



**Recommendations Toward A Prince Edward Island  
Autism Action Plan: Another Piece of the Puzzle**

Autism Action Group

September 2009



This report was prepared as an account of work sponsored by the Prince Edward Island Department of Education and Early Childhood Development in support of a Provincial Autism Strategy. Neither the observations, comments and recommendations contained in this report, nor the views and opinions of authors expressed herein do not necessarily constitute or imply its endorsement, recommendation, or favouring by the Government of Prince Edward Island, nor any department or any agency thereof.



# Table of Contents

Acknowledgements .....	
Executive Summary .....	i
Introduction .....	1
Methodology .....	10
Recommendations .....	11
Structure .....	11
Quality of Services .....	21
Capacity and Resources .....	45
Communication .....	55
External Communication .....	55
Internal Communication .....	58
Conclusion .....	61
Bibliography .....	62
Appendix A .....	A – 1
Appendix B .....	B – 1
Appendix C .....	C – 1



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Theresa Aitken ..... Autism Society of Prince Edward Island

Marlene Breitenbach ..... Special Education Autism Specialist,  
Education and Early Childhood Development

Dr. Nadine DeWolfe ..... Pediatric Psychology Services

Glenn Edison ..... Director,  
Education and Early Childhood Development

Sarah Henry ..... Healthy Child Development Coordinator,  
Education and Early Childhood Development

Cathy McCormack ..... Early Childhood Services Officer,  
Education and Early Childhood Development

Colleen McCluskey-Douse ..... Autism Society of Prince Edward Island

Peter Meggs ..... Special Education Coordinator,  
Education and Early Childhood Development

Valerie Nicholson ..... Public Health Coordinator – Central,  
Primary Care

Dawn Riley ..... Speech and Hearing Services,  
Public Health

Jason Rendell ..... A/Supervisor Social Assistance & Disability Support Programs  
Social Services and Senior

## Executive Summary

A sixteen page Executive Summary may appear to be an oxymoron. However, when considering the considerable breadth of issues that were tackled by the Autism Action Group (AAG), the reader will soon appreciate the extent this Executive Summary abridges the full report of the AAG.

The original request for this work was to develop an action plan that would help advance the Department of Education and Early Childhood Development (Ed & ECD)'s as yet unproclaimed Autism Strategy. To do so, a cross-departmental group of service providers and representatives of the Autism Society have met several times to make recommendations. However, the resulting deliverable is not an action plan. Because the AAG had difficulties achieving consensus on some elements of the (unofficial) Strategic Plan, it spent considerable time considering the Strategy itself, and making recommendations regarding a Provincial direction. The Consultant notes that the challenge the AAG had in resolving the different perspectives on how to advance the Provincial Autism Strategy was due in part to several key factors.

First, the draft Strategy documents, while still relevant to the practices within Ed & ECD, were already older than the typical lifespan of most Strategic Plans. Key elements of the Strategy require updating to accurately reflect the current practices.

Second, the unofficial Strategy was the result of an internal exercise, which did not have the benefit of broader consultation. While it assisted the development of guidelines that have been used in the design and delivery of Autism Spectrum Disorders (ASD)-specific services to children with ASD, the absence of an official status resulted in an inability to engage in discussions with other ASD-specific service providers and stakeholders regarding strategic direction. As a consequence, each service developed its own approach to ASD service delivery which may work in isolation, but which do not support a system-wide or One Island Community approach to ASD services.

Third, the original draft Strategy was prepared with the primary focus of Ed & ECD roles in ASD services. It was not readily amenable to take on the broader scope of a Provincial, cross-departmental Strategy.

Fourth, the department-based, or service-based silos are entrenched, and cannot be penetrated by the good will and intent of the AAG participants alone because each department or service applies very different approaches to ASD supports and services. At their levels within their corresponding organizations, the AAG participants did not have the authority or mandate to resolve these issues.

Despite these difficulties, there was unanimous and strong consensus for the design and delivery of ASD supports and services to be based in a cross-departmental Provincial strategy. To achieve this, strong, active leadership is required from the Deputy Minister and Director levels to address areas where consensus is not achievable. Therefore it is not surprising that there are a number of strategic recommendations regarding the coordinating structure of ASD services in

addition to the many specific action items in this document. This summary highlights *only a handful* of the items that are set out in the main document. However, it serves to profile what are considered the priority items requiring attention.

## Themed Recommendations

Given the fact that Autism Spectrum Disorders affect individuals across their life span, in many aspects of their lives, requiring services and supports from several departments as well as community organizations, it is not surprising that the AAG identified many recommendations and items for action. However, there were three clear themes for organizing the recommendations of the AAG: structure, quality of services, and communication. The highlighted recommendations are gathered under these headings. Priority recommendations are noted in orange; broadly supported recommendations are noted in green; pink recommendations denote a lack of full consensus; the blue consultant recommendations were deemed by the consultants to be sufficiently important to be included in the Strategy.

### Structure:

There was a strong, unanimous call for a provincial strategy that is proclaimed, communicated and understood by all stakeholders with respect to roles, responsibilities and extent of service. The governance recommendations were intended to support *a strategy with vision; and a need for a **Provincial** strategy where all Related Departments take ownership and are accountable and include community input; and a need to align with and leverage other strategies and services.*

Throughout the consultations with the AAG, there was a clear and consistent call for the Strategy and its Action Plan to address both the realities of the current resource context and also set stretch objectives that will support the ongoing improvement of supports and services into the future. Therefore the AAG was not prepared to be limited to immediate action items, and offered longer term goals as well. Because the unofficial Strategy is familiar to many within Ed & ECD, it was thought that the originating Department would be able to update the document more readily and adopt it, as soon as possible, with other Related Departments (Health, Social Services and Seniors, Innovation and Advanced Learning) expected to come on board shortly afterwards.

**Priority Recommendation:** That the Autism Strategy be officially acknowledged by the Department of Ed & ECD as soon as possible with the following *provisos*:

- Given the very fluid nature of knowledge regarding autism, the Strategy is to be considered *a living document* that will be regularly reviewed (at least annually) and updated in consultation with governmental, medical, and community partners; and
- The Departments of Ed & ECD, Social Services and Seniors, Health, and Innovation and Advanced Learning undertake to officially recognize the Autism Strategy as a provincial strategy by the end of the calendar year.

**Recommendation:** The Strategy and its future adaptations should be based on the stated values and beliefs set out below:

- ASD is characterized by social and communication impairments. Therefore the Strategy's interventions are designed to address these deficits.
- As with any other government-sponsored program, the Strategy's design must:
  - require informed consent;
  - respect privacy of personal information; and
  - be transparent.
- Early identification is a key element to improving the likelihood of positive outcomes.
- Early intensive behavioural intervention can have a significant and positive impact on learning and development for children with autism.
- Individuals with autism will continue to learn throughout their lifetime. They may require varying levels of individualized support and programming depending upon their strengths and challenges.
- A collaborative team approach is an essential component for person-centred service delivery.
- Active parent involvement, education, and ongoing communication maximize learning opportunities and generalization of skills for the person with autism.
- A continuum of supports must be available for the person with autism, their family and service providers to facilitate successful learning and development experiences in inclusive environments.
- Collaboration with the community is highly valued and welcomed.
- Assessment is the basis for determining appropriate programs and services. At the individual level and family level, decisions about intervention and service delivery should be outcome-based\*, using objective measures. (\*For the purpose of this document, outcomes-based refers to outcomes for *both* the person living with ASD as well as their family or support network.)
- Teaching strategies based on the science of Applied Behaviour Analysis (ABA) have been documented to be effective for many individuals with ASD.
- A variety of behavioral teaching strategies and supports based on empirical research and best practices can be utilized in school, home and/or community settings.
- The social, linguistic, cultural diversity and values of families and educators must be recognized and considered in the provision of services.
- Services must be provided by appropriately trained personnel at all levels, including appropriate educational background and ongoing professional development.
- Individual behaviour intervention, where needed, will be based on Functional Behaviour Assessment (FBA) and will emphasize positive reinforcement-based approaches, validated through research.
- Island children with ASD requiring additional resources for optimal development have access to timely, quality services.

**Recommendation:** Ed & ECD issue the Minister’s Directive on Autism Services

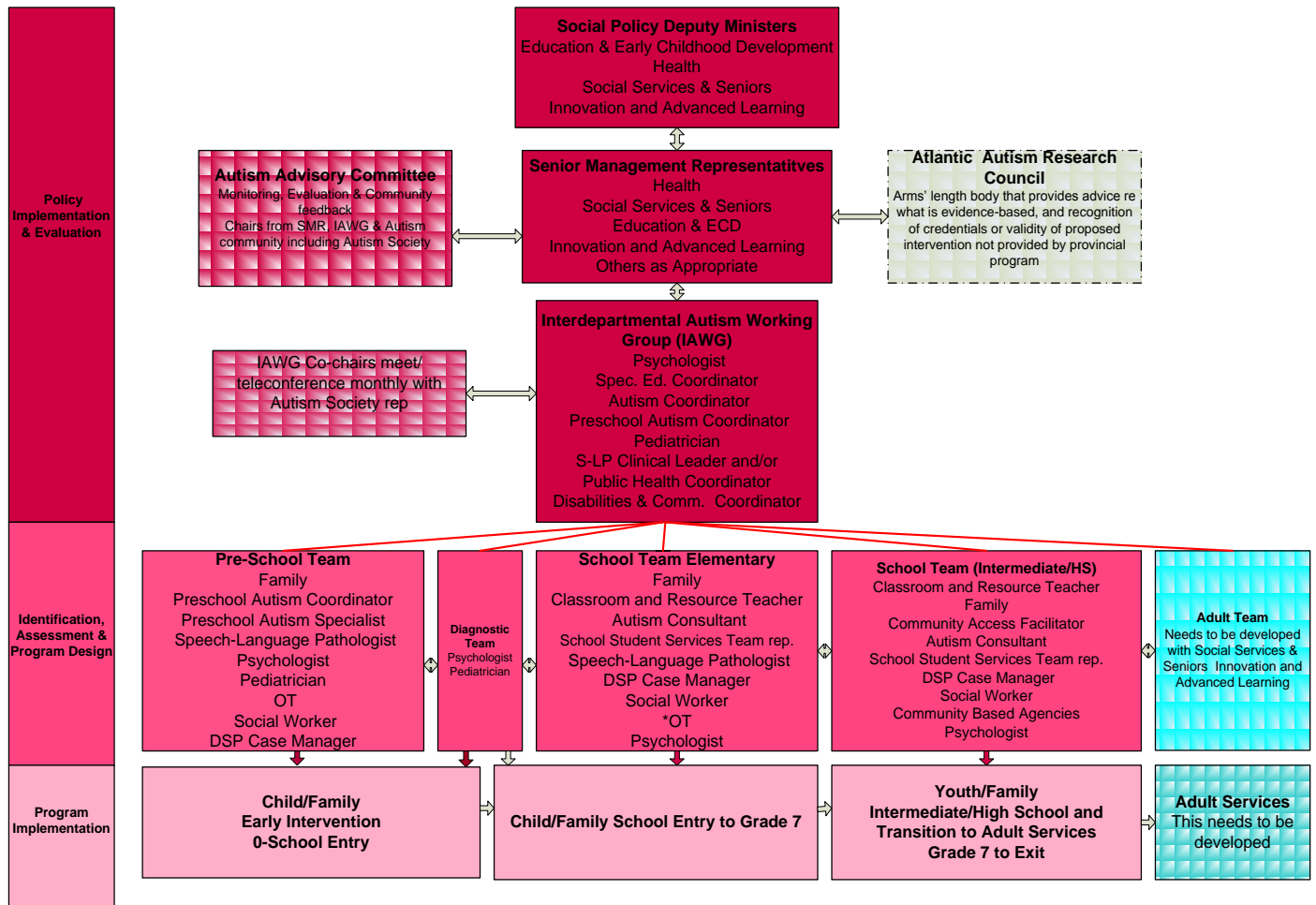
The Ed & ECD guidelines have been a vital part of the service; the Minister’s Directive must be formally adopted as a foundational instrument of the Strategy.

To support on-going cross-departmental cooperation, effective communications and coordination, the AAG recommended the following leadership structure:

**Priority Recommendation:** By June 2010, establish a governance structure that:

- is driven from the executive level of government;
- requires interdepartmental cooperation, coordination and collaboration;
- has access to an expert panel’s advice on questions of leading-edge science; and
- strengthens communication and engagement with the community input.

This structure is illustrated in the proposed organization chart below:





- In addition to the monthly updates and communication between the Interdepartmental Autism Working Group (IAWG) and the Autism Society, the Autism Advisory Committee will meet at least twice per year with Senior Management Representatives for the purposes of providing monitoring, evaluation and community feedback on autism services to the Senior Management Representatives.
- Broader community feedback will also be sought through an annual forum which will be organized and hosted by the IAWG.

The AAG is aware that it is not working in a vacuum. There is other work being done in various departments that may have an impact on the implementation of the proposed action plan, including the Disability Services Review, the Learning Disabilities Strategy, and the current work of the Early Intervention Working Group, as well as internal departmental reviews respecting specific services such as Speech-Language services and Public Health Nursing. There may be opportunities to leverage and coordinate the work of these various initiatives to mutually enhance the effectiveness of these plans. While this is outside the mandate of the AAG, participants recognize that these opportunities should be explored.

**Priority Recommendation:** Host a facilitated dialogue with Deputy Ministers and Directors with leadership roles relating to the Disability Services Review, Early Intervention, Learning Disabilities and Autism Strategies, as well as recent service reviews such as the Speech-Language Services Review and the Public Health Nurse Screening Assessment Review, to establish a broader governance structure which underpins these strategies and align them with the strategic direction of government for Island prosperity; supporting *all* Islanders in achieving their full potential.

To assist the Related Departments in adopting and leading the comprehensive Provincial Strategy, a facilitated series of meetings of the senior leadership is needed.

In addition to internal developments, the AAG was also aware that the knowledge and understanding of ASD is rapidly evolving. Determining whether new interventions or practices are evidence-based requires a high level of awareness of the most current studies and research work. The AAG is aware of leading experts in the field within Atlantic Canada and recommends that this local expertise be tapped for advice by partnering with the other Atlantic or Atlantic provinces to create an autism research council that serves as an arm's length expert panel that could provide recommendations regarding whether particular interventions or practices are evidence-based.

**Recommendation:** The Province promote the establishment of an Atlantic Autism Research Council responsible for researching autism best practices, staying apprised of developments in the field of knowledge, and providing reports and recommendations.

Decisions on what interventions or practices are eligible to be implemented or funded are to be shared between provinces, between departments, with service-providers, families and the ASD community. The interaction between the Atlantic Autism Research Council and the Provincial Autism Strategy is reflected in the preceding organization chart.

## Accountabilities and Responsibilities

**Recommendation:** Clearly state accountabilities for all stakeholders within a value-based delivery model.

To ensure that roles and responsibilities are owned and actions are taken, Departments and Stakeholders need to be held accountable for their responsibilities under the Strategy which will include annual reports on progress of autism-specific services, and sharing of statistical information that can assist with planning shared across Departments. This also includes ensuring sustainable resources.

- Departments need to make defined commitments in terms of funding and designated positions (such as S-LPs, Preschool Autism Specialists and Autism Consultants) to support the Strategy.

## Quality of Services:

The Strategy needs to support the delivery of an effective ASD service through the following elements that drive better outcomes for children and their families:

**Evaluation Framework:** An Evaluation Framework is needed to provide transparency and accountability for the provincial strategy.

**Priority Recommendation:** As an *urgent priority*, the Departments of Health, Social Services and Seniors and Ed and ECD jointly sponsor the development of an evaluation framework by June 2010.

While some members expressed concern that investing in an evaluation framework might overtax already stretched resources, the lack of a framework challenges the viability of the services. ASD supports and services are often resource-intensive. This draws criticism from other groups who are also vying for the Province's resources, or those who suggest different service design. For an evidence-based service to not have evidence of its own efficacy leaves it open to on-going pressures for resources.

- In addition to service effectiveness, measures also need to be developed to help assess the effectiveness of coordination and cooperation across Departments. Develop measures to ensure that trans-disciplinary/cross-departmental collaboration is actively being practiced, e.g. by setting specific time frames in which teams and team members must meet, and by holding individuals responsible for calling, holding and attending meetings.
- Participate in research opportunities through multi-site studies or collaborative work with other centres specializing in autism studies.

The Province is currently participating in national research, and should continue to do so. Since 2001, Prince Edward Island has participated in the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC). This study collects anonymized information (no names appear in the database) on children who have been diagnosed with ASD. It is used to monitor the prevalence of ASD, as well as that age of first diagnosis, maternal and paternal age.<sup>1</sup> There are other ASD experts and post-secondary institutions in Canada with whom relationships can be established that can support the Island's efforts to remain in tune with leading developments in the ASD field, and benefit from access to researcher resources through participation in studies. Exploring and establishing such relationships should be encouraged.

**Service Model** (which includes the employment of resources model, funding and evidence-informed service design)

**Priority Recommendation:** The current Strategy states its position on the use of evidence-based interventions. A clarification of how the Province will approach requests for emerging interventions needs to be added:

*The Autism Service is founded on evidence-based practices. However recognizing that the study of autism interventions continues to emerge, **interventions or practices that are based on behavioural principles but are not part of the Provincial service** may be considered where an evaluation framework is in place to measure its effectiveness with respect to the individual, the family, and the service.*

*Interventions need to be evidence-based.* There are frequent requests from families, and even some health professionals for interventions, treatments and therapies that are not always evidence-based. The AAG recommended that the Province adopt a clear position on this point.

**Priority Recommendation:** There should be no unreasonable wait lists for individuals with ASD to access publicly-provided interventions.

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<sup>1</sup> National Epidemiologic Database for the Study of Autism in Canada (NEDSAC), Queen's University, [www.nedsac.ca/index.html](http://www.nedsac.ca/index.html), accessed 13 Aug 09

While several members of the AAG wanted this recommendation to require that there be *no* wait lists for ASD-related services, the Consultant notes it is difficult to identify any other publicly-funded service that is not subject to wait times for access. Given the need for *early* intervention to maximize the effectiveness of interventions, wait times should not be long. The original draft Strategy referred to time frames of three months. This would appear to be reasonable.



**Recommendation:** Within 10 months, prepare a catalogue of the Level 1 suite of services by identifying, within provincial strategies such as the Disability Services Review, Early Intervention Strategy, and Learning Disabilities Strategy, the services and supports not specific to ASD, but which may enhance or assist in the service delivery to persons with ASD or their families.

The AAG was very concerned that the Early Intensive Behavioural Intervention service (EIBI) is often thought of as the *only* intervention option for children with ASD. However, just as ASD diagnoses cover a broad spectrum of social and communication impairments, there is a wide continuum of services, interventions and supports that are available to persons with ASD and their families. The AAG believed that an ASD model that recognizes this broad spectrum will assist persons with ASD and their families in understanding that. This Level 1 suite of services will have a strong overlap with early child development supports that may be identified by the Early Intervention Strategy as well as the interventions that are available under the Learning Disabilities Strategy.

**Consultant Recommendation:** Once developed, the Early Intervention Strategy should be adopted and actioned as quickly as possible to support the early intervention services available to Island children with developmental delays, including those with ASD.

It was noted that in addition to the continued hope for developmental progress that comes from having autism specialists and tutors working with the children, the presence of this service also helps families cope. Where wait lists for specific interventions cannot be immediately addressed *or* where interventions do not result in developmental progress, families continue to have a need for support, and assistance. This requires a robust continuum of early interventions available in Level 1 so that Level 2 services are not the *only* services available to individuals with ASD and their families.

Level 2 Services are services that are Autism-specific. As the service is currently designed, this includes EIBI delivered through the preschool autism specialists, ASD-specific S-LP therapy, ASD-specific parent information and training sessions as well as services delivered by other health professionals who offer autism-specific interventions, tutors and ABA-based Individual Education Plans (IEP) with autism consultants for school-age children.

**Recommendation:** Co-locate ASD-related professionals and other ASD-related service providers wherever and whenever possible.

- Ed & ECD develop agreements with Health, Social Services and Seniors to co-locate services as much as possible to physically support information sharing and to also improve the convenience to families who need to visit professionals in clinical settings. (For example, pediatric psychology services are currently in the same building as speech-language services and early childhood development offices in Charlottetown. This arrangement is seen as advantageous for these services and the families accessing them.)

**Recommendation:** Dedicate a Speech-Language Pathologist (S-LP) to a provincial role for at risk and diagnosed individuals with ASD. This S-LP will consult with the Preschool Autism Specialists, support other S-LPs in their service to these clients and deliver specialized parent training, such as the Hanen *More Than Words* program to families of children at risk or diagnosed with ASD.

S-LP led interventions and supports are an important component of both Level 1 and Level 2 continuums. The Speech Language Services group has been working diligently to allocate its resources to meet the many demands for their services, including individuals who have ASD. Given current workloads, there is little opportunity for S-LPs to take on educational and family support roles – which was clearly identified as a need.

The EIBI service details, such as the *maximum* of 20 hours per week, was an issue of significant concern to the Autism Society. The Society wants, as a *minimum*, 25 hours per week as a key element of the service. A summary of the matter is contained in the main body of this report. In short, the debate in the literature over the number of hours of intervention continues. While Ed & ECD has indicated an openness to increasing the hours of the service, the fundamental principle that the service be evidence-based suggests that there needs to be some baseline measures taken prior to a change.

**Recommendation:** Ed & ECD and Health establish a preliminary set of evaluation factors and collect benchmark data for children about to enter the EIBI service in October 2009, with a follow-up assessment of the children and evaluation of the service in June 2010. Then use this information, to inform a decision of whether to alter the intensity and length of the service taking into account staffing and coordination factors.

It was beyond the AAG's mandate to be considering service details, however, this was an area that the ASD community strongly believes needs to be addressed. This recommendation was not supported by some members of the AAG. Some wanted an immediate increase in the intensity of the EIBI service; others were concerned that to do this immediately would create an increased wait time; and yet others noted that the EIBI service is a good program, and asked "How do we know it needs to be changed"? Given the lack of data on the Island service, it is difficult to develop a basis for agreement. Therefore, the Consultant recommends that time (*but not a long time*) be taken to establish baseline measures, and to assess the effectiveness of the current service, as well as to ensure that resources will be mobilized to support any adjustment in the EIBI *without increasing wait lists*.

**Recommendation:** The Province implement a universal screen for children at risk of developmental delays and autism, linking this screen with those indicated by the Learning Disability Strategy, Early Intervention Strategy work and Public Health Nursing work.

While there was some concern regarding the impact of this recommendation on Public Health Nursing resources, and the expected increase in demand for both Level 1 and Level 2 services, the Consultant is aware that Public Health Nursing is currently considering a more robust universal screening program for children that could support this recommendation. Therefore, the Consultant has retained this recommendation. Evidence has shown that early childhood is an important period during which to provide interventions. This requires a program of early identification of children who have ASD or who *may* have ASD (provisional diagnosis).

**Recommendation:** The service objective is for diagnosis and initial evaluations to be completed within three months of referral.

The Diagnostic Team is exploring a variety of measures for children and families who are currently on the wait list. At time of writing (summer 2009), that wait list is approximately 10.5 months for the children currently on the list. The Department of Health is exploring options for outsourcing some assessments with the goal of achieving a wait time of less than three months. However, if this goal is accomplished there will be direct implications for resources to deliver EIBI.

**Recommendation:** Ed & ECD partner with Health, Social Services and Seniors, DIAL and NGOs to undertake proactive planning for appropriate adult ASD services during the high school years and into the future.

Given the importance of early intervention, much of the AAG time (and hence this report) was focussed on the Strategy as a means of addressing the needs of children. However, people with ASD grow into adulthood, and continue to need supports and services. One of the next steps for the Strategy is to examine the Disability Services Review to identify how the Provincial Autism Strategy can support gaps in ASD-specific needs for adults with ASD.

- Related Departments to create an *ad hoc* Adult Autism Advisory Committee to identify opportunities to improve services and supports to persons with ASD and their families. Ed & ECD should be part of this process because it is implicated in adult literacy and longitudinal studies for evaluation of services and supports.
- Health to ensure Mental Health services are provided to children and adults with ASD.

**Recommendation:** Create a human resources plan for *all* positions relating to the delivery of ASD services from diagnostics through to adult services and supports.

While this recommendation did not have the unanimous support of the AAG, there are significant human resource challenges that require long term planning as well as creative problem-solving.

**Immediate Action:** Confirm the current temporary or contract positions as permanent, specifically:

- Autism Coordinator position; and
- Preschool Autism Specialist positions.
- Continue to make efforts to fill the Preschool Autism Coordinator Position.

The AAG identified additional positions to address current service gaps as well as a need to address services to children in later grades and adults. There were also some actions that could be readily accomplished to improve the sustainability of the service, such as confirming



temporary and contract positions. The lack of permanent status hinders the recruitment efforts into those positions.

- Ed & ECD has been greatly challenged in its attempts to recruit and/or retain Preschool Autism Specialists, Autism Consultants and other professional service providers. Frequently, it must resort to hiring individuals with good potential, but lack the full qualifications for the work. This means that simply because a position is filled, the incumbent may not be competent to work to the full scope of their position for a year or more. Such time lags have significant impacts on the ability to deliver services, and as a result, wait lists grow.
- In addition to recruitment and retention, the qualification and competence of EIBI tutors has also been raised as a concern. Investing in design and development of individualized EIBI programming does little for children if they do not have consistent, competent tutors.
- There are also challenges with respect to the recruitment and retention of other professionals.

Therefore the Consultant believes a proactive human resource plan that supports the Strategy is important for the service's sustainability. The report includes a number of other human recommendations and suggested actions.

**Priority Recommendation:** The Related Departments need to ensure that the wages for ASD service providers reflect appropriate compensation for the work, competencies and training required, and Treasury Board should consider labour market adjustments for permanent positions.

This recommendation was unanimously supported by the AAG, particularly with respect to the need to address the wage rates for EIBI tutors. Currently, they are being paid significantly lower than educational assistants in the school system. As a result, many good tutors do not remain with the EIBI service long before seeking employment in positions with higher compensation rates. Appropriate compensation levels need to be addressed in tandem with a tutor employment model.

**Recommendation:** Ed & ECD work with Health and Social Services and Seniors to create an employment model for tutors of home-based IBI programming to relieve families of the burden of finding qualified, competent personnel.

The current system of parents as employers has created significant challenges to service provision (i.e. difficulty finding and keeping tutors, unclear communication and conflicting



supervisory roles with advice coming from public sector and private professionals, and parent-employers; and friends/family/neighbours as employees), and there are also concerns about quality assurance of tutor services under the current model. In building their relationships with families, Preschool Autism Specialists and Autism Consultants do not feel it is helpful to act as compliance enforcers, yet they sometimes become aware of situations where tutors are not following the service as designed. It is difficult to assess the efficacy of the EIBI service if the service is not being implemented consistently and appropriately. Therefore, while the Autism Society believes that enhancing the wages for tutors will largely address their concerns with respect to the tutor-employment model, AAG members who take the larger system perspective, believe that more structure is needed to ensure that tutors are competent and qualified, with clear accountabilities for their role in the EIBI service.

The AAG did not see a need for tutors to be employed directly by the Province. Instead, it preferred options where families retained some control with respect to choice of tutor:

- Develop a registry of qualified service providers (families are still employers); OR
- Contract with service provider agencies to deliver services to families (families are not employers) where families can choose agencies.

**Recommendation:** Create a social worker/navigator position to assist families with the navigation of the autism/early intervention pathways as well as to provide ongoing support to families.

Families need support. The diagnosis and the behaviours that frequently accompany ASD are extremely stressful on families. The social worker can help reduce some stress by providing a central access point for information about services available and how to access them. A social worker or counselling background would better equip the navigator to appreciate additional supports the family may need. There was a suggestion that this position belong to Department of Health as most entries into ASD services are through health-related services (Physician, Public Health Nurse). Another suggestion was that this might be coordinated through the Healthy Child Development Unit. This organization represents the seven departments that committed to the Health Child Development Strategy, including Ed & ECD, Health, Social Services and Seniors, and Innovation and Advanced Learning. Being deployed in this unit would enable the social worker/navigator to have information and contacts with the continuum of services and supports available to families. The AAG's lack of agreement of where this position should reside will require senior level leadership to resolve. Regardless of which Department owns this position, good liaising connections and information flow between departments will be essential to make this position effective. The departments will need to address families' access to the social worker/navigator when they enter the service through alternate pathways.

## Communication

The strategy will be advanced through improved access to services and navigation of the services and supports which will require enhanced external and internal communication:

### External communication

The Strategy's success will be measured in large part through heightened public and consumer awareness of what supports and services are available and how to access them. Currently, the families of children with ASD and the community lack clarity as to how to express their concerns or raise questions about what services and supports are available.

**Recommendation:** Create a communication plan to ensure that all stakeholders have input and are aware of existing services and how to access them.

The Province has a Healthy Child portal to which families, and service providers, can refer for information on what services and supports are available based on:

- open access;
- referral (and whose referral);
- diagnosis; and
- contact information if they have concerns.

In recent years, prior to the AAG work, the Province and Autism Society maintained an arm's length distance in terms of planning provincial autism services. While the Autism Society will retain its advocacy role, it is a valuable resource to the Province and to the ASD community to work collaboratively to develop programs and services that enable persons with ASD to reach their full potential:

- Ensure the Strategy recognizes the important role the community plays in its implementation.
- While recognizing that the interests of the province and the Autism Society may not always align, departments commit to collaboration with the community.

**Recommendation:** The Province partner with the Autism Society to establish an Autism Resource Centre that provides accurate information regarding the interventions, programs, services and supports available, as well as providing a lending library of resources and tools to parents and families.

**Recommendation:** Related Departments conduct a joint survey of families of all children with ASDs, not just those in the EIBI service, to receive input on their experience, the quality of the service, and gaps.

This recommendation spans both quality of services and communication themes. While input from the Autism Society is helpful, there are concerns and perspectives from families that are not active within the Society that also need to be considered, and incorporated in the dialogue between the Province and the ASD community.

### **Internal communication**

Once the trans-departmental governance structure and process is ascertained, clear and sustained channels of communication will be the glue that holds the structure together. While the Ed & ECD has had an unofficial strategy from which to work, the lack of a published strategy and policies have left various stakeholders to deal with service design and delivery with a level of uncertainty. Driven by an ‘officially’ adopted Strategy, interdepartmental communication and service delivery will be strengthened at all levels in the departments, from front-line service providers to managers, Directors and Deputy Ministers. Measures to improve internal communications need to focus on:

- Clarifying roles and responsibilities across departments and school board-based autism professionals;
- Establish channels for information sharing within teams and across teams; and
- Accountability for initiating information sharing meetings.

**Recommendation:** Create an internal communication pathway to ensure all internal stakeholders are aware of roles, responsibilities, activities and accountabilities.

IAWG be tasked with identifying information to be contained within annual reports from Departments including number of referrals for diagnosis, number of confirmed diagnoses and estimated year of entry to school system, participation in preschool and school-age service.

**Consultant Recommendation:** Appoint a project manager to oversee the launch of the recommendations of this document for an eighteen month period to be accountable for setting rapid actionable items into motion, and aiding the Related Departments in developing the needed structures and processes to support the strategy on a sustainable basis.

The scope of the AAG recommendations is very broad, and very ambitious. The very magnitude of the report creates the risk that the tasks set are too daunting for people to undertake when they have other competing priorities as well. By having a project manager who can focus exclusively on finalizing a work plan and implementing the priority items, Ed & ECD will be sending a strong signal to the Related Departments and AAG members that the Provincial Autism Strategy is a priority, and the report is being actioned.

## Summary

The recommendations above represent a cross-section of the recommendations contained in the full report. However, they also highlight the high priority, urgent and fundamental issues that need to be addressed by the Related Departments in order to advance the current array of ASD-specific interventions, supports and services into a Provincial Strategy.

# Introduction

## The Work of the Autism Action Group

Timing is everything. The Department of Education & Early Childhood Development (Ed & ECD) has had an unofficial autism strategy designed for the Department of Education side of the organization since 2000. Due to a variety of circumstances, unrelated to the Strategy, the timing for consultation and official adoption was delayed, although the Strategy was used internally, and formed the basis of a number of positive developments in the services provided by the Province for children with Autism Spectrum Disorder (ASD) and their families. Nevertheless, while it was a helpful guide for internal decision-making, its lack of official status hampered the Department's ability to communicate, both within the education sector and across departments, a direction for autism services and accountabilities.

With responsibility for Early Childhood Development being brought into the Department, the timing was right for reinvigorating the Strategy. In anticipation of the Strategy being officially adopted, an action plan was commissioned to gather the advice and suggestions of key stakeholders in the design, delivery and receipt of autism services and the steps necessary to advance the Strategy. To that end, the Autism Action Group (AAG) consisting of stakeholders from the Departments of Education and Early Childhood Development, Health and Social Services and Seniors, have come together over a series of five facilitated workshops.

In the course of facilitated discussions, it became apparent that while there was a genuinely shared passion for helping children with autism achieve their full developmental potential, agreement on the gaps and criticality of gaps, and the priorities for action were **not** readily apparent. Therefore, rather than being an exercise to tweak and action the department's strategic plan, the AAG invested considerable time identifying a number of issues of concern and grappled with finding the appropriate balance of actionable items to achieve the most beneficial effects while recognizing the resource realities. While the AAG exhibited a great desire to work together to achieve consensus, it was not possible in all areas. Therefore, where consensus could not be achieved, this report notes the lack of consensus and makes recommendations on how the Department should proceed.

The document then sets out 37 key recommendations grouped according to the themes of governance, quality of services, and communication with related actions suggested for each.

## Autism Spectrum Disorders (ASD)

The Department of Education and Early Childhood Development (Ed & ECD) projects that in the Fall of 2009 there will be 150 students with ASD in the school system and 26-28 children in the preschool IBI service. In addition, there are currently 23 children waiting for a diagnostic assessment. Approximately 67% of these children are predicted to receive an ASD-related diagnosis.

Autism Spectrum Disorders (ASD) which include Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and Asperger Syndrome involve an impairment in social interaction including impairment of communication skills and body language, difficulty developing peer relationships, spontaneous interactions with other people, social or emotional reciprocity. Individuals with ASD exhibit repetitive patterns of behaviour, preoccupations that are abnormal either in intensity or focus, and inflexible adherence to specific, non-functional routines or rituals. As the name autism *spectrum* disorder suggests, the condition varies widely between individuals with respect to how the condition first presents, how it impairs interactions, and whether and how well an individual responds to interventions.<sup>2</sup>

Despite decades of intense study, the cause of ASD and similar disorders is not well understood, although most authorities would agree that it most likely involves a combination of several factors.

## ASD Interventions

There was a general consensus within the AAG that there are a variety of interventions or childhood development tools that are beneficial to children with developmental delays in social and communication skills including speech-language therapies and activities, and behavioural-based therapies. Many of these are available to children without requiring an ASD diagnosis. However, as in other jurisdictions in North America, access to *autism-specific* interventions, such as the Early Intensive Behavioural Intervention (EIBI), requires a diagnosis. In PEI, EIBI consists of up to 20 hours per week of applied behaviour analysis (ABA)-based therapy.

While ASDs are generally regarded as life-long conditions, some investigators have claimed that there have been cases of children with well-documented ASD who have recovered. These cases have given rise to an adamant call for public support of treatments that would support optimal outcomes for people affected by ASDs. However, despite the claims of recovery, investigations indicate that while some individuals with ASD do move off the ASD spectrum (which is indeed a wonderful outcome for these people), they still have other issues.<sup>3</sup>

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<sup>2</sup> Sonya Norris, Jean-Rodrigue Pare and Sheena Starky, *Childhood Autism in Canada: Some Issues Relating to Behavioural Intervention*, Library of Parliament, January 2006.

<sup>3</sup> Molly Helt, et al., *Can Children with Autism Recover? If so, How?*, *Neuropsychology Review* (2008) 18:339-366

A wide variety of therapies are suggested for autism, including special diets and pharmacological treatments. However, “few people would argue with the statement that today the treatment of choice is that based on the behavioural model. In fact, behavioural treatment is the only treatment that has been empirically demonstrated to be effective for children with autism.”<sup>4</sup>

While there are other therapies that are showing some promise, to date, autism researchers can only class them as “probably effective”. Therefore, ABA/EIBI therapies have achieved gold standard status. As a result, the discussions of the AAG relating to interventions naturally tended to focus on the details of the current Island EIBI service despite the fact that it is just one of the services or developmental tools available to assist families.

What does *evidence-based* mean? *Evidence-based practices* usually refer to services or practices that are proven to be successful through research methodology and have produced consistently positive patterns of results. Evidence-based practices or model services that have shown the greatest levels of effectiveness are those that have established generalizability (replicated in different settings and with different populations over time) through research studies. The implementation of proven, well-researched services is rapidly becoming standard practice today and required by most funding sources.<sup>5</sup>

## ASD Intervention Litigation

In addition to the challenges of designing interventions based on emergent science, the public funding for autism interventions has been a serious challenge for families and governments across the country.

The cost of EIBI is a major concern for governments. In 2006, the costs ranged from \$15,000 to more than \$57,000 per child per year depending on the intensity of the service, and the service delivery model.<sup>6</sup> A Library of Parliament report noted that most provinces have agreed to partially fund the treatment for preschool children; for example, up to \$20,000 per child per year in British Columbia and New Brunswick. When such a ceiling is in place, most families will opt for a less intensive service if they cannot afford the difference. Intervention funding for school-age children is available in British Columbia, but it is significantly lower at \$6,000 per child per year. In other provinces, funding specifically designated for school-age children is either not offered, or it is integrated with other autism, special education and disability programs.

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<sup>4</sup> Laura Schreibman, *The Science and Fiction of Autism*, Harvard University Press, Cambridge, MA, 2005, p. 133 as cited in Norris, *op.cit.*

<sup>5</sup> A further discussion of what is evidence-based is set out in Appendix B.

<sup>6</sup> Odette Mador and Jean-Rodrigue Pare, *Provincial and Territorial Funding Programs for Autism Therapy*, Library of Parliament, 2006 <http://www.parl.gc.ca/information/library/PRBpubs/prb0622-e.pdf>

The question of whether full funding for EIBI is a legal right has been litigated in the human rights and constitutional context. The Supreme Court of Canada has ruled in the *Auton* case that EIBI is not necessarily covered by the *Canada Health Act*, since the Act does not specify which individual medical services are to be provided. Each province determines its list of medical services which are wholly or partially covered by a province's health insurance plan. The Supreme Court of Canada noted that a legislative scheme is not itself discriminatory in providing funding for services to some groups while denying funding for ABA/IBI therapy to autistic children.

The Supreme Court of Canada noted that the national health framework under the *Canada Health Act*, **is a partial health plan and its purpose is not to meet all medical needs.** To be covered by the *Canada Health Act*, EIBI would have to be included as a specific treatment in the province's list of "similar or additional services" along with the "health care practitioners" who render such services:

The *Canada Health Act* and the relevant British Columbia legislation do not promise that any Canadian will receive funding for all medically required treatment. All that is conferred is core funding for services delivered by medical practitioners and, at a province's discretion, funding or partial funding for noncore services, which in the case of British Columbia are delivered by classes of "health care practitioners" named by the province.<sup>7</sup>

Given the language of the *Canada Health Act*, each province has the right to include or exclude a specific treatment in its insured non-core services. This results in notable differences among provincial services for the treatment of autism which creates confusion and frustration for families with children with ASD in trying to determine what they have a right to expect. However, as already noted above, the science of autism treatment is still developing, and does not yet fit well with a medical model for defining and prescribing what is treatment.

This brief scan of Canadian decisions should also take note of the Island decision in *Wonnacott v. Prince Edward Island (Department of Social Services and Seniors)*, [2007] PEIHRBID No. 2 (Q.L.) While this decision did not turn directly on the issue of autism supports and services *per se*, it was a turning point for key aspects of the Province's Disability Support Program with respect to the use of screening tools and income testing.

In that case, the Human Rights Tribunal considered complaints regarding the administration of the Province's Disability Support Program funding with respect of three severely disabled children, and one severely disabled young adult, all with ASD. The complainants were particularly concerned with the discrimination results from the use of income testing, the use of the Functional Independence Measurement tool (known as the FIM) to assess levels of functioning of disabled individuals, and the capping of benefits. The issues before the panel were:

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<sup>7</sup> Supreme Court of Canada, *Auton (Guardian ad litem of) v. British Columbia (Attorney General)*, [2004] 3 S.C.R. 657, 2004 SCC 78, 19 November 2004



- Does the use of the DSP Screening Tool, called the Functional Independence Measure (FIM), discriminate against mentally disabled as compared to physically disabled persons?
- Does the income testing of parents with disabled children under the age of eighteen discriminate against those children on the basis of age and family status?
- Do ceilings on the monthly funding or lifetime caps available for supports under the DSP discriminate against severely disabled persons?

The Panel found that the core section of the FIM screening tool was weighted in favour of physical disability as compared to mental disability. This was discriminatory. The FIM screening tool used to assess their level of functioning placed the mentally disabled Complainants at a level higher of functioning than warranted by all of the needs and circumstances of their disabilities and lives. Therefore, the DSP discriminated through the differential treatment afforded to the complainants as a result of the use of the FIM screening tool. The physically disabled comparator group would not have received such differential treatment since the FIM screening tool was not weighted against them. The Panel also found that the DSP income testing for the parents of children with ASD was discriminatory.

While the Panel found in favour of the complainants with respect to the FIM screening tool and the income testing of the parents, the Panel upheld the use of funding caps, ruling at para 109:

... The DSP Program does not promise that all needs will be met. The Program is intended to assist disabled Islanders. Finite resources require that limits be set, and Legislators are entitled to deference in allotting finite resources to vulnerable groups. We find no discriminatory purpose in the capping of the amount available monthly for supports and services. .... Considering the overall purpose of the program and the needs it seeks to meet, differential treatment has not been shown. They have been granted the highest level of support available and their human dignity has not been harmed.

Therefore, while publicly funded supports and services must not be discriminatory as against other reasonable comparator groups, both courts and human rights tribunals recognize that publicly funded programs must operate within finite resource parameters. A summary of recent Canadian cases relating to autism services is contained in Appendix A.

**Note:** This brief summary of Canadian intervention decisions is intended only to set the context for the AAG's work. The Province *has* a variety of programs and services available to persons living with a wide range of disabilities including autism. Ed & ECD and Related Departments<sup>8</sup> remain committed to providing effective ASD services.

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<sup>8</sup> Related Departments include Innovation and Advanced Learning (DIAL), Health, Social Services & Seniors

## Towards a Provincial Autism Strategy

Several departments have had roles in the development of the services available to persons with ASD. Since 1996, children with autism on Prince Edward Island were educated in the public schools, first in segregated classrooms and later in inclusive settings with their age – appropriate peers. At that time there were no Applied Behavioural Analysis (ABA)-based therapies provided by province for this population.

In response to parent requests, the Department of Health and Social Services (as it then was) acknowledged the need for improving the level of services to children with autism and their families. Initially, funding was provided to enable families to access out-of-province professional expertise. In March 1998, the Department of Health (Health) hired a clinical psychologist with the expectation that 0.5 FTE would be spent working with children and families of the ASD population.

Recognizing the need to develop capacity on Prince Edward Island and reduce dependency on outside agencies, the *Autism Integration Project* was initiated in December, 1998 under the Health Transition Fund. This two year project was jointly sponsored by the Pediatric Clinic of the Queen Elizabeth Hospital and the Division of Child, Family and Community Services, Department of Health and Social Services. This effort resulted in a partnership with the community to create a Pre-School Autism Consultant position and develop a contractual relationship with Bancroft NeuroHealth to provide initial training and programming expertise.

Island-based Early Intensive Behavioural Intervention (EIBI) services to young children with autism began in January, 1999. Ongoing training sessions were offered to the parents, tutors and school staff.

In June 2000, the Department of Education (as it then was) received input on autism services in the schools through consultations with parents, school board officials, and members of the autism clinical team. A needs assessment was conducted entitled *Needs of Children with Autism* (October 2000). As a result, a Special Education Autism Coordinator position was staffed in May 2001. Subsequently, in-service workshops for teachers and teacher assistants, as well as individual assessment and consultative services for students with autism were provided in the public school system.

There will be 151 students with ASD in Island schools in September 2009. There are now Autism Consultant positions in the school systems (Western School Board, Eastern School District and French School Board) to provide leadership in Applied Behaviour Analysis and intervention for students with autism.

Intensive training for these Autism Consultants, including graduate course work in behaviour analysis and mentoring with the Autism Consultant, is funded through the Department of Ed & ECD. In 2000/01, the provincial government committed to developing

an integrated service delivery strategy for individuals with autism. The development of this strategy began with an inter-departmental working group meeting to identify a service delivery model and organizational structure.

By 2001, there was significant momentum for advancing ASD services on the Island. The Autism Society, in cooperation with Ed & ECD and Health, commissioned a report in 2001 setting out a business plan for a Behavioural Based Training Institute.

During this same time period, the Department of Health and Social Services contracted the services of consultants with expertise in the needs of adults with autism to review these issues; a day-long forum was also held with community stakeholders to gather further input.

The Department of Education (as it then was) was part of an interdepartmental committee that worked for two years to develop a draft autism strategy and guidelines. However, due to a variety of environmental factors including impact on other departments, government reorganization and renewal, the draft documents did not receive final approval. In the intervening years, Education used the draft documents as practice guidelines. Since then, the responsibilities of the Department have expanded, the program has evolved, and the needs of persons with ASD and their families have exceeded the resources available.

Given these factors, it was timely for the Department to revisit its earlier work to align the policy for the early years with the policy for the school years. To do so, Ed & ECD appointed a meeting of stakeholders with representatives from the autism community, and from across involved government departments to discuss a process for developing an action plan based on the Department's unofficial autism strategy; to examine the draft autism policy and determine what steps should be taken to make the policy a reality and to advance the goals of the policy. In accepting its terms of reference, members of the AAG stipulated that this work be endorsed by all Departments with responsibilities for persons with ASD.

The stakeholders were supportive of the project and recommended that a process of two workshops focused on identifying action items based on the strategy should be sufficient to result in a series of actionable items. Based on that advice, the Ed & ECD hired a consultant to facilitate a workshop based process for the development of an action plan. Indeed, enhancements to the autism service have been put in place over the years:

- The number of Preschool Autism Specialists to deliver the EIBI service has increased to six as the service expanded;
- Health has increased its commitment of pediatric psychology resources to the ASD Diagnostic team;
- The school age service has developed a robust transition process for children with ASD entering the school system, transitioning between grade levels, as well as a transition process to post-secondary;

- Parent information sessions and training is being offered, such as:
  - On-line resource for:
    - toilet training tutorial for families on the wait list; and
    - Autism 101 in preparation for attending Preschool Autism service training sessions;
  - Working with an S-LP in Health to offer the Hanen *More than Words* program to families this Fall; and
  - Early Intensive Behavioural Intervention (IBI) training for newly diagnosed children and their families who will be entering the Preschool Autism IBI service during summer and fall 2009;
- Ed & ECD is exploring new sources for IBI tutors (non-school-based) from the mature worker pool through the Passport to Employment Program;
- The Preschool Autism Service has moved to Ed & ECD, in the Child and Student Services Division, allowing for a better alignment of services for children with autism which can be considered on a continuum from diagnosis through to transition out of school;
- The Preschool Autism Service is adopting a revised assessment process developed to include assessment best practices based on behavioural- teaching strategies. This will include assessments when children enter and exit from the preschool service, as well as a 6 month (plus on-going) re-evaluation of progress assessments. Parents will be active participants in this assessment process;
- Preschool Autism Service staff are in the process of finalizing Individualized Family Service Plans (IFSP) to more clearly define a child's program for families; and
- All clinical staff in the preschool and school age services recently had opportunity to attend one of four autism related conferences off-Island.

At the time of writing, there are over 25 children in the EIBI service, with another 23 diagnosed and waiting to be enrolled. The Preschool Autism service has a current staffing complement of:

3 permanent Preschool Autism Specialists (PAS)	3.0 FTE
2 two-year temporary PAS (1 filled, 1 vacant – to be posted)	2.0 FTE
Bilingual Specialist in training, (80% preschool, 20% school-age)	0.8 FTE
Preschool Coordinator (vacant)	<u>1.0 FTE</u>
<b>Total Complement</b>	<b>6.0 FTE</b>

However, these positions are not completely filled. Two positions are vacant (1 PAS, and the Coordinator), one permanent PAS is working 80% until October 31<sup>st</sup> and the Bilingual Specialist is working at 80% while completing a learning component for the work.

In the School-age service, Autism Consultants, employed by the Boards, are trained and mentored by the Provincial Autism Coordinator, who is employed by Ed & ECD. The training currently requires a year of mentoring to complete and two years of course work. One Consultant completed training in 2008, and another will complete training this year (2009). The Francophone Autism Consultant will complete training in 2010. There has been high turnover in Consultant positions, with four of the ten trained Consultants no longer in these positions. At the time of writing, the Province has a complement of Autism Consultants of:

3 in the Eastern School District (one of which is in training 0.8);  
2 in the Western School Board; and  
0.2 in the French School Board.

## Methodology

The Autism Action Group (AAG) included representatives across three departments: Health, Ed & ECD, and Social Services and Seniors. The AAG also had the full participation of two representatives of the Autism Society. This group worked together through five full days of workshop activities and discussions to review the draft Autism Strategy and its accompanying guidelines, and identify the actions needed to advance the realization of the vision and principles expressed in that document. Individual members also submitted articles, flow charts, position papers and comments on work as the document began to take form.

The AAG assessed the current status of various aspects of the service, identified the desired state for the service and made recommendations at both the strategic and action level. Given the fact that Autism Spectrum Disorders affect individuals across their life span, in many aspects of their lives, requiring services and supports from several departments as well as community organizations, it is not surprising that the AAG identified many recommendations and items for action. However, there were three clear themes for organizing the recommendations of the AAG:

- Structure;
- Quality of Services; and
- Communication.

The Report is structured to follow these three themes. Priority or Immediate action items are identified. Priority recommendations are noted orange; broadly supported recommendations are noted in green; pink recommendations denote a lack of full consensus; the blue consultant recommendations were deemed by the consultants to be sufficiently important to be included in the Strategy although there may have been stronger cautions or resistance from some members of AAG.

## Recommendations

### Structure:

#### *Commitment to a Provincial Strategy*

Fundamental to the action plan gaining traction is the communication of the sanctioned autism strategy – preferably as a Provincial Autism Strategy. There was a strong, unanimous call for a provincial strategy that is proclaimed, communicated and understood by all stakeholders with respect to roles, responsibilities and extent of service. The Structure recommendations were intended to support *a strategy with vision; and a need for a **Provincial** strategy where all Related Departments take ownership and are accountable and include community input; and align with and leverage other provincial strategies and services.*

The lack of an official strategy has been an impediment to clear internal and external communications regarding how and why policy decisions were being made, and understanding accountabilities and responsibilities between stakeholders. Therefore, a pressing priority for the Action Plan relates to a declaration that the province has an Autism Strategy.

The support for such a declaration does not necessarily indicate that the AAG members were unanimous in their acceptance of all aspects and details of the Strategy. Indeed, much of the discussion of the AAG tended to focus more on amending or enhancing the Strategy itself to achieve agreement amongst AAG members rather than action items under the Strategy.

**Priority Recommendation 1:** That the Autism Strategy be officially acknowledged by the Department of Ed & ECD as soon as possible with the following *provisos*:

- Given the very fluid nature of knowledge regarding autism, the Strategy is to be considered *a living document* that will be regularly reviewed (at least annually) and updated in consultation with governmental, medical, and community partners; and
- The Departments of Ed & ECD, Social Services and Seniors, Health, and Innovation and Advanced Learning undertake to officially recognize the Autism Strategy as a provincial strategy by the end of the calendar year.

Throughout the consultations with the AAG, there was a clear and consistent call for the Strategy and its Action Plan to address both the realities of the current resource context and also set stretch objectives that will support the ongoing improvement of supports and services into the future. Therefore the AAG was not prepared to be limited to immediate action items, and offered longer term goals as well. Because the unofficial Strategy is familiar to many within Ed & ECD, it was thought that the originating Department would be able to update the document

more readily and adopt it, as soon as possible, with other Related Departments (Health, Social Services and Seniors, Innovation and Advanced Learning) expected to come on board shortly afterwards.

#### Interdepartmental Actions

- Revise the Strategy to separate out the Strategic elements from the implementation and process discussion (this will enable the Strategy to have a longer life with implementation and process evolving). The implementation and process pieces may form part of the Action plan;
- Fast track updates to Strategy to accurately reflect the Province's position;
- Revise Ministerial Directives to reflect that ECD is within Ed & ECD (but need to be careful to not place full onus of strategy on Ed and ECD when it is anticipated to be a Provincial Strategy);
- Obtain Ministerial approvals from involved Departments;
- Make Strategy available to key stakeholders and to the public generally for basis of ongoing dialogue;
- Strategy should have suite of supporting documents that provide detail on governance and implementation; and
- Ensure that the principle of a Child and Family centered approach to service delivery is included in the philosophy statement.



**Recommendation 2:** The Strategy and its future adaptations should be based on the stated values and beliefs set out below:

The AAG determined that the values that underpin the Strategy should be prioritized or “nested” such that equity of access is the primary consideration, but is assessed and determined in the context of need and outcomes. Related departments would apply the following values and beliefs in policy decision-making:

- ASD is characterized by social and communication impairments. Therefore the Strategy’s interventions are designed to address these deficits.
- As with any other government-sponsored programs, the Strategy’s design must:
  - require informed consent;
  - respect privacy of personal information; and
  - be transparent.
- Early identification is a key element to improving the likelihood of positive outcomes.
- Early intensive behavioural intervention can have a significant and positive impact on learning and development for children with autism.
- Many individuals with autism have difficulty with change. Special attention and planning is needed to prepare for transitions at key points.
- Individuals with autism will continue to learn throughout their lifetime. They may require varying levels of individualized support and programming depending upon their strengths and challenges.
- A collaborative team approach is an essential component for person-centred service delivery.
- Active parent involvement, education, and ongoing communication maximize learning opportunities and generalization of skills for the person with autism.
- A continuum of supports must be available for the person with autism, their family and service providers to facilitate successful learning and development experiences in inclusive environments.
- Collaboration with the community is highly valued and welcomed.
- Assessment is the basis for determining appropriate programs and services. At the individual level and family level, decisions about intervention and service delivery should be outcome-based\*, using objective measures. (\*For the purpose of this document, outcomes-based refers to outcomes for *both* the person living with ASD as well as their family or support network.)
- Teaching strategies based on the science of Applied Behaviour Analysis have been documented to be effective for many individuals with ASD.
- A variety of behavioural teaching strategies and supports based on empirical research and best practices can be utilized in school, home and/or community settings.
- The social, linguistic, cultural diversity and values of families and educators must be recognized and considered in the provision of services.
- Services must be provided by appropriately trained personnel at all levels, including appropriate educational background and ongoing professional development.
- Individual behaviour intervention, where needed, will be based on Functional Behaviour Assessment (FBA) and will emphasize positive reinforcement-based approaches, validated through research.
- Island children with ASD requiring additional resources for optimal development have access to timely, quality services.

**Recommendation 3:** Ed & ECD issue the Minister's Directive on Autism Services.

The Ed & ECD guidelines have been a vital part of the service; the Minister's Directive must be formally adopted as a foundational instrument of the Strategy.

**Ministerial Directive Actions**

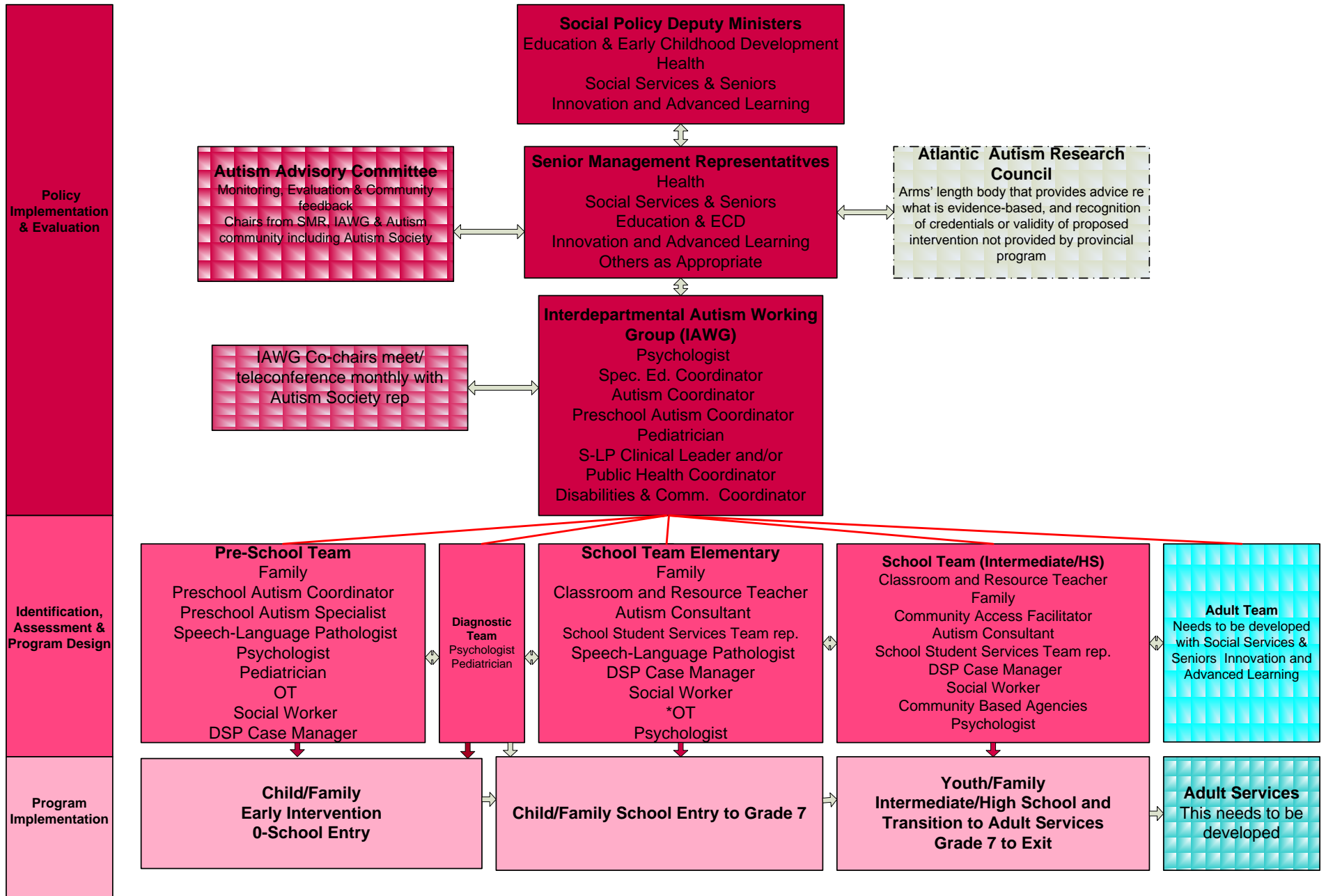
- Minister's statement related to inclusion needs to be added to the philosophy statement.
- Ensure that policies for service delivery are aligned across populations (preschool, school and adult) in accordance with Strategy's direction, values and guiding principles.
- Preschool and School-age teams identify discontinuities in policy and make recommendations.
- Adult age team be struck to review policies and make recommendations.
- Departments reach mutual agreement on revisions to policies to optimize alignment.

***A Provincial Strategy***

**Priority Recommendation 4:** By June 2010, establish a governance structure that:

- is driven from the executive level of government;
- requires interdepartmental cooperation, coordination and collaboration;
- has access to an expert panel's advice on questions of leading-edge science; and
- strengthens communication and engagement with community input.

This structure is illustrated in the proposed organization chart on the following page.



The AAG's intent was to create a structure that supported on-going cross-departmental cooperation, effective communication and coordination that involved the following recommended activities:

- The Social Policy Deputy Ministers direct that Senior Management Representatives report regularly on the status and progress of the Strategy;
- Monthly updates and communication between the co-chairs of the IAWG (with rotating leadership across Related Departments) and the Autism Society;
- Twice yearly meetings between the Autism Advisory Committee and Senior Management Representatives for the purposes of providing monitoring, evaluation and community feedback on autism services to the Senior Management Representatives; and
- Annual forums organized and hosted by the IAWG to seek broader community feedback.

The AAG is aware that it is not working in a vacuum. There is other work being done in various departments that may have an impact on the implementation of the proposed action plan, including the Disability Services Review, the Learning Disabilities Strategy, and the current work of the Early Intervention Working Group, as well as internal departmental reviews respecting specific services such as Speech-Language services and Public Health Nursing. There may be opportunities to leverage and coordinate the work of these various initiatives to mutually enhance the effectiveness of these plans. While this is outside the mandate of the AAG, participants recognize that these opportunities should be explored.

**Priority Recommendation 5:** Host a facilitated dialogue with Deputy Ministers and Directors with leadership roles relating to the Disability Services Review, Early Intervention, Learning Disabilities and Autism Strategies, as well as recent service reviews such as the Speech-Language Services Review and the Public Health Nurse Screening Assessment Review, to establish a broader governance structure which links and underpins these strategies and aligns them with the strategic public policy direction of government for Island prosperity; supporting *all* Islanders in achieving their full potential.

To assist the Related Departments in adopting and leading the comprehensive Provincial Strategy, a facilitated series of meetings of the senior leadership is needed. This requires a consideration of the Autism Strategy and Action Plan at executive and senior levels, including the Deputy Ministers' Committee on Social Policy, Strategic Planning committees and Executive Council. Such senior level support can demand accountability and require linkages to related strategies (both existing and anticipated), such as the Disability Services Review of the Department of Social Services and Seniors, the Learning Disability Strategy of Ed & ECD as well as its Early Intervention Strategy (which is just being developed).

## Provincial Strategy Actions

- Create linkages in the Provincial Autism Strategy to related programs under the Disability Supports Program, Early Intervention and other programs for people with learning disabilities, health programs, etc.
- Through facilitated dialogue at the deputy minister and director level, the Provincial Strategy will clearly delineate roles and responsibilities of departments, professionals, service providers, individuals with autism and their families so that they are clearly stated and understood.
- Within provincial strategies such as the Disability Services Review, Early Intervention Strategy, and Learning Disabilities Strategy, identify services and supports not specific to ASD but which may enhance or assist in the delivery to persons with ASD or their families.
- Include references to the Autism Strategy in other related services and support programs.
- Ensure that the Provincial Strategy acknowledges the impact of ASD not only on the person with this condition, but also on families and the Island community.
- Develop services and supports designed to address the needs of the person with autism and their family on the principle of equity of access, service and supports that are positive, and evidence-based. (For a discussion on what is evidence-based, refer to Appendix B.
- In the mid to longer term, consider developing a *Realizing Islander Potential* strategy that incorporates and aligns the full spectrum of services and supports available to Islanders with disabilities.

## *Issues Requiring Executive Leadership: Choice in a public system*

“Choice” was a value that the AAG strongly supported in the sense of families being able to choose particular programming or interventions. However the group struggled with how this value should be manifested in this public-funded service. In its discussions, the AAG noted that clinical assessments of children’s needs and how they are responding to programming need to be independent of the funding mechanism. However, some members of the AAG expressed further concerns. As with the Disability Services Review, families and clients perceive that the financial lens tends to limit the focus of the supports and services available. Therefore, while a Provincial Strategy is important for service delivery, clients find some comfort in a separation of the clinical and intervention services from the financial supports. There is a perception that financial gatekeepers may use information in a negative way to “cut off” access to supports or services.

As a result, there was a request for reassurance that “outcomes” would not be narrowly defined in terms only of the developmental milestones of the child with ASD – it was noted that the family’s ability to cope with behaviours and challenges need to also be considered in determining the outcomes of such supports and services. On the other hand, there were other voices in the AAG that did not have these concerns. One of the counter-arguments was the need for recommendations regarding resourcing and that such recommendations must be considered prudently in light of the fiscal realities of the Province.

The “choice” issue has many implications for the service and service providers including provincial capacity to deliver services, professional knowledge, currency of skills, and sustainability. An agency model might address many of the concerns regarding a separation of funding from service delivery, with flexibility to allow choices among sanctioned or approved treatment options.

The decision on how choice is manifested is also reflected in how the early intensive behavioural intervention (EIBI) service is designed and what options are available to families. For example, parental concerns with potential short-comings of EIBI delivered in community settings has been noted in the literature:

*... in practice, implementing EIBI programs in communities presents some difficulties:*

- 1) finding experts to ensure high quality treatments is not always possible and;*
- 2) some studies have shown that EIBI programs run by private agencies actually had little or no effect on children’s skills (Bibby et al., 2002)<sup>9</sup>*

The current Autism service attempts to deliver service based on family preferences and the child’s needs. While 85% of families choose centre-based IBI, some Island families prefer to have autism interventions delivered in a home-based service rather than in early childhood centre settings. These families note that in doing so, their child gets less support from the public service than those children who attend early childhood centres and therefore have access to publicly funded Special Needs Assistants in addition to the IBI time with preschool autism specialists. The Autism Society’s concern is that “choice” without financial support is not really a choice at all.

In an attempt to develop a service that can be effective in a community setting, a modified EIBI service is being piloted in Nova Scotia that is using Pivotal Response Treatment to improve children’s ability to generalize learnings in a variety of settings, and integrating families in the service so as to have greater success in day-to-day functioning. Findings from this study will soon be published and available for consideration. Results showing positive outcomes are especially evident in the group with higher IQs and cognitive abilities.

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<sup>9</sup> As quoted in *The Effectiveness of the Nova Scotia EIBI Program*, <http://www.hinnovic.org/the-effectiveness-of-the-nova-scotia-eibi-program/>

It was not possible for the AAG to achieve consensus on a recommendation for the model for the delivery of IBI. Because the province has had difficulty staffing positions, and therefore waiting lists to access IBI, some advocates are asking for funding to obtain IBI services from private or out-of-province providers. Other voices at the table noted that this type of flexibility will dilute the funds available for a provincial service, and require increased bureaucracy for auditing the flow of funds to ensure that the money is used to hire qualified and competent people to deliver an ‘approved’, recognized or sanctioned intervention. Ed & ECD will end up checking financial books rather than delivering service. These same voices note that other jurisdictions that have gone the funding route have expressed regret that they have done so. A model that straddles the two concerns might be to recognize or license agencies that use only evidence-based practices to deliver IBI and families can choose which agency they want to use options. However, this path raises the question of who or what body sanctions interventions?

The AAG did not have the competency, resources or mandate for exploring this issue. Nevertheless, this is an outstanding matter that needs to be determined. To that end, the AAG recommends:

**Recommendation 6:** The Related Departmental Deputy Ministers take the necessary steps to explore how the value of choice is reflected in other jurisdictions, and how PEI can best offer choice to families in a public system of services.

The Provincial Strategy needs direction from the Executive level in the form of a statement expressing the value placed on “choice” for persons with ASD and their families, and what is considered a choice. (For example, does choice mean simply accepting or rejecting the service as outlined, or does choice include a cafeteria style selection of service, or does choice extend to providing clients with an envelope of money to purchase services independently? What parameters can be placed on choice to safeguard the spending of public money?) However, this path raises the question of who or what body sanctions interventions? Could this be done by the proposed Atlantic Autism Research Council?

To assist the Province in maintaining a knowledge-based dialogue on choice, the AAG recommends that the Province partner with other jurisdictions to establish an arms’ length body to review and determine approval for requests of evidence-based services by qualified providers not provided by the related Departments.

**Recommendation 7:** The Province promote the establishment of an Atlantic Autism Research Council responsible for researching autism best practices, staying apprised of developments in the field of knowledge, and providing reports and recommendations.

In addition to internal developments, the AAG was also aware that knowledge and understanding of ASD is rapidly evolving. Determining whether new interventions or practices are evidence-based requires a high level of awareness of the most current studies and research work. The



AAG is aware of leading experts in the field within Atlantic Canada and recommends that this local expertise be tapped for advice by partnering with the other Atlantic provinces to create an autism research council that serve as an arm's length expert panel that could provide recommendations regarding whether particular interventions or practices are evidence-based. Decisions on what interventions or practices are eligible to be implemented or funded are to be shared between provinces, between departments, with service-providers, families and the ASD community. The interaction between the Atlantic Autism Research Council and the Provincial Autism Strategy is reflected in the preceding organization chart on page 15.

**Recommendation 8:** Identify mechanisms to help stakeholders remain up-to-date on effective intervention developments in autism for all ages.

Explore establishing a relationship with autism researchers such as Dr. Susan Bryson and Dr. Isabel Smith, both of whom are associated with Dalhousie University and the Isaak Walton Killam Hospital for Children in Halifax, to have ready access to leading developments in knowledge, have access to research funding in support of piloting programs or services and establishing evaluation.

- Host an annual Autism Focus Group, inviting direct service providers to share common effective strategies, resources, process, etc.

### *Accountabilities and Responsibilities*

**Recommendation 9:** Clearly state accountabilities for all stakeholders within a values-based delivery model.

- Given the varying service and support needs as perceived and understood by the families, the individual with ASD, and the service providers, Related Departments will need to engage in an on-going dialogue to ensure that the Strategy's values are applied consistently, and allow the services and supports to evolve;
- Clearly establish roles and responsibilities for clinical staff, including information flow so that families can have appropriately informed consent regarding how information is shared and monitored; and
- While all government departments are held to professional standards, with employees taking oaths of confidentiality, and are subject to *Freedom of Information and Protection of Privacy* legislation, the practices and expectations regarding the protection of client information may vary between departments. Given the need for an integrated, collaborative and "seamless" service for clients, related departments need to clarify their needs and agree upon information-sharing process and protocols.



### Accountability and Responsibilities Actions

- To ensure that actions are taken, Departments and Stakeholders need to be held accountable for their responsibilities under the Strategy which will include annual reports on progress of autism-specific services, and sharing statistical information that can assist with planning shared across Departments.
- Departments need to make defined commitments in terms of funding and designated positions (such as S-LPs, PAS and AC) to support the Strategy.
- Departments work collaboratively to identify best deployment given existing resources to achieve the goals of the Strategy.
- Departments remain mindful of other strategies that may overlap with Autism strategy to appropriately deploy and leverage resources.

### Quality of Services:

The Strategy needs to support the effective delivery of services through the following elements that drive better outcomes for children and their families:

- Evaluation Framework (to provide transparency and accountability for the Provincial Strategy).
- Service Model (which includes the employment of resources model, funding and evidence-informed service design).
- Sustainable resourcing.
- Human Resources (which includes competencies, training, recruitment and retention, and capacity and resources).

### *Evaluation Framework*

Principles of accountability, and the realities of ensuring the Strategy is implemented, require that the Strategy be evaluated.

**Priority Recommendation 10:** As an *urgent priority*, the Departments of Health, Social Services and Seniors, and Ed & ECD jointly sponsor the development of an evaluation framework by June 2010.

While individual children receiving autism supports, services and interventions are assessed, and their progress with respect to their individualized learning plans is evaluated on a case-by-case basis, there is no service-wide or system evaluation currently in place to help inform decision-makers with respect to effectiveness of services. This lack of an evaluation framework was a significant stumbling block to the AAG's ability to achieve consensus on service details. For example, while Society representatives expressed concern that the current IBI service and school-based supports were not effective, other members of the AAG either had a more positive impression of the effectiveness of these services or did not have sufficient information to take a position. In this era of accountability, this is not acceptable. There are several types of data, information and indicators that are already collected, or could be readily collected and used to establish a baseline for assessing the effectiveness of any future adjustments or changes to services.

There may be internal resources that could be tapped to develop the framework. If the departments need to utilize external resources, it may be of interest to note that Dr. Isabel Smith, of the IWK/Dalhousie University helped Nova Scotia develop its own framework. Furthermore, Ed & ECD is working with UPEI's Centre for Education Research to catalogue the information on early childhood development in PEI.

The Province is currently participating in national research, and should continue to do so. Since 2001, Prince Edward Island has participated in the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC). This study collects anonymized information (no names appear in the database) on children who have been diagnosed with ASD. It is used to monitor the prevalence of ASD, as well as that age of first diagnosis, maternal and paternal age.<sup>10</sup> There are other ASD experts and post-secondary institutions in Canada with whom relationships can be established that can support the Island's efforts to remain in tune with leading developments in the ASD field, and benefit from access to researcher resources through participation in studies. Exploring and establishing such relationships should be encouraged.

## Evaluation Framework Actions

### Objectives and measures

- The Social Policy Deputy Ministers should identify measurable objectives for receiving reports, such as:
  - Are people with ASDs improving?
  - Are they meeting developmental, curriculum, or life skills targets?
  - Are children developing skills to enhance their ability to live as independently as possible?
  - Are service providers meeting service standards?
  - Are families feeling supported?
  - What barriers impede children's progress?

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<sup>10</sup> National Epidemiologic Database for the Study of Autism in Canada (NEDSAC), Queen's University, [www.nedsac.ca/index.html](http://www.nedsac.ca/index.html), accessed 13 Aug 09

- Evaluation is not just of the EIBI service, but of all services and supports provided under the Strategy to people with ASD.
- The senior management representatives will develop appropriate service measures and metrics relating to service providers accountable for performance.
- The Provincial Autism Team identify or develop tool(s) for gathering information on those measures.
- Standardize entry and exit assessments, including cognitive assessment, are needed to monitor intervention effectiveness.
- The Provincial Autism Team report on an annual basis to the Social Policy Deputy Ministers on these measures.

### **Evaluation re services to individuals and across departments**

- The Departments of Ed & ECD, Health and Social Services & Seniors will collaborate to monitor and evaluate outcomes for all individuals with autism.
- This system-wide, service-wide monitoring and evaluation information will be shared with related Departments on an annual basis to inform service design.
- This information will also be included in a report to the public, and particularly to the families and ASD community to inform on-going dialogue regarding services.
- Providers of services to clients with autism (such as speech-language pathologists and occupational therapists as well as preschool autism specialists and autism consultants) provide annual assessments of how individual children are progressing using standardized measures whenever possible.
- Share evaluation information with other jurisdictions to share and receive learnings, advice and recommendations for refining future measures and responding to trends indicated in the data and integrating and comparing our results with those being found in other jurisdictions to determine whether the Island's ASD-specific supports and services are keeping up with that the literature reflects is possible.
- Continue Individualized Education Plan monitoring and explore enriching service data collection through, work samples, assessment videotapes; standardized academic, adaptive or functional behaviour assessment. More staff training needed to enable accurate data collection on developing skills.
- At one time, a standardized adaptive assessment was conducted when a child exited from the EIBI service. This was a valuable tool which provided information regarding the

child's progress within the EIBI service, as well as a baseline for child's skills. Dedicate funding for a psychologist to undertake this work.

- Participate in research opportunities through multi-site studies or collaborative work with other centres specializing in autism studies.

## Client Satisfaction

**Recommendation 11:** Related Departments conduct a joint survey of families of all children with ASDs, not just those in the EIBI service, to receive input on their experience, the quality of the service, and gaps.

This recommendation met with some reservations of the AAG. However, the value of having a tool for facilitating feedback from families is an important feature for enhancing the services.

- Ensure that developmental or learning goals for individuals with ASD are prepared in collaboration with the family as well as other intervention service providers.
- Goals and objectives may involve familial functioning as well as the individual's functioning.
- Explore a variety of platforms for receiving feedback from families.
- Parent conferences.
- Related Departments conduct a joint survey of families of children with ASDs to determine what other services or supports are needed to help them function.

## *Service Delivery Design*

**Recommendation 12:** Create a cross-departmental model that supports an integrated, client-focussed service.

As indicated in Figure 1 (pg 15), the AAG recommends an organizational structure that is driven from the senior executive level and involves interactions across Departments, requiring the responsible Directors to make recommendations on where accountabilities for information sharing and decision-making reside. The organization chart and service delivery charts are attached in Appendix C.

## Service Delivery Actions

- Ed & ECD, Health, Social Services and Seniors and DIAL work together to identify a spectrum of developmental needs receiving public supports, services and programming, and place ASD on this spectrum in relation to the Early Intervention Strategy, the Disability Services Review, the Speech-Language Services Review, and other related service or program designs.
- Clarify responsibilities across Departments and within Departments, including who is to take on leadership role at various points in a family's journey through the supports and services available to them.
- Ensure that the organizational design breaks down silos and supports person with autism/ family-centred services by:
  - holding Senior Management Representatives accountable for collaborative and cooperative work practices and information sharing to advance the work of the Strategy;
  - setting specific time frames in which teams and team members must meet, and by holding individuals responsible for calling, holding and attending meetings; and
  - improving flexibility in deploying human and financial resources (e.g. across departments, ages, and geographical limits).

**Recommendation 13:** Co-locate ASD-related professionals and other ASD-related service providers wherever and whenever possible.

There was general agreement that co-location of services was beneficial for both professionals and clients with respect to service delivery. However, because few services are purely ASD-related, co-location for these interventions may have consequences for other services or responsibilities of professionals who work with other services.

## Screening

**Recommendation 14:** The Province implement a universal screen for children at risk of developmental delays and autism, linking this screen with those indicated by the Learning Disability Strategy, Early Intervention work and Public Health Nursing work. Note that this will create pressures for interventions and services as children are identified.

Other jurisdictions have a variety of screening approaches. On the national scene, there is no consistent surveillance or screening strategy in place, nor is there a universally recommended

screening program. The 2008 report of the Miriam Foundation, *Screening, Assessment and Diagnosis of Autism Spectrum Disorders in Young Children: Canadian Best Practice Guidelines*, determined that “the recommendation for Canada is to not conduct universal screening until screening tools with higher sensitivity and specificity are demonstrated in the scientific literature.”<sup>11</sup> However, the Miriam Foundation Report also recommended that a universal developmental screen be used, and that a screen for ASD be utilized where concerns are raised.<sup>12</sup> Research is undertaking these questions and there are various tools and strategies available for screening various age populations that are discussed in the Miriam Report.

### Screening Actions

The AAG recognized that there are a variety of tools available. Each was designed for a specific purpose, such as age, sensitivity and specificity of identification, and clinical or family engagement. Therefore, without limiting the use of other screening and assessment tools, there were two recommended action items:

- Use of M-CHAT (with Denver Modifications for increased validity) was recommended for secondary screening. This is supported by the Miriam Foundation report: “Due to the generally high estimates of sensitivity and specificity, and ease of administration and scoring, this measure is recommended for practice. More research is needed on this promising measure.”<sup>13</sup>
- Identify a post-secondary institution with whom to partner regarding research and on-going developments in the field, such as early identification and family engagement.
- It is anticipated that that Early Intervention Strategy (which is currently being developed) will address universal, primary screening. With respect to a secondary, ASD screening, the Department of Health engage the public health nursing community, and the medical community in the application and adaptation of the American Academy of Pediatrics algorithm (Figure 2, page 27). Such adaptations would include a referral to Speech-Language Services as well as to the Diagnostic Team at Step 8.
- Encourage Public Health Nursing to introduce developmental screens at an earlier age than the current 4 year old screen, such as a 24 month assessment/screening.
- Mobilize resources to respond to the anticipated surge in families seeking assistance, support and interventions as screening program changes are implemented.

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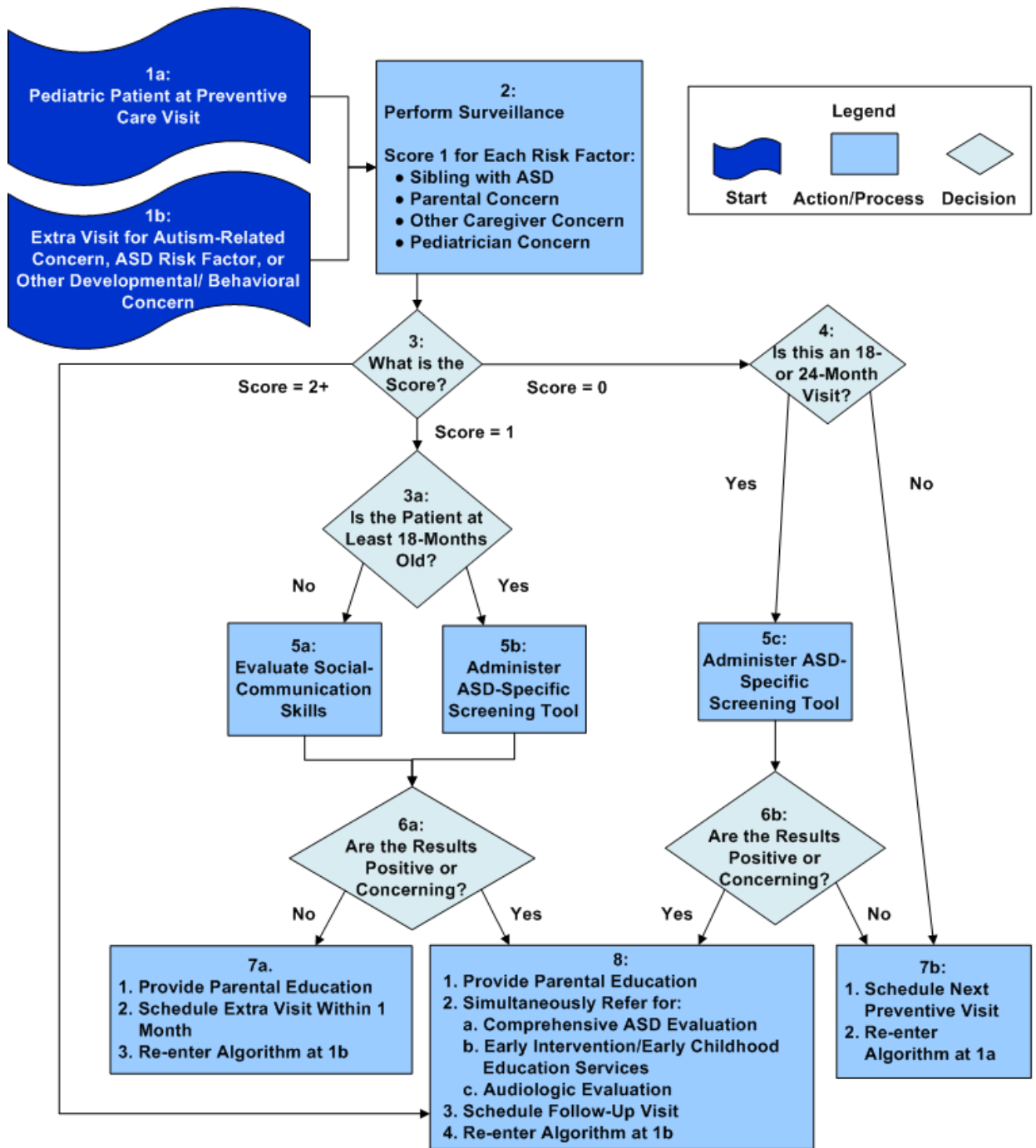
<sup>11</sup> Miriam Foundation, *Screening, Assessment and Diagnosis of Autism Spectrum Disorder in Young Children: Canadian Best Practice Guidelines*, Miriam Foundation, 2008, p. 28

<sup>12</sup> *Ibid*, p.17

<sup>13</sup> *Ibid*, p. 32

Figure 2

**SURVEILLANCE AND SCREENING ALGORITHM:  
AUTISM SPECTRUM DISORDERS (ASDs)**



In the course of its work, members of the AAG noted that there are likely to be adults with ASD who have never been screened for the condition or diagnosed. The AAG wants the Autism Strategy to be broader than a specialized early intervention strategy, therefore the AAG recommends that Related Departments should consider mid to long term opportunities to identify, and develop appropriate supports for older students and adults with ASD.

## Diagnosis

**Recommendation 15:** The service objective is for diagnosis and initial evaluations to be completed within three months of referral.

Currently, the Autism Diagnostic Team does not assess school age children. Although some physicians and psychologists use clinical judgement for the diagnosis, most are not comfortable with this and refer school aged students to the IWK where there is a long wait list for diagnosis. This is a gap. Furthermore, the Diagnostic Team is exploring a variety of measures for preschool children and families who are currently on the wait list. At time of writing (summer 2009), that wait list is approximately 10.5 months for the children currently on the list. The Department of Health is exploring options for outsourcing some assessments with the goal of achieving a wait time of less than three months. However, if this goal is accomplished there will be direct implications for the EIBI wait list.

The expectation is that all those who had been on the diagnostic wait list prior to April 2009 will be diagnosed and able to enter the EIBI service by September 2009. However, with current resources, as new clients are added on to the wait list after April 2009, their ability to access IBI will depend upon whether Ed & ECD is able to recruit an additional Preschool Autism Specialist that is fully qualified. This has not been its usual experience. Frequently Specialists have had to be hired without their full qualifications and trained in their placement. This requires a number of months during which they are unable to work independently.

## Diagnosis Actions

- As the Autism Diagnostic Team explores options to reduce diagnostic wait times, Health and Ed & ECD work together to assess impact of this work and put resources in place to support families as diagnoses are made.
- As noted above, the Autism Diagnostic Team does not assess school age children. Although some physicians and psychologists use clinical judgement for the diagnosis, most are not comfortable with this and refer school aged students to the IWK where there is a long wait list for diagnosis. The Province needs to explore the feasibility of training or recruiting a professional to address this need.
- Support the Diagnostic Team in exploring partnerships with ASD researchers to pilot screening and diagnostic tools that would streamline the diagnostic process.



## Assessment

**Recommendation 16:** The Departments of Ed & ECD, Health and Social Services and Seniors invest in formal and informal measures, including assessment tools that will not only support individual developmental/education plans, but also enable the Province to evaluate services.

Assessment is not a synonym for diagnosis. Because ASD affects each individual in very different ways, the assessment is key to determining what developmental areas need to be addressed, and in what order. Assessment also provides benchmarks against which individual progress towards developmental goals can be measured. Therefore, to support both individual service and design for system-wide service evaluation, assessment is key.

### Assessment Actions

- Department of Health consult with health professionals such as audiologists, S-LPs, OTs and Pediatric psychologists to identify resources needed for timely preschool and school-aged assessments, including evaluation, and cognitive assessments that would provide benchmarks for evaluation and/or inform the design of appropriate interventions.
- Related Departments identify and address needs with regard to the provision of AAC, both for assessment and on-going intervention.
- Department of Health continue to ensure that S-LP and OT assessments are regularly conducted in preparation for school entry, and for children with ASD, annually to track progress during their preschool and school years.
- Reinstate funding for Psychologist-administered standardized cognitive and adaptive assessment (i.e. Vineland) in preparation for school entry.

**Service Model** (which includes the employment of resources model, funding and evidence-informed service design)

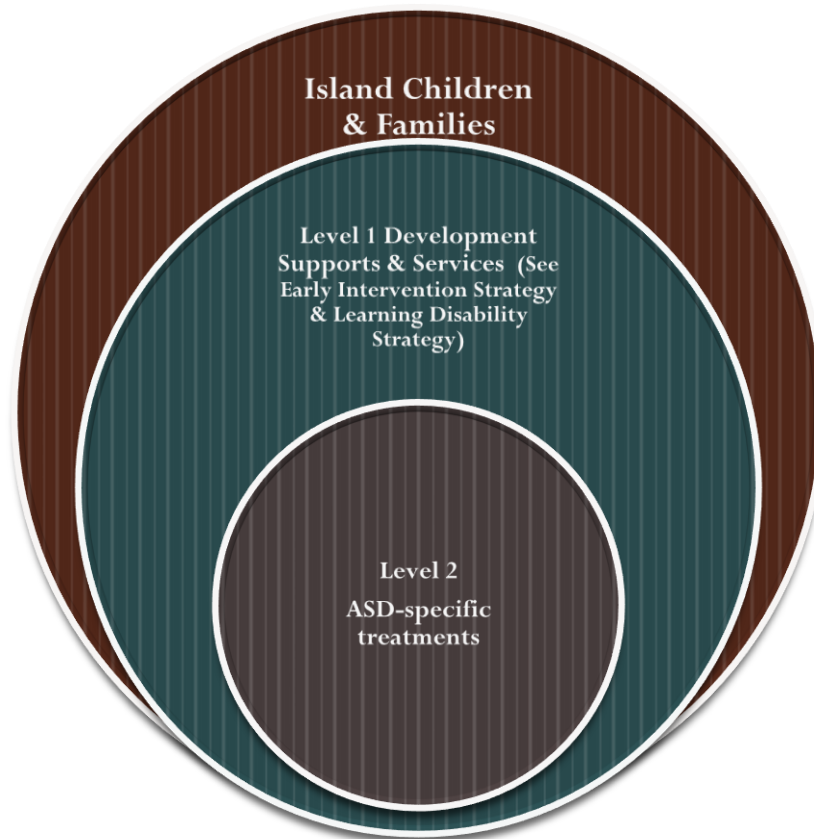
**Priority Recommendation 17:** The current Strategy states its position on the use of evidence-based interventions. A clarification of how the Province will approach requests for emerging interventions needs to be added:

*Autism services are founded on evidence-based practices. However recognizing that the study of autism interventions continues to emerge, **interventions or practices that are based on behavioural principles but are not part of the Provincial services** may be considered where an evaluation framework is in place to measure its effectiveness with respect to the individual, the family, and the Strategy.*

*Interventions need to be evidence-based.* There are frequent requests from families, and even some health professionals for interventions, treatments and therapies that are not always evidence-based. The AAG recommended that the Province adopt a clear position on this point.

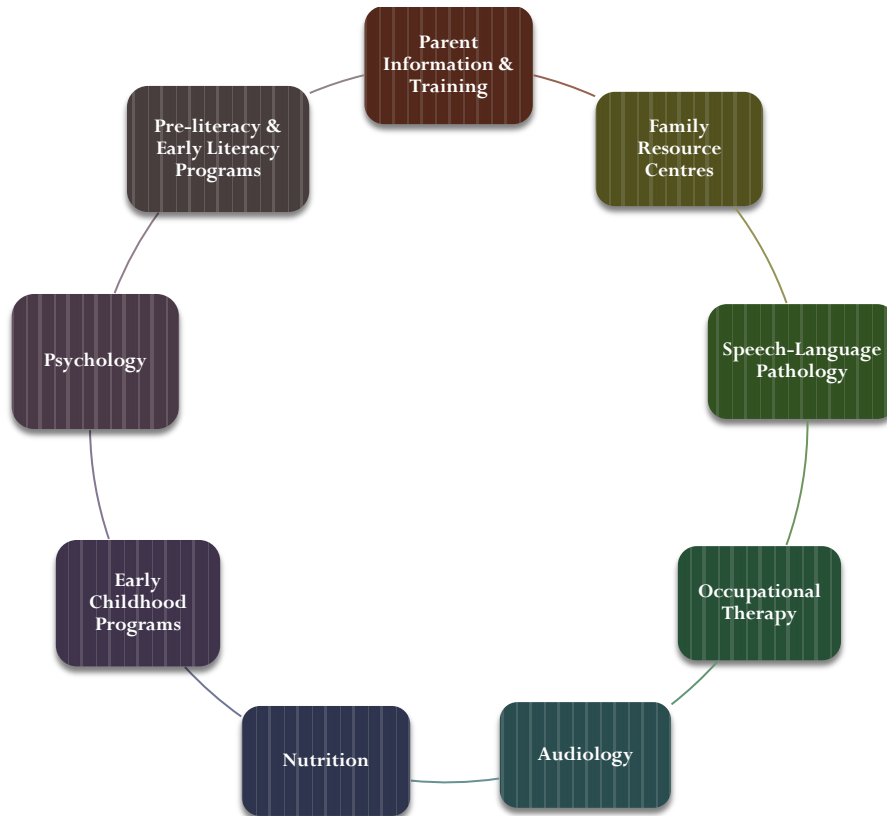
### Continuum of Services and Supports

**Recommendation 18:** As part of its broader early intervention work for the Children's Secretariat, Ed & ECD coordinate with Related Departments to identify a suite of Level 1<sup>14</sup> Tools that families and children at risk of not achieving their full developmental potential can access regardless of, or while awaiting, diagnosis.



<sup>14</sup> The reference to Levels is for the purposes of this report, and does not necessarily equate to the Levels of interventions described in the Learning Disabilities Strategy.

## Level 1 Services and Supports



The AAG recognized that given the complex nature of ASDs, there are a variety of services, supports and interventions that may be appropriate in helping a child in achieving his or her full developmental potential which are not exclusive to children with ASDs or related conditions. The AAG suggested that supports and interventions be developed as a Level 1 suite of early childhood services.

Many of these Level 1 Services and Supports are services that are currently delivered by professionals and employees in Department of Health, however there are also Level 1 supports and services relating to development of the skills for reading and literacy that may also provide supports to children with ASD and their families. The AAG envisions that these Level 1 supports and services will be addressed by the Early Intervention Strategy that is currently being developed. There are also injury prevention and family violence prevention interventions that may also be part of the Level 1 Supports.

A robust continuum of interventions available at Level 1 will be a valuable means of showing families that ASD-specific interventions are not the *only* services available to individuals with ASD and their families from which they can benefit.

**Recommendation 19:** Within 10 months, prepare a catalogue of the Level 1 suite of services by identifying, within provincial strategies such as the Disability Services Review, Early Intervention Strategy, and Learning Disabilities Strategy, the services and supports not specific to ASD, but which may enhance or assist in the service delivery to persons with ASD or their families.

**Recommendation 20:** Dedicate a Speech-Language Pathologist (S-LP) to a provincial role for at risk and diagnosed individuals with ASD. This S-LP will consult with the Preschool Autism Specialists, support other S-LPs in their service to these clients and deliver specialized parent training, such as the Hanen *More Than Words* program to families of children at risk or diagnosed with ASD.

S-LP led interventions and supports are an important component of both Level 1 and Level 2 continuums. The Speech Language Services group has been working diligently to allocate its resources to meet the many demands for their services, including individuals who have ASD. Given current workloads, there is little opportunity for S-LPs to take on educational and family support roles – which was clearly identified as a need. One member of the AAG noted that given limited S-LP resources, assessment would be a priority issue for the Autism service.

The AAG was very concerned that the Early Intensive Behavioural Intervention service (EIBI) is often thought of as the *only* intervention option for children with ASD. However, just as ASD diagnoses cover a broad spectrum of social and communication impairments, there is a wide continuum of services, interventions and supports that are available to persons with ASD and their families. The AAG believed that an ASD model that recognizes this broad spectrum will assist persons with ASD and their families in understanding that. This Level 1 suite of services will have a strong overlap with early child development supports that may be identified by the Early Intervention Strategy as well as the interventions that are available under the Learning Disabilities Strategy.

**Consultant Recommendation 21:** Once developed, the Early Intervention Strategy should be adopted and actioned as quickly as possible so that families have improved awareness and access to an array of services and supports in addition to the ASD-specific therapy.

While the AAG did not have time to consider in detail how its strategy would or could dovetail with the Early Intervention Strategy, the need for the more broadly applicable interventions and services is an important support for children with ASD and their families. In addition to the continued hope for developmental progress that comes from having autism specialists and tutors working with the children, the presence of this service also helps families cope. Where wait lists for specific interventions cannot be immediately addressed *or* where interventions do not result in developmental progress, families continue to have a need for support, and assistance.

## Level 1 Actions

- The Related Departments work together to develop identified services, supports and interventions as a suite of early childhood services with sufficient resources to meet demand, and take steps to ensure that families are informed and encouraged to take advantage of these offerings while they await diagnosis and access to diagnosis-specific interventions.
- The Related Departments identify and use all contacts with families as opportunities to inform families of the availability of Level 1 Services.
- Health and Related Departments develop and deliver parent education programs, such as the *Denver Early Start Program* and children's therapy such as *Hanen More Than Words* (the latter is a program delivered by a Hanen Certified S-LP).
- Ed & ECD explore requiring Early Childhood Education Centres to include ASD-trained Special Needs Assistants as well as broad staff training on ASD across Centres' staff mix.

**Recommendation 22:** Create a social worker/navigator position to assist families with the navigation of the autism/early intervention pathways as well as to provide ongoing support to families.

Families need support. The diagnosis and the behaviours that frequently accompany ASD are extremely stressful on families. A designated support position can help reduce some stress on families by providing a central access point for information about services available and how to access them. Such a position would also free up diagnostic team resources and preschool autism team that currently are called on provide support to families during the anxious times that often occur upon diagnosis.

## Navigator Actions

- A social work or counselling background would better equip the navigator to appreciate additional supports the family may need.
- While there was no consensus by the AAG with respect to which Department would employ this position. There are three possibilities:
  - This position could belong to Department of Health as most entries into ASD services are through health-related services (Physician, Public Health Nurse);

- Alternatively, this position could reside with the Healthy Child Development Unit, which is located within Ed & ECD;<sup>15</sup> and
- Another alternative could be to have this position reside in the Autism section of the Child & Student Services in Ed & ECD.

Each option has its advantages and drawbacks which could not be resolved at the AAG level. The AAG's lack of agreement on where this position should reside will require senior level leadership to resolve.

- Regardless of which Department or Division owns this position, good liaising connections and information flow between departments will be essential to make this position effective. The Related Departments will need to address how families access the social worker/navigator when they enter the services through alternate pathways.

## Level 2 (ASD-specific Services)

Level 2 Services are services that are Autism-specific. As the services are currently designed, this includes early IBI programming delivered through the Preschool Autism Specialists, ASD-specific S-LP therapy, and other health professionals who offer autism-specific interventions, tutors and ABA-based Individual Education Plans (IEP) with Autism Consultants for school-age children.

**Recommendation 23:** Related Departments collaborate to ensure interventions and treatments are consistent and coordinated across service providers.

A continuum of services from a variety of disciplines and across several departments requires continuous efforts to ensure that interventions and therapies are aligned with a shared plan for the person with ASD and family.

## Level 2 Actions

- Ed & ECD and Health clarify roles and accountabilities for design of interventions and development of treatment programming, as well as for delivery of intervention.
- Families, S-LPs and Autism Consultants strive to improve collaboration regarding goal development.

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<sup>15</sup> The Healthy Child Development Unit represents the seven departments that committed to the Health Child Development Strategy, including Ed & ECD, Health, Social Services and Seniors, and Innovation and Advanced Learning. Being deployed in this unit would enable the social worker/navigator to have information and contacts with the continuum of services and supports available to families.

- Provide families with information and education concerning ASD, the services available, developmental milestones, tips for supporting interventions, and coping strategies.

### **EIBI Team**

The Preschool Service Model is a team-based model relying on the Preschool Autism Coordinator, family, Preschool Autism Specialists and health professionals to provide input guiding the development of an individualized program for the child with ASD. Team behaviours are practiced throughout the design, development and delivery of early interventions.

**Recommendation 24:** The Related Departments take steps to ensure that the Pre-School Team has strong collaboration and communication practices in place to ensure an integrated service to children with ASD and their families.

### **EIBI Team Actions**

- Develop a robust series of policies and procedures that address the preschool mode, using the Preschool Team and the IAWG to identify policies that need revision to support the collaborative, family-centred approach.
- Use plain, clear language, and where necessary establish a glossary to ensure that all stakeholders share a common understanding of meanings. This task should be undertaken by the Provincial Autism Advisory Committee to recommend definitions for Departmental review.
- Clarify the intent for the kindergarten program including the possible impact of the kindergarten program on the preschool autism service; transitions for families caught waiting for IBI where the child becomes eligible for kindergarten before the child has had an opportunity to receive the IBI service; and whether children graduate out of the IBI service upon eligibility for kindergarten, or whether there might be a discretionary year to extend the therapy.
- Team members are to be held accountable for attendance at team meetings.

### **Early IBI Service**

The Province's IBI service is currently based on a maximum of 20 hours of intensive behavioural intervention from entry into the service until the child enters school or achieves age-appropriate development in key communication and learning skills. While the PEI service is less than the 40 hours per week recommended by the Lovaas research example, and less than the 25

hours suggested by the American Academy of Pediatrics<sup>16</sup>, the PEI model offers *more* hours per child than what has been offered under the Nova Scotia EIBI program of 15 hours per week for 6 months with a further 6 months of reducing intervention (three months at 10 hours per week, and 5-6 hours per week for the last three months).<sup>17</sup>

The AAG has been unable to achieve consensus on advice regarding the hours of intervention debate. *If* Ed & ECD were to increase in the IBI hours from 20 to 25, because of difficulties finding qualified people to deliver the service this would have an impact on the wait list for EIBI because an additional five hours of programming needs to be developed each week. The Autism Society notes that some families are already arranging to top up programming hours, and so do not readily accept that such an increase in IBI hours would increase wait lists. In rebuttal, others note that at the very least, this would lead to less supervision of the programming provided. As the Autism Society has raised concerns regarding the quality of intervention, this is a very real concern.

To understand why there was a lack of consensus in this area, and hence much energy and discussion invested in this aspect of the autism strategy, one must appreciate the level of debate that continues in the autism field. Consider for example the debate over *intensity* of behavioural intervention – that is the number of hours required for a behavioural-based therapy to be effective.

#### **Context**

The Province is currently challenged in delivering an early intensive behavioural intervention service consisting of a maximum of 20 hours per week. As of June 2009, any children diagnosed with ASD and referred to the EIBI service will not be able to access this intervention until September 2010. The Department of Ed & ECD posted an additional Preschool Autism Specialist position to address anticipated demand in the Fall. However, most of these postings have required the Province to hire individuals who need to complete their training in order to be fully capable of fulfilling all the job requirements. This often takes a year.

Advocates for families of children with ASD are reluctant to support any recommendation to lessen the intensity of intervention (currently at 20 hours per week) or the duration of intervention; indeed, they would strongly urge the province to increase the intensity to 25 hours per week. However, the result would be to create an even longer waiting list for children to access the intervention at all.

It is challenging to sustain such an intensive intervention for long periods. It not only requires that the family play an integral role in the therapy, but also challenges the financial capacity of most families if they choose to pay privately for additional hours. It is also a significant challenge for publicly funded services.

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<sup>16</sup> Scott M. Myers, MD, Chris Plauche´ Johnson, MD, MEd, *Management of Children With Autism Spectrum Disorders*, <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;120/5/1162.pdf>

<sup>17</sup> Nova Scotia Health, *The Nova Scotia Early Intensive Behaviour Intervention Program for Young Children with Autistic Spectrum Disorder*, July 2006



### *What is Intensive?*

Dr. Lovaas was the first researcher to undertake a scientific study of EIBI for autism from 1970 to 1984. That study indicated that given an average of 40 hours per week of one-on-one treatment for two or more years, 47% of the children recovered to the point of being indistinguishable from their normally developing peers. An additional 42% achieved substantial gains versus a control group.<sup>18</sup> These results have become the touchstone for advocating EIBI as *the* therapy for ASD. A Library of Parliament report suggests that an ideal EIBI treatment provides children with therapy for 40 hours per week, 7 days per week, 52 weeks per year.<sup>19</sup> However, while the Library of Parliament report is only three years old (dated 2006), yet the American Academy of Pediatrics states on its website that an intensive behavioural intervention requires a minimum of 25 hours per week. The study of autism continues to advance. Not surprisingly, advocates for autism therapy point to these studies and statements in support of their call for increased intensity of therapy.

Without denying the potential benefits of EIBI, recent studies have been more reserved in their evaluations of the treatment, pointing to the need for more large-scale research.<sup>20</sup> The original study has not been replicated, and several studies have failed to confirm the “best outcome” group as described by Lovaas. To understand why replication of results is so challenging, one study was designed to investigate differences in outcomes between clinic and home-based behavioural interventions. However, rather than finding differences between the groups, the researchers found differences *within* the groups: rapid learners made impressive gains in both clinic-based and home-based programs. *The intervention itself was not the determinant of success*<sup>21</sup>. A 2007 study indicated that children who “recovered” were those who were under 30 months of age when diagnosed, had milder social impairment, and higher intelligence levels:

They did not find any differences between those who moved off the spectrum and those who did not on the amount of intervention received, although this may have been an issue of restricted range.<sup>22</sup>

A November 2008 article<sup>23</sup> surveying studies of autism therapy programs offers important considerations for designing the Province’s action plan for its Autism Strategy.

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<sup>18</sup> O. I. Lovaas, “Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children,” *Journal of Consulting and Clinical Psychology*, Vol. 55, 1987, pp. 3-9; J. J. McEachin, T. Smith and O. I. Lovaas, “Long-term Outcome for Children with Autism Who Received Early Intensive Behavioral Treatment,” *American Journal on Mental Retardation*, Vol. 97, No. 4, 1993, pp. 359-372 as cited in Norris, et al., 2006

<sup>19</sup> Norris, *op.cit*

<sup>20</sup> See, for example: Canadian Coordinating Office for Health Technology Assessment, *Behavioural Interventions for Preschool Children with Autism*, August 2001; Alberta Heritage Foundation for Medical Research, *Intensive Intervention Programs for Children with Autism*, February 2001 as cited in Norris, et al., 2006

<sup>21</sup> Helt, *op.cit.*, p. 343-344

<sup>22</sup> Helt, *op.cit.*, p. 346

<sup>23</sup> Molly Helt, et al., *Can Children with Autism Recover? If so, How?*, *Neuropsychology Review* (2008) 18:339-366 (2008) 18:339-366

Helt *et al.* noted that the criteria for a good outcome has been poorly defined in many studies. However, applying their own set of criteria, the researchers found that the predictors of recovery include:

- relatively high intelligence;
- receptive language;
- verbal and motor imitation; and
- motor development.

Severity of ASD symptoms is *not* a predictor, however, an early diagnosis of Asperger's Syndrome or PDD-NOS carries a better prognosis for recovery than Autistic Disorder.<sup>24</sup>

Furthermore, the study noted:

*Since most children who receive the best intervention do not recover, the treatment alone cannot be responsible. Some combination of child and treatment characteristics therefore seems the most likely possibility.*<sup>25</sup>

In other words, while autism researchers are onto some promising paths, there are still far too many uncertainties for claiming what number of hours, or level of intensity is necessary for beneficial or optimal results.

It should also be noted that the label of “early intensive behavioural intervention” embraces a number of models of treatment. In its extensive review of 10 treatment models incorporating behavioural techniques and early intensive intervention, and the related existing literature, the American National Research Council stated in 2001 that:

The available research strongly suggests that a substantial subset of children with autistic spectrum disorders are able to make marked progress during the period that they receive intensive early intervention, and nearly all children with autistic spectrum disorders appear to show some benefit. However, the research to date is not at a level of experimental sophistication that permits unequivocal statements on the efficacy of a given approach, nor do the data support claims of “recovery” from autistic spectrum disorders as a function of early intervention<sup>26</sup>.

To add further confusion to the intensity debate, some studies might be interpreted to suggest that there is an *inverse* relationship between the number of hours of intervention and outcomes<sup>27</sup> – however, this could be very misleading, as children who respond well

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<sup>24</sup>Helt, *Ibid.*, p. 342

<sup>25</sup>Helt, *Ibid.*, p. 341

<sup>26</sup> Committee on Educational Interventions for Children with Autism, National Research Council, *Educating Children with Autism*, National Academies Press, Washington, D.C., 2001, p. 166 as cited in Norris, *et al.*, 2006

<sup>27</sup>Remington (2007) as cited by Helt, *op. cit.*, p. 346

to intervention might receive intervention for a shorter period of time. The references to these studies are **not** to suggest that the Province's Autism Strategy dole out intervention resources on the basis of IQ tests, or any of the other possible predictors of recovery; there are no definitive predictors. Instead, equity of access to give children and families an opportunity to determine if an intervention is beneficial remains a fundamental value of the Strategy. This discourse was intended only to illustrate that this area of study is still developing, and that no one can claim that they have *the best practice*, *the gold standard*, or *the answer*.

While the intensity debate was one of the most resistant to consensus, it illustrates the challenges arising from conflicting information, studies and experience in the field. It suggests that while evidence of the need to tailor or re-design the intervention service might arise, at this time, in the absence of an evaluation framework, it is premature to be recommending significant changes to the service itself.

**Consultant Recommendation 25:** Ed & ECD and Health establish a preliminary set of evaluation factors and collect benchmark data for children about to enter the IBI service in October 2009, with a follow-up assessment of the children and evaluation of the service in June 2010. Then use this information, to inform a decision of whether to alter the intensity and length of the service taking into account staffing and coordination factors.

It was beyond the AAG's mandate to be considering service details, however, this was an area that the ASD community strongly believes needs to be addressed. This recommendation was not supported by some members of the AAG. Some wanted an immediate increase in the intensity of the EIBI service, seeing no reason why this would effect wait lists; others were concerned that to do this immediately would create an increased wait time because additional hours requires additional programming (and hence, less direct service); and yet others noted that the EIBI service is a good service, and asked "how do we know it needs to be changed"? Given the lack of data on the Island service, it is difficult to develop a basis for agreement. Therefore, the Consultant recommends that time (*but not a long time*) be taken to establish baseline measures, and to assess the effectiveness of the current service, as well as to ensure that resources will be mobilized to support any adjustment in the EIBI *without increasing wait lists*.

The Autism Society also advocated for similar supports for home-based EIBI delivery as compared to Early Childhood Centre-based interventions, where the children have SNA (Special Needs Assistant) supports in addition to the official EIBI tutor hours covered by the EIBI service. The department's response is that the hours of EIBI service are the same regardless of whether it is delivered at home or in an early childhood centre. The source of the differing perspectives is the fact that the SNA is often the same person who delivers EIBI to a child for part of the day, and continues to work with the child for the remainder of the day at the early childhood centre. Families see the continuity of care as also a continuity of the EIBI service, whereas the EIBI service designers would respond that specific programming is limited to the EIBI hours, and that additional time is child care time.

### Preschool Services Actions

- Ed & ECD ensure appropriate resources (both human and financial) are in place to meet the demand for accessing EIBI as wait time to diagnosis is shortened. Ed & ECD does not want to simply exchange one wait list for another.

### School-age Services Actions

ASD supports are different from learning disability supports because of their very specific targeting on ASD-related issues. Nevertheless, ASD supports are part of the inclusive education piece, and supports are determined by educational, behavioural and social needs of the student.

- Within the scope of the Strategy, the School Autism Team review current services and identify opportunities for improvement and make recommendations to Ed & ECD.
- Include a social worker in the School Autism Team to continue to support families in navigating supports and services. This may be the navigator noted earlier.
- Without losing the value of inclusion, persons with ASD have opportunities to access skill-specific programs. Provincial Autism Advisory Committee consider parameters on such programs (such as APSEA's short-term residential programs, or Alternative Education programs) that enhance student's life-skills without creating a segregated program.
- DSP provides funding for school aged children with ASD for after school supports and services. Related Departments need to explore partnering with community organizations for the delivery and administration of such support and services.
- Related departments collaborate with non-governmental organizations and other community partners to offer services and supports when persons with ASD are not in school (after school, breaks).
- In the mid to long term, the Related departments provide a consultant to help program after-school time.
- Children with late diagnosis or start school prior to receiving diagnosis (and therefore with little or no access to IBI prior to starting school) is a real gap. Ed & ECD needs to identify whether IBI, a modified form of IBI or other therapy or intervention is appropriate for late recognition of ASD and who provides such services.

## Employment Model

**Recommendation 26:** Ed & ECD work with Health and Social Services and Seniors to create an employment model for tutors of home-based IBI programming to relieve families of the burden of finding qualified, competent personnel.

This recommendation was unanimously supported by the AAG, particularly with respect to the need to address the wage rates for IBI tutors. Currently, they are being paid significantly lower than educational assistants in the school system. As a result, many good tutors do not remain with the IBI service, seeking employment in positions with higher compensation rates. Appropriate compensation levels need to be addressed in tandem with a tutor employment model. This is addressed in the Human Resources section of this report. However, the majority of the AAG believed that in addition to higher wages for tutors, the employment model requires further consideration.

The current system of parents as employers has created significant challenges to service provision (i.e. difficulty finding and keeping tutors, unclear communication and conflicting supervisory roles with advice coming from public sector and private professionals, and parent-employers, and friends/family/neighbours as employees). There are also concerns about quality assurance of tutor services under the current model. In building their relationships with families, Preschool Autism Specialists and Autism Consultants do not feel it is helpful to act as compliance enforcers, yet they sometimes become aware of situations where tutors are not following the service as designed. It is difficult to assess the efficacy of the EIBI service if the service is not being implemented consistently and appropriately. Therefore, while the Autism Society believes that enhancing the wages for tutors will largely address their concerns with respect to the tutor-employment model, AAG members who take the larger system perspective, believe that more structure is needed to ensure that tutors are competent and qualified, with clear accountabilities for their role in the EIBI service.

### Employment Model Actions

The AAG did not see a need for tutors to be employed directly by the Province. Instead, it preferred options where families retained some control with respect to choice of tutor, such as:

- Develop a registry of qualified service providers (families are still employers); OR
- Contract with service provider agencies to deliver services to families (families are not employers).

## Adult Services

**Recommendation 27:** Ed & ECD partner with Health, Social Services and Seniors, DIAL and NGOs to undertake proactive planning for appropriate adult services during the high school years and into the future.

ASD-specific adult services and supports have not been the focus of provincial services to date. While the emphasis on early and intensive interventions and school-age programming is appropriate, this should not be to the total exclusion of adults. A follow up to the Disability Services Review to determine if it meets the needs of the adult ASD community is needed. Ed & ECD are part of the process as transition planning begins at age 14.

### Adult Services Actions

- Related Departments to create an *ad hoc* Adult Autism Advisory Committee to identify opportunities to improve services and supports to persons with ASD and their families. ED & ECD should be part of this process because it is implicated in adult literacy and longitudinal studies for evaluation of services and supports.
- Review Strategy in light of Disability Support and Services Review to ensure its approach is aligned with Review's recommendations.
- Appoint and assign Adult Services Leader role (this position may have a larger role to play under Disability Services Program).
- DIAL to partner with post-secondary institutions to design opportunities for continued learning for persons with ASD.
- Related departments work together to review services for older children and adults and seek out science on ABA philosophy application to later ages.
- Related departments to provide NGOs/community with training for offering services to adults with ASD.
- Health to ensure Mental Health services are provided to persons with ASD.

## Transitions

Transitions into school, between grades, and at school exit require additional support to the child and family in understanding and affecting a successful transition. It is also an appropriate time to conduct assessments of the child's progress both for informing the transition process, as well as for evaluating the quality and effectiveness of the service.

**Recommendation 28:** Continue to invest resources in comprehensive transition processes, including assessment and evaluation.

Transitions are highly anxious times for parents as this is a period of many changes to routines, services, and people involved in their lives. The AAG has identified the need for a social worker/navigator position to assist families in the early transitions into Level 1 & 2 services. This position may also assist families in making appropriate connections with the school-entry transition process.

The school entry process has been in place since 2002. It includes parent information meetings, direct observation and assessment by involved professionals, case conferences and IEP planning meetings beginning 6 months before school entry; information about the process has been shared with Early Childhood Centres across the Island. While school-based service providers report that this process is going well, the Autism Society reports that some parents are *not* satisfied with transitions whether at school entry, between grades or transitioning into post-secondary life. The draft Strategy currently states that decisions about the child's placement are the responsibility of school and school board/district officials, but that parents will be consulted in this process. *If* there is no consensus on a child's placement, the Autism Society reported that some parents feel frustrated that their views are not heeded.

#### General Transitions Actions

- Provide a means of inviting parental feedback on transition process to identify sources and extent of concern and improve communication, including a survey of parents one year after the transition to learn how the process went.
- Require the Social Worker/Navigator to provide a report on the needs identified through the course of their work.
- Ed & ECD determine if the appeal mechanism under the *Schools Act* is sufficient to give parents an opportunity to present their reasons for concern regarding a placement decision. A pilot of a mediated dispute resolution process may provide a less adversarial means of addressing concerns.
- The inclusionary model of education acknowledges the importance of allowing students to proceed through the grade levels in the company of their age-appropriate peers. While respecting the principle of inclusion, parental input into whether child is ready to move from junior high to high school (an additional year) is to be given serious consideration with respect to the needs of the student.
- Ensure parents are aware that if they feel they need an advocate to assist them in sharing their views with the team, they are welcome to bring such a person (such as from active communities, the autism society, or a case manager from DSP).



### Preparation for Postsecondary Transition

- While there is a process in place to begin post-secondary planning in Grade 8, the transition process into Adult Services needs to be strengthened. There are currently large gaps for students with ASD exiting school:
  - residential options;
  - transportation options;
  - vocational options; and
  - social/recreational options.
- Allot more time for Resource Teachers to implement the transition planning process to increase parent and student involvement in planning exit transition.
- Ensure that the Ed & ECD Career Development Framework that includes a significant co-op or volunteer component for all students is used to provide coaching assistance as needed through the student's last four years of school.
- Adopt and/or adapt a Life Skills course and curriculum for more severely affected students.
- Provide additional training specific to Intermediate and High School students regarding puberty, sexuality and related safety issues.
- Curriculum materials in this area are lacking. Acquiring or development of appropriate materials is needed.

### Family Supports

General supports to families of persons with ASD are addressed by the Province's Disability Support Program. The values of the Provincial Autism Strategy include consideration of the needs of the family as well as the person with ASD. This requires an on-going dialogue between families and Related Departments to ensure that family needs and available supports are understood.

**Recommendation 29:** Charge the Autism Advisory Committee with seeking community input and providing recommendations for family supports.



## Capacity and Resources

### *Human Resources*

**Priority Recommendation 30:** There should be no unreasonable wait lists for individuals with ASD to access publicly-provided interventions.

This requires Related Departments to:

- Establish appropriate wait times for interventions;
- Create positions that will enhance access and delivery of services; and

Set workload parameters for ASD service providers.

#### Human Resource Actions

In considering actions that can improve access, enhance quality, and support persons with ASD and their families, a number of positions were identified. While the AAG identified a number of positions for coordinating services, in the current climate of extensive wait lists as well as fiscal prudence, it will be essential that any additional positions be directly linked to improving access to service and to address significant service gaps, such as services to adults.

- **Priority Action:** Ed & ECD confirm the:
  - Autism Coordinator position; and
  - Preschool Autism Specialist positions as permanent positions.

It is difficult to recruit and retain specialized individuals in temporary positions.

- **Immediate Action:** Add an additional full-time Preschool Autism Specialist position and an additional Autism Consultant position. If, after three unsuccessful months of trying to recruit, recruit appropriate candidates to be trained to fulfill needs. Note, that this is not a “quick fix”, as training can take up to 18 months. Since 2001, the Department of Ed & ECD has invested in an Intensive Training Model in partnership with an American university to develop Autism Consultants and Preschool Autism Specialists.
- Employ Preschool Autism Specialists and Autism Consultants in accordance with appropriate case loads (six to seven children for Preschool Autism Specialists; 20-25 students for Autism Consultants).<sup>28</sup>
- ASD service providers, particularly Preschool Autism Specialists and Autism Consultants, receive inquiries and requests to offer assistance outside of the autism

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<sup>28</sup> The PAS workload was determined initially by Andrea Noonan after researching practices in other jurisdictions. AC's are unique to PEI. Their workload is based on the assumption that school boards will allow consultants to balance caseloads with one-third requiring intensive support, one-third requiring moderate support and one-third requiring only support on an as needed basis.

services (such as children who do not have an ASD diagnosis). This adds to the Consultant workload, and may contribute to the turnover in these positions. These professionals need support from their supervisor in establishing work parameters and focusing on their core function of providing services and supports to those enrolled in the autism services.

- Related Departments create a social worker/ navigator position to assist families with the navigation of the autism/early intervention pathways as well as to provide ongoing support to families. This recommendation was already listed in relation to the Leveled Services model. However, because this would be a new position, and because it was strongly supported by the AAG, it called for placement here as well.
- Department of Health support and expand S-LP expertise in ASD by dedicating a Speech-Language Pathologist to a provincial role for at risk and diagnosed individuals with ASD (at risk and diagnosed). This S-LP will consult with the Preschool Autism Specialists, support other S-LPs in their service to these clients and deliver specialized parent training, such as the Hanen *More Than Words* program to families of children at risk or diagnosed with ASD.
- Department of Health provide training and education to develop expertise on ASD within the Community Mental Health service to providing counselling services to people with ASD and their families.
- Autism Consultants are employees of the individual School Boards, and therefore are not easily shared across school boards, and creates a dual accountability for Autism Consultants: to their employer Board; and to the Autism Coordinator for clinical supervision. Ed & ECD needs to explore with the Board whether there are means of addressing the sharing of resources, and clarifying accountabilities.
- Other provinces have Augmentative and Alternative Communication teams that include assessment, intervention and follow-up. This is a gap in Prince Edward Island that affects a broader population than just individuals with ASD. This may require a specific study to address, including, whether an organization, such as the Atlantic Provinces Special Education Authority (APSEA), could meet the Province's needs in this area.
- Add a Social Worker to the School Autism Team or include a school counsellor in the School Autism Team who would also provide school/home support liaison position to help families coordinate school-based and home-based plans.
- DIAL in concert with Ed & ECD, partner with Holland College to ensure supply of tutors with appropriate competencies. AAG discussions indicated that ECE program graduates are often better able to appreciate the developmental milestones and ABA-based principles. This observation should be part of the discussions.

- One of the objectives at the junior and senior high level is for building independence for students with Asperger's or other high functioning ASD. Nevertheless, for some students, continuing EA support may be beneficial. To that end, Ed & ECD needs to build Education Assistant capacity for human resource support at Junior and Senior High School.
- The Community Access Facilitator is a valuable position in supporting the transition of students with special needs. This aspect of the service requires continued support. Ed & ECD recommend to the Department of Social Services and Seniors to address the needs of adults with ASD, and Ed & ECD coordinate and assist in transitioning individuals exiting the education system to the supports and services needed for their adult life.

### *HR Planning*

In recent years, the Province has made a number of advances in its services and supports to individuals with ASDs and their families. For example:

- The hiring of an Autism Coordinator;
- The development of Autism Consultants to work with the school-aged population;
- The development of the Early Intensive Behavioural Intervention service;
- The increasing number of Preschool Autism Specialists to deliver the EIBI service;
- The increasing commitment of pediatric psychology resources to the ASD Diagnostic team;
- Parent information sessions;
- On-line resource such as:
  - toilet training tutorial for families on the wait list;
  - Autism 101 in preparation for attending Preschool Autism Service training sessions; and
  - Working with an S-LP in Health to offer the Hanen More than Words program to families this Fall.
- Training for tutors and families of children who enter the IBI program;
- Exploring new sources for tutors from the mature worker pool through the Passport to Employment Program;

- Regular opportunities for professional development for Autism Specialists and Consultants. For example, all clinical staff in the preschool and school age services recently had an opportunity to attend one of four autism related conferences off-Island;
- The Preschool Autism Services has been moved to Ed & ECD, in the Child and Student Services Division, allowing for a better alignment of services for children with autism who can be considered on a continuum from diagnosis through to transition out of school;
- A revised assessment process is being developed to include assessment best practices based on behavioural-teaching strategies. This will include assessments when children enter and exit from the Preschool Autism Service, as well as a 6 month (plus on-going) re-evaluation of progress assessments. Parents will be active participants in this assessment process; and
- Preschool autism staff is in the process of finalizing Individualized Family Service Plans (IFSP) to more clearly define a child's plan for families.

Despite these successes, there continues to be a high demand for further service enhancements from both the Autism Society as well as service providers, particularly regarding further improvements to early interventions and the need to address supports and services for adults with ASD. Tutors are at the very front line of the EIBI service. In these positions, people need an understanding of early child development, work within well-defined services that are designed by autism professionals, satisfy the family, and have extremely good coping skills in working with the child with ASD. These skills are highly transferable and can earn a significantly higher wages in other settings (such as educational assistants within the schools). Therefore, many families have had to cope with a high turnover of tutors. This is not only frustrating and time consuming at the administrative level, but also impedes the delivery of a consistent EIBI service to the child. Therefore, wages for tutors is an important issue that needs to be addressed.

**Priority Recommendation 31:** The Related Departments need to ensure that the wages for ASD service providers reflect appropriate compensation for the work, competencies and training required, and Treasury Board should consider labour market adjustments for permanent positions.

It is increasingly challenging to find and recruit individuals into key positions in Autism services, from tutors to Coordinators. Therefore, opportunities to address the human resource challenges form a significant element of the Autism Action Plan.

**Recommendation 32:** Create a human resources plan for *all* positions relating to the delivery of ASD services from diagnostics through to adult services and supports.

Challenges in recruiting tutors, Preschool Autism Specialists and Autism Consultants are forerunners of challenges for recruitment of other allied health and educational personnel who are fully qualified to carry on the work of the Provincial Autism Strategy in the years ahead. Therefore, Related Departments must be proactive in anticipating need and building capacity to develop the needed skills.

#### HR Planning Actions

- The Department of Ed & ECD partner with the Department of Health's Recruitment and Retention Secretariat to develop a human resource plan for allied health positions that work in or provide services across departments, such as Speech-Language Pathologists.
- Build on the human resource planning work being done in support of the early childhood education program to identify opportunities to recruit and retain special needs assistants and tutors.
- Ed & ECD ensure that job descriptions for IBI service providers are current, and support the recruitment and retention of needed staff.
- Continue the use of "return of service agreements" to ensure that personnel in whom the Department of Ed & ECD has invested expensive autism training make a reciprocal investment in the organization.
- Continue to explore under-utilized populations, such as mature workers, as a potential source of tutor recruits.
- Resources for Autism, Early Intervention, Children with Exceptional Needs, and Healthy Child Development, if coordinated, may improve the recruitment and retention package. Explore opportunities to partner with other strategic initiatives to combine funding.
- Determine if there are sufficient francophone human resources to deliver ASD services under the service delivery model.
- In addition to the traditional review of sources and supplies of trained personnel, the HR Plan will also need to consider means of optimizing the deployment of resources.
- Ed & ECD consult with Department of Health regarding the Speech-Language Services strategy and S-LP resources to ensure that consistent S-LPs are available and consistent in following standards of care in treating and assessing preschool and school age clients with ASD, This would also be true for other allied health resources (i.e. Psychology, OT, Mental Health therapists) that support treatment and interventions to individuals with ASD.

- Ed & DCD develop agreements with Health, Social Services and Seniors to co-locate services as much as possible to physically support information sharing and to also improve the convenience to families who need to visit professionals in clinical settings. (For example, pediatric psychology services are currently in the same building as speech-language services and early childhood development offices in Charlottetown. This arrangement is seen as advantageous for these services and the families accessing them.) Note: that as always, there are also a disadvantage to co-location, as it weakens the connection between Early Child Development employees with their Child and Student Services colleagues. This issue should be resolved by determining what is best for the child and family.

**Recommendation 33:** Related Departments dedicate resources to build capacity in the competencies needed by the Autism Strategy.

While it is generally recognized that working with individuals with ASD and their families requires training and special skills, and recruiting and retaining people for these competences is a challenge. In order to develop a human resources plan and to address the quality of human resource needs of its autism services, the Related Departments must dedicate resources to build capacity in the competencies needed by the Autism Strategy.

- Ed & ECD confirm a budget allocation to training. Training allocations have been unstable, being halved, completely cut, then re-instated, making it difficult to plan, or recruit interested candidates. The development of needed resources should not be vulnerable to early cuts in times of fiscal restraint.
- Ed & ECD provide a bursary to teachers who take the academic courses identified for autism consultants or provide a reimbursement for course fees when these individuals are accepted into an autism consultant position (rather than waiting for a vacancy before starting to build the skills to fill it).
- Department of Ed & ECD partner with a post-secondary research institute, such as the Centre for Education Research at UPEI, to identify the key competencies for the various service providers who work with children with ASD:
  - Special Needs Assistants;
  - Early Childhood Educators;
  - Tutors;
  - Teachers; and
  - Educational Assistants.
- Department of Innovation and Advanced Learning (DIAL), in concert with Ed & ECD, partner with UPEI and Holland College to develop courses, modules or programs that

will strengthen these competency areas both for full-time students, for professional development of autism service providers, and for families.

- Encourage UPEI to have the B. Ed. and M. Ed. programs include a unit on ASD.
- Department of Ed & ECD explore opportunities to share resources within Atlantic Canada to offer summer institutes or utilize current professional development days to provide continuing education on ASD-related issues.
- DIAL and Ed & ECD encourage UPEI to include behaviour management, ABA theory, and ASD information in its Certificate in Inclusive Education program; and the Province recognize the value of the M. Ed. in Inclusive Education at UPEI.
- Encourage Holland College to provide modules on ASD, ABA principles, inclusive education, and other approaches used by the Autism, Learning Disabilities and Early Intervention Strategies, that can be taken by persons with ECE or human services background either in their initial diploma program or as continuing education.
- Provide more training needed for teachers and resource teachers in effective IEP writing.
- Ed & ECD ensure more timely access to school psychologists for services, including cognitive assessments.
- DIAL ask Holland College to provide additional training specific to Human Services students in the area of Puberty, Sexuality and related safety issues for persons with special needs.
- Increase accessibility to staff training, including online and distance learning options<sup>29</sup> such as a departmental portal to share information, and teaching strategies.
- Department of Ed and ECD provide staff with additional training in data collection and monitoring progress.
- Department of Health provide education opportunities for Island pediatricians, psychiatrists and psychologists in the diagnosis of ASD<sup>30</sup> and information for family physicians regarding when to refer.

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<sup>29</sup> Note the CD and DVD material that is available for early childhood workers developed by the Centre of Excellence for Children and Adolescents with Special Needs at Mount Saint Vincent University at [www.msvu.ca/child\\_youth/coeei/work\\_autism\\_sample.asp](http://www.msvu.ca/child_youth/coeei/work_autism_sample.asp) )

<sup>30</sup> Ask the Department of Health to sponsor a session with the Medical Society to have a professional development day session for family physicians and pediatricians with a panel made up of the Island's diagnostic team and a guest such as Dr. Bryson or Smith to discuss indicators, and risk factors

- Department of Health identify other people to be trained as part of Diagnostic Team. Given the small number of professionals with the training to participate on the ASD Diagnostic Team, any fluctuation in demand for the service, or drop in availability of a team member can have a significant impact on the service. Therefore, if other pediatricians and psychologists have the capacity to assist, the stability of the Diagnostic services will be improved.
- Ed & ECD identify and develop other people to be trained as part of Preschool Autism Specialists (PAS) and Autism Consultants (AC). Given the small number of professionals with the training to deliver EIBI or provide ABA support, any fluctuation in demand for the service, or drop in availability of a PAS or AC can have a significant impact on the service. Therefore, by adopting a succession planning approach, the Province can create a pipeline of people drawn from the early childhood development and education ranks who can more readily be called upon to take up a PAS or AC position will help prevent wait lists or disruption of services when PAS or AC leave their positions or take temporary leaves.
- Explore train-the-trainer opportunities to engage S-LPs, public health nurses, Preschool Autism Specialists and Autism Consultants to deliver information sessions to families, and training to tutors. Furthermore, peer-to-peer education might also support the qualification of other individuals to provide services, e.g., only one S-LP is currently certified to deliver the Hanen *More Than Words* program – this S-LP may be able to help others achieve this standing.



*Qualification of ASD Service Providers*

- Assess resources and identify factors that contribute to burnout or exits from ASD service provision to support a human resource plan that maintains a cadre of trained preschool autism specialists and autism consultants.
- The Department of Ed. & ECD work with the Boards to ensure that succession planning is in place for autism resources by working with PASs and ACs to identify their exit horizons and have other individuals being developed in order to be ready to take on these roles as incumbents exit these positions.
- ASD Preschool Specialists and Autism Consultant training funding needs to be increased or other online options explored for ongoing Professional Development.
- Training for Early Childhood and Kindergarten staff on Autism Spectrum Disorders to promote earlier identification and understanding of nature of challenges.
- Support the ASD professionals (diagnostic team, S-LP, OT, Public Health Nurses, Community Mental Health, PAS, ACs, tutors and other allied health professionals) in ongoing professional development and regular collaboration with other Atlantic professionals to continue to build diagnostic capacity.
- Provide separate information/training sessions for parents and tutors – they have different needs.
  - Provide on-going sessions for parents; and
  - Provide on-going sessions for tutors.
- Explore opportunities to open these events to community, ECE, and home-based providers.
- Explore opportunities to collaborate across Departments to develop other information and learning sessions across Government and to the community.
- Support the development of a virtual knowledge community. The knowledge and understanding of ASD remains an active field, with theories and interventions being further explored and refined on an on-going basis. It can be challenging for professionals to keep abreast the latest developments. A virtual community where professionals can share experience and knowledge via teleconferences, webinars, e-distribution lists, would enable the Island community to feel more connected to the ASD research community during those periods between face-to-face meetings and conferences.

**Longer Term Options for Action:****• Behaviour Based Training Institute.**

A business plan has been developed for the establishment of a Behavioural Based Training Institute. This plan concludes that there is a Canada-wide need for a training institute to provide quality education and certification to ensure qualified staff at all levels of service delivery. Further work on this proposed endeavour is required. The Institute must show potential for being self-sustaining before a final decision can be made whether to move forward. The Institute should provide course work focussing on a broad application of educational and behavioural strategies, including strategies of particular benefit to children with autism.

**• Post Secondary Training Opportunities**

Explore the possibility of working with provincial educational institutions to develop additional curriculum offerings for teachers, teacher assistants and tutors focussing on essential components of Applied Behaviour Analysis.

**• Non-violent Crisis Intervention**

At times, individuals with autism may exhibit behaviours that put themselves or other people at risk. Training for staff and families is important to ensure that the individuals can be supported appropriately. Personnel need to be identified and certified as a trainer in the use of safe procedures. Certified staff would provide training across departments provincially.

## Communication

The Strategy requires enhanced external and internal communication to improve access to services and navigation of the services and supports.

### External communication

The Strategy's success will be measured in large part through heightened public and consumer awareness of what supports and services are available and how to access them. Many families who access autism specific services in PEI report a positive experience. However, the Autism Society reports that some families of children with ASD and the community lack clarity as to how to express their concerns or raise questions about what services and supports are available.

**Recommendation 34:** Create a communication plan to ensure that all stakeholders have input and are aware of existing services and how to access them.

#### External Communication Actions

- Create an Autism Advisory Committee with participation across departments and includes parents and community partners.
- Organize and coordinate the suite of services available for the healthy development of children so that information on available resources, and how to access them is readily available to the public.
- Package the information so that it is accessible to the public to assist in ASD awareness.
- Develop a package of information (e.g. directory, an on-line portal, the employment of a navigator) and distribute to parents of children who are exhibiting a need for developmental support, but who are awaiting diagnosis.
- The Province has a Healthy Child portal to which families, and service providers, can refer for information on what services and supports are available based on:
  - open access;
  - referral (and whose referral);
  - diagnosis; and
  - contact information if they have concerns.
- Create a directory of key contacts and open referral programs that can be available through physician offices, public health offices, health centres, ECEs, and to MLAs for their ease of reference. Make this information available off a link in the Healthy Child section of the government website.

#### Raise Community Awareness

While there may be many health professionals who have contact with young children and their families, not all are familiar with ASD. Furthermore, school psychologists, speech language pathologists, early childhood educators and special education professionals need to know how to/to whom to make suspected ASD referrals.

- Develop a communication tool that can be shared across the health system to existing practitioners and health care providers.

- Coordinate education with ECE, family physicians, SLPs, public health nurses, OT and AS regarding the screening and assessment tool(s) selected by the IWAG.
- Provide/support members of the Autism teams in making continuing education presentations to professional association PD events.
- Provide this information to post-secondary health programs to share with those entering the health care field.
- Provide information on risk factors, reliable indicators and screening tools to health care and early childhood professionals and collaborate with appropriate community resources to facilitate heightened public awareness of autism spectrum disorders.
- Develop parent/professional teams to conduct presentations to community service organizations. Involve community groups (e.g. Autism Society) in these efforts.
- Develop and distribute brochures and posters, with contact/referral information.

In recent years, prior to the AAG work, the Province and Autism Society maintained an arms' length distance in terms of planning provincial autism services. While the Autism Society will retain its advocacy role, it is a valuable resource to the Province and to the ASD community to work collaboratively to develop services that enable persons with ASD to reach their full potential.

- Ensure the Strategy recognizes the important role the community plays in its implementation.
- Departments commit to collaboration with the community, recognizing that the interests of the Autism Society and the Province may not always align.

## **Families**

- Create communication tool for informing families and health professionals about open referral services that are not diagnosis dependent (Level 1 Services).
- Communicate to families that IBI is not the only service or support that may benefit their child.
- The Social Worker/Navigator work with Provincial Autism Team to schedule regular information and training sessions for parents on waiting lists.
- Related Departments should explore with ASD community the interest in creating parent-to-parent opportunities at information sessions for families to share information and experiences.

## Service Information

There is a significant division of perception of the quality of and quantity of ASD-specific interventions available for both preschool and school-aged children. Educators believe the children actually receive *more* intervention in school, although it is not one-on-one, whereas parents may perceive this to be less desirable than the EIBI one-on-one intervention model. This divergent understanding or perception of the ASD-specific services is one of the sources of frustration for those families (a minority, but an assertive minority) who believe that the preschool model is superior.

- Once the details of the services are finalized and approved, the Related Departments develop clear communications to ensure that all stakeholders are able to understand what is available (and why – even if that why is financial constraint) so that providers and parents are able to understand (not necessarily agree) what services and supports are available under the Provincial Autism Strategy.

**Recommendation 35:** The Province partner with the Autism Society to establish an Autism Resource Centre that provides accurate information regarding the interventions, services and supports available, as well as providing a lending library of resources and tools to parents and families.

- Dissemination of information to primary service delivery professionals regarding early diagnosis of autism will be done regularly.
- With added Preschool Autism Specialists, the Preschool Autism Team members will take turns providing training and information for medical and mental health professionals, early childhood educators, etc. providing basic information on autism and warning signs.
- Explore train-the-trainer opportunities to engage public health nurses, Autism Social Worker, Preschool Autism Specialists and Autism Consultants to deliver information sessions to families, and training to tutors.
- Parents and the public in general will have access to an easily understandable description of the pathway from early identification of needs through diagnosis and the suite of services available to meet those needs, including IBI.
- Parents have many needs for information concerning the diagnosis, treatments and how they can participate in child's development. Information in a variety of formats (leaflets, brochures, web portal or websites, information sessions and training sessions) is available to parents to support their information needs.
- Related departments work with the Autism Society to identify a library of resources (toys, books, software).
- Explore use of \$100/mo under IBI Resource (or share with families).

- Ensure autism services, supports and resources are available in both Official Languages. Ensure Autism Resource Centre has library of French language resources.
- Increase francophone consultant time to ensure family information sessions and training sessions are available in French.
- Explore working with French Language Health Services Network to identify resources and strategies to strengthen services and supports in French.
- EAL/FAL services are available for families who need it.

## Internal communication

Once the trans-departmental governance structure and process is ascertained, clear and sustained channels of communication will be the glue that holds the structure together. While the Department of Ed & ECD has had an unofficial strategy from which to work, the lack of a published strategy and policies have left various stakeholders to deal with service design and delivery with a level of uncertainty. Driven by the Strategy, interdepartmental communication and service delivery will be strengthened at all levels in the departments, from front-line service providers to managers, Directors and Deputy Ministers. Measures to improve internal communications need to focus on:

- Clarifying roles and responsibilities across departments;
- Establish channels for information sharing within teams and across teams; and
- Accountability for initiating information sharing meetings.

**Recommendation 36:** Create an internal communication pathway to ensure all internal stakeholders are aware of roles, responsibilities, activities and accountabilities.

### Internal Communication Actions

- **Immediate Action:** Roles and responsibilities of Board Consultants, Schools and Department need clarification. Practice Guidelines and Minister's Directive on Autism have been drafted and require approval. The Provincial Autism Team should review these guidelines and Directive and recommend necessary amendments and promulgation as soon as possible.
- All professionals have their role in supporting persons with ASD and their families clearly defined and acknowledged by team members. Work must be done in consultation with them to identify best means for describing their role, and their fit within the models, particularly discussions regarding preschool versus school age clients.

**Teams**

- There needs to be a sharing of information between pre-school and school autism teams. Such sharing should be across all Related Departments in accordance with information sharing guidelines and legislation.
- Greater collaboration between Diagnostic team, SLP/OTs, Preschool Autism Specialists and the Preschool Autism Coordinator is needed through clearer understanding of their roles and responsibilities.
- The participating Departments strike committees as identified on page 19 as that structure was designed to promote and enhance communication within departments, across departments and with the community.

**Funding**

- Participating Departments create a joint communication tool that provides clear information to all interested parties regarding funding.

## *Pulling It All Together*

**Consultant Recommendation 37:** Appoint a project manager to oversee the launch of the recommendations of this document for an eighteen month period to be accountable for setting rapid actionable items into motion, and aiding the Related Departments in developing the needed structures and processes to support the strategy on a sustainable basis.

The scope of the AAG recommendations is very broad, and very ambitious. The very magnitude of the report creates the risk that the tasks set are too daunting for people to undertake when they have other competing priorities as well. By having a project manager who can focus exclusively on finalizing a work plan and implementing the priority items, Ed & ECD will be sending a strong signal to the Related Departments and AAG members that the Provincial Autism Strategy is a priority, and the report is being actioned.



## Conclusion

So what is PEI's answer to the puzzle? As with any other publicly-funded service, the Province needs to be prudent in investing in services and supports that are evidence-based. Given that there are not yet any generally-accepted standards for behavioural-based therapies, the Island needs to invest in an evaluation framework to measure the effectiveness of services and the resultant outcomes for children, their families and their Island community. At this time, the "best practice" for Prince Edward Island is to offer an early behaviour-based intervention service targeting social and communication impairments and that reaches as many ASD children as early as possible and be responsive to new developments in the field. Requests to consider other forms of intervention should only be considered where evidence indicates a promising practice and a robust evaluation plan is in place.

### *What gets measured gets addressed*

In support of this approach, an evaluation framework will be a key touchstone to holding the many stakeholders accountable. The need for basic evaluation measures was readily apparent whenever consensus-building amongst the AAG members was difficult. As noted above, there are a number of studies and commentary from reputable sources sufficient to support a variety of differing approaches and standards, as illustrated by the intensity debate. Because there is no evaluation program in place to measure the effects of the Island's intervention services, neither view has good evidence to support the claim. In a service that claims to be evidence-based, this is a fundamental gap that must be addressed.

While there remain some thorny subjects that will continue to challenge the Province's Autism Strategy, the AAG is confident that the Province, through its "*One Island Community*" approach, can and will support children with ASD and their families in achieving their potential.

The AAG only had a brief amount of time to come together to work on the action plan proposals. Although the time together was extended, the AAG still felt that more time would have been beneficial given the complexity of this service area and the number of service providers involved. The additional time needed to enable the group to share their views, their concerns, and grapple with the strategy itself is indicative of the lack of opportunity the stakeholders have to do this in the ordinary course of the day-to-day work. This is not to say that team meetings do not happen. However, the extent of the workloads being carried by these people is such that attendance at meetings hosted by other departments tends to be sacrificed in order to get the priority work of service delivery.

The limited communication between the stakeholders was illustrated frequently at the AAG meetings, as different players learned *after* the fact of workshops, meetings and developments that would have been of interest to them. Without addressing the interdepartmental need for improved communication and information flow, such missed opportunities, miscommunications and misunderstandings will continue. For this reason, attention to the governance, service structure and interdepartmental policies and protocols that underpin the service structure and delivery need to be given priority.

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# Appendix A

# Appendix B

# Appendix C