



Regina Qu'Appelle Health Region Autism Services Review

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Preface

Mary's Story

A typical situation of a parent of a child with autism within the current service provision environment

Mary is concerned about her only son, David, who is two and one-half years old. She had been worried that he wasn't talking yet, but when she went to see her physician, the physician assured Mary that it was nothing to worry about.

Mary was relieved, but continued to wonder about David's behaviours. David seemed to lack interest in others and had angry outbursts when Mary interrupted his play. After a few months with no change, Mary made another appointment with her family physician. He agreed to provide her with a referral to a psychologist for an assessment. The physician was unsure about the referral process and had heard that there were waitlists at both agencies. He referred David to the Wascana Children's Program and Regina Child and Youth Services so that David would have the best chance of getting in as soon as possible.

After being on the waitlist for both agencies for several months, David was seen by a psychologist, and a speech and language pathologist at one of the agencies. The psychologist told Mary that he suspected David may have autism. However, instead of making the diagnosis at this time, Mary was told that David would be put on a waitlist to see a medical doctor who would confirm the diagnosis. She was provided with some information about autism, as well as handouts about community agencies in the area. She was assured that while they waited for a diagnosis, intervention services could begin.

Due to David's speech and language delays, the SLP began a program with David and his mother. Mary contacted the Autism Resource Centre and was told that David's name could be put on their waitlist for services as soon as there was a diagnosis. The waitlist time was approximately 4 years. Mary began reading about autism on the internet, and learned about the importance of early intervention services. She contacted the Early Intervention Program who provides in-home intervention services to preschoolers, and put David's name on the waitlist there. Having read about the need for occupational therapy for children with autism on the internet, she asked her psychologist about those services. The psychologist told her that those services were only available at another agency, and that she would need a referral from her physician. Mary went back to her physician, and received another referral. David was placed on a waiting list for OT.

Mary had a friend of a friend with a child with an ASD. She arranged to meet with the other mom for coffee. Through the conversation she learned about the Discovery Pre-School Program through the Regina Public School system.

Because they only accepted children in September and January and it was already February, she would have to wait until September to gain entry for David.

In the meantime, ARC contacted Mary and informed her that she could have access to their summer program. Mary was delighted, nearly six months had passed and the only intervention David had received was SLP. She was feeling exhausted with the care of her son and managing the paper work of all these organizations. She called her friend to gain some recommendations on respite workers. Sadly, her friend informed her that there were not respite workers available who were trained in autism and that she would likely not receive funding because David had not yet been diagnosed. Mary and her friend agreed to care for each others children when they needed a break.

Mary's New Story

A typical situation of a parent of a child with autism following implementation of the proposed recommendations

Mary is concerned about her only son, David, who is two and one-half years old. She had been worried that he wasn't talking yet. Mary went to see her physician. Although her physician was sceptical that anything was wrong, decided to refer David for further assessment. He was aware through a recent RQHR announcement concerning a new strategy for autism that all children were being assessed for diagnosis through a single agency. He provided her with a referral. Mary asked how long she would have to wait. The physician recalled that waitlists were to be kept under three months.

Within the three month period, Mary had taken David for an assessment. Mary received an immediate diagnosis. She was fraught with emotion but settled when she was provided with information on next steps and information concerning parent support groups. Because David's behaviours were complex, Mary was provided with a referral for a comprehensive assessment for intervention. Within a couple of weeks, David had seen the Psychologist, SLP and OT and was provided with a comprehensive case plan for intervention.

Mary attended a parent information night where she received information on advocating for her child, early entrance programs into pre-schools, respite care, information concerning tax benefits and where to go in case of an emergency. Mary felt in control of her situation and clearly understood what the next year would bring for David.

Executive Summary

The Regina Qu'Appelle Health Region (RQHR) commissioned the services of Dr. Lynn Loutzenhiser and Valerie Sluth to conduct a review of services to children with autism. The review is guided by three project objectives as defined by the RQHR:

1. To undertake a review of the clinical and research literature on evidence-based practices for Autism Spectrum Disorders and provide a brief overview of the service delivery system for this population that exists in other Canadian provinces.
2. To review the range of services available in the Regina Qu'Appelle Health Region for children and adolescents (up to age 21) with Autism Spectrum Disorders, identifying strengths and gaps in the service delivery system. Also, to identify areas which require further research.
3. To make recommendations concerning systems improvements needed to address service gaps for this population.

The project was informed through an extensive review of literature, review of policies in all other Canadian jurisdictions as well as interviews, focus groups and surveys with health service delivery stakeholders. Primary data sources include:

- Health care professionals working with children and youth with autism (e.g. physicians, psychologists, speech language pathologists, occupational therapists, social workers).
- Community based agencies responsible for service provision to children and youth with autism (e.g. Autism Resource Centre, SCEP, Early Childhood Intervention Program).
- Governmental agencies responsible for service provision to children and youth with autism (e.g. Wascana Rehabilitation Centre Children's Program, RQHR Child and Youth Services, Department of Community Resources Community Living Division, Department of Education Day Care Branch, Cognitive Disabilities Strategy).
- Parents of children and youth with autism and parent advocacy groups (e.g., SaskFEAT).

When balancing best practices is service delivery against the services that are currently provided in the RQHR for children and youth with autism, significant service delivery gaps were evident. In summary, service provision for children with autism in the RQHR could best be described as:

“a growing population group, currently provided with insufficient quantity of service, delivered at a quality below best practices standards, spread across numerous delivery agents, which lack system coordination and

alignment, while providing limited education and support for families to understand the system and make appropriate choices for the needs of their child in an absence of a unifying regional or provincial strategy". (see page 42)

Specifically, the following gaps are noted:

- An absence of an ABA/IBI intervention program
- No clear entry point for diagnosis or intervention
- Quantity of services do not meet demand for services
- Lack of service coordination and alignment
- Lack of comprehensive case workers
- Lack of information for families regarding services, systems and training
- Lack of ASD-specific training for professionals
- Lack of services for adults with ASDs over the age of 21

Consultants put forth the following recommendations to address services provision gaps:

1. Create an ASD services vision and strategy and provide the necessary resources to develop and sustain it.
2. Measure demand for ASD services in Saskatchewan.
3. Standardize a pathway toward diagnosis to provide clarity for professionals and clients and to increase system efficiencies.
4. Develop a single point of entry for intervention services
5. Coordinate services children and youth with ASDs and their families.
6. Work toward providing best practice intervention programming including:-
 - Individualized services for children and families.
 - Active engagement in an intensive instructional program for young children (at least 20 hours per week) in any natural environment (home, childcare centre, preschool) throughout the year
 - Systematically planned developmentally appropriate activities aimed toward identified objectives.
 - Intervention in natural environments with typically functioning peers to the extent that interactions lead to specified educational goals.
 - Sustained family involvement.
 - Educational interventions incorporating Applied Behavioural Analysis (ABA) principles of positive behavioural support and functional assessment for challenging behaviours.
 - Emphasis on the development of social and pragmatic language skills.

- Ongoing assessment of a child's progress, with adjustments in programming as required.
- 7. Provide support for parents including increased respite services with trained respite providers, provide access to emergency support services and better parent education.
- 8. Targeted ASD training and educational opportunities for parents and professionals
- 9. Utilize existing programs for service provision when possible.
- 10. Increase training for ABA/IBI service providers .

In addition to recommendations, the consultants identify issues for future consideration or further research. These observations include:

- Validation of existing services - Analysis and recommendations in the report are based on the self-reports of individuals and agencies. Further validation may be required when assessing agency specific programs.
- Review of services for adults with ASD - Parents and service providers are concerned about the lack of services available for adults with ASDs. Further research should be undertaken to measure gaps in services for this population.
- Consideration for a provincial ASD strategy - While the report identifies gaps in services within a specific region in Saskatchewan, it is reasonable to assume that similar gaps exist across the province.

Table of Contents

Acknowledgement	7
1.0 Introduction	8
2.0 Project Overview and Methodology	8
2.1 Terms of Reference	8
2.2 Data Sources	8
2.3 Project Limitations	10
3.0 Literature Review	11
3.1. Autism Spectrum Disorder	11
3.2 Evidence-Based -Practice in the Assessment and Diagnosis of ASDs.....	11
3.3 Evidence-Based Practice for Interventions.....	14
3.3.7. Best practices in the design of effective intervention programs for school- aged children with ASDs	23
3.4.8 Best practices to support families of children and youth with ASDs	23
4.0 Inter-jurisdictional Service Review	24
5.0 Inventory of Services in the RQHR	25
6.0 Stakeholder Feedback	31
6.1 Assessment for Diagnosis.....	31
6.2 Assessment for Intervention Planning.....	32
6.3 Intervention Services	33
6.4 Training.....	34
6.5 Support for Families	35
6.6 Delivery System.....	37
6.7 Stakeholder Concerns for the Future	38
6.8 Stakeholder Priorities.....	38
7.0 Gap Analysis	40
8.0 Recommendations	43
8.1 Create an ASD Services Vision and Strategy	43
8.2 Measurement of Demand	44
8.3 Standardize a Pathway toward diagnosis	44
8.4 One point of entry for intervention services.....	45
8.5 Coordination of services	45
8.6 Best effort to provide best practice intervention programming	46
8.7 Provide support for parents	48
8.8 Targeted training and educational opportunities	48
8.9 Utilize existing programs for service provision	49
8.10 Increased Training for ABA/IBI Intervention Service Providers	49
9.0 Future Research	50
References	51
Appendix A: Research Questions	54
Appendix B: DSM-IV criteria for Autism Spectrum Disorders	57
Appendix C: Inter-Jurisdictional Review	60

Acknowledgement

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The responses and comments provided by all contributors were given in the interest of advancing services for children with autism. Their sincere participation was very much appreciated.

1.0 Introduction

The Regina Qu'Appelle Health Region (RQHR) commissioned the services of Dr. Lynn Loutzenhiser and Valerie Sluth to conduct a review of services to children with autism. This eight week study commenced in October, 2007. This report provides the reader with a review of literature in best practices for service to children with autism, an overview of delivery structures in other Canadian jurisdictions, stakeholder feedback on the current status of service delivery in the RQHR, and recommendations. Suggestions for next steps and future research are further provided.

2.0 Project Overview and Methodology

2.1 Terms of Reference

This review is guided by three project objectives as defined by the RQHR:

4. To undertake a review of the clinical and research literature on evidence-based practices for Autism Spectrum Disorders and provide a brief overview of the service delivery system for this population that exists in other Canadian provinces.
5. To review the range of services available in the Regina Qu'Appelle Health Region for children and adolescents (up to age 21) with Autism Spectrum Disorders, identifying strengths and gaps in the service delivery system. Also, to identify areas which require further research.
6. To make recommendations concerning systems improvements needed to address service gaps for this population.

2.2 Data Sources

The project was informed through the following sources:

1. Literature Review – The clinical and research literature review on evidence-based practices for Autism Spectrum Disorders was focused primarily on consensus guidelines for practice in this area, large scale literature reviews from professional organizations and researchers, and policy documents. Information regarding the delivery of services for this population across Canada was obtained through provincial and

federal government documents, as well as telephone conversations with some of the provincial Autism Societies. A complete reference list can be found at the end of this document.

2. Focus Groups/Interviews— Primary data was gathered through the implementation of ten focus groups (comprised of a maximum of eight individuals) and ten interviews. A summary of the questions asked of each focus group and interviewee is provided in Appendix A.

Focus Groups:

- Regina Child and Youth Services (RCYS) Children's Program Staff
- Wascana Rehabilitation Centre Children's Program (WRCCP) Staff
- Autism Resource Centre (ARC) Staff
- ARC Board of Directors
- Department of Community Resources, Community Living Division
- RQHR Child Psychiatrists and Developmental Paediatricians involved in the diagnosis and treatment of autism
- Cognitive Disabilities Strategy Steering Committee
- Parents of children with autism living in Regina
- Regina Public School Board Staff
- SCEP Centre Staff, Board Members and Parents

Interviews:

- JoAnne Phillips, Manager, RCYS
- Deb MacDonald, Director, Early Childhood Intervention Program (ECIP)
- Terri Carlson, Manager, WRCCP
- Theresa Savaria, Director, ARC
- Jean Bacon, Supervisor Student Services, Prairie Valley School Division
- Sandra Baragar, Supervisor Student Services Regina Catholic School Board
- Jeff Christianson, Regional Inter-sectoral Committee (RIC) Co-ordinator
- Lisa Simmerman, SaskFEAT (Saskatchewan Families for Effective Autism Treatment)
- Two separate interviews with parents of children with autism living in a rural area

3. Surveys – Three separate written surveys were prepared and distributed electronically to RQHR paediatricians, Saskatchewan Learning Day Care Branch, and parents of child with autism as gathered through the SaskFEAT membership list.

2.3 Project Limitations

As with any project, time/resource limitations and stakeholder participation impact the breadth of data and analysis. The consultants note the following limitations in conducting this project:

- The practices and guidelines with respect to early identification and screening for Autism Spectrum Disorders (ASDs) are not included in the review.
- Limited responses to surveys resulted in minimal data from paediatricians, day care branch, and parents of children with autism. Parent data was augmented with focus groups and interviews.
- Primary data gathering was limited to focus groups and interviews during which stakeholders, parents and delivery agents self-reported on practices and system observations. The consultants did not conduct direct observations. Data is therefore limited to the perspective of focus group and interview participants.
- Data concerning other provincial jurisdictions is based on a parliamentary report and discussions with individuals associated with some provincial autism societies. The consultants did not conduct interviews with service providers in other jurisdictions.
- Project scope is limited to reviewing services for children and youth up to the age of 21.

3.0 Literature Review

3.1. Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a term used to describe a subset of five pervasive developmental disorders that are classified in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 1994). Most commonly, researchers and clinicians using the term ASDs are referring to three of these five disorders: Autistic Disorder (usually referred to as Autism), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger's Disorder. These three disorders are thought to vary according to their developmental severity, with Autistic Disorder considered to be at the more severe end of the spectrum, PDD-NOS in the middle of the spectrum, and Asperger's Disorder at the less severe end of the spectrum. Consistent with similar review documents, the term ASD in this document will be used to describe children with Autistic Disorder, PDD-NOS, and/or Asperger's Disorder (Perry & Condillac, 2003; Roberts & Prior, 2001). Appendix B contains the DSM-IV diagnostic criteria for these three disorders.

ASDs are viewed as neuro-behavioural disorders present from birth or very early on in development (NRC, 2001). ASDs are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behavior (NRC, 2001). As a result, no one child with an ASD has exactly the same strengths and/or deficits than another.

ASDs are one of the most common developmental disabilities affecting Canadian children (Autism Society of Canada, 2004). According to the Autism Society of Canada, approximately 1 in 200 children born today have an ASD, and the prevalence rates for this disorder are on the increase (Frombonne, 2005).

3.2 Evidence-Based -Practice in the Assessment and Diagnosis of ASDs

An evidence-based practice approach to the assessment and diagnosis of ASDs requires a process that is guided by relevant legislation, professional college standards, and the clinical and research literature (Perry & Condillac, 2003). In terms of legislation and professional college standards, the process of making and communicating a diagnosis of ASD is a controlled act that may only be performed by certain professionals. In Saskatchewan, diagnoses of ASDs can be made and communicated only by professionals registered with either the

Saskatchewan College of Psychologists or the College of Physicians and Surgeons (Government of Saskatchewan Psychologists Act, 1997; Medical Profession Act, 1981).

Consensus guidelines (e.g., Filipek et al., 1999; Myers & Plauche Johnson, 2007; NYSDH, 1999) set the standards for evidence-based practice in the assessment of ASDs by identifying the areas that need to be assessed and the specific measures that should be used in each of these areas. In this document, the guidelines for assessment for the purposes of diagnosis will be considered separately from the guidelines for assessment for the purposes of intervention planning. Although it is not necessary to view assessment for diagnosis as distinct from assessment for intervention planning (NRC, 2001), making this distinction can be useful when providing clinical services (e.g., Alberta Children's Services, 2002). For example, assessment for diagnostic process does not necessarily require the use of a multidisciplinary team, nor does it require as comprehensive an assessment process as would be involved in the development of an intervention plan. Thus, when making decisions regarding the allocation of resources, distinguishing between these two processes may be helpful.

3.2.1. Assessment for Diagnostic Purposes

Based on a comprehensive review of the literature, Perry and Condillac (2003) suggest that the diagnostic assessment process requires the following components:

- Clinical judgement (including reliance on the DSM-IV diagnostic criteria).
- Observation.
- Developmental and medical history.
- The use of standardized measures:
 - o Autism Diagnostic Observation Schedule (ADOS) and
 - o Autism Diagnostic Interview-revised (ADI-R) or
 - o The Childhood Autism Rating Scale (used primarily by physicians).

Given these guidelines, diagnoses of ASDs in Saskatchewan may be made by a single professional (i.e., physician or psychologist). Canadian clinical practice guidelines tend to support the use of single professional diagnosis for children with clear symptoms of Autistic Disorder (e.g. Alberta Children's Services, 2002). For more complex cases, a multidisciplinary team assessment involving other professionals such as speech and language pathologists, occupational therapists, physiotherapists, and/or educators, may be required (e.g., Alberta Children's Services, 2002; British Columbia Ministry of Health Planning, 2003). However, although the multidisciplinary approach may be necessary in these more complex cases, the structure of the multidisciplinary approach may vary, depending upon the child's presentation and the physical location of the professionals. For example, multidisciplinary assessments may contain a

collection of assessments from different sources in the community (e.g. educators) that are not at the same location (Alberta Children's Services, 2002).

3.2.2. Assessment for Intervention Planning

One of the main purposes of diagnosis is to provide a context for intervention (NRC, 2001). For children and youth with ASDs, evidence-based practice requires the development of a thorough intervention plan, designed to target the core symptoms of autism (NRC, 2001, Perry & Condillac, 2003; Myers & Plauche Johnson, 2007). Perry and Condillac (2003) suggest that assessment for intervention planning needs to be based on information from the following 6 areas of functioning:

- 1) Diagnostic Process
- 2) Cognitive level
- 3) Adaptive level
- 4) Language/communication
- 5) Functional/curriculum/behavioural
- 6) Medical investigations and other assessments: from medical history and previous reports

Perry and Condillac (2003) also identify the routinely used measures, and optional measures that professionals can use to assess each of these areas. To assess the cognitive functioning of children and youth with ASDs, they recommend one of the following instruments: Wechsler Intelligence Scales for Children-4th Edition, Wechsler Preschool and Primary School Scales of Intelligence-3rd Edition, Bayley Scales of Infant Development, 3rd Edition, the Stanford-Binet Intelligence Scales- 5th Edition, Mullen Scales of Early Learning. Optional tests of cognitive functioning may include tests of memory, attention or other neuropsychological tests. To assess the adaptive functioning of children and youth with ASDs, they recommend one of the following instruments: Vineland Adaptive Behavior Scales, 2nd Edition, Scales of Independent Behaviour-Revised.

To assess the language/communication abilities of children and youth with ASDs, they recommend one of the following instruments: Rosetti Infant-Toddler Language Scale, Communication and Symbolic Behavior Scales, MacArthur Communicative Developmental Inventories, Sequenced Inventory of Communication Development. Optional tests include those to assessment preverbal or phonological/speech.

To assess the functional/curriculum/behavioural levels of children and youth with ASDs, they recommend one of the following instruments: Assessment of Basic Language and Learning Skills, Brigance Diagnostic Inventory of Early Development-Revised, Portage Guide. Optional assessment in this area may

include a functional assessment of challenging behaviours. Medical investigations and other assessments are informed by the medical history of each child and will vary accordingly (Perry & Condillac, 2003).

As will be examined in more detail below, it is the information from these areas of functioning that will lay the groundwork for the individual intervention plans for children with ASDs.

3.2.3. Best Practice Service Delivery for the Assessment of ASDs

Based on the literature review, the following components should be in place to ensure best-practice service delivery for the assessment of children and youth with ASDs and their families:

- Early identification of children who may have an ASD.
- The referral pathway for the assessment of children who may have an ASD is clearly understood by professionals.
- The services are coordinated within and across sectors.
- The services provided in a timely manner.
- The diagnostic and intervention planning assessment processes follow consensus guidelines.
- Multidisciplinary assessments are available when necessary.
- Professionals are trained in ASDs, have a good understanding of the range of ASD symptoms as well as co-morbid conditions across developmental stages.
- Family members are provided information on how to find and access information and support.
- The information designed for families is comprehensive, yet easy to read, and contains developmentally appropriate information as well as information on funding sources and treatment options.

3.3 Evidence-Based Practice for Interventions

An evidence-based practice approach to interventions for children and youth with ASDs also requires a process that is guided by the clinical and research literature (Perry & Condillac, 2003). Intervention approaches have been classified into the following categories: Expressive Psychotherapies, Biomedical Interventions, and Educational/Behavioural Interventions (Mesibov, Adams & Klinger, 1997; Roberts & Prior, 2004). Following a brief review of expressive psychotherapies and biomedical interventions, this document will focus primarily on the evidence to support the use of educational/behavioural interventions for children and youth with ASDs.

3.3.1. Expressive Psychotherapies

Expressive psychotherapies include individually-based therapeutic treatments that are designed to address symptoms of ASD (Roberts & Prior, 2004). As Perry and Condillac (2003) highlight in their review, due in part to the large number of individuals with ASDs who also suffer from cognitive impairments, there is little evidence to support the use of expressive psychotherapies. Although there is some limited evidence to support the use of Cognitive Behaviour Therapy (CBT) with high functioning individuals with autism, Roberts and Prior (2004) cautions that it needs to be combined with practical advice about functional problem solving in order to be effective. Other psychotherapies, while they may be enjoyable for individuals with ASDs, do not have adequate empirical evidence for their use at this time: Music therapy, Pheraplay, Sand Tray Therapy, Art Therapy, Options Therapy. Finally, Holding Therapy does not have adequate scientific evidence to support its use, and carries with it the potential for harm (Perry & Condillac, 2003).

3.3.2 Biomedical Interventions

At this time, there is no medical treatment or cure for the core symptoms of autism (Freeman, 1997). However, pharmacological treatment has been used effectively to treat particular symptoms and/or co-morbid disorders (e.g., A-D/HD) (Perry & Condillac, 2003). Myers and Plauche Johnson (2007) provide an extensive review of the medical concerns of children and adolescents with ASDs, and the use of medications to treat them. In general, there is empirical evidence to support the use of some medications to treat some individuals with ASDs and not others (Myers & Plauche Johnson, 2007; Perry & Condillac, 2003).

The use of complementary and alternative medicine (CAM) is common in children and youth with ASDs (Myers & Plauche Johnson, 2007). CAM therapies used to treat ASDs include non-biological therapies (e.g., behavioural optometry) as well as biological therapies (e.g., dietary restrictions of food allergens, gastrointestinal treatments such as gluten/casein free diets). The majority of CAM therapies lack empirical study, thus, evidence-based recommendations can not be made to support their use at this time. However, given the large number of parents who use CAM therapies for their children, Myers and Plauche Johnson (2007) suggests that physicians treating children with ASDs should be knowledgeable about them, provide balanced information about treatment options, and provide parents with information about how to evaluate the scientific merit of such therapies.

3.3.3. Educational/behavioural Interventions

Educational/behavioural interventions include both comprehensive programs designed to target the core components of ASD and individually based interventions designed to target specific areas or behaviours (NRC, 2001). Most of the educationally-based programs have been targeted toward young children. However, before the literature on the effectiveness of these programs is considered, the terms Applied Behavioural Analysis and (Early) Intensive Behavioural Intervention will be briefly discussed. Then, the methodological issues that impact the research on the effectiveness of educational/behavioural interventions will also be addressed.

a) Applied Behavioural Analysis and Intensive Behavioural Intervention Programs

Applied Behavioural Analysis (ABA) is a general term used by behaviourists to include any method that changes behaviour in systematic and measurable ways (Sulzer-Azaroff & Mayer, 1991). Based on behaviourist principles, this is an approach to modifying behaviours that involves operant conditioning and other learning principles. Interventions using this approach range from a focus on changing single behaviours to targeting the core symptoms of autism in an attempt to improve overall functioning (Herbert, Sharp, & Gaudiano, 2001). While one of the most frequently used methodologies in ABA programs is Discrete Trial Training (DTT), which will be discussed in more detail below, other ABA strategies are also employed, including chaining, shaping, graduated guidance, and functional assessment.

Intensive Behavioural Intervention (IBI) is also a general term that refers to the intensity of an intervention program in terms of the number of hours per week of program delivery and the nature of the program delivery (e.g., staff-to-child ratio). According to the NYSDH (1999) review, IBI programs involve the following:

- systematic use of behavioral teaching techniques and intervention procedures,
- intensive direct instruction by the therapist, usually on a one-to-one basis,
- extensive parent training and support so that parents can provide additional hours of intervention.

The term IBI is often equated with the Lovaas Program (Young Autism Project), however, other intervention programs may also be classified as IBI programs, depending upon the intensity and comprehensive nature of their treatment delivery. Educationally-based comprehensive intervention programs for children with ASDs can be classified into three types, based on their philosophies and use of particular techniques.

These types are:

- Traditional Behavioural/Discrete Trial Training Approaches,
- Contemporary or “Modern” Applied Behavioural Analysis Approaches,
- Developmental/Pragmatic Approaches (Prizant & Wetherby, 1998).

These approaches vary according to aspects such as: the use of prescribed versus flexible teaching strategies, the use of adult-centred versus child centred strategies, an emphasis on child response versus child initiation, the reliance on naturalistic settings, the importance of the generalization of learning, the use of artificial versus natural reinforcers, and the extent of inclusion of typically developing peers (Ministries of Health and Education, 2006). Thus, strategies and techniques used in interventions for children and youth with ASDs may be classified as reflective of one of these three approaches, but it also important to note that there are some strategies and techniques that are utilized in more than one type of approach (e.g. the ABA strategy of functional assessment).

b) Traditional behavioural/Discrete trial training Approaches

Traditional/behavioural approaches to the treatment of ASDs (e.g., Lovaas' Young Autism Project), employ as their main technique Discrete Trial Training (DTT). DDT can be defined as “an instructional strategy in which a task or trial is isolated and taught to an individual by being repeatedly presented to them” (Ministries of Health and Education, 2006, p.71). Using this method, the adult records the child's responses for each trial or command, and continue working on this until the child has demonstrated mastery. Lovaas and his colleagues recommend that children receive one-on-one instruction for 35-40 hours per week, for up to 52 weeks per year (Lovaas, 2005 - 2007). This approach employs adult-centred teaching strategies that emphasize children's responses to predetermined activities. In terms of generalization of behaviours from the teaching setting to a naturalistic setting, generalization is a planned activity that takes place once predetermined criteria have been reached. It employs a one-on-one teacher to child ratio, and tends to occur in young children's homes. Some of the strengths of this approach include the focus on developing attention skills, the clear guidelines for teaching tasks, and the breaking of tasks into small, more manageable components (Ministries of Health and Education, 2006). Some of the limitations of this approach include its focus on speech as opposed to social communication, difficulties with generalizing skills learned to natural settings, and the fact that some of the core deficits such as initiation, shared attention and imaginative play are not targeted (Ministries of Health and Education, 2006).

c) Contemporary/Modern Applied Behavioural Analysis Approaches

Contemporary/Modern Applied Behavioural Analysis approaches to the treatment of ASDs (e.g., TEACCH, Pivotal Response Training) utilize ABA strategies such as functional assessment and incidental teaching. These approaches tend to be carried out in naturalistic settings, with a focus on generalization of the strategies learned. They employ adult-centred teaching strategies at the beginning of treatment; however, there is a goal of transferring more control to the child over time. Functional assessments are one of the main ABA strategies used to provide information regarding the child's motivation, strengths and interests. This information is then used to plan intervention goals (Ministries of Health and Education, 2006). Some of the strengths of this approach include the combination of the use of ABA principles with a developmental focus, and the inclusion of the child's motivations, interests, and initiations of responses. One of the main weaknesses to this approach is that it requires trained professionals to develop and supervise the individual programs of intervention based on the behavioural and developmental needs of each child (Ministries of Health and Education, 2006).

d) Developmental/Pragmatic Approaches

Developmental/Pragmatic Approaches to the treatment of ASDs (e.g., SCERTS) focus on the use of the child's natural interests and motivations to encourage social communication (Prizant & Wetherby, 2001). This is a child-centred approach, with an emphasis on spontaneous social communication, and play. This approach is flexible, uses naturalistic settings chosen for their functionality and to correspond with the child's interests and motivations (Ministries of Health and Education, 2006). Strengths of this approach include its focus on core deficits, such as initiation, shared attention and spontaneous communication, and the development of functional skills that can be applied in everyday routines. Weaknesses include the need for children to have a skilled communication partner, and the lack of program prescription, which might make it difficult for teachers and parents to implement (Ministries of Health and Education, 2006).

3.3.4 Evidence regarding the effectiveness of the comprehensive intervention approaches

There are a number of limitations inherent in literature on the effectiveness of various intervention approaches for children and youth with ASDs. First, much of the research literature focuses on interventions for young children with ASDs, as opposed to school-aged children (NRC, 2001). Second, the research on

interventions for young children is limited by a number of methodological issues. Some of those identified by the Ministries of Health and Education (2006) include the lack of control groups, the use of instruments to assess outcome/treatment success that are not consistent across studies (making comparisons difficult), and the fact that most of the effectiveness data is derived from university-modelled programs (which involve high staff ratios, extensive staff training and high levels of supervision to ensure staff adherence to treatment protocols). Third, there are many differences in opinion and controversies about treatment methodologies (NRC, 2001).

Overall, there is consensus in the literature that intensive intervention programming can result in positive outcomes for children with ASDs (Conrad & Stone, 2005; NRC, 2001) and that the earlier the intervention begins, the better the intervention outcomes (Eaves & Ho, 2004; Harris & Handleman, 2000). However, there is not clear evidence in the literature regarding program intensity in terms of the exact number of hours per week necessary to affect change (Szmari & Reitzel, 2004). Thus, recommendations for program intensity in terms of hours per week per child for ASD interventions range from 15 hours (Canadian Paediatric Society, 2004; Dawson & Osterling, 1997) to 40 hours (Lovaas, 2005 - 2007), with consensus guidelines recommending no fewer than 20 hours per week (NYSDH, 1999). A connected issue to the number of hours per week required to affect change is that it makes a difference whether or not the child is actively engaged in the intervention (Ministries of Health & Education, 2006). This is because children with an ASD may not necessarily utilize the opportunities for participation that are available for them through educational programming. Thus, just placing a child with an ASD in an educational environment such as a preschool program does not ensure engagement in the activities available in that setting. One way to encourage active engagement is to ensure there are systematically planned, developmentally appropriate activities available for the child in the educational setting (e.g. home, school).

There is scientific evidence that behavioural interventions have produced positive outcomes for children with autism (NRC, 2001). However, there is not yet evidence to support the exclusive use any one comprehensive approach for all children with ASDs (NRC, 2001). Of the three approaches identified above, the Traditional Behavioural/Discrete Trial Training Approach has received the most empirical attention. In his original study, Lovaas (1987) found evidence to suggest that young children achieved significant gains in intellectual functioning, and that some children were actually cured. However, the methodological flaws of this study have been well documented (Herbert et al., 2001; Roberts & Prior, 2004), and the claim that children can recover from or be cured of autism has generated much controversy (Herbert et al., 2001; Roberts & Prior, 2004). Some of the components of the contemporary approaches, such as functional assessment, have also received empirical support for their effectiveness for children with ASDs (Perry & Condillac, 2003). However, the Developmental/Pragmatic Approach, which is the newest, has received the least

amount of empirical attention. There are also questions about the necessity for the exclusive use of comprehensive programs, such as the ones based on the above approaches, as the basis of intervention programs for children and youth with ASDs. At this time, there is a lack of empirical support for many of the widely promoted comprehensive programs (NRC, 2001), these programs are difficult to implement due to the fact that the majority are university-based, and require high levels of staff training and supervision to ensure treatment adherence, and not all children with ASDs will benefit from them (Szatmari, 2006).

3.3.5. Best practices in the design of effective intervention programs for young children (up to age 8).

Given the lack of clear evidence for the effectiveness of any one approach with all children with ASDs, experts have turned their attention to identifying the core components of an effective program. According to the consensus guidelines (e.g. NRC, 2001), an effective intervention program for children up to age 8 has the following components:

- Early intervention programs as soon as an ASD is suspected.
- Individualized services for children and families.
- Active engagement in an intensive instructional programming in any environment (home, childcare centre, preschool) for at least 25 hours a week, for 12 months a year.
- Low student-to-teacher ratio to allow sufficient amounts of 1-on-1 time and small-group instruction to meet specific individualized goals.
- Inclusion of a family component/family involvement.
- Systematically planned developmentally appropriate activities aimed toward identified objectives.
- Educational interventions that incorporate ABA principles of positive behavioural support and functional assessment for challenging behaviours.
- Intervention in natural environments with typically functioning peers to the extent that the interactions lead to specified educational goals.
- Ongoing assessment of a child's progress with adjustments in programming at least every 3 months.

In addition to the recommendations just listed, the NRC (2001) also identified six instructional priorities for educational intervention programs.

- Functional, spontaneous communication.
- Social instruction in various settings throughout the day.
- Teaching of play skills, focusing on play with peers and peer interactions.

- Instruction leading to generalization and maintenance of cognitive goals in natural contexts.
- Functional assessment and positive behavioural support to address problem behaviours.
- Functional academic skills when appropriate.

3.3.6. Targeted Interventions for children and youth with ASDs and Empirical Evidence to support their effectiveness

While comprehensive intervention programs are one approach to the treatment of ASDs, other programs utilize strategies designed to target individual areas of impairment. Some of these strategies may be employed in comprehensive programs, but they can also be used on their own. These targeted areas include: language/communication skill, social skills and play, challenging behaviours, and sensory/motor difficulties. Commonly used targeted approaches and the empirical evidence for their effectiveness will be reviewed below.

a) Language and Communication Skills

There can be a wide range of communication and language impairments in children and youth with ASDs, especially in areas of social and pragmatic language. There is a trend toward emphasizing the importance of encouraging initiation and spontaneous communication, through interventions that take place in natural settings, within natural routines, and which use natural consequences (American Speech-Language Hearing Association, 2006). In their guidelines, the American Speech-Language Hearing Association (2006) suggest that children will benefit from communication goals that are carefully planned and implemented by teachers and caregivers throughout the curriculum and throughout the day, rather than in one-to-one therapy sessions with an SLP in a clinical setting on a more intermittent basis. While approaches that support this trend, such as the "Hanan More than Words" Program, are receiving attention in the literature, there is not adequate empirical evidence at this time to make claims about their effectiveness. At this time, only two approaches have been demonstrated as effective in increasing communication skills for individuals with ASD. These are augmentative communication strategies for non-verbal children and youth, and the use of the Picture Exchange System (PECS), which has been found to be most effective for children with absent or severely delayed language skills (Perry & Condillac, 2003; American Speech-Language Hearing Association, 2006).

b) Social Skills and Play

The main goal for interventions in this area is to improve relational skills by teaching skills that support the core areas impacted by ASDs (e.g., social

interest, social initiation, social responsiveness, perspective-taking). Clinicians have highlighted the connection between social skills and communication skills, as the inclusion of communication partners, in particular peers, is necessary to teach both types of skills (American Speech-Language Hearing Association, 2006). As with communication skills, there has been a shift from teaching social and play skills in isolated, adult-driven settings to natural settings with more involvement of typically developing peers. This shift is due in part to the empirical evidence that suggests that while child-specific interventions (e.g., increasing eye contact), peer-mediated interventions (children with ASDs reinforcing other children with ASDs, use of non-inclusive social skills groups), and the development of social stories are effective in increasing social skills, children do not tend to generalize these skills from the training experience to natural conditions (American Speech-Language Hearing Association, 2006; Perry & Condillac, 2003).

c) Challenging behaviours

Challenging behaviours in children and youth with ASDs include aggression, stereotyped behaviours, and self-injury. Not all children with ASDs demonstrate these behaviours, and these behaviours may be occasional or frequent, mild or intense. As Matson and Milshwai (2006) highlight in their review, these types of behaviours are pivotal to address because they interfere with the learning process, and skill-building cannot take place. Interventions in this area include interviewing caregivers to identify challenging behaviours and develop interventions to address these, and the use of functional assessment. Functional assessment is a positive reinforcement strategy used to reduce challenging behaviours. Based on operant conditioning principles, the focus is on the antecedents, behaviours and their consequences. Clinicians attempt to determine what events are causing and maintaining the target behaviours. Functional assessment has been found to be effective in reducing challenging behaviours in children and youth with ASDs (NRC, 2001).

d) Sensory/Motor Difficulties

Sensory/motor difficulties, such as unusual sensory responses, are common in children and youth with ASDs. However, interventions to address these difficulties, particularly the use of occupational therapists to provide sensory integration therapy, have not received empirical support (Perry & Condillac, 2003). While OT services may be helpful with respect to self-management skills (e.g., dressing, using utensils), efficacy research with respect to sensory integration therapy has not demonstrated empirical support for its use (Myers & Plauche Johnson, 2007; Perry & Condillac, 2003). However, programs may still address sensory difficulties. According to Myers and Plauche Johnson "sensory activities may be helpful as part of an overall program that uses desired sensory experiences to calm the child, reinforce a desired behavior, or help with transitions between activities" (2007, p.1166).

3.3.7. Best practices in the design of effective intervention programs for school-aged children with ASDs

The effective components of intervention programs for school-aged children with ASDs have received less attention in the empirical literature than those for young children. Based on the existing literature on school-aged interventions (see Ministries for Health and Education, 2006) and the NRC (2001) guidelines for younger children, the following components should be considered in school-aged intervention programs:

- Individualized services for children and families.
- Systematically planned developmentally appropriate activities aimed toward identified objectives.
- Intervention in natural environments with typically functioning peers to the extent that the interactions lead to specified educational goals.
- Educational interventions should incorporate ABA principles of positive behavioural support and functional assessment for challenging behaviours.
- There should be an emphasis on the development of social and pragmatic language skills.
- Ongoing assessment of a child's progress, with adjustments in programming at least every 3 months.

3.4.8 Best practices to support families of children and youth with ASDs

The families of children and youth with ASDs are the most important people in their lives. The families' needs must be taken into account as well. Although the needs of the families with children and youth with ASDs may vary depending on a number of factors, some common services and supports have been identified as particularly important (American Speech-Hearing Association, 2006). These include the provision of parent education about ASDs, intervention approaches, how to access available services and resources (e.g., parent support groups) , as well as the provision of parent training programs, respite care, and coordinated case management, and assistance in planning for the future (Ministries of Health and Education, 2006; Perry & Condillac, 2003).

4.0 Inter-jurisdictional Service Review

Given the support for the use of ABA/IBI programs in the treatment of ASDs, particularly for young children, the availability of these types of programs across Canadian provinces and territories was reviewed. Information was obtained from the Madore and Pare (2006) document entitled: Provincial and Territorial Funding Programs for Autism Therapy. In addition, telephone calls were made to provincial autism societies to get additional information on the services. A table outlining the services can be found in Appendix C. It is important to note that Saskatchewan is the only Canadian province not offering ABA/IBI services for preschoolers with ASDs. Only one of the three Canadian territories, Nunavut, lacks these services.

5.0 Inventory of Services in the RQHR

Information regarding assessment for diagnosis, assessment for intervention purposes, and intervention services was obtained through interviews and focus groups with representatives from service providers within the RQHR. Therefore, it is important to note that this data is based on self-reports only, as opposed to direct observations and evaluations of actual service provision. Given this significant limitation, it is beyond the scope of this report to assess the evidence-based integrity of the content of these services.

Regina Child and Youth Services

Caseload

- There are approximately 130 children diagnosed with ASDs receiving services from RCYS.

Assessment for Diagnosis

- Parents can self-refer or child may be referred by their family physician.
- Assessment for diagnosis may be generated through the Children's Services Program, Youth Services Program or Cognitive Disabilities Program.
- Assessment for diagnosis is conducted by psychologists and/or physicians (Child Psychiatrist or Developmental Paediatrician) with input from other professionals.

Assessment for the purpose of intervention planning

- May be completed through the assessment for diagnostic process or as a separate process.

Intervention Services

- Intervention services are available to pre-school and school-aged children with the exception of SLP services which are available to pre-school children only.
- At this time, professionals at RCYS are doing their individual parts of the assessment, may meet and discuss a plan, but tend not to plan an integrated treatment plan.
- Psychology services are primarily diagnostic in nature, but the psychologists can also provide case management, parental assistance, behaviour management, support to families, and consultation with other organizations involved in the child's case plan.

- Psychiatric Services.
- Speech and Language Pathologists are providing direct services to preschoolers on-site and in daycare settings. May also provide consultation to the parents and/or other agencies involved with the child.
- RCYS has some access to OT services through the Cognitive Disabilities program.
- Social Workers are available to provide case management.

Wascana Rehabilitation Centre Children's Program

Caseload

- Approximately 60 children diagnosed with ASDs per year at the WRCCP.

Assessment for Diagnosis

- Referrals can only be made by physicians, with the exception of SLP services which can also be initiated by public health nurses.
- Assessment for diagnosis is conducted by a psychologist and/or the Developmental Paediatrician with input from other professionals.
- Only pre-school children are referred for diagnosis unless the child is already on the WRCCP admission list.

Assessment for the purpose of intervention planning

- May be completed through the assessment for diagnostic process or as a separate process.

Intervention Services

- At this time, professionals at WRCCP are doing their individual parts of the assessment and then meet to discuss a plan. The treatment plan may or may not be integrated across intervention services. Whenever a treatment plan is done at the WRCCP, other agencies are invited to attend at the parent's request (e.g. school personnel, care providers). When requested, the results of this assessment are discussed at a meeting with the school for planning purposes.
- Psychology services are primarily diagnostic in nature, but the psychologists can also provide case management, parental assistance, behaviour management, support to families, and consultation with other organizations involved in the child's case plan.
- Speech and Language Pathologists provide direct services to preschoolers both on-site and through out-reach. SLP's provide ongoing consultation to daycares and non-funded preschools provided.
- Occupational therapists are available to provide intervention services.
- Social Workers are available to provide case management.

Autism Resource Centre

Caseload

- ARC is currently providing services to 57 school aged children (and 15 adults).
- ARC has 160 children on their waitlist for services (110 are school-aged and 50 are preschoolers).
- The total number of participants in the Winter, Spring, Summer and Social Skills Groups is 114 participants. Out of the 114 participants, 76 are from the waitlist and 38 are from present ARC caseload.

Assessment for Diagnosis

- No diagnostic services are provided at ARC.

Assessment for the purpose of intervention planning

- Can self-refer or be referred by school or professionals.
- Autism Resource Centre (ARC) provides a functional assessment at intake that is used to develop an individual services plan for children consistent with ARC programs and services. The functional assessment is reviewed with the family and school staff when completed. When there is agreement on program approaches, the school staff will use the same program approach as the ARC Family Support Worker.
- Functional assessments are completed for only those children on the ARC full-time caseload. There are no pre-school aged children on the caseload due to an extensive waiting list.

Intervention Services

- ARC provides support to families on the full-time caseload and some assistance to those families on the waiting list. Full-time caseload support includes attending school and medical meetings and assisting with transition periods.
- ARC facilitates a family/parent network group that meets monthly.
- ARC provides up to 3 hours per week of programming in the home or in community setting for school-aged children and their families.
- ARC provides social skill training to individuals for individuals ages 6 to 22. Participants attend one session after school every two weeks.
- Seasonal programming is provided to children on full-time caseload and those on the waiting list. Seasonal programming involves full-day one on one contact during which the child may undertake learning exercises, life skills or vocational skills as well as recreational programming.

- ARC provides parent training opportunities 4 times per year.

SCEP Centre

Caseload

- Typically serve between 2 to 4 children diagnosed with ASDs. Currently, one child with ASD is in the program.

Assessment for Diagnosis

- No diagnostic services are provided at SCEP.

Assessment for the purpose of intervention planning

- Can self refer or be referred by parents or professionals.
- SCEP intake process involves assessment of child and family to provide information relevant to their program approach.
- Undertake a family centred approach whereby they view the family as the client not only the child.

Intervention Services

- SCEP provides educational services provided in a centre-based environment for children with behavioural and social difficulties. The program is not specifically designed for children with autism. Programming typically involves 12.5 hours per week of instruction often 1:1 or 1:2 student/instructor ratio.
- SCEP provides family consultative services.
- SCEP staff participates in consultation with agencies involved with the child. Support includes attending school and medical meetings and assisting with transition periods.
- OT services are contracted by SCEP to provide consultations to staff and sometimes provide direct services to children in the program.
- SLP services are contracted by SCEP to provide consultations to staff and sometimes provide direct service to children in the program.
- Services are directed to pre-school aged children only, but children up to age 7 have received services.

Early Childhood Intervention Program (ECIP)

Caseload

- ECIP currently has between 5 and 12 children diagnosed with ASDs on their caseload.

Assessment for Diagnosis

- No diagnostic services are provided at ECIP.

Assessment for the purpose of intervention planning

- Referrals can be made by parents or professionals.
- ECIP intake process involves assessment of child and family to provide information relevant to their program approach.

Intervention Services

- ECIP engages the child in play within the child's natural environments. Two four-hour sessions are held weekly – one in the home with parent participation and one in the day care setting. ECIP has recently received funding for an autism specialist to deliver these services.

Cognitive Disabilities Strategy and Department of Community Resources Community Living Division

- The Cognitive Disabilities Strategy (CDS) provides case work and funding support for families who cannot access appropriate programming. Funding may be used for respite services and private intervention services.
- The Community Living Division (CLD) provides a funding benefit and minimal case work support to families with a child who has been diagnosed with mental retardation and a tested IQ under 70. Families of children with ASDs meeting this requirement are eligible for this benefit.

School System - Regina Public Schools, Regina Catholic Schools, Prairie Valley School Division

Assessment for Diagnosis

- No diagnostic services are provided through the school systems.

Planning for intervention

- All school systems develop a Personal Program Plan (PPP) when the child enters the school system. WRCCP and C&Y professionals may participate in the development of this program if requested.

Intervention Services

- Intervention services are provided in the school systems to children without a mental health diagnosis.
- Early entrance programs are provided in the school systems. Children can enter half-day pre-school programs five days/week at the age of three.
- School-aged children are provided with an academic program that best meets their needs. This can range from full classroom integration to inclusion of a learning resource teacher, to one-on-one ongoing instruction from a para-professional. Teachers, learning resource teachers and teacher's aids/paraprofessionals may or may not have training in ASDs.
- Intensive individual services are reduced starting in grade four through to the end of high school.
- Speech and Language Pathologists are providing direct services on-site up to a maximum of one hour per week.
- Some OT services are available.
- Some psychological services are provided.

Day Care/Child Care settings

- Daycare settings provide one-on-one support to children with ASDs who are the recipients of the Enhanced Accessibility Grant

6.0 Stakeholder Feedback

This section provides a reporting back of common themes derived from the stakeholder focus groups, interviews and surveys.

6.1 *Assessment for Diagnosis*

Assessment for diagnosis of ASD is generally regarded as a service delivery strength relative to other services for children with autism in the RQHR. Stakeholders commented that diagnosis is generally thorough, timely (4 – 6 month wait) and tends to be derived from common accepted standardized testing procedures. Although assessment for diagnosis may be conducted by the family physician or paediatrician, consultations suggest that the majority of diagnoses are done in a multi-team environment at either RCYS or WRCCP. Multi-teams consist of the physician/Psychiatrist and psychologist and may involve other professionals such as a Speech & Language Pathologist, Occupational Therapist or physio-therapist.

Despite the perceived strength in diagnostic services, stakeholders also identified concerns with this process. Some consultations revealed that not all diagnosing professionals are trained in standardized diagnostic instruments (i.e. ADOS and ADI-R). Consistent with this, concerns were raised regarding consistency in diagnosis and integrity of the diagnosis itself.

Parents of children with autism reported challenges in acquiring a referral for a diagnostic assessment. Parents reported experiencing health professionals discounting their concerns regarding their child's development. Many parents describe their efforts as "pushing" their doctor for a referral.

There appears to be a lack of clarity over which professionals and agencies are conducting diagnostic assessments. Parents and professionals reported confusion over whom to approach and whether a physician referral was necessary to access services.

Finally, once a diagnosis is made, parents received little guidance from health professionals and professionals are frustrated by a lack of services to which to refer. As one physician stated, "I make the diagnosis, now what..." implying that lack of intervention services.

6.2 Assessment for Intervention Planning

Assessment for intervention planning for children and youth with ASDs may be done by a single professional and/or agency or with input from multiple professions and/or agencies. Stakeholder feedback on intervention planning indicated that entry into the school system (at either early entrance or at kindergarten), facilitated the development of an individualized Personal Program Plan (PPP) for each child. This PPP is viewed by parents as primarily reflecting the goals for intervention within the school system, and important in that it lays the groundwork for service provision within the school system. Both parents and professionals also highlighted the fact that a PPP can be developed without a formal diagnosis of an ASD, and that school-aged children who receive a diagnosis following entry into the school system will also receive one. The development of the PPP was viewed as something that was going well in the RQHR with respect to assessment for intervention planning.

Consultations also revealed that health professionals and agencies tended to make individual plans for interventions for children and youth with ASDs based on their individual assessment processes. These plans were usually developed based on the diagnostic assessment information as well as additional sources of assessment information, and were viewed as a strength in the system by the stakeholders. However, it was also reported that the majority of these plans were made in isolation from the plans of other professionals or agencies who were also involved. This leads to individual children having a number of different plans for intervention across health professionals and agencies, instead of having one comprehensive plan. As a result, parents (and sometimes case managers) are left to try to coordinate and access services on their own. Parents report a lack of capacity to do this work appropriately and case worker time is too limited to ensure seamless coordination. This lack of a comprehensive intervention plan also leaves parents unclear about the types of services that might benefit their individual children, so many parents report spending hours each day trying to access every possible service available. This also results in added work for the service delivery system, responding to repeated enquiries from parents desperate to find services.

Consultations also revealed that comprehensive intervention planning is not happening in a timely manner. While best practices suggest that intervention planning should occur at time of diagnosis or shortly after if additional professionals are required, this practice was not evident in the consultations. Moreover, there is limited planning for transition periods (e.g. preschool to kindergarten) and it is usually not coordinated across agencies or sectors. For example, a preschool child who receives SLP services from RCYS will no longer be able to see that SLP when she enters the school system. Some parents reported not taking advantage of the early entrance school programming due to

this unwelcome discontinuation of services. This lack of continuity in service providers can be particularly disruptive to children with ASDs.

6.3 Intervention Services

Overall, the majority of the comments reported by stakeholders regarding the quantity and quality of intervention services available in the RQHR reflected limitations, not strengths, in service delivery. Stakeholders identified three strengths: the provision of emotional and practical support for parents, individual professionals providing appropriate intervention services to children with ASDs, and the opportunities provided by the school system for programming and integration with typically functioning peers. However, as will be addressed in more detail below, only one of these, the emotional and practical support that parents reported that they received from health professionals, organizations and agencies, can actually be considered a strength in the service delivery system.

In terms of identified strengths, stakeholders reported that individual professions (e.g. SLP, OT, Psychologists, Psychiatrists, Developmental Paediatricians) tend to be delivering service that is in keeping with the standards of their respective profession. However, as identified earlier in this report, the intervention services of individual professionals lack coordination. Parents report having to “patchwork” services together in order to develop some type of comprehensive program for their child. Moreover, consultations revealed that there are a limited number of professionals available within the RQHR to provide services to children and youth with ASDs and their families.

Another identified strength was that parents reported being appreciative of the services they receive at the school and believe that the school provides the best opportunity for consistency in programming and mainstream integration. However, they also reported being concerned about the quantity and quality of services that their children are receiving within the school system. They report that there are not enough SLPs and OTs in the school system, and, as a result, children do not receive enough hours of service. Parents also reported that there is a lack of consistency in programming across schools, using as examples cases where children with similar needs receive completely different programming depending upon the school they attend. These differences are reflected in hours of time spent with SLPs and OTs, as well as time spent working on curriculum goals.

Professionals, parents and members of community organizations expressed concerns about the lack of ASD specific training for providers working with children and youth with ASDs. More specifically, health care providers may or may not have specific training in ASDs, and many teachers, teacher’s assistants and para-professionals tend to have little more training than attendance at one

workshop or some self-directed learning. As such, there is limited evidence of intervention that is consistent with best practices evidenced in the literature.

There is a lack of availability of evidence-based intervention practices for children and youth with ASDs. Stakeholders report that the quantity of intervention services available is minimal at best and is often crisis-driven. Consultations revealed that there are currently no intensive behavioural intervention programs that provide one-on-one ABA--based educational programming within the RQHR for children with ASDs. Moreover, parents and professionals report that it is unlikely that any child (pre-school or school aged) will receive more than one or two hours of one-on-one specialized services per week unless provided with a para-professional in a daycare or education setting. However, just being in an education setting neither guarantees interventions are actually taking place, nor does it guarantee the quality of those interventions. Some families report purchasing private services (e.g. SLP, OT) but they report a lack of available high-quality private service providers as well.

Professionals and parent both stress that the level of service provided to a child is largely dependent on the ability of the parent to advocate and navigate the system on behalf of the child. It is those children of educated, system savvy parents who fair better in this situation.

Finally, parents and concerned professionals are extremely anxious about the availability of services to these children past the age of twenty-one. Parents recognize a paucity of intervention services for adults with autism. Once outside of the school system, parents have no sense of where to turn for long-term intervention.

6.4 Training

Despite the increased attention to funding training opportunities for professionals and parents in the RHQR in 2007-2008, the process mirrors the lack of comprehensive planning and integration found in service delivery. First, many of the upcoming training offerings are not aligned with the services being delivered in the RQHR. For example, training in comprehensive programs such as TEACCH or SCERTS may provide some strategies for professionals but at this time comprehensive programs cannot be practically implemented or sustained in the RQHR. This is due to the lack of resources currently available in the RQHR to support and sustain a comprehensive program, as well as the lack of consistency in treatment approaches across agencies and organizations. This lack of service alignment is also evident in training opportunities offered by community organizations, such as ARC. Thus, if parents and some professionals receive training on a particular type of intervention (e.g., the PECS communication system), there is no guarantee that

this strategy will be consistently employed for this child across professionals and settings.

A second limitation to the training opportunities is the fact that the upcoming sessions are providing training in intervention strategies from competing, not complementary, perspectives. Consultations revealed that while some professionals may be attending training in one type of program, others are attending training in another. These methodologies are not coordinated and this negatively impacts opportunities for cooperation and transferability of clients across organizations. It does not make sense to have professionals across agencies (and perhaps within the same agency) using philosophically different treatment approaches.

Third, professionals are concerned that prospective training may be a “one-off” due to the finite nature of funding. For example, many training programs involve several modules; one year of training resources does not accommodate completion of modules. Service provider organizations also report significant staff turn-over, so they need repeated opportunities for training in order to train new staff.

Finally, parents report a lack of learning opportunities designed to help them understand autism and the most effective treatment interventions so they often resort to internet-based resources.

6.5 Support for Families

All agencies consulted in the review operate using a family centred approach. Their focus is to ensure interventions are appropriate for families and do what they can to build capacity within the family to support interventions at home. Further, all agencies are providing some degree of consultative support or case worker services. What is apparent however, is that no one agency is offering comprehensive case worker support. Families report receiving minimal casework support from health professionals, and that what they often receive is a referral to another agency and another waitlist. The end result is a frustrating circle of referrals resulting in minimal service. Professionals supported this observation when describing the services they were able to provide. A lack of case work support to assist families in navigating across the array of services and service provider agencies is perhaps the most common theme across all consultations. Parents reported that they would like to receive a handbook, at the time of diagnosis, providing information not only about ASDs, but also about intervention options, local resources and organizations that provide services, and support services for families. As one parent said “When we got together, we realized we had each spent lots of time searching out the answers to the same questions. What if we had just been given a handbook?”

Respite support is also a primary concern for families. The pool of respite service providers is extremely limited and is further reduced when seeking respite workers with experience or knowledge in working with children with autism. Funding for respite poses a further challenge. Department of Community Resources, Community Living Division (CLD) provides an income-based benefit to families with children diagnosed with mental retardation and an IQ under 70. This excludes high functioning children with ASDs and the many children with ASDs who cannot be assessed. The Cognitive Disability Strategy potentially provides support to those families that fall through the cracks; however, professionals reported that there is limited awareness of this program. Some families who receive CDS funding for respite services report using the resources for intervention services, such as OT or SLP services, simply because there are no respite workers available.

As children grow into adults, support for families is further limited. CLD reports limited community living placements or day programs for adults with and ASD. Families without access to day programs may be left in a situation of having to hire full-time home-based support or quit their jobs to stay at home and provide care.

A lack of emergency services was cited as a primary concern for families. Families in crisis have no place to turn for immediate assistance. Situations cited include the death of a parent or circumstances where there is risk of physical harm, but parents are more worried about an emergency response provider who is not trained in ASDs not dealing appropriately with their child than being harmed themselves.

Comment [la11]:

The seasonal programming provided through ARC is highly regarded by all system stakeholders. This program offers continuity in learning and structure for the child and support to family members who would otherwise be seeking at-home care during school vacations. It is also available to children who are on the waitlist for services at ARC, which was mentioned as a support for families.

6.6 Delivery System

Health service delivery for children and youth with ASDs and their families is shared across WRCCP and RCYS. According to stakeholder reports, the relationship and coordination between these two agencies has been improving over the last few years. Moreover, professionals expressed a willingness to continue to improve the coordination of services across these two settings. Despite this, the coordination between these two agencies, as well as that of the other service delivery agencies in the community (e.g., schools and community based organizations including but not limited to day cares, ARC, ECIP and SCEP) continues to be disjointed and in some instances, territorial.

Throughout the stakeholder conversations, the following themes emerged as system-based issues in service delivery:

- **Disjointed services.** Families are patch-working services together from a variety of professionals and agencies which results in service delivery that is inconsistent and lacking in coordination.
- **No clear diagnostic pathway.** WRCCP and RCYS utilize different referral processes and criteria for the provision of services. Although not stated in their organizational policies, some parents and professionals believe that the agencies serve children of different ages. Thus, parents of preschoolers are being told that they can only be seen at one agency, while school-aged children are told they can only be seen at the other. Some professionals are referring children to both agencies, resulting in children being placed on the different waitlists. This is resulting in added administration in the system. Within the RQHR, some pediatricians diagnose ASDs while others do not. This is confusing for both parents and professionals in the system.
- **Duplication of diagnostic and intervention services.** WRCCP and RCYS are offering similar but not identical services. This lack of a service baseline creates parity issues. In fact, one professional told a story of having a child on her caseload and the child's sibling on the caseload of the other agency. Parents were transporting to both child to different locations for appointments and receiving differing services.
- **Confusion about who is provides services to whom and when.** Differing policies and procedures across organizations creates confusion for parents in navigating through the array of services. For example, WRCCP requires a physician referral while RCYS does not. ARC requires a formal diagnosis of an ASD before children are put on their waitlist, while the Cognitive Disability Strategy does not.

- **Lack of planning and integration at transition points.** Throughout the consultations professionals and parents noted gaps in service continuity at transition points (e.g. entry into school, school holidays, and change in service provider). Of most concern was the transition in SLP from WRCCP and RCYS to the school system.

In the school environment, professionals suggested that the quality of school-based programs is largely dependent upon the knowledge and commitment of school leadership, particularly the individual principal. School programming can vary greatly from one school to another within the same school system.

Community-based organizations and parents suggested that staff turn-over rates in these organizations creates issues of continuity and consistency in service provision. These organizations are have limited funding and cannot compete with salary levels offered in governmental organizations.

6.7 Stakeholder Concerns for the Future

Stakeholders were asked to comment on their concerns about the future of service delivery for children with ASDs in the RQHR. All those interviewed expressed are concern about the increased incidence of ASD with an inadequate service infrastructure to support growing demand. This is particularly true to the pre-school years when intervention has the potential to have the greatest positive impact on development. The current lack of treatment choices will simply be exacerbated by increasing caseloads.

Due to a lack of information from service providers, parents are becoming influenced by inaccurate information available through the internet and popular media. Professionals are concerned that an over-reliance on this information may influence policies and practices through political agendas or result in an overemphasis on one form of treatment versus another (e.g. Lovaas IBI).

The lack of available services for adults with ASDs past the age of 21 prevailed throughout the conversations. Parents and professionals are concerned about the ongoing quality of life for individuals with ASDs, their parents and their siblings in an environment of limited community living placements or day program options.

6.8 Stakeholder Priorities

As a means to understand priorities, stakeholders were asked to describe how they would spend additional resources for autism service delivery if given the power to do so. The following list itemizes those areas most commonly cited:

- Train autism specialists in each of the professions delivering diagnostic and intervention services to children with autism.
- Increase quantity of professional service providers and intervention services.
- Provide ongoing support for relevant education/ training for both parents and professionals.
- Coordination of services.
- Provide case management services.
- Quality assurance – ensuring services are appropriate and relevant to the needs of children with ASDs.
- Provide Respite services – access to funding and increased number of respite providers.

7.0 Gap Analysis

In summary, service provision for children with autism in the RQHR could best be described as:

A growing population group, currently provided with
insufficient quantity of service, delivered at a
quality below best practices standards, spread across
numerous delivery agents, which
lack system coordination and alignment, while providing
limited education and support for families to understand the system and
make appropriate choices for the needs of their child in an
absence of a unifying regional or provincial strategy.

Based upon the literature and the consultations, the consultants observed the following gaps in services delivery for children with ASDs:

Absence of an ABA/IBI intervention program

Although there are disagreements in the literature about the best approach to treat all children with ASDs, treatments involving IBI programs based on ABA strategies have received the most empirical support. The literature demonstrates the efficacy of IBI programs for preschoolers in particular, as programming for this age group has received the most attention in the literature. It is important to note that there are **no** IBI programs for either pre-school or school-aged children in the RQHR. As identified earlier in this report, just enrolling a child in an educational program does not ensure the delivery of appropriate interventions service, nor does it ensure that the child is actually engaged in the program. Moreover, professionals, agencies and organizations that are utilizing one or two strategies those delivered in an IBI program can not be viewed as delivering an IBI program. One of the most important contributions of an IBI program is that it is designed to target the core symptoms of ASDs in a comprehensive manner. More specifically, it allows parents, caregivers and professionals to work together to ensure that the child with an ASD to receive interventions consistent with planned, developmentally appropriate goals that are designed to help improve communication and social skills and reduce repetitive behaviours. IBI programs are educational intervention programs, designed to lead to behavioural changes

in children with ASDs. At this time, children with ASDs in the RQHR do not have the opportunity to participate in an IBI program, as there are none available.

No clear entry point for diagnosis or intervention

Much confusion exists about how to access diagnostic services and, once diagnosis is confirmed, necessary intervention services.

Quantity of services

The quantities of services available for children and youth with ASDs do not meet the demand for services. This gap will become larger as increasing numbers of children are diagnosed and placed on waiting lists. Children are receiving minimal amounts of service from an array of providers none of which is delivered at an intensity where consistent developmental progress can be achieved.

Lack of service coordination and alignment

Services are disjointed and lacking alignment. This is due in part to the lack of a comprehensive case plan for individual children. This lack of service coordination is evident within sectors (i.e. health or education) and across sectors (i.e. integration between health and education).

Lack of comprehensive case workers

Due to the lack of services and disjointed nature of services, families require greater support in piecing together case plans for their children. This level of case work support is not available. Families are receiving minimal support from each of the organizations but there is no case worker available to provide comprehensive care to individuals and their families. Most case workers are limited to offering referrals to other agencies which results in a frustrating circular exercise of accessing no services. Better service coordination would result in a reduced demand on case workers.

Lack of information for families regarding services, systems and training

Families have no easy access to comprehensive information regarding necessary services, service providers and training. From the point of diagnosis, parents are provided with little information to assist them in providing care for their child and family. Better communication would further assist in reducing the demand on case workers.

Lack of ASD-specific training for professionals

Many professionals providing service to children with ASDs have limited training and experience in ASDs. Although greater amounts of training are available this year through one-time funding for ASD training, training programs are not consistent with the services offered in delivery agencies and may in fact be contradictory to services provided in other delivery agencies in the RQHR. This results in further disjointing of services across organizations and wasted resources on training in methodologies that will not be implemented.

Services for adults with ASDs over the age of 21

The long term outlook for children with ASDs and their families is bleak. There are limited community living placements and day programs for adults with ASD. Families can look forward to a lifetime of care for their adult child with ASD.

8.0 Recommendations

8.1 Create an ASD Services Vision and Strategy

An overall vision and strategy for the provision of services for children with ASDs and their families is overdue. The system has grown incrementally over several years without consideration for the system as a whole. Children and families have been served largely through an adaptation of existing programs and service to try to address the needs of children with ASDs. As evidenced through this report, it is time to develop an overarching vision and strategy for ASD services, seeking integration of professionals and agencies while focusing on the unique needs of children and families coping with ASD. In order to successfully implement this vision and strategy, adequate funding needs to be available on an on-going basis.

It is difficult for an ASD strategy to be developed in absence of a provincial agenda. Other Canadian provinces have developed a provincially based strategy to address the delivery of services to children and youth with ASDs, and Saskatchewan would benefit from utilizing a similar approach. This is particularly evident when addressing the needs of individuals in rural areas who may cross health regional boundaries for health and education services. Additionally, it is critical that health and learning collaborate on a regional and, if possible, provincial level to agree upon a vision and seamless strategy.

Due to the unique needs and attributes of pre-school aged and school aged children with ASDs, separate yet aligned strategies may be required. Pre-school aged children in particular stand to benefit greatly through specific intervention strategies; to consider pre-school aged children within the mix of an overall strategy may result in a watering down or averaging effect when intensive services are necessary.

To address the issues outlined within this report, a strategy must include but not be limited to the following:

- Determination of a menu of services available to children with ASDs and their families.
- An education and training strategy for professionals to support selected diagnosis and intervention methods.
- An education and training strategy for parents and families (including siblings).
- Communication strategy for families, stakeholder agencies and professionals.

8.2 Measurement of Demand

Determining demand for autism services is a complicated matter. Because it is a spectrum disorder and each child's needs are unique, diagnosis and service needs vary. The manner in which services across an array of agencies also make demand measurement virtually impossible. Despite these challenges, measurement is critical in order to plan, predict, develop policy and appropriately resource agencies and programs.

It is recommended that a classification system be developed for the purposes of measurement. The classification system must take into consideration the functional level of the child, age, location (rural versus urban) and required services.

8.3 Standardize a Pathway toward diagnosis

A standardized pathway to diagnosis is recommended to provide clarity for professionals and clients and to increase system efficiencies. The following procedural considerations are recommended:

- **Engage only necessary professionals to enhance timeliness and efficiency of diagnosis.** For example, best practices dictate that a physician and/or psychologist can diagnose independently in clear cases. In complex cases both the physician and psychologist may be required as well as other professionals such as an SLP. Procedures must allow for the most efficient means possible to the necessary end. Thus one approach may be to separate diagnostic assessment from assessment for intervention planning purposes.
- **Ensure consistent practices across diagnosing agencies or streamline diagnosis to one agency.**
- **Streamline training on diagnostic instruments to those professionals conducting diagnostic assessments** (i.e. psychologists and physicians). Providing diagnostic training to professionals not involved in the diagnostic process is unnecessary, inefficient and misleading to professionals.
- **Establish acceptable waiting times.** Current waiting times seem to vary between four and six months for diagnosis. Waitlist time for intervention is not known. Decisions regarding an acceptable waiting time are necessary and must reflect the impact of early intervention. Further, appropriate measures must be put into place to ensure adherence to wait time benchmarks.

- **Communicate diagnostic pathway to referral agencies.** A communications strategy is necessary to ensure that health and education service providers understand and can advise parents regarding the pathway to diagnosis.
- **Enable parents to self-refer.** Findings in this report suggest that parents are generally the first to notice questionable behaviours but experience an uphill battle in gaining recognition from front-line service providers (i.e. family doctor, public health nurse). To avoid delays, it is recommended that system enable parents to self-refer for diagnosis.
- **At the diagnosis, parents should receive an intervention plan or a referral to an intervention planning team.** According to best practices, it is necessary for parents to understand next steps immediately upon receiving a positive diagnosis. The diagnostic process may enable the immediate development of an intervention plan. If not, a referral should be provided for the development of an intervention plan. Parents should also receive necessary information concerning next steps and appropriate community resources.

8.4 One point of entry for intervention services

Every child with an ASD in the RQHR should be provided with one point of entry for intervention services supported by a comprehensive case plan and case worker. This approach will ensure integration of necessary therapies across both health and education delivery systems and ensure intervention is continuous and strategic throughout the child's development, particularly during transition periods (e.g. entry into pre-school, entry into kindergarten).

8.5 Coordination of services

Coordination of services is perhaps redundant to recommendation 8.1 (creation of a vision and strategy) but, in light of the service review findings, warrants particular note. It is critical that services within both health and education sectors and across these sectors are coordinated and aligned in the best interests of the child's comprehensive case plan and the family's needs. This includes governmental and community-based programs.

8.6 Best effort to provide best practice intervention programming

This recommendation reflects the realization that there are large gaps in the availability and provision of intervention services in the RQHR, and that changes in current practices, as well as the addition of new services, will take time to develop. According to the literature, the components of best practice intervention programs for children and youth with ASDs include:

- **Individualized services for children and families.** This component addresses the need for the development of intervention programming specific to the needs of each individual child with ASDs and their families. In Saskatchewan, children and youth with ASDs currently receive a Personal Program Plan upon entry into the school system, and community based organizations may develop individual plans for intervention services within their own agencies. However, these individualized plans need to include services from RQHR, and to be consistent across agencies and sectors. This component also reflects the fact that not every child with an ASD will benefit from the same intervention plan.
- **Active engagement in an intensive instructional program for young children (at least 20 hours per week) in any natural environment (home, childcare centre, preschool) throughout the year (seasonal programming).** This component speaks to two issues: intensity of early intervention programs and the best practice settings for these programs. In terms of the intensity of the programming, recommendations in terms of hours per week per child range in the literature from 15 hours to 40 hours per week. In Canada, the majority of provinces are currently funding at least 20 hours a week (Madore & Pare, 2006). However, it is also important to note that not every child will require the same level of program intensity. As Dr. Peter Szatmari stated "It is true that early intervention makes a difference but it is not true that all children need exactly the same type of treatment. Not all children need incredibly intensive intervention that takes up between 20-40 hours per week. Some children do respond, but other children do not respond to even that level of intensity and can do just as well with less intensive forms of treatment that are carried out in more naturalistic settings. We do not know the relative proportion of those types of children but there is now more and more scientific evidence showing us that different forms of intervention can be adapted to different types of Autism Spectrum Disorder" (Szatmari, 2006).

The above quotation also supports the second component that recent trends in the provision of intervention services are highlighting the need for treatment to occur in natural environments. Although researchers acknowledge that some children have difficulty with inclusion, particularly

early on, the provision of treatment services outside of segregated centre-based programs is the primary model of treatment across Canada.

- **Systematically planned developmentally appropriate activities aimed toward identified objectives.** This component speaks to the importance of having planful intervention activities, based upon the objectives identified in the individual program plan. Thus, it can not be assumed that merely placing a child with an ASD in a preschool or daycare program is an intervention. Instead, there needs to be a clearly defined plan, from which appropriate opportunities are made available to reach the identified objectives. This can also be extended to the involvement of professionals, such as psychologists, SLPs and/or OTS.
- **Intervention in natural environments with typically functioning peers to the extent that interactions lead to specified educational goals.** This component speaks directly to interventions designed to increase social skills and communication. As in the above, it is not enough to just place a child or youth with an ASD in an environment with typically functioning peers. Instead, these interventions need to be planful and take into account the strengths and weaknesses of the individual child.
- **Sustained family involvement.** Families play an integral role in the development and maintenance of any intervention plan. Thus, effective programs take into account the needs of the family as well as the child, in the intervention context.
- **Educational interventions should incorporate principles of positive behavioural support and functional assessment for challenging behaviours.** The literature indicates that functional assessment and positive behavioural approaches are the most effective for the management of challenging behaviours.
- **There should be an emphasis on the development of social and pragmatic language skills.**
- **Ongoing assessment of a child's progress, with adjustments in programming as required.** As highlighted above, not all children will respond to the same types of interventions. The NRC (2001) recommends changing/modifying treatments when there is no evidence of progress over a period of time (no more than 3 months), so it is important to monitor each child's individual progress.

8.7 Provide support for parents

- **Increased respite services with trained respite providers.** Parents of children and youth with ASDs can be under enormous strain due to the 24-hour-a-day demands. It is important not only that they have access to respite services through funding opportunities, but also that there is a pool of respite providers trained in ASD who are able to provide the care.
- **Provide access to emergency support services.** Children and youth with ASDs provide unique challenges to emergency service personnel, who tend to lack training with ASDs.
- **Parent education.** Parents need access to information about ASDs in general, as well how to access services and supports, and what intervention options are available. More specifically, it is recommended that parents are provided with the following:
 - o A resource package that provides preliminary information
 - o A web-site for ongoing information
 - o A chat room for parents to share information
 - o Parent support groups
 - o Triage education to be delivered immediately after diagnosis

8.8 Targeted training and educational opportunities

- **Choose training opportunities to support diagnostic and intervention approaches that can be sustained within the RQHR.** As highlighted in the literature review, there are many programs, sometimes based on competing philosophies about treatment, that are available for parents and professionals. It is important that the training opportunities provided are evidence-based, chosen to reflect intervention practices that are consistent with those in the RQHR and are sustainable. Thus, comprehensive programs, which require high numbers of trained professionals, as well as ongoing training and assessment may not be as sustainable as programs that allow for a more consultative approach.
- **Select appropriate individuals to attend training that is relevant to their work.** Given the limited resources for training opportunities, specific training opportunities should be offered to those professionals most likely to employ them. For example, given that only psychologists and physicians can legally make a diagnosis of an ASD, they should be given first priority with respect to training on diagnostic instruments.

- **Increased awareness of alternative bio-medical approaches for physicians working with children with ASDs.** As highlighted in Myer's (2007) report of the American Academy of Pediatrics, many parents are seeking out complementary, alternative treatments for ASDs. Physicians seeing children and families need to be aware of these alternative treatments and have enough knowledge of the literature to be able to talk to families about them.

8.9 Utilize existing programs for service provision

Agencies currently delivering services are well intended and motivated to provide quality intervention services. These agencies should be included in a comprehensive strategy for ASDs but must modify existing services to meet best practice standards. Attention to program/service alignment and coordination across organizations is important to ensure that services are not unnecessarily duplicated.

There are a multitude of community-based mainstream programs that can be adapted to accommodate the needs of children and youth with ASDs. Greater programming capacity is necessary to meet demand but not all programs need to be nor should be outside of the mainstream community. Programs such as City of Regina swimming lessons or Boy Scouts could accommodate participants with ASD if training/coaching was provided to the program leader. This approach provides an opportunity to significantly increase community programming capacity without the expense and segregated nature of centre-based programming.

8.10 Increased Training for ABA/IBI Intervention Service Providers

Assuming implementation of recommendation 8.6, the development of a training program for interventionist in ABA/IBI will be necessary to meet best practice standards. At this time, there are few qualified professionals in RQHR to deliver these types of ABA/IBI services through either a consultative or direct service model. While in the initial stages, qualified professionals will have to be drawn from other jurisdictions, a local ongoing training program will be necessary to sustain demand. This will likely involve a partnership with secondary educational institutions such as the University of Regina or SIAST. Further, given the lack of qualified behavioural interventionists across the province, this recommendation should likely be considered in a provincial context.

9.0 Future Research

Some questions regarding the review of services to children and youth with ASDs remain outstanding. This section provides suggestions for future research and investigation.

Validation of Existing Services

Observation of intervention service delivery was outside of the scope of this review. Analysis and recommendations are based on the self-reports of individuals and agencies. When moving toward implementation of this report's recommendations, it may be necessary to conduct direct observations of current programming practices.

Review of Services for Adults with ASD

It was apparent through the consultation process that parents and service providers were concerned about the lack of services available for adults with ASDs. Further research should be undertaken to measure gaps in services for this population.

Consideration for a Provincial ASD Strategy

While this report identifies gaps in services within a specific region in Saskatchewan, it is reasonable to assume that similar gaps exist across the province. Other Canadian jurisdictions have developed strategies for children and youth with ASDs at a provincial/territorial level. Recommendations provided in this report are written on the assumption that a regional strategy is possible however, implementing recommendations on a provincial scope will increase potential impact and opportunities for economies of scale.

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Appendix A: Research Questions

The following research questions were asked during the consultations. Not all questions were asked of each respondent; questions were selected based on the role and scope of involvement of the respondent in providing

1.00 What services are currently available for preschool and school-aged children (up to age 21) in the RQHR for the assessment/diagnosis of ASDs?

- 1.10 Do you (your agency/organization) assess and/or diagnose pre-school children with Autism Spectrum Disorders? School-aged children?
- 1.20 Which professions are doing the assessments and/or diagnosis?
- 1.30 Do you utilize a multi-disciplinary team approach? Do you believe this type of approach is necessary for the assessment/diagnosis of ASDs? Who should be on this team?
- 1.40 What assessment tools are most commonly used for pre-schoolers? School-aged child?
- 1.50 What types of training and/or qualifications do you (other members of the team, your staff) have in diagnosing and assessing children with ASD's?
- 1.60 Are there specific training opportunities with respect to the assessment/diagnosis of ASDs that you would like to see available for yourself (your team, your staff)?
- 1.70 How do children/families access your assessment and diagnostic services?

2.00 What services are currently available for preschool and school-aged children (up to age 21) in the RQHR for the intervention/treatment of ASDs?

- 2.1 Once the child has been diagnosed, what kinds of intervention services does your organization provide?
- 2.2 Do you (your agency, your staff) have a particular philosophy on working with children with autism/PDD?
- 2.3 How many hours per week (month) of services would be typically provided to one pre-school child? School aged child?
- 2.4 How much of the service provision is one on one time with the pre-school child? School aged child?
- 2.5 Please describe a typical intervention program experience for the pre-school child? School aged child?
- 2.6 What education, qualifications and training do service providers in your organization have?
- 2.7 What experience, qualifications and training does the person who supervises the program have?
- 2.8 How closely does the program supervisor work with the therapists, teachers and parents?

- 2.9 What kinds of ongoing training do your full- and part-time staffs participate in?
- 2.10 Are parents involved with planning as part of the intervention team?
- 2.11 Do you provide a parent training program?
- 2.12 How do parents and family members support the program interventions at home on a day to day basis?
- 2.13 Do parents participate in or observe programs/interventions?
- 2.14 What techniques do you use to manage difficult behaviors?
- 2.15 Do you ever use physical aversives or any physically restraint procedures? If yes, please describe them.
- 2.16 Please describe your program for communication and language development. Do you use a picture communication system, sign language, other kinds of communication systems, or all of these?
- 2.17 Are there opportunities for integration with typically functioning children?
- 2.18 How do you evaluate the child's progress, and how often?
- 2.19 How do you keep parents informed of the child's progress?

3.0 How do families experience and perceive the services?

- 3.1 How was your child diagnosed with an ASD?
- 3.2 Who (which agency) did the diagnosis/assessment? How much information were you provided at the time of diagnosis?
- 3.3 What happened following the diagnosis with respect to intervention services, referrals etc.
- 3.4 What kinds of intervention does your pre-school child receive? School aged child?
- 3.5 How many hours per week does your child receive intervention/therapy?
- 3.6 How much of this time is one on one time with your child?
- 3.7 Please describe a typical intervention session with your child.
- 3.8 With whom and how do you communicate with the therapist, supervisor, teacher, etc. and how often?
- 3.9 As a parent are you involved with planning as part of the intervention team?
- 3.10 Have you participated in a parent training program? What training did you receive?
- 3.11 How are you involved in supporting the intervention programs from home?
- 3.12 Do you participate in or observe therapy and/or group sessions?
- 3.13 Does your child have opportunities for integration with typically functioning children?
- 3.14 How is your child's progress evaluated and how often?
- 3.15 How are you kept informed of the child's progress?

4.00 What is going well with respect to service delivery to ASD child in your organization? In the RQHR? (strengths)

5.00 What are the limitations/gaps in services have you observed within your organization? Within the RQHR?

- 6.00 How could services to families with a child with an ASD be improved within the RQHR?**
- 7.00 What issues do you foresee in the future that may impact your ability to deliver services to ASD children?**
- 8.00 If additional resources were made available to autism in Saskatchewan, where best would those resources be allocated?**

Appendix B: DSM-IV criteria for Autism Spectrum Disorders

299.00 Autistic Disorder

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 other people (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 in, 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 initiate 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, interests, and activities as manifested by at least one of the following:

- (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or 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 whole-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.

299.80 Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)

This category should be used 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, interests, 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 of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

299.80 Asperger's Disorder (or Asperger Syndrome)

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

- (1) 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
- (2) failure to develop peer relationships appropriate to developmental level
- (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
- (4) lack of social or emotional reciprocity

B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
- (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
- (4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

Appendix C: Inter-Jurisdictional Review

Province/ Territory	Provincial/Territorial Funding Programs for Autism Therapy								
	IBI for Preschoolers	Hours/ Week	IBI for School- Aged Children	Hours/ Week	Theoretical Model Specified	Theoretical Model	Home- Based	Delivered through inclusive preschool/ centre based programs	Delivered through segregated centre-based programs
Alberta	YES	maximum 30-40 hours per week	YES	maximum 20 hours per week	YES	ABA principles	YES	YES	NO
British Columbia	YES	Not specified	YES	Not specified	YES	ABA principles	YES	YES	MINIMALLY-3 centres in all of B.C. for small number of children
Manitoba	YES	36 hours per week (5 hours of these provided by family)	YES	Not specified	YES	ABA principles	YES	YES	NO
Ontario	YES	up to 40 hours per week, depending on individual child's needs	YES		YES	ABA principles	YES	YES	YES
Quebec	YES	up to 20 hours per week	NO		YES	ABA principles	YES	YES	NO
Nova Scotia	YES	up to 15 hours per week at the beginning, gradual reduction in hours after 6 months	NO		YES	ABA principles (Pivotal Response Training)	YES	YES	NO
New Brunswick	YES	Not specified	NO		YES	ABA principles	YES	YES	NO
Newfoundland	YES	up to 30 hours	NO		YES	ABA principles	YES	YES	NO
Saskatchewan	No		NO						
Prince Edward Island	YES	up to 20 hours per week	NO	N/A	No-focus on increase in skills across developmental domains		YES	YES	NO
Nunuvot	NO		NO						
Northwest Territories	YES	Not specified	YES	not specified	YES	ABA principles	YES	YES	NO
Yukon	YES	Not specified	YES	Not specified	YES	ABA principles	YES	YES	NO

The Madore, O. & Pare, J-R (2006). Provincial and territorial funding programs for autism therapy. Parliamentary Information and Research Service, Library of Parliament.

