



**Services Guide for Children
with Autism Spectrum
Disorder – From Diagnosis
Until Adolescence**

Services You Should
Know About ...
But Didn't Know to Ask

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Edition

 **Autism Society of British Columbia**

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Abbreviations

MOH	-	Ministry of Health
MCFD	-	Ministry for Children & Family Development
MOE	-	Ministry of Education
ASBC	-	Autism Society of British Columbia
ASD	-	Autism Spectrum Disorder
EIBI	-	Early Intensive Behavioural Intervention

Introduction

Discovering that your child has an Autism Spectrum Disorder, including Asperger Syndrome and Pervasive Developmental Disorder, can be overwhelming for families. However, there are many treatments and services that can help a child reach their potential, which for our children can be considerable.

Lack of a centralized source of information about relevant services available from government agencies has prompted ASBC to produce this guide. We have also included information about non-profit societies and private service providers. The purpose of this guide is to inform families of where to go for help. To advocate effectively for your child you must know what services they are entitled to, even if initially this only means adding your child's name to the waiting list.

A particular problem facing our children is that their disability is essentially invisible. Unlike disabilities that can be screened for at birth, it can take a long time to get a diagnosis of autism spectrum disorder. Thus the long waiting period for services that frequently follows diagnosis, is particularly harsh. ASBC has information on how to advocate for your child as well as more detailed information on the services listed in this guide. Please contact us if we can be of further assistance.

Please keep in mind that this is a list of services available throughout the province. As the Ministry for Children and Family Development has now has 11 regions with each one having autonomy to deliver services differently, there is considerable regional variation. The situation is similar for school districts – they also have a great deal of independence in how they deliver services for children with disabilities. (However, the principle of equity can at least be argued.) if a certain service is not available in your region, you should ask for what is available as an alternative.

A last point: **this services guide is not an endorsement of any of the interventions or service providers**. The Autism Society of British Columbia (ASBC) is a non-profit society that exists to promote understanding, acceptance and full community inclusion for people with Autism Spectrum Disorder in British Columbia. People on this spectrum vary dramatically. **Interventions and services need to be individualized. One of ASBC's primary roles is to provide families with the information they need to make informed choices.**

While we have tried to make this guide accurate and comprehensive as of the date of printing, if you find any oversights, or if you have any additional information useful for future editions of this guide, including information on your region, please send them to ASBC by fax, letter or email marked ASBC Services Guide – Children Update. We are currently preparing our services guide for adolescents and adults in BC.

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Medical Services

Diagnosis

Description: Autism Spectrum Disorder (ASD) is not a simple condition to diagnose. An assessment is made based on how a child behaves compared to typical children of the same age. It is considered best practice that a multi-disciplinary team diagnose a child suspected of being on this spectrum. This team may include a developmental pediatrician, a speech pathologist and a psychologist or psychiatrist. For the purpose of receiving services a multi-disciplinary team diagnose is not always required if a qualified diagnostician has identified the child as having Autism Spectrum Disorder. To become proficient at diagnosing Autism Spectrum Disorder, a specialist must have seen a number of children to understand the range of atypical behaviours associated with autism. If a professional is not experienced with autism, they are frequently reluctant to give a definitive diagnosis to a child under four. An experienced professional will be aware that early identification and intervention is the best way of insuring an optimum outcome for a child on the autism spectrum.

Similar therapeutic strategies used in early intervention programs for children with autism can be effective for a child who is said to have autistic characteristics or tendencies, Asperger Syndrome or Pervasive Developmental Disorder. While a small minority of children grows out of what may be identified as tendencies, most do not. To reach their potential, all children diagnosed with Autism Spectrum Disorder require and benefit from early intervention.

Another important factor to bear in mind is that there are a number of medical conditions that may not be identified in

children with autism because they frequently cannot express their discomfort/pain with words. Their “difficult” behaviours may be due, in fact, to pain and not only to autism. Having a pediatrician as part of the assessment team is essential for proper care. The Ministry of Education and the Ministry for Children and Family Development (MCFD) will accept a diagnosis from a number of sources: a registered psychologist, a psychiatrist, or a pediatrician. A full multi-disciplinary assessment is not currently required for service from MCFD. Sunny Hill Health Centre for Children in Vancouver and Queen Alexandra Centre for Children’s Health on Vancouver Island are currently the two main diagnostic centres in British Columbia which offer full team assessments for children of all ages. Referral to these centres is made by the child’s general practitioner.

Another source of diagnostic support, with an interest in children with Autism Spectrum Disorder is the Infant Psychiatric Department at BC Children Hospital in Vancouver that will accept referrals for children six and under. The Department of Psychiatry at BC Children’s Hospital works with older children.

The costs of these diagnostic services are covered by Medical Services Plan, with the exception of a diagnosis by a private psychologist.

Even without a definitive diagnosis of autism, families are entitled to some services from the Ministry for Children and Family Development, based on their child’s needs (see Supported Childcare section).

Getting the Service: If you suspect your child may have an autism spectrum disorder,

ask your family doctor to refer you to a psychiatrist, psychologist or a pediatrician **with experience in diagnosing autism**. ASBC can provide a list. To contact the Development and Behaviour Program at Sunny Hill Health Centre, call (604) 434-1331. For assessment at Queen Alexandra, call Coordinated Intake Services on (250) 721-6756. The Intake Worker at BC Children's Hospital's Infant Psychiatric Department can be reached on (604) 875-2719. The Department of Psychiatry at BC Children's Hospital can be reached at (604) 875-2720.

If your family doctor will not refer you immediately, you may want to consult another family doctor.

Note: *A word of advice. Should you suspect an Autism Spectrum Disorder, start researching intervention programs for your child while waiting for your assessment. The diagnosis will not bring with it any magic set of intervention providers – those have to be set up separately, largely through your social worker. Also, be certain that your referral has been received and that you are on the appropriate waiting list. Asking for notification in writing is advised. A full multi-disciplinary diagnosis may provide important information for purposes of treatment planning but is not currently required for services provided by the Ministry of Children and Family Development.*

Family Doctors/Pediatricians (MOH)

Description: Many parents have found it beneficial to have a family doctor and a pediatrician who have experience and knowledge specific to autism. Doctors with such additional knowledge are typically more sensitive to the specific issues and needs of you and your child. In addition, a pediatrician with an interest in developmental pediatrics will arrange the

basic medical and audiological investigations. S/He may also organize referrals to local resources such as speech/language pathologists, pre-school or Infant Development Programs. Your family doctor may also play a role in securing various supports for your family and child with autism. Including requests for respite. ASBC has a list of service providers available in our booklet entitled *professionals with Experience with Autism Spectrum Disorders*.

Getting the Service: Every British Columbia resident for three months or longer has access to a family doctor paid for through the BC Medical Plan. In order to access a pediatrician, you must have a referral from your family doctor.

Psychiatrist (MOH)

Description: Psychiatrists can offer a variety of services to your child and your family. A psychiatrist may be helpful in providing support in the following areas: assessment and re-assessment of your child, monitoring prescriptions and/or medical treatments, providing family counseling.

Getting the Service: Psychiatrists are available by referral through your family doctor. Some special needs daycare may also retain psychiatrists for consultation. Psychiatrists typically specialize in the services they offer and techniques they use; therefore, you may wish to contact ASBC, or the BC Directory of Psychiatrists from the College of Physicians at 1-800-461-3001, to find a psychiatrist who can meet your specific needs.

Community Health Nurses

Description: Community Health Nurses can provide a valuable conduit to services in your community. They can visit the family at home and help assess to what services a child should be referred. Often they have

greater experience of normal child development than general practitioners and more opportunity to visit the child at home and assess whether the family has cause for concern. They are also aware of local services, including speech and language and hearing assessments.

Getting the Service: Call your local Health Unit, listed in the blue pages of the 'Telus White Pages' under Health Authorities, and ask for a Community Health Nurse.

Behavioral Psychologists

Description: Behavioral Psychologists may be employed for assessment or reassessment purposes, or to offer assistance in developing treatment and education plans, or decreasing undesirable behaviors of your child. It is important to access a behavioral psychologist who is experienced with autism may come from your family doctor, ASBC, or the BC Psychological Association at 1-800-730-0552.

Getting the Service: Psychologists are typically contracted on a self-referral basis. The BC Medical Services Plan does not cover services provided by private psychologists. Some parents may, however, be able to charge psychological consultation fees to an Extended Health Plan provided by their place of employment. Psychological services are available free of charge through some children's health centres. In addition, some special needs preschools may offer a consulting psychologist to those children registered in their program.

Note: See Behaviour Consultants.

Dental Care

Description: Finding a dentist sensitive to your child's specific needs can make the world of difference to you and your child. Most pediatric dentists should have had some training in working with children with special needs; however, you should contact

the dentist in advance to discuss your child. The best strategy is to develop a good dental regime with your child before they develop an aversion to the dentist. If your child is extremely resistant to any attempts to provide dental care, you may wish to consider finding a dentist with hospital privileges so that a general anesthetic can be used as a last resort.

Getting the Service: Contact ASBC for information on proactive dental care, dentists in your area or you can call Dental Health Services at your local health unit or the College of Dental Surgeons (604) 736-3621

Genetic Counseling

Description: A number of family and twin studies support a strong genetic link for autism – although this does not mean that all cases are the result of genetic conditions. Genetic counseling is particularly valuable to families considering whether or not to have another child. With recent advances in genetics, neurobiology, and behavioral pattern analysis, there has been a rapid expansion of multi-disciplinary expertise and studies aimed at determining the biological basis of autism. A Medical Geneticist plays an important role in this process.

Getting the Service: The consultation services of a clinical Medical Geneticist are available upon referral by your family doctor, pediatrician or other medical specialist. The BC Provincial Program in Medical Genetics is based at the Children's Hospital and Women's Health Center in Vancouver and coordinates its work with other provincial centres and outreach programs in the delivery of medical genetic services for children with disabilities including Autism Spectrum Disorder. Call (604) 875-2157.

Note: Dr. Suzanne Lewis, Medical Geneticist with the BC program is collaborating with Dr. Jeanette Holden (Queen's University) in a significant research project aimed at identifying genes that are important in the susceptibility to autism spectrum disorders. If you are interested in more details on this research, or would like to become part of this research project., contact Dr. Holden at the Cytogenetics and DNA Research Laboratory, Ongwanda, 191 Portsmouth Avenue, Kingston, Ontario K7M 8A6. Tel: (613) 548-4417 ext. 165; Fax (613) 548-8135; email: holdenj@post.queen.ca or call Dr. Lewis at 604-875-2157.

Ministry for Children and Family Development (MCFD)

Social Worker (MCFD)

Description: Children with a diagnosis of an Autism Spectrum Disorder including Autistic Disorder, Asperger Syndrome, PDDNOS are eligible for services provided by the Ministry for Children and Family Development, through the Community Living Branch of the Ministry which may be called Services for Children with Mental Handicaps in some regions. With the exception of access to Supported Childcare (see Supported Childcare section) they need to have a social worker to access services. A social worker is your connection to these government-funded programs and services. One of the roles of a social worker is to provide you with the information about MCFD programs and resources in your community, and ensure that you receive the appropriate services for you and your child. However, the high turnover in social workers in recent years has resulted in some workers being fully unaware of some of MCFD's programs appropriate to children

with Autism Spectrum Disorders. Families may have to bring them to the attention of their social worker. ASBC has been advised of situations where the social worker did not tell the family about a service because it had such a long waiting list. Remember if you do not go on the waitlist you will never receive the service! You may have to insist that your child be placed on a waiting list for services that MCFD is using only for families in crisis before your family circumstances reach a crisis, because waiting lists can be as long as two years or more. Services are best initiated pro actively and not when families are exhausted and a child's behaviours are entrenched. Document your requests in writing. Requests for services have been lost in the turnover to a new social worker.

Getting the Service: Social Workers are available to all children with special needs and their families. To be assigned a social worker, contact your local Ministry for Children and Family Development office, listed in your telephone directory in the Province of British Columbia section of the Blue pages. Over the last year, families have been told on occasion by MCFD that they will have to wait for a social worker to be assigned. If you have to wait for more than two weeks for a social worker it is worth writing a letter to MCF noting your concern or to telephone the supervisor. Please copy such letters to ASBC. We can also help you with the correct wording for such a letter and to whom it should be directed.

At Home Program: Medical & Respite (MCFD)

Description: The At Home Program was designed to help parents care for their children (under the age of 18) with "severe disabilities that require long-term medical supports and services, and can be expected to cause excessive costs in maintaining the child at home. Severe disability is currently

defined as **total dependence** for eating, toileting, washing and dressing. It is not defined by diagnosis, social factors or needs. Determination of "Total dependence" is based on eligibility criteria developed by provincial input and based on a significant delay in developmental norms." At Home Program Handbook Feb. 1998.

According to their application, the At Home Program provides: "health care coverage for approved medical equipment and its repair and maintenance, medical supplies, medical transportation, exceptional therapy costs, drug coverage, dental and medical plan coverage and respite care. Details are available on request."

The At Home Program is divided into the Medical and Respite portions. Families are often given the choice of having one or another. The Medical portion is ventrally administered by MCFD in Victoria and there is no limit on the costs it will cover, although there are limitations on what they will fund. Speech Therapy is covered but there is a procedure that must be followed.

The Respite portion is administered through each of the regions of MCFD. There is a limit of \$2,800 per year set aside for respite under the At Home program. Usually the family receives approximately \$200 a month unless they can make a case for being financially unable to make a contribution to respite. It is the family's responsibility to locate and employ a caregiver that meets their needs. Discuss with your social worker the daily spending limits for this type of respite.

Nursing respite is available on a planned or emergency basis for families of children with complex medical care needs. Nursing respite may be available to those families not otherwise covered by the At Home Program (contact your local Health Unit for further details).

Getting the Service: Applications may be obtained from you local Health Unit or

MCFD office. The application must be completed and signed by you and your child's doctor. The application should then be returned to your Health Unit to be assessed. The assessment is then reviewed by a Regional Eligibility Committee of MCFD to determine eligibility for admission to the Program. An assessor will visit your home to gauge how much personal care your child requires. The five main areas that are looked at are: washing, toileting, dressing, eating and mobility. Unless the assessor has experience with the particular challenges faced in parenting a child with an Autism Spectrum Disorder, you may have to make a strong case for the high degree of supervision or even hand over hand prompting required to make sure that you child does what is required. This program was set up primarily to address the needs of children with disabilities affecting their physical mobility or general health. There is a toll-free At Home Program number to answer questions about medical program policies 1-888-613-3232. This contact should also put you in contact with the person in your region of MCFD responsible for the At Home Respite Program. You can also call your MCFD office directly. If you are turned down for this program you have the right to appeal.

Note: There is currently no waiting list for the Medical portion of the At Home Program but the Respite portion has long waiting lists in most regions. If you are turned down you only have one month to appeal.

Community Respite (MCFD)

Description: In many regions of the province MCFD funds local agencies or individuals to provide respite to families who have children with disabilities. Respite is a service that provides care for a child so the parent and other family members may have some time away from caring for the

child with ASD. Sometimes this means there is a respite home to which the child can go. In certain circumstances the child goes to the caregiver's home. In others, the family goes out and the child is cared for in the family home. The emphasis of this service is on providing help for families under great stress and not on working with the child in a therapeutic environment.

Getting the Service: MCFD social workers control access to this program. If you feel you need respite badly and you are not being taken seriously, you may need to go to your family doctor, other professionals or advocates to get their help in making your case with your social worker.

Note: *A significant number of families have complained to ASBC that the respite services available to them are not appropriate for children with autism. Many would prefer to hire their own workers rather than hire through an agency that may not have the knowledge to hire or train people to work with children with autism. You may want to get together with other families in your region and approach your local office of MCF to find a resolution of the problem. If you have one in your community, your local ASBC Community Group is often a good place to start.*

Homemakers (MCFD)

Description: Homemakers are trained personnel who assume full or partial responsibility for child or adult care, and for household management, and for maintaining a wholesome atmosphere in the home. These services are usually provided by non-profit or commercial agencies, but may also be provided by an individual under exceptional circumstances.

Getting the Service: Homemaker services may be obtained from the Ministry for Children and Family Development, through your social worker. To assess eligibility for Homemaker services, families are income-

tested. Family Support long term, or intermittent periods when a primary caregiver requires assistance to adequately care for his/her child with special needs.

Providers of Early Intervention Services

Infant Development Program (MCFD)

Description: Infant Development Programs (IDP) are funded by MCFD to provide support to parents of developmentally delayed infants up to the age of three years. Infant Development Consultants will visit your home to assess your child and design an individualized learning and activity program. These programs are designed to help your child develop in areas or skills that he/she may be behind in. The consultants may provide resource materials, such as books and developmental toys and access pediatric physiotherapists. They also can play an important role in helping families access diagnostic services and appropriate resources in their community. In addition, IDP consultants can help families come to terms with the diagnosis their child receives and link them to families in their community who have similar concerns.

Getting the Service: Referrals to your local Infant Development Program are open referral, that is anyone can refer your child to the program (you, your social worker or doctor). Their child does not need a diagnosis. For information contact your local MCFD district office, your local health unit or the IDP of BC at (604) 822-4014.

Early Intensive Behavioural Intervention (MCFD)

Description: EIBI programs are currently being developed throughout British

Columbia. These programs are offered by MCFD in collaboration with Ministries of Education and Health. These services are for children under six years old with Autism Spectrum Disorders and their families. EIBI involves providing one-to-one therapy and support services as soon as possible after a child is diagnosed with ASD. EIBI services will be provided based on current best practices in the field of autism research and treatment. By 2003 EIBI programs should be available in all regions of BC for children under age 6 years with ASD and their families.

Getting the Service: Contact your MCFD social worker. If your region does not currently have an EIBI program discuss with your social worker interim service options.

Speech-Language Therapy (MCFD)

Description: Speech-Language pathologists are professionals trained to communicate. The speech-language pathologist will work with you to identify communication goals for your child's specific needs. Children with autism generally respond best to the use of visually cued instruction. It is important to discuss with the service provider how experienced they are in working with children with autism. Children on the autism spectrum are exceptional in the way they respond to speech therapy. Pathologists with experience in autism are often far more successful in encouraging communication.

Getting the Service: The services of a speech and language pathologist may be obtained through a variety of sources. Up until your child enters school. Speech therapy may be obtained through your local Child Development Center or local health unit. School districts, and some preschools, also employ Speech-Language Pathologists although they are funded by MCFD. Private practitioners are also available but are costly. To receive a list of private speech pathologist calls the BC Assoc. of

Speech/Language Pathologist and audiologists at (604) 420-2222. Funding for speech therapy may also be obtained through the At Home Program, medical portion only (see At Home section). Families with Extended Health Plans may have coverage for some speech therapy.

Note: *Parents are encouraged to seek speech therapy as soon as a communication problem is apparent. Waiting lists are often lengthy. It is important to ensure that the person who will be working with your child has appropriate experience with Autism Spectrum Disorders. Also families should be aware that in some regions, if a family has a private speech therapist, they will be denied access to government funded services.*

Physiotherapy and Occupational Therapy (MCFD;MOH)

Description: Physiotherapists and Occupational therapists often work together to assess and develop specific gross and fine motor skills: major movement skills, like walking or clapping; and more delicate movements, like holding a spoon or pushing a button. They can help your child improve their physical dexterity. Occupational therapists who have an understanding of Sensory Integration can be particularly helpful because many children with Autism Spectrum Disorder benefit from this approach.

Getting the Service: Both physio and occupational therapy are generally available through Child Development Centres. Physiotherapy is available to the public through the Medical Service Plan (MSP) coverage. There is a user fee per visit at a private physio clinic. Children supported through the *At Home Program* medical portion, if the child is of school age, (see At Home section) may also have this user fee billed to MSP by showing their Care card at the time of the appointment. Physiotherapy and Occupational therapy should also be

available in school districts but families frequently have to initiate the request and services may be primarily consultative to staff working with the child rather than therapy directly with the child.

**Supported Child Care (MCFD)
(Daycare, Pre-School,
After School Programs)**

Description: Pre-school, Daycare and After-School Programs for children with disabilities are funded by the Ministry for Children and Family Development. Under the provisions of the Supported Child Care Program throughout BC, children who are recognized to need extra support (a medical diagnosis is not necessary) are able to go to neighbourhood childcare centers. MCFD provides funding for the extra staffing needed to enable the child to attend. Only families where both parents work are eligible for full daycare. All children with special needs are eligible for pre-school. Families are expected to pay the basic cost of the placement as though their child did not have special needs. However, if the family is in financial need extra subsidies are available. In addition, \$107 a month is the subsidy paid by the Ministry directly to all families towards the basic cost of the child care placement for a child who needs extra support. This service is income tested. The extra expense of providing increased support for a child with disabilities is the responsibility of the Ministry for Children and Family Development. This could be in the form of a full-time or a part-time one to one aide, and/or the professional services of consultants who will visit the centre to enable them to support the child properly. The centre should develop an individual program plan for each child in order to address both short-term and long-term individualized goals.

When you are looking for a centre for your child, a critical factor to consider is whether they have experience working with children

with Autism Spectrum Disorders, and how much training their staff has received. ASBC can often put you in touch with families in your community so you can ask them about their experiences. We also have information about what constitutes an appropriate program for a child on the Autism Spectrum.

In Home Daycare : Families who can't find appropriate daycare/preschool programs have increasingly been requesting In-Home Daycare, under the Supported Child Care Program. The program works by paying the family directly on a monthly basis and the family is accountable for paying the child care providers directly. Often families "cash in" their community respite hours, homemaker support, their childcare hours as well as their pre-school programs in order to increase the funds directly available through the In-Home Program. It is then the responsibility of the family to set up an appropriate program for their child. ASBC can help with information on the components of a good support program.

Note: *Some regions are more flexible than others in allowing families to do this. Careful negotiations are usually necessary.*

Getting the Service: It is not necessary for a child to have a specific diagnosis to access Supported Child Care services. They can be referred by an Infant Development Program worker, a community health nurse or another professional, as well as the parent, on the basis that there are concerns that the child has a significant developmental delay. The family does not have to have a social worker but access to funding for a Supported Childcare placement is in the hands of the local office of MCFD. Parents should note that in many communities these services are in great demand; a substantial waiting list may be in effect. If possible, parents should inform their social worker of their interest in Supported Child Care long before they require the service.

Special Needs Preschools and Daycares

Description: Traditionally, special needs daycare and preschools offered programs for children 3 to 5 years of age with emotional, behavioural or developmental delays, usually in specialized programs side by side with typical children. However, the approach has changed since the implementation of Supported Childcare, bringing into question the long-term future of some of these programs. See note.

The following are some of the programs available in the Lower Mainland. In other parts of the province, programs are often available through Child Development Centres.

Berwick Preschool – serves UBC and Greater Vancouver residents. (604) 822-6616

Champlain Child Centre - serves the Vancouver area. (604) 438-5525

Langley Children's Centre – serves Langley and Aldergrove area. (604) 534-1155

LEAP Preschool – serves Delta, Surrey, Aldergrove, Langley and White Rock with an internationally recognized integrated program for children with autism or autistic tendencies. (604) 946-0337

Laugh-N-Learn Family Daycare – offers integrated daycare in the Surrey and Delta area. (604) 590-8883

North Shore Neighbourhood House – offers integrated preschool, daycare and after school programs for North Shore children ages 2-12. (604) 987-2052

Surrey Association for Early Childhood Education –SAEC- integrated preschool program located in five schools throughout Surrey. (604) 597-3200

Small Talk Preschool – serves Vancouver (604)872-3132

Step-by-Step Preschool – serves Coquitlam, Maple Ridge, Port Coquitlam, Port Moody and Pitt Meadows. (604) 939-7436

Treehouse Preschool – serves the Richmond area. (604) 279-7050

South Fraser Child Development Centre Preschool – serves Surrey and White Rock. (604) 584-1361

Getting the Service: Parents wishing to enroll their child in a special needs daycare or preschool should contact the centre. Funding for the extra support that your child needs has to be approved by your local office of MCFD. Call ASBC for more information

Note: This Supported Childcare model envisions the end of bloc funding to specialized centres in favour of integrating all children with special needs into their neighbour childcare centres with the provision of extra supports. While laudable in intent, many families of children with Autism Spectrum Disorder are concerned that neighbourhood centres will not be able to provide trained staff able to provide the therapeutic interventions that children on the Autism Spectrum require.

Alan Cashmore Centre

(formerly Blenheim House)

Description: The Alan Cashmore Centre offers programs to families who have children, birth to six years of age with emotional and behavioral problems. Therapy and counseling services are available. Services available to people in Vancouver and Richmond.

Getting the Service: No referral needed. Call (604) 454-1676. Please note there is usually a wait list for this service. Call the Centre for more information.

Note: While the mandate of the Alan Cashmore Center does not specifically include children with ASD, the centre has helped many children on the Spectrum.

Children's Center for Ability Division of the Neurological Centre

Description: Community-based rehabilitation center that provides therapy and support services to children with special needs, including Autism Spectrum Disorders, for pre-school children in Vancouver, North and West Vancouver, Richmond and Burnaby. While intensive levels of services are not available, the Neurological Centre does provide physiotherapy, occupational therapy, speech and language therapy and family support and counseling. They have a particular expertise in the area of sensory integration. There is also a Family Resource Center that provides materials and Internet Access for families.

Children's Centre for Ability is a division of the Neurological Center. They provide therapy and support services for infants up to preschool age, through direct treatment and consultation. Referrals from parents and doctors.

Getting the Services: Parents have to request service directly, no referral is needed for pre-school children. Waitlists vary from 3-6 months. There is no cost to families for these services. Call (604) 451-5511.

Lions Society of BC

Description: Provides services to children with disabilities, including Easter Seal camps, transportation, respite care and development centres. To contact call Sheila Simpson at Easter Seal House at (604) 736-3475.

Child Care Worker (MCFD)

Description: Child Care Workers (CCW) are trained to work with your child to teach the developmental goals you set for your child. The amount of CCW hours depends on the needs of your child, service provider availability, and MCFD budgets. Typical CCW contracts are written for a period of 3 months then reviewed and renewed as

appropriate. Additional CCW hours are sometimes offered during the summer months to allow your child to participate in a community summer program. (Enhanced Services) Some regions provide group sessions for children with special needs in an effort to limit waitlists. *Parents are urged to discuss with their social worker the numbers and profiles of children in these groups to ensure that the goals for their specific child in the program can be met when children with very divergent needs participate.*

Getting the Service: Requests for a Child Care Worker, or additional CCW hours during the summer, should be made to your Social Worker. The actual number of hours a CCW will spend with you child will depend on the needs of the child and MCFD budgets. If you are denied the services of a CCW or you have been given insufficient hours, you have the right of appeal. In many regions there is a non-profit agency with which MCFD contracts to provide this service, in others it is left to the family to find an individual to do the work. ASBC may be able to put you in touch with an individual in you area interested in CCW work.

Behaviour Consultants (MCFD)

Description: Behaviour consultants offer assistance in dealing with issues related to the behaviour of your child, much of which is believed to be related to their inability to communicate and the subsequent growth in frustration. Families may wish support of this kind in order to encourage communication skills, to stop potentially damaging behaviours, to reduce behaviours that may impede social and educational development, and to help teach specific life and educational skills. A competent behaviour consultant should help the family with developing their child's communication and socialization skills but they seldom

actually work hands on with the child. In cases where a family is exhausted, it is often effective to match the services of a behaviour consultant with a child care worker or an equivalent one to one worker who can help a family implement a program. There are a number of agencies that offer behaviour consultancy services including;

C.B.I. Consultants (Communication, Behavior and Instruction)

Lower Mainland (604) 469-2727

Gateway Behavioral Support Services

Lower Mainland (604) 946-2422

Kootenays (250) 352-6026

Northern BC (250) 561-1194

Laurel Group

Lower Mainland (604)298-3434

Victoria (250) 595-4998

Vancouver Island Community Support Services

(205) 751-1550

Getting the Service: In order to receive publicly funded behavioural support for your child, a referral to the service agency must be sought through your social worker. The demand for support from these agencies is high, and there may be a delay in receiving this service. To be effective these services should start with helping a child develop difficult or anti-social behaviours, preferably as soon as a child is diagnosed. However, these services are so heavily waitlisted that increasingly they are only being used for families in crisis to deal with dangerous behaviours. For further information regarding behaviour consultancy services in your area, contact ASBC. Or your social worker.

Note: In some regions outside the Lower Mainland, MCFD has ended contracts with behaviour consultants. Some of these consultants are now available on a private basis. Laurel Group and Gateway Behavioural Support Services will also see clients privately. Because of the waiting lists for MCFD funded behaviour consultants, ASBC is starting to develop a directory of

private behaviour consultants. Please call us to see if there is anyone available in your area. These consultants are not screened by ASBC; references must be checked thoroughly. If your local MCFD office tells you that they do not fund behaviour consultants or if there is a long waiting list, it is appropriate to lodge a formal complaint. Please keep ASBC informed.

Applied Behaviour Analysis (ABA) Consultants (private)

Description: All competent behaviour consultants should be using the principles of Applied Behaviour Analysis as the foundation of their work with people with autism. However, the term Lovaas ABA is commonly used to refer to intensive programs that focus on developing the communication and cognitive skills of young children with Autism Spectrum Disorder through the use of discrete trials, using trained therapists, under the supervision of someone with a higher degree in a field related to ABA. This approach was first developed by Dr. Ivar Lovaas at the University of California. While some researchers dispute how applicable his very positive results are in working outside a university research program, many families in BC are hiring ABA consultants from the U.S. because of the lack of individualized intensive programs available in BC. ABA programs are extremely demanding of families, both financially and in terms of time. However, many families are very pleased at the progress their children have made in communication and social abilities.

Getting the Service: ASBC has a list of consultants who offer ABA. Most are U.S. based and expensive. Laurel Group based in the Lower Mainland does offer an ABA program. The initial cost of Laurel Group setting up a program is comparable to the cost of importing American expertise, although families are spared high travel

costs. Families who use Laurel Group behavior consultants, funded through the Ministry of Children and Family Development, have had the initial cost of this covered by MCFD. Other families hire the service privately with the consultants billing \$60.00 an hour. While the services of a consultant are expensive, there is the additional expense of hiring a team of therapists to implement the program for anywhere from 10-40 hours a week.

Note: *Please note that not all ABA consultants are of equal value. Your best assurance of a reputable practitioner is to ask what their training and experience has been. Ask for professional references. Follow them up. A well-qualified consultant should have done intensive training and had a great deal of practical experience with a number of children over a number of years before becoming a consultant as opposed to a therapist. Specifically, they should have been an actual ABA therapist for at least two years under the supervision of someone who in turn has a higher degree in a field related to ABA. Many families are also happy to have new families sit in on a training session so you can see if a particular consultant would suit your family's style.*

Additional Source of Information on ABA

- F.E.A.T. (Families for Early Autism Treatment) of BC, offers workshops and advice to families on ABA as well as providing training opportunities to therapists. Contact F.E.A.T. at (604) 513-7233 or check out: www.featbc.org
e-mail: skfreeman@aol.com

ABA Consultancy Groups:

- Autism Partnership, in Calgary: (310) 424-9293
- Laurel Group, Lower Mainland: (604) 298-3434
- Project PACE, in Oregon: (503) 643-7015
- Young Autism Project (UCLA) in Los Angeles: (310) 825-2961

- Wisconsin Early Autism Project (WEAP) (608) 288-9040

Education (MOE)

Description: Under the School Act, school boards are required to make available educational programs to all school age persons resident in the district. In addition, A Ministerial Order requires the integration of students with special needs with typical students, in most instances.

“Integration involves placing students with special needs in classrooms with their age and grade peers, then providing them with the necessary support, accommodation and adaptations – determined on an individual basis – to enable them to be successfully included.” A Manual of Policies, Procedures and Guidelines, Special Education Services, M.O.E.

Each school board has a great deal of latitude in how they provide an educational program for a child with autism. The best source of information is often other families in your community. ASBC can usually put you in touch with another family and advise you on strategies to work effectively with your neighbourhood school. We also have education packages for both parent and teachers.

For children who do not have a diagnosis of Autistic Disorder, but are still on the Autism Spectrum because their disability falls under the category of Pervasive Developmental Disorder, it is significant that the Manual of Policies, Procedures and Guidelines states: *“Students who present with any of the cluster of disabilities referred to as “pervasive developmental disorders” should not be identified in the autism funding category, but should be assigned to the category that best reflects the nature of their disabling conditions and the type and intensity of interventions required. These*

should be based on the assessment required in the category in which they are reported.” If a child with a PDD diagnosis needs a level of intervention equivalent to that of a child with autism, the school district can apply for the same level of funding through the Chronic Health category, in order to provide a child with what they require. ASBC can provide you with a document which offers advice to School Districts regarding placing students on the Spectrum in the Chronic Health Category. A family may have to actively advocate for this approach, as not all school districts are aware that they can be placed according to need rather than diagnosis. Alternatively, some children on the Autism Spectrum may better fit the severe learning disability or behaviour category that is funded at a lesser amount.

Getting the Service: One of the thorniest educational issues is the practice of attaching services to the diagnosis and not to the needs of the child. It is possible to appeal a school board decision. ASBC has more information available on this and many other facets of education.

Full Time Kindergarten

Students who have autism (funded in the autism category) may be eligible full time instruction immediately when they enter kindergarten. This happens, however, only in districts where such an option is available. In some cases, school districts may contract for services through a preschool or child development centre for some portion of the kindergarten year. Parents should discuss this with their school district special education personnel when planning school entry.

Speech, Occupational and Physiotherapy for School Age Children (MCFD)

Description: The above therapies are delivered through schools to children with Autism Spectrum Disorders throughout the

province, but they are delivered very differently depending where you live. For example, in North and West Vancouver only, local school boards contract with The Children’s Centre for Abilities to provide Occupational Therapy services for school age children.

Getting the Service: Although this service is funded by the Ministry for Children and Family Development, referrals are made by the school. Parents should request the school to make a referral as soon as possible as there are waiting lists in most areas of the province.

Provincial Outreach Program for Autism and Related Disorders (MOE)

Description: The Provincial Resource Program for Autism and Related Disorders (POP), formerly known as Gateway, is funded by the Ministry of Education to provide consultation and support services to school districts throughout the province. In some districts in the province, POP has trained a local ‘Autism Team’ to provide these services in the district. In other districts POP sends in consultants directly from their centre in Delta. Either way an assessment should be done with a behavior plan recommended to the school for implementation.

Getting the Service: The request should come from the local school district. Some may be reluctant fearing there is a cost to the School District involved. This is not the case. POP also offers a one week training program for parents. This is free to children who are being seen through the POP program. There is a cost to other families, which is sometimes met by the Ministry for Children and Family Development. For more information on the POP contact (604) 946-3610.

Note: *Often individual schools are unaware of the services provided by POP, it is worth calling PRP for more information and*

bringing it directly to the school's attention. You may also contact, or suggest your school contact, the School District's 'District Partner' to the POP. The name of this person should be available from the local School District office.

Special Education Technology (SET-BC)

Description: SET-BC is a provincial resource program of the Ministry of Education established to assist school districts to educate students whose access to the curriculum is restricted due to their special needs. SET-BC supplies computers and other assistive devices to children who need them. For children with Autism Spectrum Disorder, many of who are good visual learners, computers can be an important education/communication tool.

Getting the Service: To apply for this program, school districts request service from SET-BC. A screening checklist helps districts determine which applicant would benefit most from it. Contact SET-BC Provincial Centre at (604) 261-9450 to visit their library or attend one of their information workshops.

Note: *In recent year children with Autism Spectrum Disorders have had difficulty accessing services from SET-BC but it is worth being persistent. This is a heavily waitlisted program.*

Ministry of Education: homepage provides a number of publications on education and special needs. – <http://www.gov.bc.ca/beed/>
Special Education Unit Home Page:
<http://www.bced.gov.bc.ca/specialed/>

Chris Rose Therapy Centre for Autism

Description: Chris Rose Therapy Centre for Autism West is an independent program for children (6-12) with a diagnosis of

autism, who live in Kamloops. The program is based on the Sensory Integration model with a strong behavioural component. Children attend the centre five days a week, until they are ready to integrate into a regular school. This process starts with one day a week and progresses to four days a week in a regular classroom. The program in the centre includes occupational and speech therapy, music therapy, classroom academics individual self-care skills and experience in the community.

Getting the Service: Due to the Ministry of Education's funding requirements, intake is only in September of each year. There is a fee of \$300 to help defray costs. Contact Giant STEPS West at (250) 374-6400 or Fax: (250) 374-2232

Glen Eden School

Description: Glen Eden School is a private school, run by a non-profit organization in Vancouver for elementary and secondary school students who need the special services offered by the school.

"Students accepted by Glen Eden range from low-average to above-average intelligence levels. In assessing each applicant, Glen Eden evaluates not only intelligence level, but also emotional status, behavioral analysis, cognitive development level, energy level, developmental history, and other factors that might indicate the student has a higher learning potential." – Glen Eden brochure

While Glen Eden is not equipped to offer programs for students with Autistic Disorder who are seriously developmentally disabled, it does accept some children on the Spectrum. It is also developing a residential program.

Getting the Service: Glen Eden can be reached at (604) 267-0394 Fax: (604) 267-0544

Note: *If your child has high needs Glen Eden can be extremely expensive. However, because of the therapeutic nature of the program, there have been some unusual instances of either or both of the Ministry for Children and Families and the Ministry of Education contributing to a program at Glen Eden.*

Organizations You Should Know About

Autism Society of British Columbia (ASBC)

Description: The Autism Society of British Columbia is a non-profit organization and a provincial resource of the Ministry for Children and Family Development. ASBC's mission is to promote understanding, acceptance and full community inclusion for people with Autism Spectrum Disorder in BC. Fifty percent of ASBC's family support and training programs are funded by MCFD. All others are supported solely through the fundraising efforts of staff and volunteers. ASBC provides support and advocacy to parents and adults with autism. If a service is not available in a timely fashion in your region, we recommend using the complaints procedure within the relevant ministry, the offices of the Child and Youth Advocate and the Ombudsman, as well as your Member of the Legislature. ASBC has a network of community groups throughout the province, facilitated by volunteers. The Buddy Volunteer Program gives an opportunity for community volunteers to develop a friendship with a person with Autism Spectrum Disorder with the objective of increasing social and communication skills. ASBC provides limited funding for summer programs* for children and adults, maintains a resource library, as well as providing information and referrals. In addition, ASBC

offers informative workshops on autism for both parents and professionals. You can keep up to date on Autism in BC by subscribing to our bi-monthly newsletter or visiting our Web site.

Getting the Service: ASBC can be reached in the Lower Mainland at (604) 434-0880/fax (604) 434-0801. Toll free 1-888-437-0880. E-mail info@autismbc.ca. We also have branches on Vancouver Island (250) 714-0801/fax (250) 714-0802. E-mail Nanaimo@autismbc.ca and Prince George (250) 561-0881/fax (250) 561-0887. E-mail autismbc_pg@uniserv.com Web site: <http://www.autismbc.ca>

***Note:** *Applications for the summer program begin in the spring. Typically the deadline for applying for funds is in June to allow us to raise money. Call ASBC for details.*

ANCA Consulting Inc.

Description: *'Specializing in autism; support and development for autistic people by autistic people'* ANCA offers services that include panel presentation, workshops, and consultations, to parents, professionals, individuals and support groups.

Getting the Service: For more information contact ANCA Consulting Inc. in Vancouver at (604) 879-2522.

British Columbia Association for Community Living (BCACL)

Description: BCACL is a provincial association that advocates for people with developmental disabilities and their families. BCACL also acts as a resource for local associations that provide services to people with developmental disabilities throughout BC, as well as families, individuals, and the general public. In addition, BCACL provides educational workshops and publications and continues to organize many

Provincial Review Panels dealing with issues related to special needs.

Getting the Service: BCACL can be reached at (604) 875-1119.

Associations for Community Living (ACL)

Description: ACL's are non-profit societies that offer programs for children and adults with a developmental disability and their families, i.e. vocational, training, respite, preschool and infant development.

Getting the Service: Call BCACL (see above) for information on your local Association for the Mentally Handicapped or your local Community Living Association. BCACL – (604) 875-1119.

Family Support Institute (F.S.I.)

Description: The Family Support Institute provides information, training, and province-wide networking to assist families of children with disabilities and their communities to share strengths. It brings families together to share common issues, needs, concerns, and solutions through a parent network. *Regional Resource Parents* are volunteer parents trained by FSI to act as sources of information and support to other parents in their local communities. FSI also collects and provides up-to-date information on government services, current practices, and educational, recreational, and respite care options.

Getting the Service: To contact FSI or a *Regional Resource Parent* in your community call (604) 875-1119.

British Columbia Confederation of Parent Advisory Councils Advocacy Project (BCCPAC)

Description: The BCCPAC Advocacy Project helps students, parents and BCCPAC

member school district councils (PACs/DPACs) to solve problems students may have in the BC public school system. It provides advocacy materials and information, presentations and workshops, a toll free message line for parent leaders and parents who are struggling with issues such as treatment of students, bullying, school fees, fear of retribution, appeals and student discipline. Within this project individual District Parent Advisory Councils may have set up their own advocacy project. It is important to note that the expertise of these advocates regarding special needs education may vary considerably. Toll Free message line 1-888-351-9834.

Children and Adults with Attention Deficit Disorders (CHADD)

Description: Gives information and support to individuals diagnosed with ADD, their families and professionals. There are 16 chapters all over BC; to find the one in your area call (604) 271-9285 or (604) 271-8338.

Federation of Invisible Disabilities (FIDS)

Description: Raises public awareness through education and information. Provides publications and some networking and advocacy services in various locations throughout the province. Toll Free: (800) 549-1999. Web site: www.fids.bc.ca

Learning Disabilities Association of British Columbia (LDABC)

Description: Non-profit society providing information, referral and support throughout BC. To find the chapter in your area call/fax (250) 542-5033.

Teachers' Tutoring Service

Description: Non-profit society of qualified teachers who provide tutoring services. Individual tutors may be experienced with special needs children and English as a second language. To contact call (604) 736-1712.

Canadian Academy of Therapeutic Tutors (Orton Gillingham)

Description: A central information list of qualified Therapeutic Tutors who provide Orton Gillingham Tutoring which is a systematic, individualized, multi-sensory form of tutoring. For more information call 604-261-3125.

PLAN – Planned Lifetime Advocacy Network

Description: Provides advocacy and legal information on wills, trusts, financial and estate planning. To contact call (604) 439-9566 or fax (604) 439-7001. In Prince George call PLAN Coordinator, Terry Robertson, Ph 250-561-7300, fax 250-564-5681, email planpg@chpg.net

Government Funded Agencies that Provide Advocacy & Related Services

Ombudsman

Description: The Ombudsman is an Officer of the Legislature whose office has the statutory power to investigate complaints by people who feel they have been treated unfairly through the action and/or decisions of Ministries, Crown Corporations, local governments, schools, hospitals, and regional health authorities. The Ombudsman

is responsible for making sure that administrative practices and services of public bodies are fair, reasonable and appropriate. The Ombudsman carried out the duties of the Office through the management of a group of professional staff in Victoria and Vancouver and reports on the activities of the Office to the Legislative Assembly. He/She may recommend a change in a government agency's decision, action or practice if he/she thinks you have been treated unfairly.

Getting the Service: To use this service, contact the Office of the Ombudsman at – 800-567-3247. web site address is www.ombd.gov.bc.ca

BC Human Rights Commission

The mandate of the BC Human Rights Commission is to investigate and mediate complaints of discrimination, to educate the public about their rights and responsibilities under the Human Rights Code and to promote understanding and compliance with the Code. Individuals may file complaints if they feel they have been discriminated against. There are also provisions within the Human Rights Code for a systemic complaint to be filed.

Getting the Service: In Victoria, Phone: 250-387-3710 Fax: 250-387-3643, In Vancouver, Phone: (604) 660-6811, Fax: (604) 660-0195, Toll-free outside Victoria and the lower mainland: 1-800-663-0876. Web sit address www.bchre.gov.bc.ca

Child Youth & Family Advocate

Description: The Advocate's work includes helping children and youth who are having difficulties with services provided by the Ministry for Children and Families. This includes foster care, family support services, mental health services and community-living services, as well as others.

Getting the Service: The Advocate is funded by government but is independent of any government ministry. To contact the office of the Child Youth & Family Advocate, in BC call 1-800-476-3393; in Vancouver call (604) 775-3203. Web site address www.advokids.org

Office of the Public Guardian and Trustee

Description: The Public Guardian and Trustee is the person appointed to protect the legal rights and financial interests of children under 19 years of age and vulnerable adults. This includes managing of finances, ensuring adequate legal representation and conducting inquiries into complaints.

Getting the Service: To contact the Public Guardian and Trustee call (604) 660-4444. Toll free: 1-800-663-7867. Web site address www.trustee.bc.ca

The Children's Commission

Description: The Commission is an independent agency set up to monitor government services for children & youth. Their mission is *"to oversee the child and family serving system of government to promote fairness, accessibility and responsiveness to the needs of children under age of 19."* The Children's Commission is independent of the Ministry of Children and Family Development and reports to the Attorney General.

Getting the Service: Toll Free: 1-800-859-1441. In Vancouver 1-250-356-0831

Government Information Lines

Health Information Line: The Ministry of Health's toll-free number is: 1-800-4654911

Enquiry BC: The Ministry of Government Services operates a toll free information service for **provincial** government services. If you do not know the name of the ministry, branch or department, just the concern/question you need answered call: in Greater Vancouver 660-2421; in Greater Victoria call 687-6121; elsewhere in BC 1-800-663-7867

Passes, Discounts and Credits

Disability Tax Credit: If you have a child with a permanent disability like Autism Spectrum Disorder you are eligible for annual tax credit –**retroactive to the 1985 taxation year or the year of you child's birth if after 1985.** For more information, contact your district taxation office for tax form T2201.

Home Owners Grant: If you have made expensive changes to the inside of your home due to child's disability, you may be entitled to a Home Owner's Grant. Though this grant is for people with permanent physical disabilities, you can apply and it will be up to the provincial government to decide whether you qualify. Ask for an application through your local municipal government office. Your doctor will have to fill out a certificate and questionnaire. Include receipts if possible.

HandyDart and HandyPass: HandyDart is a special door-to-door transit service for persons who are unable to use the regular fixed-route transit system. The overriding eligibility guideline is that a person has to have a physical or mental disability that prevents them from using conventional public transit. Applications are available from BC Translink at (604) 453-4643.

Taxi Saver Program The Taxi Saver Program is a subsidized taxi service that allows individuals with permanent physical or cognitive disabilities spontaneous travel. Travel saver coupons booklets are sold to anyone with a valid HandyPass and are available for purchase at your local HandDart office. For a list of participation cab companies or for more information call (604) 453-4634. a list of cab companies is also available from the ASBC office.

Fuel Tax Rebate: If you have a disability and own a vehicle, you can complete an “Application for Fuel Tax Rebates for Handicapped Persons” form – available from the Consumer Taxation Branch.

BC Ferries Pass: BC Ferries provides reduced rate for your special needs child and his/her escort upon eligibility. Contact BC Ferries, 1112 Fort Street, Victoria, BC V8V 4V2 phone 1 (888) 223-3779 then press “O” for an “*Application for Disabled Identification Card*”. Fax: (604) 388-7754.

BC Parks Pass: If your child meets the program’s eligibility criteria, he/she can camp free in BC provincial parks and recreation areas. For more details, contact BC Parks at Ministry of Environment, Lands and Parks, Second Floor, 800 Johnson Street, Victoria, BC V8V 1X4 phone (250) 387-5002 Fax (250) 387-5757 for a “*Disabled Access Pass Application*”.

Leisure Access Card: In Vancouver this gives people on restricted incomes access to basic Park Board programs and services like pools and fitness centres. Some communities offer special discounts for people with disabilities or their caregivers. To get more information on similar services operated in your community, contact your local Municipal Parks and Leisure office.

Travel Assistance Program (TAP):

TAP is funded by the Ministry of Health. This program is designed to reduce the costs of long distance travel for people who much leave home for non-emergency medical services.

Check with the following carriers for more information on discounts for passengers and attendants:

Air BC	Air Canada
Harbour Air	BC Rail
VIA Rail	BC Ferries
Pacific Coach Lines	Malaspina Coach Lines

For more information in BC call 1-800-661-2668; in Victoria call 952-2657 or 952-2998 **before** you travel.

* Many thanks to the Edmonton Autism Society for allowing us to ‘borrow’ the title of their services guide.
