include a strong component of behaviour management. Once a child can communicate his/her needs, incidents of behaviour problems decline, lessening the need for expensive long-term behavioural support from consultants as a child enters school.

The BC Council on Autism is concerned that resources may be spread even more thinly if the reorganization of services within MCF does not recognize the importance of timely

behaviour consultation services before the child becomes set in his or her behaviours and the brain's ability to compensate for early neurological impairment recedes.[40]

Recommendation 8: The B.C. Council on Autism recommends that timely and intensive behaviour consultation services are available in conjunction with child care workers and other intervention services. These should be subject to impartial baseline and outcome assessments so that the relative effectiveness of service providers can be gauged. For older children, consultants should be free to consult both with the school and the home, providing seamless cost-effective service.

Portability of Services

Currently families are held captive by their services in the region in which they were living when they first received them. In other words, if a family in Kamloops is receiving respite and childcare through the Ministry of Children and Families, they will move to the bottom of the waiting list if they move to a different region of British Columbia. As waiting lists for most services are in the range of two years, families have extremely difficult decisions to make. Often promotions and transfers have to be turned down. Or families are split up, with one parent remaining with the children while the other commutes. The financial and emotional stress that this policy causes for families who are already stretched to the limit is unreasonable.

Recommendation 9: The B.C. Council on Autism recommends the implementation of a province-wide policy to protect families from having services removed or losing their positions on waiting lists, if they move from one region of British Columbia to another. We urge the establishment of a province-wide fund to enable regions to continue to fund services to families who have had to move within British Columbia, without affecting people already on waiting lists in the region accepting new clients.

Crisis at Puberty – the need for residential treatment alternatives

Puberty is a period of extreme stress for many young people with autism. Often families cannot cope because they have not had proactive help. With certain young people, the emotional turmoil becomes so overwhelming that their parents must find a good therapeutic teaching home to help their child make the transition to adulthood because the person is a threat either to themselves or their family.

Currently, the only center providing specialized help for high-needs young people with autism is in the Lower Mainland. While families would much prefer specialized residential

[40]Time Magazine - Fertile Minds, June 9, 1997**

services offered in their own community, as endorsed by the Ministry of Children and Families,[41] they do not wish the current facility to be down-sized until alternatives are up and running throughout the province. They are also adamant that treatment to address the need to alleviate/eliminate some of the typical symptoms of autism is not overlooked:

"The overriding concern of the parents is the preservation of a treatment facility for the high needs children with autism. As the parents know, these children require intensive, and extensive treatment. Any provincial facility must clearly be responsible for providing "TREATMENT".[42]

Given the waiting lists for residential services throughout British Columbia, there is ample demand for the immediate establishment of new facilities in the regions before the Lower Mainland facility, run by Gateway, is scaled back.

Recommendation 10: To address the needs of high-needs adolescent children with autism in their communities, the B.C. Council on Autism recommends the establishment of new specialized residential facilities in each region if the Lower Mainland facility is downsized. There should be a reasonable transition plan and appropriate dollars allocated with necessary supports for educational programs provided by the Ministry of Education, Skills and Training. If this cannot be accommodated, the facility needs to remain viable.

[41] Gateway Task Force Report, October 6, 1997

[42] Report of Gateway Parents Group, submitted to Minister For Children and Families, October 14, 1997 p. 1.**

The Education System - de-targeting, insufficient funding and lack of training threaten successful inclusion

The plans to de-target funding for special education in time for the 1998-99 school year seriously concerns the members of the B.C. Council on Autism, as it does the B.C. Association for Community Living. De-targeting should not be implemented in the absence of province-wide standards. There is a potential for unsympathetic or uninformed school boards to further starve special education, with its limited pool of users, to the detriment of the most vulnerable members of society – children with disabilities.

Recommendation 11: The Council agrees with the B.C. Teachers' Federation that the targeting system for special education should not be removed until the following five principles are embraced: "Total transparency; Agreed-on best practice; Assessment and identification; Identification leads to resources; Accountability for district, school and classroom support."[43]

Current Level of Education Funding is Insufficient

Even without de-targeting, The B.C. Council on Autism shares the concerns of families at the present uneven level of services to children with autism. The fact remains that the present funding level of $12,000 per student with the autism diagnosis (in addition to the $4,000 typical students have) does not provide a level of service that allows the successful implementation of an inclusive education for truly challenging children. Many children with autism fall into this category, especially if they have not benefited from early intervention. This is particularly the case as schools are often forced to provide services for children on the autism spectrum who do not have an autism diagnosis (which carries dollars) because without an aide the child is not safe from their own dangerous behaviours.

The lack of realistic levels of funding, due to successive waves of funding cuts have affected children with disabilities disproportionally. This threatens the successful implementation of inclusion despite the excellent work being done by committed people throughout the system. Currently, the growing caseloads of resource teachers responsible for helping classroom teachers to include children with disabilities, are seriously compromising their effectiveness. Teachers themselves, although committed, often lack the training it takes to effectively integrate a child with autism into the classroom. This leads to unnecessary stress levels for teachers and threatens the future of inclusion.

Administrators and teachers have a legal responsibility for providing education programs. They must be competent and able to effectively deploy and manage resources for children with disabilities, including classroom aides. Many teachers and special

[43] Targeted Funding for Special Education; A BCTF Discussion Paper, May 1997**

education assistants have benefited from the training they have received from the Gateway Provincial Resource Program, funded by the Ministry of Education. However, a strong case can be made for the need for school trustees and administrators to receive an education in autism so that their decision making can become more effective.

Recommendation 12: The B.C. Council on Autism recommends that the Ministry of Education stop the practice of starving special education of funding. It is threatening the successful implementation of its own policy of inclusion. In addition, administrators and teachers must have further training on autism to improve the effective use of resources.

Special Education Assistants: the need for training and an end to bumping

A vital need is for better standards of training for non-teaching staff working with children with autism within the education system. There are no province-wide standards of training on autism that apply to Special Education Assistants. Some school boards do not require any training, or experience. This permits the bumping of union members to switch directly from secretarial or maintenance duties to working with extremely challenging children, based on union seniority. Given the workloads of the classroom teacher, it is the Special Education Assistant who bears the brunt of implementing successful inclusion. In the interests of the child and to ensure job satisfaction for the SEA, proper training must be required.

While we recognize the need to protect the rights of employees, there is also a widespread problem of union seniority issues resulting in effective aides who have bonded with their charges being bumped by individuals with more seniority. This can cause a domino effect with several children losing their aides who have been trained to work with them, in order to accommodate seniority rights. Children with disabilities should have the right to have their educational interests factored into this equation. Children with autism, in particular, take a long time to develop a comfort level with a caregiver; rapid turnover is highly disruptive for their education. Indeed, the Autism Society has seen a number of cases in which children have regressed both academically and behaviorally because of arbitrary staff changes. Given that these children are already profoundly developmentally delayed, many parents and professionals believe that such changes, especially for younger children, can further compromise their already limited window of opportunity. Currently, parents associated with the Autism Society, are preparing an overture to CUPE to request that children with autism not be subjected to arbitrary bumping of their special education assistants for reasons of seniority.

Recommendation 13: The B.C. Council on Autism recommends that children with autism must not be subjected to the bumping of their Special Education Assistants because of union seniority issues.

Children with autism require an individualized education

Children with autism need to be treated as individuals because as a spectrum disorder, the impact of autism can vary dramatically. One child may be able to read at three, while many older children may not comprehend the spoken word. Most can benefit from full inclusion, given appropriate supports. Others need a highly structured environment, for at least part of the day, in order to learn. They should be included in regular classrooms based on whether they will benefit from that environment, not on whether or not the local school board is willing to fund the necessary supports.

The commitment to **education** as well as inclusion should not be forgotten. Simply placing the child in a regular classroom without a trained aide or the support of a knowledgeable resource teacher can deny the child an education, though it may provide an inclusive environment. Families, who will bear the burden of an ineffective education program, need to be fully accepted as partners in developing appropriate programs. It is families and the social services network who bear the future burden of ineffective education, just as it is the families and the schools who have to cope with the effects of inadequate early intervention.

Specialized centres are a necessary alternative for some

Specialized centres are an option that should not be viewed as a politically incorrect alternative to total inclusion. This is not a call for a return to the institutionalization of children with autism but a recognition that for some children a specialized center can be beneficial to overcome the sensory issues that initially compromise their ability to cope in a typical classroom. There is overwhelming evidence to show that the vast majority of children with autism benefit from modeling themselves on their typical peers. With specialized intervention at a pre-school level, accepting of the unique needs of these children, most children with autism can be prepared for inclusion in typical classrooms. Specialized centers, such as the Giant Steps Centre in Kamloops, which stress one-to-one therapeutic interventions, can play a vital role in preparing school age children for full or partial inclusion. The alternative may be that a child is barred from attending school because their behaviours become disruptive or aggressive. This may often be because they are so distressed by the environment of a typical classroom.

Medical exclusions deny many children with autism an education

We are very concerned that schools that cannot cope with children with autism are resorting to medical exclusions. In some instances the exclusion is triggered by the stress the child is subjected to in a busy school environment. More often it is because school personnel are either unwilling or not knowledgeable enough to put into place the proper supports. Using medical exclusions, ostensibly to protect other children and staff, contravenes the Ministry of Education policy of not allowing expulsions or suspensions unless an alternative educational program is provided. The two hours per week of tutoring that is currently offered as an alternative educational program does not appear to be legally acceptable under the terms of the Canadian Charter. As the Ministry for Children and Families does not provide services during school hours, the family is left to cope

without supports. Medical exclusions discriminate against a child's right to an education and push families into crisis.

There is a popular misconception that the Supreme Court of Canada ruled against inclusion in its judgement on the Eaton v. Brant County Board of Education. It should be clearly understood that the judgement was in favour of educating the disabled child, preferably in an inclusive environment. Placement is to be based on an objective and detailed assessment of the individual needs of the child, not on the willingness or otherwise of the local school board to provide the necessary funding:

"In some cases, special education is a necessary adaptation of the mainstream world which enables some disabled pupils access to the learning environment they need in order to have an equal opportunity in education. While integration should be recognized as the norm of general application because of the benefits it generally provides, a presumption in favour of integrated schooling would work to the disadvantage of pupils who require special education in order to achieve equality. Schools focused on the needs of the blind or deaf, and special education for students with learning disabilities indicate the positive aspects of segregated education placements. Integration can be either a benefit or a burden depending whether the individual can profit from the advantages that integration provides. "[44]

Choice is essential

Finally, we would like to echo the Autism Society of North Carolina on 'Autism and the Importance of Choice":

"It is therefore essential that educational options be tailored to the real needs of each child, whether it is a self-contained classroom or mainstreaming, or somewhere in-between. And it is essential residential options include group homes, supervised apartments, and independent living, as best serves the person's needs. What is not important is whether it sounds good, or fits a particular philosophy, or makes someone else feel good." [45]

Recommendation 14: The B.C. Council on Autism strongly recommends that B.C. maintains its current policy of including children with autism in regular schools. However, the needs of the child for an education must be properly met. Simply physically integrating a child with autism in a regular classroom does not mean that the child is included. To include a child, proper supports must be put into place so that s/he receives an education and benefits from associating with his peers. There must also be recognition that for some children with autism, full-day placement in a regular class room may be too challenging, at least in the short-

[44] Eaton v Brant County Board of Education, Supreme Court of Canada, February 6, 1997 p. 407

[45] 'Autism and the Importance of Choice' - A Position Paper of the Autism Council of North Carolina. http://www.unc.edu/depts/teacch/choice.http **

term. Alternatives must be provided to enable the child to be included gradually. This inclusion should be based on the child's needs and abilities. The practice of medically excluding children with autism must end.

Transition to Adulthood:

Turning nineteen is a time of great stress for families of children with autism and for these young adults themselves. No one is magically cured at this age, yet services can decrease drastically or even cease to exist, especially for those who have an IQ over 70, in particular those diagnosed with Asperger Syndrome.

In some regions the funding is so inadequate that adults who are totally dependent have no supports or day programs to attend once they leave high school. Schools are increasingly being asked by the Ministry for Children and Families to allow these young adults to attend for an extra year after they are 19 because there is no support for them. Parents are panicked by the knowledge that, in June, they will be totally responsible for their child's day. They are forced to quit jobs and become prisoners in their own homes in order to supervise their now adult child. Fourteen adults with autism and other mental disabilities will be out of school this June in the Vancouver region and no provisions have been made.[46] The same story is being repeated throughout the province and the desperation of families is mounting.
Housing options are scarce for young adults. Adults with autism and other disabilities are being put on long waiting lists for residential placements. For example, in the Vancouver Region there is up to a six year wait for housing.[47]

Young adults with mild autism and Asperger's Syndrome continue to fall through the cracks because of the IQ requirement which denies adults services if their IQ is over 70. Most continue to need support even though they have reached the age of nineteen. Often they need a minimal amount of support to help them continue or finish their education and/or find employment. They are cut adrift and flounder, becoming a burden on the system instead of becoming taxpayers.

With the restructuring of the B.C. Benefits system, many adults who have 'high functioning' autism or have Asperger Syndrome, are left without the option of the "unemployable" category. At this point, they must prove on an individual basis that their disability is lifelong. This qualifies them for Disability Level II. If their diagnosis is not accepted, their alternative is to live on subsistent welfare rates. This income assistance category forces them to look for employment. While many of them would be employable if they received the supports they need in the work place, these are not generally available.

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[46] Based on information provided to ASBC by MCF Vancouver Region, and families.
[47] Source: MCF, Vancouver Region.

There is a related problem. Many people with high functioning autism or Asperger's Syndrome are very vulnerable to abuse and exploitation because they are often unaware of the manipulative behaviour of others. The result of being forced into the employment market without protection and support is a grave increase in stress in their lives and a related increase in psychiatric problems.

Recommendation 15: The B.C. Council on Autism recommends that High Functioning Autism and Asperger Syndrome should be considered disabilities under B.C. Benefits along with autism, and that more attention be paid to helping people with autism find suitable supported paid employment.

Specialized Professional Training is Essential

Specialized training in autism spectrum disorders should be developed at the college and university level for teaching, medical and social work professionals. Serious considerations should be given to establishing a university affiliated program as is the practice is the United States. However, this will produce results only in the medium to long-term. It would make sense to develop and upgrade the skills and expertise of professionals already working in the field within B.C. by providing funding so that they can access professional development opportunities outside the province. For example, there is great interest in Lovaas type Applied Behavioural Analysis programs in B.C. but there are no Lovaas trained consultants available. However, there are professionals in B.C. who would be willing to go and acquire these specialized skills if funding was available. The professionals who deliver these programs must be accountable to families and to taxpayers for providing the support that will build independence to the degree that each individual is capable.

Recommendation 16: The B.C. Council on Autism recommends serious attention be paid to improving professional training in autism in British Columbia.

Conclusion

As the various ministries go forward with redesigning programs, how these changes will impact on these very vulnerable families and their highly dependent children must be considered. For some it will take very little to put them over the edge with a huge cost, both in the anguish of their families and in the financial costs to society. The new Ministry of Children and Families with its emphasis on an integrated, pro-active approach to all the services that children need is a wonderful opportunity to make a difference for all children. Yet in the effort to streamline and rationalize, let us not forget the disabled minority. In the words of the Supreme Court of Canada:

"Rather, it is the failure to make reasonable accommodation, to fine-tune society so that its structures and assumptions do not result in the relegation and banishment of disabled

persons from participation, which results in discrimination against them…It is recognition of the actual characteristics, and reasonable accommodation of these characteristics, which is the central purpose of s. 15(1) (of the Canadian Charter of Rights and Freedoms) in relation to disability. [48]

People with autism require specialized help, as a result of their disability. International research has demonstrated that specialized interventions are what it takes to make reasonable accommodations for them, to allow them to participate. There is a great deal of good practice occurring in B.C. However, the lack of sufficient numbers of trained personnel; generic programs that do not address their specific needs; long waiting lists, and serious gaps in service provision are already plunging families into crisis throughout the province. Further changes in service provision, if they continue to ignore the needs of this group, will be at a tremendous human and financial cost.

[48] Eaton v Brant, p. 405-406.

Appended Documents

These are listed in the order they first appear in the Brief

1. *Targeted Funding for Special Education; A BCTF Discussion Paper*, May 1997

2. '*Some impact' on wait-lists by April 1: Priddy's promise'*, The Province, Jan. 6, 1997

3. '*Financial Cost and Benefits of Intensive Early Intervention for Young Children with Autism'* - Pennsylvania Model Achieving Cost Savings - A briefing. Jacobson, J.W. & Mulick, J.A. & Green, G., October, 1996

4. '*Early Intervention Victory'* by Karen Hovestad, Autism BC Newsletter, Feb. 1997

5. '*Psychological markers in the detection of autism in infancy in a large population'*, Baron-Cohen, S. et al. (1996) British Journal of Psychiatry, 168: p.158-163.

6. '*Study recommends listen to Parents!'* Autism Research Review International, Vol. 11, N.2 1997

7. *Fertile Minds*, Time, June 9, 1997 p. 45-54.

8. '*Family Resources and Successful Adaptation to Autistic Children'*, Bristol, M., from The Effects of Autism on the Family , Schopler, E. & Mesibov, G.B., Plenum Press, 1984

9. *'Are autism and Asperger syndrome (AS) different labels or different disabilities*?' Journal of Autism and Developmental Disorders. Vol.26. No.1, 1996

10. Excerpts from '*A Delicate Balance'* *(A Brief on Asperger's Syndrome*), 1996, including a supporting letter from Dr. Jane Garland.

11. '*What Children with Autism/PDD Need to Learn Before School.*' – Sunny Hill Health Centre for Children

12. '*Intensive and Long Term Behavioural Treatment for Four to Seven Year Old Children with Autism: A One Year Follow-up*,' Preliminary Report Presented at the P.E.A.C.H. Early Intervention Conference, U.K., September 12-13, 1997

13. '*Intensive Behavioural Intervention with Young Children with Autism'* by Ivar Lovaas & G. Buch, from Prevention & Treatment of Severe Behavior Problem. Models and Methods in Developmental Disabilities edited by Singh, N.N., Brooks/Cole Publishing 1997

14. Submission to the B.C. Council on Autism, submitted by F.E.A.T of B.C.

15. Petition, F.E.A.T. of B.C.

16. Letter from Autism Society of B.C. to At-Home Coordinator, June 16, 1997

17. Letter from Rhonda Garside, Executive Director of the Autism Society of B.C. to the Director of the Child Protection Division, M. C. F., Dec. 15, 1997

18. *Report of Gateway Parents Group*, submitted to M. C. F., Oct.14, 1997