

**A SYSTEM OF CARE
FOR CHILDREN WITH
AUTISM**

EXPERT PANEL REPORT

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For more information, please contact:

Intergovernmental Initiatives & Policy Research, Alberta Children's Services, (780) 427- 3446

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Executive Summary

Autism is a developmental disorder of neurobiological origin that is defined on the basis of behavioral and developmental features. It is characterized by deficits in reciprocal social interaction, impaired reciprocal verbal and nonverbal communication, and restricted and repetitive patterns of behavior, interests and activities.¹ The prevalence of autism has increased over the past thirty years.

An increasing number of families in Alberta are requesting funding from the Ministry of Children's Services through Resources for Children with Disabilities (RCD) for intensive intervention programs for their children. One program model, Intensive Behavioral Intervention (IBI) has received much attention. Approximately half of children with autism who receive funding through Resources for Children with Disabilities are using an Intensive Behavioral Intervention program. Although Resources for Children with Disabilities' policy limits funding for Intensive Behavioral Intervention to three years, approximately 28%² of the children receiving Intensive Behavioral Interventions are "on extension". Extensions were granted by Ministerial Directive after parents started an appeal process.

In April 2002 the Ministry of Children's Services, in partnership with Health and Wellness and Alberta Learning, convened an Expert Panel on Autism composed of twelve working members, eight (8) members representing key professions closely involved in service to children with autism, service providers and parents, plus four (4) members from the ministries of Health and Wellness, Alberta Learning and Children's Services. The Expert Panel was mandated to review the research literature, consider current best practice experience and recommend best practice guidelines for programming for pre-school children with autism and for transition services for school aged children.

The Expert Panel's recommendations regarding a system of care for children with autism are summarized below.

¹ National Research Council. (2001) Educating Children With Autism. Washington D.C.

² 318 children receiving IBI; 98 of these children "on extension" See appendix for details

Recommendations

1. Ensure availability of the **Early Intervention Program** in all regions.

Currently 14 of 17 regional health authorities provide an Early Intervention Program under the auspices of the Ministry of Health and Wellness.³ The Panel recommends that this program be available in all health regions.

The Early Intervention Program provides an excellent first level of screening and support for children with developmental delay or disability, including autism. In addition the Early Intervention Program provides an important component of early treatment for very young children (age 0 to 18 months) and for those children (up to age 3) where a diagnosis is provisional or uncertain.

2. A **new diagnostic entry system should be adopted**

The new system for diagnosis and entry into the service system for children with autism spectrum disorders and their families attempts to streamline the process for diagnosis and service access in order to increase system efficiencies and make services more accessible to children and families in order to ensure appropriate intervention “as early as possible”.

3. A **diagnosis of autism spectrum disorder** together with the child's **developmental needs** and his or her **functional abilities** should be considered necessary **in determining eligibility** for Intensive Early Intervention.

Any system of care for children with Autism Spectrum Disorder should recognize the degree of variability demonstrated by these children both within developmental domains and across the developmental spectrum as well as the family's preferences and ability to incorporate intervention into family life. Consequently intervention should be matched to the needs of the child and the family, to the greatest extent that this is possible. As a result diagnostic assessment carried out for the purposes of accessing interventions should make reference to the child's developmental and functional needs, with recognition that a multidisciplinary assessment may not be feasible or even desirable in many situations (Please refer to Section 2.3 Screening, Assessment and Diagnosis)

4. At least two **Centres of Excellence** should be established with expertise in the assessment and long term outcomes of children with developmental disabilities, including **specialized cross-disciplinary Autism Teams**.

The Centres of Excellence and specialized cross-disciplinary Autism teams should be funded through Alberta Health and Wellness, and closely linked to the

³ Early Intervention Program is not available in Headwaters Region (Okotoks/High River/Canmore), Region Five (Drumheller) and Northwestern Region (High Level).

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ministries of Children's Services and Alberta Learning. Ideally, they should be in close conjunction with the Alberta Children's Hospital and the Stollery Children's Centre. They should involve integrated consultations from multiple disciplines to provide: diagnostic services, monitoring regarding progress and medical complications, and management guidance and advice. They should be coordinated with existing community diagnostic and management services, and support transitions to other services as appropriate.

5. Move to a **developmentally based system of care** for children with autism.
 - Enhanced Early Intervention (for children age 18 to 30 months of age)
 - Intensive Early Autism Intervention program (from age 2.5 years until the child reaches student status – i.e. age 6 on or before Sept.1)
 - School aged services

Treatment type, intensity and location (home, centre, or school based) should be flexible to accommodate the child's developmental stage, age at diagnosis, family circumstances, and community considerations.

The system of services for school aged children with autism proposed as part of the Therapeutic Program Matrix is intended as an **interim model to be tested over a three year period**. During this three year period, evaluation should be conducted to gather more research evidence about the effectiveness of the model. Evaluation could then be used to inform longer term plans for provision of services for school aged children with autism.

6. Implement **regular developmentally appropriate functional assessments** based on the proposed treatment outcomes, as a basis for individual program planning and design.

Functional assessment should be used to guide programming development and to match resource levels to the individual needs of the child.

7. Enhance **cross-ministry funding for school aged children** with complex needs who require cross-ministerial involvement (Alberta Learning, Children's Ministry, Health and Wellness).

Some high needs school age children will require support services at home and in the community that are in addition to the supports provided by the Alberta Learning Ministry within the school environment. In order to ensure maintenance and enhancement of gains realized during the preschool years, continued support may be necessary as the child enters school. Families will also require continued access to respite and aide service to a level appropriate to the needs of the child and family.

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8. Develop a provincial **Clinical Advisory Panel** composed of key multi-disciplinary clinical representation and parents.

Clinical Advisory Panel members could provide expert consultation in a number of different areas such as:

- review of diagnosis and assessment reports
- develop certification process for service providers
- review service provider credentials
- develop best practice operational definitions for the critical elements of intensive autism services
- monitor/audit programs,
- advise the three ministries (Alberta Learning, Children's Ministry, Health and Wellness)
- facilitate the development of a distance learning program
- identify areas of needed research

9. Move to a **Provincial Funding Model**.

In order to ensure consistent access to the range of programming and services recommended for children with autism, and to ensure high quality, cost effective service, the Expert Panel recommends that Children's Services funding for "intensive intervention" services move from Regional to Provincial funding. Moving to a provincial funding model will allow for the development of best practice guidelines, service provider certification processes, ongoing monitoring and targeted research initiatives.

10. Develop an "**Essential Components**" document for school programs.

An "Essential Components" document would provide support and guidance to individual schools in the development of appropriate educational strategies for school age children with autism.

11. Develop "**Best Practices**" guidelines for "intensive intervention" programs for preschool children with Autism Spectrum Disorder.

Best Practices guidelines could be used to establish a **certification process for services providers**, as well as ensuring consistent high quality service across programs.

12. Develop **Best Practice standards and a certification process for service providers**.

While the Expert Panel supports both home, centre, or school based program options, development of best practice standards and a process for certification, monitoring and review of service providers is recommended.

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13. Develop an **information/resource package and/or web site for parents and professionals.**

Parents and professionals involved with young children need accurate information to dispel myths, to outline diagnostic, assessment and treatment services, to understand potential supports and funding systems, and to answer common questions.

14. Develop **autism training packages** providing a core of essential information for professionals.

In order to ensure that school aged children with autism spectrum disorder have access to consistently high quality programming in their local school setting, training should be made available to teachers, teacher assistants, therapists, multidisciplinary assessment team members, day care providers, early intervention staff, public health and other related professionals.

Distance education and/or community colleges should be considered as possible venues for training.

15. Provide **incentives and/or supports** for training.

In order to participate in training, teachers and aides may need incentives such as **release time**. In addition, local **mentors** could be identified to guide teachers, parents and schools in the development of high quality programming, environmental accommodations, strategies for behavior management, etc. Support and encouragement from the Regional Boards across ministries would help this to happen.

16. **Invest in research.**

There is currently little research to guide best practice recommendations, especially for interventions with school age children. Better data on outcomes is needed to truly understand the effectiveness of Intensive Early Intervention investments, and the implications of continued investment of resources for school age children.

There should be a strong evaluation and accountability framework in place for programs providing intensive autism intervention.

1.0 Introduction and Background

Effective intervention strategies for Autism Spectrum Disorder have received considerable attention in recent years. The following report recommends strategies aimed at guiding the development of services for children with Autism in Alberta. These strategies were developed from the current best practices literature and from the clinical experience of Panel members.

1.1 Expert Panel on Autism

At the request of the Minister for Children's Services, an Expert Panel was invited to undertake a review of the research literature, consider current best practice in various treatment realms and within a number of service systems (e.g. health, education, early childhood), and to make recommendations for future best practice programs and services. The Expert Panel consisted of eight voting members with expertise in autism, comprised of five professionals and three parents, and four ex officio supporting technical advisors from the Ministries of Alberta Children's Services, Health and Wellness, and Alberta Learning.

The Children's Services Expert Panel on Intensive Early Intervention Services for Children with Autism was mandated to:

- Advise on issues regarding the provision of Intensive Behavioral Intervention (IBI) and other intensive early intervention services for children with autism;
- Determine appropriate strategies for early intervention for children with autism and their families; and
- Identify best practices in early intervention supports for children with autism and their families, and important aspects of quality control and financial management.
- Recommend appropriate resources and supports for children with Autism Spectrum Disorder making the transition to kindergarten, grade one, grade two and beyond.

The Expert Panel undertook an extensive review of the literature, with individual members contributing the most recent research available in their field of practice. Ministry representatives supplemented the discussion with related statistics, definitions and policy information from their particular Ministry. The recommendations for best practice and guidelines for service are the result of a series of lengthy and focused meetings where members of the Expert Panel explored possibilities and engaged in open, collegial debate from multiple perspectives.

All Expert Panel members were active contributors to the discussion and the formulation of recommendations. All Expert Panel decisions and recommendations were reached by consensus.

1.2 Research

“Autistic spectrum disorders are present from birth or very early in development and affect essential human behaviors such as social interaction, the ability to communicate ideas and feelings, imagination, and the establishment of relationships with others. Although precise neurobiological mechanisms have not yet been established, it is clear that autistic spectrum disorders reflect the operation of factors in the developing brain. Autistic disorders are unique in their pattern of deficits and areas of relative strengths. They generally have lifelong effects on how children learn to be social beings, to take care of themselves, and to participate in the community.”⁴

A careful review of current research undertaken by the Alberta Heritage Foundation for Medical Research (2001) on comprehensive treatment programs for children with autism concluded that “it appears that children improve in functioning with intensive intervention programs, but it remains to be determined if any one program is more effective than another. There is insufficient evidence to establish a relationship between amount (intensity and duration) of any intensive intervention treatment program and outcome measures (intelligence tests, language development, adaptive behavior tests).”⁵

A national Health Technology Assessment (2001)⁶ indicates that “though limited, findings of existing studies suggest that preschool children with autism exhibit cognitive and functional improvement when receiving behavioral intervention with applied behavioral analysis for approximately 20 hours per week or more. It is not clear, however, which subset of children with autism derive the most benefit, which components of therapy are integral to positive outcomes, whether similar results would be observed in older children with autism, whether there are definable long term functional benefits . . .”

Appropriate goals for children with autistic spectrum disorders are the same as those for other children: personal independence and social responsibility. These goals imply progress in social and cognitive abilities, verbal and nonverbal communication skills, and adaptive skills; reduction of behavioral difficulties and generalization of abilities across multiple environments.⁷

There is relatively strong consensus across programs regarding the characteristics of effective interventions. These include early entry into an intervention program; active engagement in intensive instructional programming, use of planned teaching opportunities, and sufficient amount of adult attention in one-to-one or very small group instruction to meet individualized goals. In *Educating Children With Autism*, the

⁴ National Research Council (2001) *Educating Children with Autism*. Washington D.C.

⁵ Ludwig, S. Harstall, C. (2001) *Intensive Intervention Programs for Children with Autism*. Alberta Heritage Foundation for Medical Research, Health Technology Assessment – 8: Series B

⁶ McGahan L. Behavioural interventions for preschool children with autism. Ottawa: Canadian Coordinating Office for Health Technology Assessment; 2001. Technology report no 18. p.iv

⁷ National Research Council (2001) *Educating Children with Autism*. Washington D.C.

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committee on educational interventions for children with autism of the United States National Research Council recommends that the priorities of focus for programming should include functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to behavior problems.⁸

The challenges presented by children with autism have serious impacts on their families. “Many families benefit from the availability of both formal and informal social support to handle the complex demands in their lives.”⁹ Parents must learn specialized skills and actively engage in programming at home to support and enhance gains made by the child in their intensive programming. Parents often act as the primary case manager in organizing, implementing and supervising their child’s program. Parents are the essential advocate for their child within the service system and in collaboration with service professionals.

1.3 Historical Developments In Alberta

Children with autism in Alberta receive a wide range of services primarily from the Ministries of Children’s Services, Alberta Learning, and Health and Wellness.

Resources for Children with Disabilities (RCD) [formerly known as Handicapped Children’s Services (HCS)] first began to fund Intensive Behavioural Intervention (IBI) services in the mid-1990s due to parents’ requests, Child Welfare Appeal Panel decisions and a court challenge.

The Ministries of Alberta Learning, Health & Wellness, and Children’s Services worked collaboratively to develop IBI (Intensive Behavioral Intervention) Provincial policy and to undertake a research and program evaluation process. In August of 1998, the Ministry of Family and Social Services approved an interim policy for the provision of Intensive Behavioral Intervention. In May 1999, a formal policy on Intensive Behavioural Intervention services for children with autism was developed.

Resources for Children With Disabilities provides funding to assist with the cost of Intensive Behavioral Intervention programs as early intervention for children with a diagnosis of autism or pervasive developmental disorder not otherwise specified (PDD-NOS).

IBI policy, as established in May 1999, provides for a maximum of three years of programming for preschool children with autism or, if they have not yet received three years, to the end of the first full school year (grade one).

IBI policy also requires that in addition to the child having a diagnosis of autism or PDD-NOS, a comprehensive multidisciplinary assessment of the child be completed and report provided, to determine eligibility for IBI services. The multidisciplinary

⁸ National Research Council (2001) *Educating Children with Autism*. Washington D.C.

⁹ National Research Council (2001) *Educating Children with Autism*. Washington D.C.

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assessment should also indicate the child's intervention goals and rationale for the recommendation of an IBI program rather than another treatment option.

According to provincial policy, IBI programs consist of intensive one to one teaching based on behavioral strategies, a structured, routine program that is developmentally appropriate and based on the child's individual goals as well as health therapies (including speech, physiotherapy and occupational therapy) as recommended by the assessing health professional.

Alberta Learning provides Program Unit Funding (PUF) to school authorities to support the implementation of developmentally appropriate programs for children with severe disabilities 2.5 to 6 years of age. School authorities may use Program Unit Funding to purchase or provide IBI services as a component of the child's overall education program. Programs for "students"¹⁰ are supported through the severe disabilities funding provided to school authorities.

Three specialized assessment and consulting teams funded by Alberta Learning, located in Grande Prairie, Edmonton and Calgary, provide regional assessment and consultation services to assist school jurisdictions and private operators in the provision of educational support services for students with complex learning needs. Students 2.5 to 20 years of age who meet criteria associated with sensory-impaired multi-handicapped disorders, severe communication disorder or autism/PDD qualify for services. Services provided by the regional teams include assessment, consultation and in-service. These teams do not provide direct intervention on an ongoing basis.

Alberta Health and Wellness provides a variety of assessment, diagnostic and medical services to children with autism, but does not fund IBI programming. The Early Intervention Program (EIP) is a home-based support program provided in 14 of 17 regional health authorities to assist young children with developmental delays or disabilities and their families.

As part of the cross-ministry Early Childhood Development (ECD) work being undertaken in Alberta, the ministries of Children's Services, Health and Wellness and Alberta Learning are exploring possibilities for a province-wide population-based screening for cohorts of young children (see definitions). The goal of this work is to explore opportunities for methods of providing screening which lead to subsequent assessment and intervention for young children identified through the screening process and provide recommendations related to potential screening tools, processes and tracking system. It is expected that the end result of implementing screening programs at key stages will be that high-risk children and children with disabilities/special needs will be identified as early as possible, that these children and families will access available supports and interventions, and that the children will have an improved readiness to learn when they begin school.

¹⁰ A student is defined under the School Act as every individual who at September 1 is six years of age or older and younger than 19 years.

1.4 Current Status

Over time the system of services for children with autism has evolved in response to government policy and community needs. The following discussion points out a number of issues or diversions that have arisen within the service system. These issues have impacts on how service is delivered and accessed.

Policy governing the provision of IBI programming was developed at the provincial level but is implemented by Regional Child and Family Service Authorities. One of the problems that has developed is an inconsistency in interpretation and implementation of Resources for Children with Disabilities (RCD) policy among the various Regional Authorities for Children's Services.

Core programs such as the Early Intervention Program (EIP) for children age 0 to 3 (provided through Health and Wellness) and Behavioral Outreach Programs for school age children and adults (provided through Children's Ministry and Persons With Developmental Disabilities) are not available in all regions and appear to be eroding over the past few years.

Smaller regions often have fewer service options available than larger regions, resulting in the need to develop alternative systems of care. This situation can create equity and access issues, but in some cases it has resulted in innovative and creative approaches to service design and delivery.

Provincial policy dictates that a multidisciplinary assessment is required to determine eligibility for Intensive Behavioral Intervention (IBI) services but many children have received funding for IBI services without this type of assessment. One of the reasons for providing services without a multidisciplinary assessment and recommendation, is the perceived long waiting list for children to be seen by a multidisciplinary team.

On a more philosophical level, Resources for Children with Disabilities' policy provides for individualized supports and services with the degree of flexibility necessary to address children's unique needs and family circumstances. However, the program was never intended to provide therapeutic or educational services.

Over time, Intensive Behavioral Intervention (IBI) has come to be viewed, by many interested parties, as a necessary early intervention program. Although IBI treatment was originally intended as an intensive intervention for pre-school children¹¹, some parents and professionals have identified the need for IBI services to continue as part of the child's long-term program.

Currently approximately 318 children are receiving IBI services in Alberta and almost half of these children are school aged. Of the 136 school aged children (age 7+) involved with IBI, eighty-nine (89) children are currently receiving extensions of IBI

¹¹ Lovass, O.I. (1987) Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology* 55:3-9

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services beyond policy parameters, to August 31, 2002. The current extension was intended to enable children to make a transition to appropriate community supports and school programs as well as to provide adequate time for completion of the formal IBI evaluation.

One problem with the current status of children “on extension”, as families and service agencies point out, is that there are few appropriate community supports into which their children can effectively transfer. In addition, sufficient resources do not exist to support children and their families in the transition from Intensive Behavioral Intervention (IBI) services to school programs at the end of the three years of programming provided for in policy. Therefore, the perception is that there are no alternatives to Intensive Behavioral Intervention (IBI). Even so, the Child Welfare Appeal Panel has been confirming the Director’s decision not to provide Intensive Behavioral Intervention services to school aged children, stating that these cases fall within the jurisdiction of Alberta Learning.

Equitable access to service becomes another issue when policy limits IBI service to children with a specific diagnosis. Interest has been expressed in IBI services or similar specialized early intensive intervention programs for children with diagnoses other than autism who also experience functional or behavioral difficulties.

Even within the group of children diagnosed with autism access to services is not equitable.

As in every diagnostic category, there is some imprecision in the diagnosis of autistic spectrum disorder (in this case when identifying very young children, children with significant additional disabilities or children with mild or atypical symptoms). The availability of a particular model of service (i.e. IBI) being dependent on the diagnostic label puts significant pressure on clinical assessments, as families seek a diagnosis of autism in order to receive access to Intensive Behavioral Intervention services.

The limited number of IBI service providers also influences the number of children able to commence IBI programs. In addition, qualified staff to implement the various components of the program, including behavioral interventionist aide support, speech/language pathologists, occupational and physical therapists, etc. are unavailable.

The demand for IBI programming has created a market for IBI services providers. However, regulatory standards and quality assurance have lagged behind. At present, there are very few controls placed upon service provider organizations.

2.0 Guidelines for Best Practice

The Expert Panel considered best practice for treatment programs and services from a number of perspectives including a thorough review of the literature on autism treatment, grounded in the broader context of child development theory, communication theory and recent research in brain development. Where there was no specific research available to guide recommendations, Expert Panel members drew on available research, best practice examples and their extensive experience with children with autism to formulate the following guidelines for service development. The following recommendations provide guidelines for service development and should be considered recommended best practice where conclusive evidence is not yet available.

2.1 Screening, Assessment and Diagnosis

The prevalence of Autism appears to be increasing and is now estimated at approximately 2.6 per 1,000 live births.¹² With approximately 40,000 births per year in Alberta this should result in a rate of approximately 100 new cases per year.

Despite many recommendations that screening for autism take place, there are no empirically validated screening tools currently available for identification of Autism. The modified Checklist for Autism in Toddlers (CHAT), Screening Tool for Autism in Two Year Olds (STAT), or Pervasive Developmental Disorders Screening Test I (PDDST2) are all contenders, and should be adopted if/when they are adequately validated. The Communicative and Symbolic Behavior Scale - Developmental Profile (CSBS-DP) Checklist might also be appropriate as a mechanism for screening social communicative behavior. General developmental screening tools could also be used for autism surveillance in young children. Good systems exist within Alberta for early developmental screening (i.e. public health nurse) and for surveillance (i.e. Alta. Health & Wellness - Early Intervention Program).

Screening is a population-based activity applying a simple, accurate method for determining which children in the population may need special services in order to develop to their fullest potential. Assessment is a much lengthier process to gather and analyze detailed information relevant to an individual's special needs to determine the nature of the condition or issue, provide strategies for intervention and plan for achievable outcomes. Assessments are highly specific to a condition or disorder and are administered only to those individuals who have an identified concern.¹³

Currently Resources for Children with Disabilities policy requires that "in addition to the child having a diagnosis of autism or PDD-NOS, a comprehensive multidisciplinary assessment of the child be completed and report provided, to determine eligibility for

¹² Fombonne, E. et al (2001) Prevalence of Pervasive Developmental Disorders in the British Nationwide Survey of Child Mental Health. *J. Am. Acad. Child Adolesc. Psychiatry.* 40:7.

Feinberg, E. et al (1998) Creating Public Policy in a Climate of Clinical Indeterminacy. *Inf. Young Children* 10:3.

¹³ Working definition taken from the cross-ministry Early Childhood Development Preschool Screening Steering Committee (ECD) working group in Alberta (2002).

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Intensive Behavioral Intervention services. The multidisciplinary assessment should also indicate the child's intervention goals and rationale for the recommendation of an IBI program rather than another treatment option."¹⁴

Interpretations of what may be accepted as "multidisciplinary" vary but often refer to assessments carried out by three specific "teams" located at the Glenrose Hospital, Edmonton; Children's Service Centre, Red Deer and Alberta Children's Hospital, Calgary. However, multidisciplinary assessments may in fact contain a collection of assessments from different sources in the community (e.g. family physician, speech pathologist, occupational therapy, etc.) particularly in smaller communities. It is the collation and integration of these assessment which defines a "multidisciplinary team" rather than the location of its members.

The Expert Panel recommends the following system for screening, diagnosis and assessment based on the notion that children present within three broad categories requiring different diagnostic approaches:

- the child with "classic autism"
- the child with a broader Autism Spectrum Disorder
- the child whose diagnosis is unclear

¹⁴ Autism Expert Panel, Terms of Reference, Background April 2002.

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1. **Universal screening of general child development** using validated tools is recommended. **Surveillance for autism** should be included within this general screening. Screening for autism is not possible currently. The evidence in this area should be reviewed regularly, and screening for autism instituted as soon as there is an adequate instrument to use.
2. The Early Intervention Program (EIP) provided through Health & Wellness should be available in all Regions.
3. Adapt the current Children's Services IBI policy to allow for diagnostic services to be more individualized (at present policy stipulates that a multidisciplinary assessment is required):
 - a) **Single Discipline Diagnosis**
 - Appropriate when the child presents with "classic autism"
 - Diagnosis accepted from: Developmental Pediatrician, Child Psychiatrist, or Chartered Psychologist
 - The diagnosis must be made using established DSM-IV criteria and the report should stipulate which criteria were met
 - The diagnostic process should involve direct observation of the child, consideration of developmental history and a parent/caregiver interview
 - b) **Multidisciplinary Assessment**
 - Appropriate when the child appears to present with a broader Autism Spectrum Disorder
 - The assessment may involve input from a variety of disciplines (e.g. Pediatrics, Psychiatry, Psychology, Speech Pathology, Occupational Therapy, Education, Physiotherapy) and the obtained information should be integrated in order to arrive at a diagnosis.
 - A structured observation using an instrument such as Autism Diagnostic Observation Schedule (ADOS), or the Childhood Autism Rating Scale (CARS) must be part of the data. The Communicative and Symbolic Behavior Scale (CSBS), while not autism specific, also provides opportunities for structured observation.
 - The diagnosis must be made using established DSM-IV criteria and the report should stipulate which criteria were met.
 - The multidisciplinary team does not need to be hospital-based to satisfy the above requirements.
 - c) **Diagnostic Therapy Assessment**
 - Appropriate when the diagnosis is not clear and the professional would like to gather additional information and defer diagnosis for 2-3 months.
 - The child would be enrolled in an intervention program for the purpose of diagnostic therapy. Structured observation as outlined in section 3(b) would be included as part of the intervention program.
 - At the end of the treatment block the issue of diagnosis would be considered in light of the child's response to treatment, the observations of the treatment staff, etc.
 - The assessment may involve input from a variety of disciplines (e.g. Pediatrics, Psychiatry, Psychology, Speech Pathology, Occupational Therapy, Education, Physiotherapy) and the obtained information should be integrated.
 - The diagnosis must be made using established DSM-IV criteria and the report should stipulate which criteria were met

Chart 1: Diagnostic Entry System

2.2 Treatment Programs and Services For Pre-School Children With Autism

Treatment programs and services for preschool children with autism need to be specifically designed to address the range of unique characteristics and challenges associated with autism spectrum disorder. Generic programming designed for children with developmental disabilities may not be particularly effective for children with autism. The following discussion of treatment services represents the best thinking of Expert Panel members based on evidence available from the research literature as well as extensive personal and professional experience in working with children with autism. Figure 1 demonstrates the system of care that is envisioned.

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Service Delivery Model

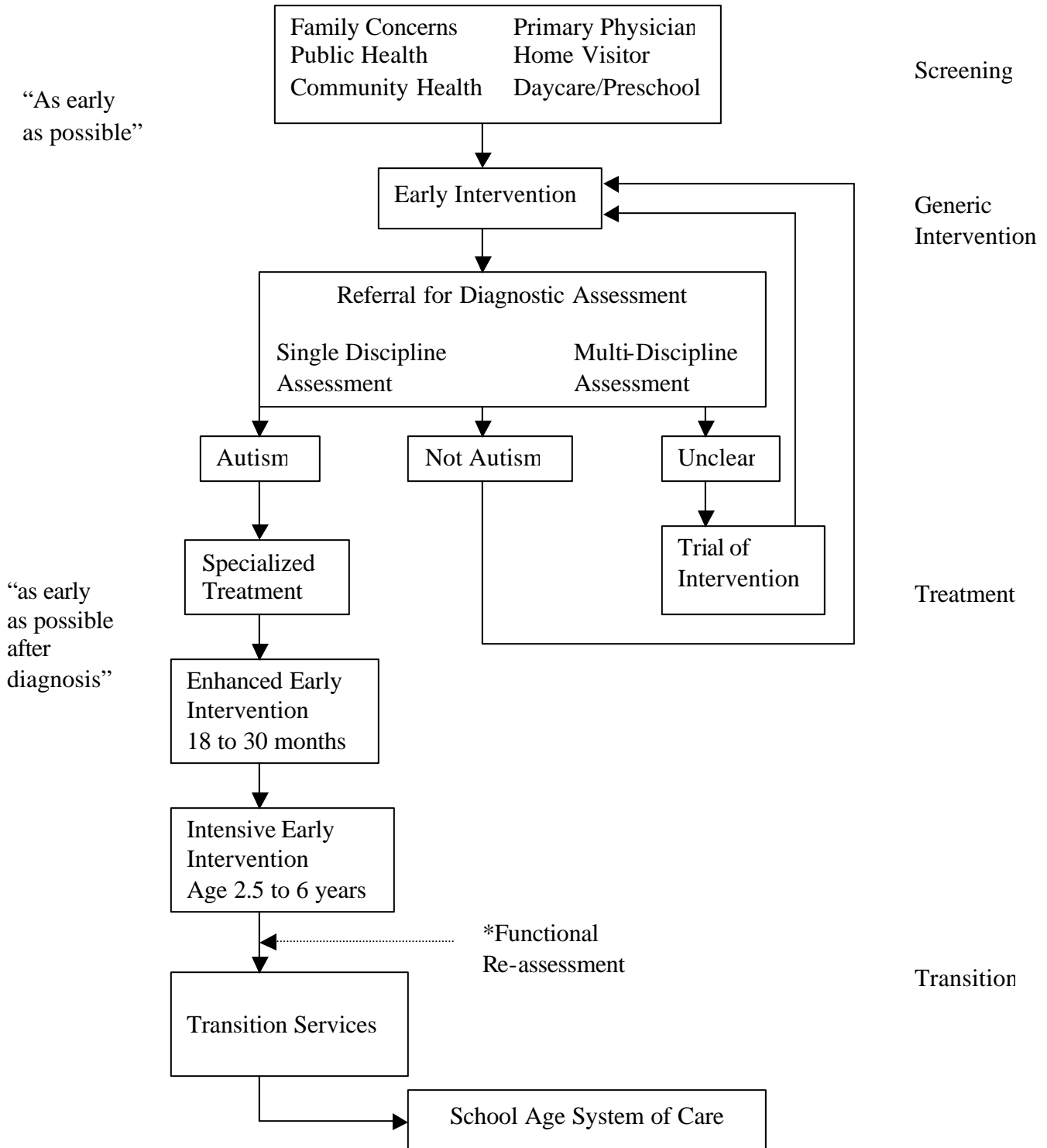


Figure 1: Service Delivery Model

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Very Young Children

Where there are concerns about a child's social or learning development between the ages of 18 and 30 months, whether or not the child is diagnosed, the family should take advantage of generic health services such as Early Intervention Services (e.g. EIP), referral to a play social development group (.e.g. through local health authority or an integrated child care setting), enhanced observation and surveillance, with priority for early access to assessment and intervention services.

Pre-School Children Over 30 Months of Age

This is the group of children where intensive services for autism have demonstrated efficacy. Any system of care for children with Autism Spectrum Disorder should recognize the degree of variability demonstrated by these children both within developmental domains and across the developmental spectrum as well as the family's preferences and ability to incorporate intervention into family life. Consequently intervention should be matched to the needs of the child and the family, to the greatest extent that this is possible. As a result the functional assessment should make reference to the child's developmental and functional needs, with recognition that a multidisciplinary assessment may not be feasible in many situations.

Determining Eligibility

While a **diagnosis of autism spectrum disorder** should be considered necessary, the child's **developmental needs** and his or her **functional abilities** should also be considered in determining eligibility for Intensive Early Intervention.

2.3 Critical Elements for Treatment for Children With Autism

In order to ensure program quality and efficacy, specialized programs for children with autism over the age of 18 months should contain the following sixteen (16) critical elements.

1. Goodness of fit/individually adapted

Treatment type, intensity and location (home, centre, or school based) should be flexible to accommodate the child's developmental stage, age of diagnosis, family circumstances, and community considerations. Treatment interventions should be designed around the specific level of disability and individual needs of the child.

2. Early and appropriately timed

Treatment should commence as soon as possible for all children with suspected delays. Specialized treatment programs for children with autism should begin as soon as possible after a confirmed diagnosis. The intervention should consider the child's developmental stage.

3. Intense

For children with autism, intense intervention is important during the pre-school years when the brain is undergoing rapid development. Intensity refers to hours of service, year round programming, high staffing ratios and the range of therapeutic interventions required. Intensity should vary with the developmental stage and age of the child. The Expert Panel has recommended guidelines for age appropriate intensity in the chart **Therapeutic Programs and Services For Children With Autism** on page 21.

4. Functional Behavior Analysis

Functional Behavior Analysis refers to a systematic process that is employed to acquire understanding of an individual child/student's problem behavior and in particular the manner in which the behavior is related to and influenced by the environment (Sugai & Lewis, 1999). Typically challenging behavior is communicative in nature (Beukelman & Mirenda, 1998). Consequently a critical component of functional behavioral analysis is the identification of the communicative function the problem behavior is currently serving (Schlosser, 1997) in order to replace it with a more appropriate communicative act. (Please see expanded definition in the appendix.)

5. Developmentally appropriate

Treatment intervention design must take into consideration the child's developmental stage and the appropriate developmental tasks associated with that stage. (Please see expanded definition in the appendix.)

6. Address core characteristics of Autism Spectrum Disorder

Treatment interventions should be designed to address core characteristics of Autism Spectrum Disorder such as social/communication skills, social behavior, constructive play/recreation, basic self help skills, etc. (Please see outcomes on page 22)

7. Comprehensive/ multidisciplinary

The treatment plan should provide a comprehensive/multidisciplinary wrap around service that addresses the full range of autism related needs presented by the child and family.

8. Explicit instruction (high intensity and graded according to need of child)

Instruction should be based on clearly defined goals, should be intensive and graded according to the needs and developmental stage/age of the child. (Please see expanded definition in the appendix.)

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9. Functional approach

The focus of treatment intervention goals should be to enhance the child's ability to function in natural environments.

10. Family involvement

Families must be fully informed and involved in their child's treatment in order to support gains made during treatment and to assist with the transfer/generalization of skills to the home and community environment.

Families require training in the specific treatment techniques to be used with the child. Family input must be legitimized and supported in order to maximize effectiveness of any treatment.

11. Least restrictive treatment continuum

Programs should be based on a model of positive programming/positive behavior supports. That is, there should be evidence that the program has tried all other options prior to use of a restrictive environment or treatment method.

12. Plan for generalization and maintenance

Treatment interventions should be developed with functional outcomes in mind, in order to ensure that skills learned during treatment can be transferred/generalized to the natural environment.

13. Transition addressed from beginning of program

Interventions should include strategies for generalization and maintenance within the child's natural environment, and for optimum transition to new settings (e.g. school).

14. Knowledge of Autism "Best Practices"

Service providers should demonstrate knowledge of autism "best practices" and these should be reflected in the treatment intervention/program design.

15. Culturally appropriate

Program design should take into consideration the child's cultural background and environment to ensure that interventions fit with cultural norms and are supported by the family. Immigrant families may require translation services to fully participate in their child's program.

16. Continuous evaluation, monitoring of program

A process for continuous review, monitoring and evaluation of the treatment intervention and outcomes should be in place in order to ensure maximum treatment effectiveness and to modify or adapt programs as goals are achieved, the child's developmental stage/age change, and new opportunities for learning are presented.

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Therapeutic Programs and Services For Children With Autism					
Direct Intervention (Home and/or Centre and/or School Based)		Professional Involvement Suggested Guidelines for Blended Direct Services and Consultation Across Settings (Home, School and Community)			
Age Group	Treatment Intervention	Case Management Program Coordination	Psychology, Behavior, Education (school age) Consultation	Speech Language Services	Occupational Therapy OT/Sensory Integration Physio Therapy
Young 18 to 30 months of age	Enhanced Early Intervention services For a maximum of 15 to 20 hours/week	Parent handbook of information & resources		Available as required	
Pre-school years 2.5 to 6 years of age (i.e. prior to student status)	Intensive Early Intervention For a maximum of 30 to 40 hours/week	3 to 6 hours per month	1 to 2 visits for a total 2 to 4 hours per month	4 to 8 hours per month	2 to 6 hours per month for physically related therapies and consultations
School Age 6 years of age and older (i.e. student status)	Supplementary integration/behavioral programming (home and community) for a maximum of 20 hours per week	3 to 6 hours per month (coordinate home/school programs)	1 to 2 visits for a total 2 to 4 hours per month with a focus on consultation and training	3 to 6 hours per month	2 to 4 hours per month

* A student is defined under the School Act as every individual who at September 1 is six years of age or older and younger than 19 years.

Chart 2: Therapeutic Programming

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2.4 Desired Treatment Outcomes

The following treatment outcomes provide guidelines for functional assessment of ongoing development for the purpose of individual program design. The outcomes do not provide indicators for specific levels of intervention or duration of particular program components. Decisions regarding intensity and duration of programming should be based on the individual needs of the child as per their functional assessment.

Outcome #1: Enhanced communication skills with particular emphasis on the development of pragmatic skills	
What does it look like? <ul style="list-style-type: none">• Demonstrates increasing comprehension of communication and language• Displays range and variety of communicative functions (e.g. requesting, protesting, commenting, etc.) as appropriate for developmental age and environmental opportunity.• Engages in conversations at increasing levels of sophistication. This includes managing the interaction (e.g. initiating, taking turns, terminating, repairing communicative breakdown) as well as contributing to the content of the conversation (e.g. introducing topics, maintaining them, building upon them, and terminating them). It also includes using conversational styles that are appropriate for the situation (e.g. simpler language in talking to a very young person; more formal language in speaking to a person in a position of authority) as developmentally appropriate.	How will we know? <ul style="list-style-type: none">• systematic (informal and/or formal) measurement of communication involving multiple measures indicates increases in the frequency and complexity of communicative behavior across:<ul style="list-style-type: none">○ 1) functions (e.g. request, reject, comment, protest, gain attention, label)○ 2) content (e.g. more sophisticated vocabulary and ideas)○ 3) setting (home, school, community)○ 4) persons (parent, teacher, assistant, sibling, peer, other community adult)• systematic (informal and/or formal) measurement of communication involving multiple measures demonstrates ability to engage in reciprocal conversation across settings; persons

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Outcome #2: Enhanced cognitive skills in the areas of symbolic play, basic concepts, and early academic skills	
What does it look like? <ul style="list-style-type: none"> • Increased acquisition and generalization of skills considered to be prerequisite to formal instruction involving increasingly complex language, literacy and numeracy 	How will we know? <ul style="list-style-type: none"> • systematic measurement involving multiple measures demonstrates increasing mastery of targeted skills in the following areas: <ul style="list-style-type: none"> ○ settings ○ materials ○ people

Outcome #3: Increased flexibility in adapting to differing environmental demands	
What does it look like? <ul style="list-style-type: none"> • Is able to accommodate an increasing intensity and variety of environmental stimulation associated with setting, activities, sensory experiences or changes associated with any of these or all of the above 	How will we know? <ul style="list-style-type: none"> • systematic observation indicates child experiences reduced anxiety and reductions in excessive behavioral/emotional responses to <ul style="list-style-type: none"> • number of settings • sensory experiences • activities • changes in schedules or sequences of activities

Outcome #4: Increased engagement in appropriate play/recreation	
What does it look like? <ul style="list-style-type: none"> • child demonstrates increasing levels of self-initiated, independent and appropriate toy play and/or engagement in recreation activities • social complexity of play progresses (parallel to associative to interactive) 	How will we know? Systematic observation indicates: <ul style="list-style-type: none"> • increased duration of time spent in developmentally appropriate play/recreation • increases in the number and variety of play materials selected for play/recreation • increases in the range and complexity of play behavior in both symbolic and social dimensions • decreases in the level of adult support and prompting required to maintain play behavior

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<p>Outcome #5: Replacement of problem behaviors with more conventional and appropriate behaviors.</p>	
<p>What does it look like?</p> <ul style="list-style-type: none"> • Decrease in the intensity, severity and pervasiveness of behaviors that interfere with functioning, social acceptance and learning within particular environments. 	<p>How will we know?</p> <ul style="list-style-type: none"> • Systematic observation (frequency counts, duration, percentage of observations, etc.) indicate reductions in challenging behavior across the three dimensions of <ul style="list-style-type: none"> ○ severity ○ intensity ○ pervasiveness ○ across all setting • Systematic observation suggest an increase in adaptive behavior considered to be “functional equivalents” of the challenging behavior
<p>Outcome #6: Social skills to enhance participation in family, school and community activities.</p>	
<p>What does it look like?</p> <ul style="list-style-type: none"> • Child demonstrates increasing levels of meaningful social engagement with family members, peers, adults across environments • Child demonstrates increasing levels of spontaneous imitation of peers and appropriate adult models 	<p>How will we know?</p> <ul style="list-style-type: none"> • Systematic observation and measurement of quality and quantity of social interaction • Demonstrates progression from proximity tolerance to reciprocal interaction • Increased levels of spontaneous imitation across settings • Decreased need for one to one support
<p>Outcome #7: Increased capacity to learn through environmental and instructional accommodations.</p>	
<p>What does it look like?</p> <ul style="list-style-type: none"> • Child demonstrates the ability to develop skills and abilities and display pro-social behaviors with reduced levels of support and accommodation • Child demonstrates social/survival skills including the ability to follow classroom rules, organize and complete developmentally appropriate tasks and demonstrate self management tasks, and self help skills 	<p>How will we know?</p> <ul style="list-style-type: none"> • Systematic measurement of supports and accommodations required • Demonstrated reduction of need for adult prompting and supervision • Identification of effective accommodations and structural strategies that can be adapted to future environments (e.g. school, home, community) • Increased academic engagement within small group and whole class instruction

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Outcome #8: Increased independence with respect to self care and personal safety	
What does it look like? <ul style="list-style-type: none"> • Child demonstrates increasing levels of personal independence with respect to self care across home, school and community environments • Child demonstrates increased awareness of and avoidance of potentially dangerous behaviors and situations across home, school and community environments 	How will we know? <ul style="list-style-type: none"> • Decreased need for adult prompting and supervision to complete self care tasks and routines • Decreased need for adult prompting and supervision to maintain personal health/safety

Outcome #9: Family Adaptive Functioning	
What does it look like? <ul style="list-style-type: none"> • Family is able to establish and maintain daily family routines • Family is able to establish and maintain social, spiritual, recreational, cultural activities (and community participation) • Family has identified (and accesses) supports and/or strategies for coping with challenges presented • Families understanding of their child's behavioral, functional and emotional needs leads to an improved quality of life (for the child and other family members) 	How will we know? Parent reports: <ul style="list-style-type: none"> • Increased ability to maintain daily family routines (e.g. sleeping, eating, household routines, time available to spend with other family members) • Increased ability to participate in social, spiritual, recreational, cultural activities of their choosing • Able to identify resources and/or strategies for coping • Ability to parent child with decreasing levels of support and increasing levels of confidence • Ability to adapt and modify routines and activities to accommodate child's needs while maintaining family functioning

Chart 3: Desired Treatment Outcomes

2.5 Developmentally Appropriate Functional Assessment

The Expert Panel recommends the ongoing use of developmentally appropriate functional assessments based on the nine key treatment outcomes described above for development of treatment goals and programs, including determination of the level of intensity most appropriate to the individual needs of the child. All children making the transition from kindergarten to Grade one should have a functional assessment to assist with planning for transition support. (see definitions)

2.6 Transition from Pre-School to School Programs

Transition experiences are frequently difficult for children with autism. They often have problems with generalization (i.e. transferring skills learned in one environment to another). Recognition of these issues has direct implications for programming. “The process of generalization of learning needs to be anticipated and supported. . .”¹⁵ Intensive programming during the pre-school period should include attention to preparing the child for the transition to school and gradual replacement of artificial supports and reinforcers with natural supports and peer influence.

Some children may require additional support during the transition period (e.g. some home based evening or weekend support for one to two months). It would be helpful to consider graded integration and supports during the transition period. The following suggestions provide a guide to the transition experience:

In The School Environment

- plan for the transition in the preschool period – children need to learn skills and schools need to prepare to work with the child
- develop a mechanism for communication between the “intensive intervention” service provider, parents and school authority to provide information about “intensive intervention” programming and to inform the school about the child’s particular program, behavior, interventions, etc.
- provide the opportunity to do home work on transition skills they didn’t pick up in the preschool period – part of maintenance
- complete a multi-disciplinary functional reassessment for program planning prior to entry into school (grade 1 or equivalent).
- greater emphasis within “intensive intervention” programs on school-based learning experiences during the transition year (e.g. an emphasis on teaching social/survival skills, alignment of cognitive/academic skills with the Program of Studies, use of prompting, cueing and instructional accommodations that are compatible with a school environment.
- functional programming
- ensure flexibility – different children will need different amounts of support

In The Home Environment

- parental engagement with the school system
- flexibility is important as needs can change dramatically
- intervention to address core elements of autism
- support to generalize what is learned in school into the community and home beyond the transition
- support for the family through access to respite services and behavioral consultation

National Research Council (2002) Educating Children with Autism. p.35

2.7 Transition Planning Elements (as per Desired Treatment Outcomes)

The following elements should be considered in planning a transition for children with autism. They are based on the desired treatment outcomes presented above with specific adaptation for children preparing for and making the transition to school. The transition plan for the child should address these items.

Outcome Objective 1: Communication

- frequent consultative ongoing support from an SLP and direct service on an ongoing basis where required (school, home, community)
- classroom adaptations for communication

Outcomes Objective 2: Cognitive Skills

- access to appropriate assessment and educational services
- ongoing support for development of cognitive symbolic skills not addressed within school – given there are not as many opportunities for targeted development of symbolic play skills at school — when skills pre-taught at home they are picked up more quickly in the school

Outcome Objective 3: Increased Flexibility

- may require additional monitoring and adult support and opportunity to increase accommodation for environmental stimulation (both in and out of school)
- may require flexibility in programming, physical arrangement of home-classroom and scheduling of activities to build tolerance for environmental stimulation

Outcome Objective 4: Increased Engagement in Appropriate Play/Recreation

- may require additional supports for age appropriate play/recreation (role of adult support is to fade out – transfer support function to peers or others in the natural environment)
- system of peer support
- support the systems (e.g. school – information re normal developmental issues in the context of kids with special needs)

Outcome Objective 5: Replacement of Problem Behaviors

- access to high quality functional assessment
- ongoing monitoring, evaluation and support for implementation of positive behavioral supports
- sufficient resources for enhanced behavioral support for children who are at risk for withdrawal or exclusion from school and/or home due to behavior
- case management of complex cases requiring wrap around services and inter-ministerial involvement

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Outcome Objective 6: Social Skills to Enhance Participation

- frequent and meaningful interaction with non-handicapped peers
- planned opportunities for successful social interaction based on the student's current language, cognitive and social capacities
- modification of the social environment to accommodate the student's social processing difficulty (e.g. disability awareness, posting of visually-based rules, training adults and peers how to initiate and sustain social interaction, etc.
- see also objective #4

Outcome Objective 7: Increased capacity to learn through environmental and instructional accommodations

- program planning includes strategies for fading adult support
- Individual Program Plan (IPP) includes:
 - transitional goals related to developing increasing independence in the areas of organizational skills, work skills, acquisition of critical classroom behaviors and self-management skills
 - specification of strategies for achieving goals listed above
- access to in-service and consultation related to appropriate and individualized environmental and instructional strategies.

Outcome Objective 8: Increased Independence with respect to self-care and personal safety

- increased supervision and vigilance particularly outside of home and classroom environments
- identification of effective strategies (social stories, peer modeling, direct instruction, etc.) based on the child's language and cognitive levels to teach behaviors that enhance physical safety (awareness of physical boundaries, functional communication skills, appropriate responses to posted cautions/signs, etc.)
- family access to behavioral services to assist with teaching self-help and personal safety skills

Outcome Objective 9: Family Adaptive Functioning

- improved access to clear and consistent information on available resources and services from front line workers/professionals upon point of entry and onward.
- improved access to resources and services with more effective and flexible collaboration between families and agencies of the different ministries.
- increased collaboration between ministries to ensure families are being supported.
- more advocacy and support from front line workers/professionals to ensure the child and family are receiving the necessary services appropriate to the individual needs of the child and family

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- increased recognition of the value of parental input and respect for differences in individual family cultures.
- increase the parents' ability to more effectively plan for the long range life plans of the child
- assistance for parents to identify the day to day needs which will contribute to diminishing undue stress and increased family health

2.7 Services for School Aged Children

There are three considerations related to children who reach student status. One concern is the special supports required to assist children making the transition from pre-school to school. The second concern is the ongoing supports required by school aged children as they progress from intensive early intervention (pre-school services) to services that become more and more community based. The third concern is that there is a paucity of research to guide recommendations regarding best practice interventions for school aged children with autism.

A system of services for school aged children with autism is proposed as an **interim model to be tested over a three year period**. During this three year period, evaluation should be conducted to gather more research evidence about the effectiveness of the model. Evaluation findings could then be used to inform longer term planning for provision of services for school aged children with autism.

The following elements are considered critical in planning services for school aged children with autism.

Personal/Learning Support

- needs based levels of support to maximize functioning, learning and quality of life at school, home, community
- options for summer programming
- case management for complex cases

In-service/Professional Development

- access to pre-service or in-service training for teachers, developmental assistants, in-home workers in critical areas of knowledge re behavior management, teaming, autism-specific information, etc.
- development of easily accessible distance learning with access to expert support (e-mail, tele-conferencing, video-conferencing, phone, etc.)
- support/incentives/encouragement for inservice
- "intensive intervention" service providers need to develop an awareness of contextual factors that influence long term effectiveness of programs including family functioning and school culture
- hiring practices for teaching assistants should take into consideration previous experience, training, goodness of fit when hiring an aide (vs only seniority)

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Supervision/Consultation

- teacher has access to expertise and specialists as needed (behavioral, educational – adapt curriculum, speech, occupational therapy)
- linking with Master Teachers and opportunities for mentoring
- standards or essential components documents
- coordination of IPP between home and school – maybe case management role – need to free up teacher to be involved
- support for collaboration/coordination of services including relief time

Family Support

- needs based menu of services (respite, sibling care/supports, homemaker, etc.)
- access to information, resource library or source of information, website, like BC family manual

Crisis Management

- priority access to behavioral and/or medical support
- priority access to respite
- support for short term (short stay) out of home placement
- case management for high risk situations (e.g. when you have IBI you have this)

Planned Transitions between schools/grades

- transition from intensive individual programming to school based programming and inclusion.
- dependent on level of intervention received during pre-school years
- aides should work directly with the child -range of roles should be defined

3.0 Support Systems

3.1 Expert Support for Diagnosis and Treatment Service Systems

Programming for children with Autism would be enhanced by a clinical advisory panel or panels that would fulfill three distinct functions. These functions are:

- an **advisory function** focusing on review of complex diagnoses and assessments, review of credentials for providers, treatment standards, and treatment efficacy;
- a **monitoring function** with the capacity to observe children in their programs and assess program effectiveness; and
- a **hands-on clinical training, support and mentoring function** providing hands-on support to schools, teachers, parents (home outreach), and other programs in the development, and design of model programs.

The Expert Panel recommends that a Clinical Advisory Panel be developed, composed of key multi-disciplinary clinical representation and parents. Different professionals may be involved in different aspects of the key functions listed above. In addition to the functions listed, the Clinical Advisory Panel could advise staff from the three Ministries (Children's Services, Health and Wellness, Alberta Learning) and address questions raised by professionals in the community.

3.2 Ensuring Quality Programming

Currently intensive intervention services are delivered by a multitude of private providers as well as a number of larger human service organizations. There are no specific standards for determining a quality program. While the Expert Panel supports home, centre, and school based program options, development of best practice standards and a process for certification, monitoring and review of service providers is recommended.

3.3 Building Adequate Community Support Systems

Specialized services for children with autism should exist within a framework of quality generic services for children with developmental challenges. In some regions creative use and coordination of such services have provided strong programming for children with autism. Services such as the Early Intervention Program (EIP) and Behavior Outreach have provided strong community support for children with autism as well as other children with special needs.

Within a strong framework of generic services, there need to be dedicated program resources for this special high needs population. Programs intended to serve children across a broad range of disabilities may not provide an adequate level and, in some

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cases, appropriate model of service delivery for many children with autism. Existing services include the Student Health Initiative; and the regional assessment and consultation teams funded by Alberta Learning.

Collaboration and coordination of policies and services among the three key ministries of Children's Services, Health and Wellness and Alberta Learning is critical. In the more complex and high need cases, cross-Ministerial funding should be available.

Within the generic service systems, information, training, and mentoring support should be made available to professionals, schools, and parents. Incentives/supports (e.g. release time for teachers) should be developed to encourage teachers, aides, and other professionals who are key participants in the treatment program to improve their professional practice abilities, and ensure quality service to children with autism.

3.4 Family Support and Involvement

Families should be supported and empowered to be an active partner in their child's treatment program. "It is important . . . to recognize that parents need both initial training and on-going support for trouble shooting if they are to sustain their effort at home teaching" (Harris, 1986). Families should be supported to develop and maintain healthy routines for family living that support all members of the family. Supports to families may include information, training, involvement in program design and delivery, respite and supports for better mental health.

4.0 Recommendations

1. Ensure availability of the **Early Intervention Program** in all regions.

Currently 14 of 17 regional health authorities provide an Early Intervention Program under the auspices of the Ministry of Health and Wellness.¹⁶ The Panel recommends that this program be available in all health regions.

The Early Intervention Program provides an excellent first level of screening and support for children with developmental delay or disability, including autism. In addition the Early Intervention Program provides an important component of early treatment for very young children (age 0 to 18 months) and for those children (up to age 3) where a diagnosis is provisional or uncertain.

2. A **new diagnostic entry system should be adopted.**

The new system for diagnosis and entry into the service system attempts to streamline the process for diagnosis and service access in order to increase system efficiencies and make services more accessible to children and families in order to ensure appropriate intervention “as early as possible”.

3. A **diagnosis of autism spectrum disorder** together with the child’s **developmental needs** and his or her functional abilities should be considered necessary in **determining eligibility** for Intensive Early Intervention.

Any system of care for children with Autism Spectrum Disorder should recognize the degree of variability demonstrated by these children both within developmental domains and across the developmental spectrum as well as the family’s preferences and ability to incorporate intervention into family life. Consequently intervention should be matched to the needs of the child and the family, to the greatest extent that this is possible. As a result diagnostic assessment carried out for the purposes of accessing interventions should make reference to the child’s developmental and functional needs, with recognition that a multidisciplinary assessment may not be feasible or even desirable in many situations (Please refer to Section 2.3 Screening, Assessment and Diagnosis)

4. At least two **Centres of Excellence** should be established with expertise in the assessment and long term outcomes of children with developmental disabilities, including **specialized cross-disciplinary Autism Teams.**

The Centres of Excellence and specialized cross-disciplinary Autism teams should be funded through Alberta Health and Wellness, and closely linked to the

¹⁶ Early Intervention Program is not available in Headwaters Region (Okotoks/High River/Canmore), Region Five (Drumheller) and Northwestern Region (High Level).

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ministries of Children's Services and Alberta Learning. Ideally, they should be in close conjunction with the Alberta Children's Hospital and the Stollery Children's Centre. They should involve integrated consultations from multiple disciplines to provide: diagnostic services, monitoring regarding progress and medical complications, and management guidance and advice. They should be coordinated with existing community diagnostic and management services, and support transitions to other services as appropriate.

5. Move to an **developmentally based system of care** for children with autism
 - Enhanced Early Intervention (for children age 18 to 30 months of age)
 - Intensive Early Autism Intervention program (from age 2.5 years until the child reaches student status – i.e. age 6 on or before Sept.1)
 - School aged services

Treatment type, intensity and location (home, centre, or school based) should be flexible to accommodate the child's developmental stage, age of diagnosis, family circumstances, and community considerations.

The system of services for school aged children with autism proposed as part of the Therapeutic Program Matrix is intended as an **interim model to be tested over a three year period**. During this three year period, evaluation should be conducted to gather more research evidence about the effectiveness of the model. Evaluation could then be used to inform longer term plans for provision of services for school aged children with autism.

6. Implement **regular developmentally appropriate functional assessments** based on the proposed treatment outcomes, as a basis for individual program planning and design.

Functional assessment should be used to guide programming development and to match resource levels to the individual needs of the child.

7. Enhance **cross-ministry funding for school aged children** with complex needs who require cross-ministerial involvement (Alberta Learning, Children's Ministry, Health and Wellness)

Some high needs school age children will require support services at home and in the community that are in addition to the supports provided by the Alberta Learning Ministry within the school environment. In order to ensure maintenance and enhancement of gains realized during the preschool years, continued support may be necessary as the child enters school. Families will also require continued access to respite and aide service to a level appropriate to the needs of the child and family.

8. Develop a provincial **Clinical Advisory Panel** composed of key multi-disciplinary clinical representation and parents.

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Clinical Advisory Panel members could provide expert consultation in a number of different areas such as:

- Review of diagnosis and assessment reports
- develop certification process for service providers
- review service provider credentials
- develop best practice operational definitions for the critical elements of intensive autism services
- monitor/audit programs
- advise the three ministries (Alberta Learning, Children's Ministry, Health and Wellness)
- facilitate the development of a distance learning program
- identify areas of needed research

8. Move to a **Provincial Funding Model**

In order to ensure consistent access to the range of programming and services recommended for children with autism, and to ensure high quality, cost effective service, the Expert Panel recommends that Children's Services funding for "intensive intervention" services move from Regional to Provincial funding. Moving to a provincial funding model will allow for the development of best practice guidelines, service provider certification processes, ongoing monitoring and targeted research initiatives.

9. Develop an "**Essential Components**" document for school programs

An "Essential Components" document would provide support and guidance to individual schools in the development of appropriate educational strategies for school age children with autism.

10. Develop "**Best Practices**" guidelines for "intensive intervention" programs for preschool children with Autism Spectrum Disorder

Best Practices guidelines could be used to establish a **certification process for services providers**, as well as ensuring consistent high quality service across programs.

11. Develop **Best Practice standards and a certification process for service providers.**

While the Expert Panel supports home, centre and school based program options, development of best practice standards and a process for certification, monitoring and review of service providers is recommended.

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12. Develop an **information/resource package and/or web site for parents and professionals.**

Parents and professionals involved with young children with autism spectrum disorders need accurate information to dispel myths, to outline diagnostic, assessment and treatment services, to understand potential supports and funding systems, and to answer common questions.

13. Development of **autism training packages** providing a core of essential information for professionals.

In order to ensure that school aged children have access to consistently high quality programming in their local school setting, training should be made available to teachers, teacher assistants, therapists, multidisciplinary assessment team members, day care providers, early intervention staff, public health and other related professionals.

Distance education and/or community colleges should be considered as possible venues for training.

14. Provide **incentives and/or supports** for training

In order to participate in training, teachers and aides may need incentives such as **release time**. In addition, local **mentors** could be identified to guide teachers, parents and schools in the development of high quality programming, environmental accommodations, strategies for behavior management, etc. Support and encouragement from the Regional Boards across ministries would help this to happen.

15. **Invest in research**

There is currently little research to guide best practice recommendations, especially for interventions with school age children. Better data on outcomes is needed to truly understand the effectiveness of Intensive Early Intervention investments, and the implications of continued investment of resources for school age children.

There should be a strong evaluation and accountability framework in place for programs providing intensive autism intervention.

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6.0 Expert Panel Members

Dr. Margaret Clarke (Chairperson)
Division Head Developmental Pediatrics
and Adolescent Medicine
Alberta Children's Hospital, Calgary
Associate Professor Pediatrics
University of Calgary

Dr. Keith Goulden
Director, Division of
Neurodevelopmental/Neuromotor
Pediatrics
Glenrose Rehabilitation Hospital,
Edmonton
University of Alberta

Dr. Kimberley Ward
Chartered Psychologist
Society for Treatment of Autism,
Calgary

Dr. Joanne Volden
Speech Pathology and Audiology
Faculty of Rehabilitation Medicine
University of Alberta

Dr. Bruce Perry
Medical Director
of Children's Mental Health
Alberta Mental Health Board

Dabby Fong (Parent)
Chartered Psychologist Autism Society
of Alberta

Kevin Humphreys (Parent)
Families for Effective Autism Treatment
of Alberta

Jackie Ryan (Parent)
Executive Director
Family Linkages Foundation of Alberta

Tony McClellan
Manager, Special Programs Branch
Alberta Learning

Fern Miller
Project Team Leader
Population Health Strategies
Alberta Health & Wellness

Christine Ferbey
Manager/Senior Analyst – Program
Support
Resources for Children with Disabilities
Children and Family Services Ministry

Sherry Thompson
Director, Intergovernmental Initiatives
and Policy Research
Alberta Children's Services

Appendix I

Definitions

Intensive Behavioral Intervention (IBI) is a generic term referring to intensive and comprehensive behavioral interventions.

Applied Behavioral Analysis (ABA) involves the application of experimental analysis of behavior to problems of social importance. Individual analyses of a child's functioning are undertaken to identify and task analyze skills needed for improved performance and functioning. Subsequent to such identification, systematic teaching and intervention methods are used to train students to independently perform desired responses (Heflin & Simpson 1998). Applied behavioral analysis is not a procedure specific to students with autism. Rather it is a general strategy that has wide applicability to various groups and settings.

Discrete Trial training is specific, systematic method by which ABA is implemented with students who have autism. Typically based on one-to-one methodology, discrete trial training follows a basic pattern where an instructor gives a cue for a student to perform, provides reinforcement for the desired behavior, and conducts ongoing evaluations of student performance.

Intensive Early Intervention Services help children from birth to six years who have special needs through providing supports, services and programs to assist children in reaching their full potential by: preventing and minimizing the effects of handicapping conditions and mild delays, improving the child's ability to function in the home and community; and increasing parents awareness of other resources and supports that will assist them with raising and nurturing their child with a disability

Explicit Instruction: Explicit instruction involves a number of validated teaching procedures involving the following components:

- Establishment of appropriate learning conditions
- Defining of targeted responses
- Timely delivery of appropriate consequences (e.g. feedback, social praise, tangible reinforcement, etc.)

Explicit instruction should be matched to specific children (i.e. children with imitative skills versus children without imitative skills), particular kinds of learning (i.e. self initiated learning versus self help skills), instructional groupings (i.e. individual versus group instruction) and specific environments (i.e. home-based versus school-based programs). Examples of explicit instruction include embedded instruction, direct instruction, systematic use of incidental instruction, carefully planned naturalistic instruction, precision teaching, discrete trial instruction, and "structured teaching".

Developmentally Appropriate Practice (DAP): Statement of broad principles governing the format and content for educational programs for young children. The concept of developmental appropriateness includes two dimensions 1) age appropriateness which includes the predictable sequences of growth and change that occur in all children during the first few years of life, and 2) individual appropriateness which involves the individual pattern and timing of growth as well as individual personality, learning style and family background. Developmentally appropriate practice requires that educational programs for young children should be based both on child development knowledge and an understanding about individual children's growth patterns, strengths interests and experiences.¹⁷

Functional Behavioral Analysis: A systematic process that is employed to acquire understanding of an individual child/student's problem behavior and in particular the manner in which the behavior is related to and influenced by the environment (Sugai & Lewis, 1999). Functional behavioral analysis should result in a plan of positive behavioral support based on testable hypothesis regarding the function of the behavior. The resulting plan should focus on the prevention of problematic behavior through environmental change (manipulation of the setting events, antecedents and consequences) and the replacement of the difficult behavior with an equally effective but more appropriate behavior (sometimes referred to as a "functionally equivalent").

Typically challenging behavior is communicative in nature (Beukelman & Mirenda, 1998). Consequently a critical component of functional behavioral analysis is the identification of the communicative function the problem behavior is currently serving (Schlosser, 1997) in order to replace it with a more appropriate communicative act.

Components of a Population-Based Screening Model

- Multifaceted screening components (i.e. screening data are collected about the infant's biological circumstances and developmental competence as well as family needs, strengths, resources, support systems, and quality of the child parent relationships)
- Multiple information sources (i.e. parents, professionals, other family, or community members who know the child and family well)
- Periodicity (screening should occur on multiple occasions in the first 3 years of life to account for the wide variability in child development and because of late-appearing manifestations of risk)
- Dual level screening: Level 1 screening is very brief and is intended to capture highly significant, macro-scopic components that can be used to identify children in need of more in-depth follow-up. Level 2 screening is conducted within the home. It is a

¹⁷ adapted from Developmentally Appropriate Practice in Early Childhood Programs Serving Children From Birth Through Age 8. National Association for the Education of Young Children (1987). See appendix for Principles of Developmentally Appropriate Practice and Principles of Developmentally Appropriate Practice adopted for Young Children with Severe Disabilities

comprehensive process that includes information on the child" developmental competence; family strengths, needs, and support systems; and the generic quality of the caregiving environment.¹⁸

¹⁸ Shondoff, J. P. & Meisels, S.J. (2000), Handbook of Early Childhood Intervention, Second Edition, Cambridge University Press, U.S.A.

Appendix II

**RESOURCES FOR CHILDREN WITH DISABILITIES
INTENSIVE BEHAVIOURAL INTERVENTION (IBI) STATISTICS**

Based on provincial Resources for Children with Disabilities (RCD) statistics for March 2002, there were **654 children with a diagnosis of Autism** and **6 with Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)** receiving Resources for Children with Disabilities (RCD) supports and services provincially.

Age of Children	# of Children	Percentage		Age of Children	# of Children	Percentage
Infant	0			10 years	54	8%
1 years	1	0%		11 years	43	7%
2 years	8	1%		12 years	34	5%
3 years	35	5%		13 years	23	3%
4 years	56	8%		14 years	18	3%
5 years	63	10%		15 years	23	4%
6 years	65	10%		16 years	18	3%
7 years	67	10%		17 years	23	4%
8 years	62	9%		18 years	2	0%
9 years	65	10%		Total # of Children	660	100%

Children with a diagnosis of Autism or PDD-NOS represented approximately 8% of the provincial caseload (8607) in March 2002.

As of November 2001, **318 are children receiving Intensive Behavioral Intervention (IBI) services** provincially, approximately 89 children (28%) are exceeding the three years of programming available in policy. These children have received extensions of IBI services to allow for transitioning from IBI programs to school and community programs as well as to allow for the completion of the formal IBI evaluation.

Approximately half of the children with a diagnosis of autism or Pervasive Developmental Disorder (PDD-NOS), currently receiving services from Resources for Children with Disabilities, are not receiving IBI programs. These children may be of school age and therefore denied IBI services, have completed their IBI programs or their parent’s may not have requested IBI services.

Based on available statistics, representing approximately 85% of Intensive Behavioral Intervention cases, the ages of children currently receiving Intensive Behavioral Intervention services are as follows:

Age of Children	# of Children	Percentage
2 years	0	
3 years	12	4%
4 years	28	10%
5 years	48	17%
6 years	61	21%
7 years	66	23%

Age of Children	# of Children	Percentage
8 years	47	17%
9 years	13	5%
10 years	6	2%
11 years	2	1%
12 years	1	0%
13 years	1	0%

Of the children currently receiving IBI services 52% are 3 to 6 years of age, while 48% are age 7 to 13.

DSM-IV DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER

A DIAGNOSIS OF **autistic disorder** is made when the following criteria from A, B, and C are all met.

A. A total of six (or more) items from (1), (2), and 3), with at least two from (1), and one each from (2) and (3):

(1) *Qualitative impairment in social interaction, as manifested by at least two of the following:*

- (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- (b) failure to develop peer relationships appropriate to developmental level
- (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with others (e.g. by a lack of showing, bringing, or pointing out objects of interest)
- (d) lack of social or emotional reciprocity

(2) *Qualitative impairments in communication as manifested by at least one of the following:*

- (a) delay I, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- (b) in individuals with adequate speech, marked impairment in the ability to initiative or sustain a conversation with others
- (c) stereotyped and repetitive use of language or idiosyncratic language
- (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) *Restricted, repetitive, and stereotyped patterns of behavior, interest, and activities, as manifested by a t least one of the following:*

- (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whoe-body movements)
 - (d) persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder.

**TABLE III – 2
DSM-IV DIAGNOSTIC CRITERIA FOR PDD-NOS**

A diagnosis of pervasive developmental disorder, not otherwise specified (PDD-NOS) is made when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interest, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder. For example, this category includes “atypical autism” – presentations that do not meet the criteria for autistic disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

From the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-TR. Copyright 2000 American Psychiatric Association.