

Report on the National Autism Research Symposium

Toronto, Ontario - November 8 & 9, 2007

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Introduction

The National Autism Research Symposium was held on November 8 and 9, 2007 at the Four Points Sheraton Hotel, Toronto. Part of a series of initiatives on autism announced by the federal Minister of Health, Tony Clement, in November 2006, the symposium brought together researchers, health professionals, educators, service providers, family members and persons with autism, as well as community organizations and government representatives. Held under the auspices of the Canadian Institutes of Health Research (CIHR), Health Canada and the Public Health Agency of Canada, its purpose was to inform participants about the current state of knowledge on autism, to further the dissemination of ideas and to assist the research community in planning research.

In accordance with the symposium's goal of information sharing, the event provided an opportunity for a variety of individuals to convey their knowledge and views on a diverse set of issues related to autism. The opening evening, for instance, featured a group of speakers who shared their insights and knowledge on living with the condition – a young man with autism, the parent of a child with autism, and a prominent researcher in the field. The second day of the event offered an opportunity for participants to learn about the state of the science on autism, with presentations by twelve leading Canadian researchers. The symposium also featured break-out discussion sessions, through which all participants were invited to share their thoughts on many different aspects of the condition.

This report provides an account of these informative presentations, and discussions.

1.0 Autism: Challenges and Successes

On November 8, 2007, the symposium opened with three informative presentations on some of the challenges that autism research must address. This issue was explored from the diverse perspectives of a person with autism, the parent of an autistic child and a researcher in the field. The following section offers a summary of these presentations.

1.1 Living with Autism

Daniel Share-Strom, University Student

Daniel Share-Strom, a 17-year-old university student, helped set the scene for the symposium with a personal account of his own experiences in living with Asperger Syndrome. He also offered his suggestions for changes that would benefit the autism community.

“I am an example of how we can succeed when we get the help we need,” Mr. Share-Strom told the audience, contrasting his current situation as a successful and socially adept student with his experiences as a child who could not make friends with others, couldn't perform manual tasks such as tying his shoelaces, seldom communicated and tended to squawk, rock, spin and lick objects. He said his condition was not diagnosed until he was 10 years old. His symptoms, which included learning disabilities, poor

fine motor skills, poor non-verbal communication, poor social skills, repetitive behaviours and obsessions, and sensory integration dysfunction, had been misdiagnosed in various ways before that.

His subsequent improvement, he said, was not the result of any “magic bullet”, but “daily hard work and lots of help.” He also stressed that he is not now “cured” of his problems and still has to deal with issues such as anxiety and difficulties with organization, interpretation of language, grooming, motor skills and learning disabilities. Mr. Share-Strom mentioned that having routines is very helpful in managing these issues.

In the light of his own experience, Mr. Share-Strom made the following suggestions:

- Provincial initiatives should attempt to improve communication among the helping professions to improve the speed and accuracy of diagnosis.
- Efforts should be made to ensure that schools and teachers provide the academic support that people with autism require.

A provincial ministry branch should be established to co-ordinate services for each person with Autism Spectrum Disorder—from diagnosis and for the rest of their life.

1.2 It’s Autism: Now What?

Jennifer Overton, parent and playwright

“Eleven years ago our son was diagnosed with autism and our world turned upside down overnight,” playwright Jennifer Overton said, as she began her personal account of the challenges she faced as the parent of an autistic child. She described how her family physician failed to recognize the symptoms, even though she had expressed her concerns to the doctor several times over an eight month period. She also noted that when the doctor eventually and reluctantly agreed to make a referral to a developmental clinic, she and her husband were told there was a 14 month waiting list.

“Eleven years later, our current GP still does not have an early signs of autism checklist,” Ms. Overton said.

Ms. Overton said she and her husband used their own financial resources for a private consultation and their child was diagnosed first with Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) and later with Autism Spectrum Disorder.

She explained that a play she has written entitled *God’s Middle Name*, chronicles her journey to acceptance of her son’s autism. “The title represents my son’s need to make concrete an abstract concept like God – needing to know his last and middle names – because, on May 14 2004, ‘Dad said that everybody has a last and middle name’. Luckily my husband came up with a plausible last name for God – ‘Almighty’ – and that bought us some respite.”

Confronted with a lack of information and resources following her son’s diagnosis, Ms. Overton says she “joined societies, online chat rooms, went to conferences, became part of the autism subculture and read all the research – all the conflicting research.” Not knowing what to believe, she said, “Desperation, love and guilt made us susceptible to every claim out there. We stopped using fluoride, stopped vaccinations and antibiotics and restricted his diet.” Since there were no specialized local programs available, Ms.

Overton explained that she and her husband took out a second mortgage on their house to fund a pre-school pilot project, bringing specialists in from the United States. Subsequently, when her son entered a school system where no one was trained in autism, she said, “We paid for private speech and language therapy and private psychology. We used every resource, material and emotional, to get him the help that he needed, and not surprisingly, we started to wear down... Having to constantly lobby for our son and advocate for change made us cynical. We were broke, exhausted, our marriage was at risk, and we resented having our lives consumed by autism. We burned out big time.”

“What would have helped our son and family a lot would have been support from all levels of government: for educated general practitioners; for a trained and educated school system; for easy access to professionals and specialists who could navigate and guide us through the maze of research and treatments so that even if there are no simple answers our family could have found perspective, hope and balance,” she said, noting that more resources are now available in Nova Scotia, but that there are still many families across the country whose experience is similar to hers.

Currently, Ms. Overton said her son is preparing for high school and beyond. “We spend a lot less time worrying now and spend more time celebrating him and his unique perspective of the world. But there will always be challenges.”

1.3 Autism Spectrum Disorders: Recent Advances and Outstanding Research Questions

Dr. Susan Bryson, Craig Chair in Autism Research, IWK Health Centre-Dalhousie University

Dr. Bryson began her overview with a brief history, noting that autism was first documented formally in 1943. While it was first considered to be a biologically determined disorder, the theory that its causes were psychological was prominent until the 1970s, causing immeasurable damage to parents, until this explanation was replaced by today's scientific approach.

Dr. Bryson explained that autism, as it is understood today, forms part of a spectrum of related conditions, known as the Autism Spectrum Disorders (ASDs) and encompasses a wide variation in levels of functioning, particularly in language and communication skills. The disorder, which affects one in 150 individuals (4 males for every 1 female) is characterized by:

- Social difficulties: relating emotionally and socially to and understanding others; and
- Anxiety and difficulty coping in response to novelty, change and unpredictability

Recent advances in understanding autism were described, including:

- Understanding that genetics plays a significant role, and recent significant advances in research on autism genetics; and
- Better understanding of the neurologically-based differences that characterize autism - evidence of over-connectivity in local or focal areas of the brain that might explain some abilities (e.g. unusually acute auditory and visual abilities) and exceptional skills and, on the other hand, a lack of connectivity between different regions of the brain which might

explain why people with autism have difficulty integrating information from different modalities at one point in time

Dr. Bryson also spoke about the issue of detection, discussing:

- Progress in identifying the earliest signs of autism that can, in some, be detected by 12-18 months of age, allowing earlier intervention
- Calls from various professional groups for universal screening of autism at 18 and/or 24 months of age

With respect to screening, Dr. Bryson identified two challenges: firstly, the need for a sound method of autism screening, and secondly, the need for access to appropriate evidence-based early intervention that can help the individuals identified by early screening.

In regard to the treatment of autism that Dr. Bryson highlighted:

- Accumulating evidence for the efficacy/effectiveness of early intervention; and
- Efforts increasingly aimed at evaluating a broader range of behavioural and medical treatments

Dr. Bryson concluded by stating that many questions remain. For instance, she noted that we need evidence regarding what treatment is most effective for whom, and for what intensity and duration. She also stated that we lack evidence on the effectiveness of community programs, and how best to intervene with individuals of school age and beyond, including dealing with the challenges of co-morbid (co-occurring) psychiatric conditions. Finally, she expressed a need for greater attention to the question of what can be done to better support families.

2.0 Autism: Evidence & Knowledge

On November 9, 2007, a large portion of the day was devoted to presentations by leading Canadian researchers in the field, who shared up-to-date information on autism. These presentations focussed on: the state of the science; early intervention; and screening, alternative treatments and lifespan issues. Summaries of the day's opening remarks, the research presentations, and related discourse are presented in the following sections.

2.1 Opening Remarks by the Minister of Health

Dr. Michael Kramer, Scientific Director, Institute of Human Development, Child and Youth Health, at the Canadian Institutes of Health Research (CIHR) opened the full day session of the symposium by introducing the federal Minister of Health, the Honourable Tony Clement.

Dr. Kramer explained that the symposium was designed to further develop and disseminate knowledge among researchers, health care professionals, community groups, teachers, individuals with Autism Spectrum Disorders (ASDs) and their families, stating that "It has brought together many of Canada's leading ASD researchers to share the scientific evidence on the causes, prevalence, diagnosis, treatment and prognosis of children, youth and adults with ASD". Dr. Kramer also noted that "the Canadian Institutes of Health Research are proud to be funding the work of many of these remarkably talented and committed researchers."

On behalf of CIHR, Health Canada and the Public Health Agency of Canada, Dr. Kramer thanked the Minister for his support and for coming to open the symposium.

For the text of Minister Clement's opening speech, please see Appendix C.

2.2 State of the Science

The first three presentations of the day reported on the current state of scientific knowledge about autism, focusing on genetics, epidemiology and cognitive neuroscience. The following sections offer a summary of these presentations.

2.2.1 Autism genetics: What We Know Now and Why It Is important!

Dr. Stephen Scherer, Hospital for Sick Children, Toronto

In highlighting the significance of recent breakthroughs in genetic research, Dr. Stephen Scherer said studies of autism among siblings, together with other significant evidence, shows that genetics contributes to autism. He added, however, that autism is a very complex disorder and the way in which it is transmitted in families is very hard to trace. He said we need to understand the genes involved in autism in seeking answers to commonly asked questions, such as:

- What is the underlying reason for autism?
- What is the chance my child will be autistic?
- What can I do to help my child and other families?

Providing the symposium with a brief primer on the human genome – the complete complement of DNA found in all cells – Dr. Scherer emphasized that there is no such thing as normalcy, stating “none of us are normal” – yet only 0.5 percent of human DNA accounts for all the differences that make each person unique. Dr. Scherer informed the symposium that new technologies are contributing to better understanding of the genome and that Canadian scientists are playing a leading role, thanks to federal government funding, in the groundbreaking Autism Genome Project, which brings together 170 scientists from 19 countries, including 14 Canadians. Through this initiative, genetic studies have been carried out on 1600 families having two or more children with ASD. This project is beginning to provide answers. Dr. Scherer stated that for the first time researchers have been able to show how changes in some specific genes contribute to autism and now have a model of how genetics contributes to the condition. The findings indicate that autism genes may act differently in boys than in girls, and that all autisms are not the same genetically, with some linked to a single gene and others to a combination of genes. Dr. Scherer noted that chromosome alterations have been detected in about 10% of autism cases, with some of these changes being inherited and others occurring *de novo*. Recent research has also begun to identify proteins and areas of the brain involved, thus pointing to potential possibilities for future therapeutic intervention and genetic testing. Dr. Scherer noted that environmental factors could be modifying the expression of genes. “We’re very excited,” said Dr. Scherer, indicating that there will be many other discoveries coming in the next 12 months.

In response to a question, Dr. Scherer noted that the research team is still collecting samples from families with siblings and is particularly interested in families with female siblings in order to search for possible gender specific differences. Dr. Scherer was also asked whether one’s DNA changes over the course of a lifetime. He responded that DNA is “pretty static,” except for some deleterious changes that may be caused by events such as cancer. According to Dr. Scherer, what does change is the way DNA expresses itself through RNA and proteins. Dr. Scherer explained that DNA expression can be affected by environmental influences. He also stated that the question of whether autism can affect gene expression is an interesting one that scientists are thinking about, but that little research has been done to date in this area.

2.2.2 Epidemiology of Autism Spectrum Disorders: Current Rates, Time Trends and Surveillance

Eric Fombonne, McGill University

In reviewing numerous studies and estimates of autism rates in the population since the 1960s, Dr. Fombonne has found no evidence of an autism epidemic and no evidence to support commonly voiced concerns about a link between childhood vaccinations and autism. He said large recent Canadian and international studies, however, do show that Autism Spectrum Disorders and pervasive developmental disorders (PDDs) are more prevalent than was previously thought and "and more frequent than cerebral palsy, cystic fibrosis and other well known childhood disorders." He noted that the studies indicate an

autism rate of at least sixty children per 10,000, meaning that autism may affect one child in every 165 or close to 50,000 Canadians under the age of 20.

Dr. Fombonne acknowledged that estimates of the incidence of autism in the population have increased, but he noted that the early studies used a very narrow definition of autism and symptoms now linked with autism were then diagnosed differently. According to Dr. Fombonne, better diagnostic techniques, better reporting of autism cases, and a broader definition of autism have also contributed to a higher reported incidence, as have new laws on reporting and the availability of new treatment programs. He explained that a 1979 review of older data using a broader definition of autism than was used in earlier studies concluded that the rate was 20/10,000 – not much lower than rates being currently reported (60-70/10,000). He also said that even this discrepancy can be largely explained by cases being missed historically because of lower awareness of autism, and by lack of recognition of high-functioning autism (e.g Asperger's).

Dr. Fombonne informed the group that while there is no convincing evidence that there is an autism epidemic, as we do not yet have adequate data to assess trends over time, the possibility cannot be ruled out, stating "we cannot be sure, so we need to entertain the possibility that there might still be an increase due to factors that are not yet identified."

With respect to fears about possible links between autism and childhood vaccinations, Dr. Fombonne noted that there are two separate hypotheses – one related to the use of the measles mumps rubella vaccine, the other related to the use of mercury in childhood vaccines (a practice largely abandoned in Canada) – neither of which is supported by scientific evidence. "The epidemiology has been very important in ruling out any connections between immunizations and autism" he said, suggesting that families should vaccinate their children as unvaccinated children are at risk for serious infectious diseases that are preventable. Since there is no evidence of mercury-induced autism, he added, there is no need for chelation therapies that remove metals from the body but may be dangerous.

Dr. Fombonne was asked about the presence of mercury in flu and hepatitis B vaccines. He said that it is true that a very low level of mercury may be present in flu vaccines. However, he said, flu vaccines are not routinely given to children and, in any case, the amount of mercury is very small and is excreted fairly quickly. He said new research by the Center for Disease Control in the U.S. looked at children exposed to far higher levels of mercury in the 1990s and found there was no detrimental effect from exposure to mercury at relatively high level.

Asked about rates of autism in adults, Dr. Fombonne said this is a very important question that has not yet been answered by research. "We need to do those studies," he said, also identifying the need to look at services for adults.

2.2.3 Cognitive Neuroscience in Autism: Where are we? What are the Challenges?

Dr. Laurent Mottron, Université de Montréal

Dr. Laurent Mottron began by providing an overview of the current state of understanding of autism in the field of cognitive neuroscience. Noting that autism is currently defined as mainly based on social impairment, his first area of focus was on the “social brain,” the processing of information from observation of other humans that elicits an emotional reaction. He said research points to some differences, but not a deficit in face and voice processing; a delay in mastering some tasks that measure understanding of other’s people intentions in among individuals with limited oral skills; and an unexpectedly typical performance in perception of basic emotions, depending on task design and task demands. With regard to language, he said there is currently absolutely no biological evidence for differences between autism with and without fluent oral speech. “Nobody is able to provide a clear picture of the relation between language and autism,” he added.

Moving from the specific domain of processing of social information to the higher level of general cognitive processes, Dr. Mottron noted that there are certain peculiarities in the way people with autism process certain perceptions, but these do not translate into overall perception deficits. Since intelligence testing is strongly affected by choice of instrument, he said, “We are at risk of underestimating the level of intelligence, if we use verbally mediated tests, even for verbal autistics.” One unexpected finding from research is that there is “no disproportionate impairment in novel problem solving or in processing complex material,” he added. Also, he said the research has shown conflicting evidence about the rates, nature and implications of mental retardation in autism – “The relation between mental retardation and autism is not understood.” Dr. Mottron also reported inconclusive findings with respect to the neural organization and wiring of the brain, and how various brain regions work together. According to Dr. Mottron, we don’t know whether observed differences in brain structure or function enhance, diminish, or have no effect on performance.

Dr. Mottron also identified various unresolved issues. For example, Dr. Mottron explained that differences disappear with different task instructions, experimental design or conditions, and are not found in all autistic individuals. He concluded by stating two certainties. The first is that autism is “a *distributed* difference – it’s not the cascade effect of a single difference at the genetic or the brain level.” The second certainty is that “describing *differences* should not lead to modifying the status of autistic people as belonging to and contributing to humanity.”

In response to questions about intelligence tests, Dr. Mottron noted that people with IQs of over 70 still need support. Dr. Mottron explained that IQ differences in people with autism do not reflect actual differences in adaptation or intellectual potential, due to the inadequacy of the usual IQ tests to measure autistic information processing.

In responding to a question about learning style and capitalizing on abilities, Dr. Mottron said “We have to bet on the intelligence of an autistic child even if he has the phenotype of retardation.” According to Dr. Mottron, while a certain fraction of autistic children may have ‘true’ mental retardation, there is also a population with a phenotype of low functioning autism which in fact presents a typical level of non-verbal intelligence. For this reason, he suggested, these children should be exposed to printed material and complex material, even without indication of overt attention to this material during its initial presentation – in just the same way that one would not assume that a deaf child could not understand such material.

2.3 Panel Discussion: Research Perspectives on Early Intervention

Dr. Susan Bryson moderated a panel discussion that brought together five leading researchers from different parts of the country, each of whom made a brief presentation on their perspectives around early

intervention. Dr. Bryson noted at the outset that we are at very early stages in early intervention research and that there is limited data to date.

2.3.1 The Behavioural/Developmental Continuum of Interventions for Autism Spectrum Disorders: A Systematic Review

Dr. Veronica Smith, University of Alberta

Dr. Smith presented the findings of a systematic review covering more than 100 studies of autism interventions dealing with the whole lifespan and all intervention types. She explained that the purpose of the review was: to identify the efficacy and effectiveness of studies of interventions for children with autism; to describe participant characteristics, interventions, settings, and outcomes; and evaluate the methodological quality of the studies and the quality of the evidence. The review examined 101 studies, of which 86 were clinical trials, most of them conducted since the 1990s. Participant numbers in the studies were small, with a median of about 20. The average age of the individuals involved in the studies was five. The review characterized the studies according to the types of intervention involved and for the purpose of her presentation Dr. Smith focused on three categories: studies involving Applied Behaviour Analysis (ABA), Contemporary ABA and developmental interventions.

Dr. Smith's review of 31 studies involving ABA indicated that 60% reported statistically significant results that favoured ABA therapy, while a review of 12 studies involving Contemporary ABA showed that 100% of the studies reported statistically significant results that favoured Contemporary ABA. Of the 12 developmental intervention studies reviewed, 83 % reported statistically significant results that favoured developmental interventions. However, the review concluded that the overall quality of the studies was poor. Dr. Smith noted the following issues: 83% of the studies failed to describe the participants adequately to replicate the sampling procedure; the quality of reporting of intervention was variable; only 32% monitored fidelity which is a significant factor; less than half (43%) reported independent outcome assessment; and only 54% reported sources of funding. "We were able to make only five comparisons across the studies and of those we found only two clinically significant findings," she said.

According to Dr. Smith, the implications of the review for researchers are that "we need to make some decisions around participant sampling – either homogeneity or increasing sample sizes. There's a clear indication that we need to provide good treatment descriptions and monitor fidelity, and there needs to be a description of the comparison group". She said the implications for policy makers and families are that there is evidence of effectiveness within this research, but the practices should be employed with caution and closely monitored until a greater accumulation of evidence is present.

2.3.2 Outcomes in the Ontario Intensive Behavioural Intervention Program

Dr. Nancy Freeman, Surrey Place Centre

Dr. Nancy Freeman presented research data from a major Ontario study on the effectiveness of the province's Intensive Behavioural Intervention (IBI) program. She explained that IBI, a specialized form of intervention, considered best practice for young children with autism, has been publicly funded in Ontario since 2000, with services delivered via public programs or by

private providers in a variety of settings, including homes and child care centres. The study examined the files of 332 children in the program (80% of them boys) toward the severe end of the autism spectrum. The average starting age was four and a half years, with 32% starting under age four. According to Dr. Freeman, it was one of the largest (and only) studies to investigate the “real world” effectiveness of IBI in a large and diverse community sample. It looked for answers to two questions:

- Do children improve?
- What factors predict improvement?

According to Dr. Freeman, the study found that IBI significantly reduced the severity of autism symptoms, with children exhibiting less repetitive behaviour when they left the program compared to when they entered it. She explained that these children were relating better to people, with better verbal and nonverbal communication skills, and improved imitation abilities. She also noted that there were significant and sometimes dramatic improvements in cognitive and developmental skills, including self-help skills, social skills, motor skills, and cognitive scores. Children’s progress was quite variable, but as a group, children developed twice as quickly while they were in the program, as compared to before therapy.

Dr. Freeman noted that it is extremely difficult to predict in advance how well any individual child will improve in the program: as expected, there was a wide range of outcome, and not all children do well. According to Dr. Freeman, however, some children achieved average functioning, similar to the “best outcome” children described in other research. Generally, the study indicated that younger, less developmentally delayed children tended to do better, but this was not always the case. Dr. Freeman noted that it was not possible to predict poor outcomes in individual cases. The results support the effectiveness of IBI, when provided in a large community-based program, she concluded.

2.3.3 Early Intervention Outcomes in British Columbia: Two- and Five-Year Follow-up

Dr. Pat Mirenda, University of British Columbia

Dr. Pat Mirenda presented preliminary data from a study that tracked the progress of British Columbia school children during and following early intervention (EI) programs. Between the ages of four and six, the children were enrolled in 15 to 20 hours-a-week of one-to-one programming under a provincial government direct service program, or were receiving equivalent services purchased by parents under a provincial funding program. The study monitored and updated their progress several times until the summer of 2006 when the mean age of the group of 53 children was nine years and four months. The study provides “the only data we know of in Canada that reflect what kids look like after they leave EI,” Dr. Mirenda said.

Dr. Mirenda explained that various tests were used to measure the children’s vocabulary, daily living, communications and social skills, as well as their parents’ stress levels. The study found that children with autism developed more rapidly while in the program than before they entered the program or after they left it. Their rate of change while in the program was, in several categories, faster than the rate of change seen in typical children of the same age. According to Dr. Mirenda, in vocabulary tests the

children with autism changed three to four times faster while in the program, and their rate of change in daily living and communications skills increased from 30% to 50%. After early intervention, their rate of change decreased in most categories to between 25% and 50%. Dr. Mirenda noted that improvements in socialization were not as dramatic as in other areas studied.

According to Dr. Mirenda, the study also found that parenting stress decreased significantly during early intervention and did not increase after the early intervention program was completed.

2.3.4 Effectiveness of the Nova Scotia Early IBI Model: Preliminary

Data

Dr. Isabel Smith, Departments of Pediatrics & Psychology, Dalhousie University and IWK Health Centre

In presenting preliminary data from a newly developed early intervention program in Nova Scotia, Dr. Isabel Smith stressed the need for more information about the effectiveness of community-based programs. She stated that there is essentially no information available about alternate models of early intervention implemented in the community. Dr. Smith explained that the Nova Scotia program, implemented in the summer of 2005, is based on naturalistic applied behaviour analytic intervention, and an essential element is the involvement of families. It employs "pivotal response treatment," which targets areas of development, such as self-initiation and motivation, in order to generate collateral changes - for example, encouraging further opportunities for learning by assisting a child in initiating behaviour. The goal of the program is to enhance social, communication and other adaptive skills.

Dr. Smith described the study, which tracked the progress of 27 children (24 of them boys) with ASD and a range of functioning, through one year of the program, which involved (in addition to parent training) up to 15 hours a week of one-to-one intervention in homes, day cares and other community settings. The children, who ranged in age from two to six, with a mean age of 4.2, had high levels of autism symptoms, with 22% having no functional speech and 52% with an IQ measured to be under 50. The study used a variety of qualitative and quantitative measures. Measurements were taken at baseline and following 6 and 12 months of intervention.

Dr. Smith noted that the children's IQ's at the start of intervention were strong predictors of outcome. Therefore, results were displayed separately for two groups of children, those with IQs of 50 or above, and those with lower IQs. Dr. Smith reported significant and dramatic gains in the children's expressive language skills, with age equivalent scores increasing for both groups of children, though the scores of children with higher IQs increased more sharply in the first 6 months. There were similar gains in cognitive ability, as well as improvements in receptive language. Both groups demonstrated comparable decreases in behaviour problems and parents reported that adaptive behaviour improved after six months.

Describing the results as "very encouraging early data in terms of the effectiveness of a different, less resource intensive model of early intervention," Dr. Smith noted that parent training is a key element of this model of community intervention.

2.3.5 The Development of Clinical Practice Guidelines for Intensive Behavioural Intervention in Ontario

Dr. Peter Szatmari, Offord Centre for Child Studies, Chair of an Expert Clinical Panel established by the Ontario Ministry of Children and Youth Services

In reporting publicly for the first time on the development of new clinical practice guidelines in Ontario for Intensive Behavioural Intervention, Dr. Peter Szatmari said the expert panel he chaired has attempted to "arrive at some consensus and synthesis of evidence around early intervention, a controversial area within the field."

Dr. Szatmari explained that the panel was convened in response to a request from Ontario's Ministry of Children and Youth Services, which was seeking to learn: how to tell if a child will benefit from IBI; how to monitor a child's progress while receiving IBI; and how to determine when a child has achieved expected benefit from IBI. The panel conducted a literature review which examined 3,000 studies, but found just seven reports on five separate studies that addressed the questions and met the panel's strict inclusion criteria: the study group had to have no co-morbid medical conditions (e.g. epilepsy) or severe intellectual disability, the IBI treatment used had to be strictly defined, only randomized controlled trials and controlled clinical trials were considered, quantitative measures to help answer the questions had to be used, and treatment must have started between 24 months and seven years.

Dr. Szatmari reported that the review identified evidence gaps and the panel consulted national and international experts about these, before developing draft guidelines and submitting these to stakeholders for feedback. Dr. Szatmari emphasized that the clinical guidelines were developed through an arms-length process, independent of the Ministry and explained that the guidelines are decision-making tools to guide clinical decisions, based on a synthesis of evidence, stakeholder and expert opinion.

Dr. Szatmari explained that the guidelines established by the panel state that IBI is an effective treatment for children with autism and Pervasive Development Disorder – Not Otherwise Specified (PDD-NOS), but children with a co-morbid medical/sensory problem that *interferes with learning* would not benefit from IBI. The panel recommended starting IBI for children at around 18-24 months of age, beginning with a trial six month period to see if they can tolerate the intensity of the program. Six month trial periods are recommended for children who *start* IBI over the age of seven and children with profound intellectual disability. It is recommended that progress should be monitored with respect to IQ, language, adaptive skills, autistic symptoms and challenging behaviours, so that children can continue in IBI if certain benchmarks of progress are met.

Dr. Szatmari noted that certain issues remain to be resolved, however, including specification of the benchmarks, as well as implementation and evaluation of the guidelines. The panel also recommended

that the guidelines be reviewed as new evidence accumulates. Dr. Szatmari said the panel's next step is to conduct a literature review of non-IBI treatments for children with ASD.

2.3.6 Panel Discussion

Following the presentations of the five panelists, Dr. Bryson provided two points of clarification, noting that the studies reviewed by Dr. Smith and Dr. Szatmari were international studies and that the term "fidelity" used in treatment studies refers to the quality with which the treatment has been implemented. According to Dr. Bryson, few studies monitor the quality of the treatment.

Several symposium participants asked whether skills learned through ABA or IBI interventions can be generalized across different contexts. Dr. Isabel Smith noted that there is evidence from small-scale controlled research studies that naturalistic behavioural interventions do produce more generalization of skills, particularly communication skills, compared with discrete trial based early interventions. Dr. Szatmari said that from IBI programs there seems to be reasonable evidence of language skill improvement, but much less consistent evidence of socialization, daily living skill improvement or changes in autistic symptoms. Dr. Bryson noted that experts acknowledge that these issues need to be more systematically evaluated.

The panel then responded to a series of questions relating to what happens after early IBI, and transitions into school. Dr. Miranda noted that a slowing of children's rate of change after IBI does not necessarily indicate that the children are not doing well. "I don't think we know the answer. People have been so busy evaluating early intervention programs that people are not paying a whole lot of attention to what happens after they leave," she added, saying that she could think of just one follow up study and this group of children did well after IBI.

Dr. Bryson noted parent concerns about the focus on intervention for pre-schoolers, and acknowledged the need to start evaluating interventions in children over six, including the whole issue of which interventions and supports are most appropriate for whom, given the variation in the children. Adolescents and adults should also be considered, she noted in response to a question about the evidence-based treatment available to people who didn't receive a diagnosis until later childhood or adolescence. Panellists responded that there is a wealth of literature that hasn't been well reviewed describing single-cases or small case series of individuals over six years old, from which we can certainly learn.

Other questions concerned what to do when some children are not benefiting from the treatment they are getting and/or even experience counter-therapeutic effects, such as high anxiety levels. Participants also asked the panellists how treatments are monitored in order to introduce modifications if appropriate. Dr. Miranda responded by referring to a study of pivotal response training that identified early building block skills that were missing in children who were not doing well in the program. Remedial work on these skills was done and the children subsequently made progress in the treatment program. "That is what we need to be doing. But clinically to manage that is an incredibly challenging task in terms of funding, because we need to evaluate, we need to have an alternative treatment to offer them, and we even may need to put them into an entirely different treatment on a permanent basis. That means every province needs to be able to offer an array of treatments that can be given to kids depending on their skill levels

and we still don't know from research how to match kids with individual treatment," said Dr. Mirenda, noting that this is one of the goals of a CIHR pathways study of 500 kids currently underway.

Dr Bryson suggested that there is also a need for research guidelines that address clinical child and family issues, as it is important for treatment providers to be able to adapt to different and changing family circumstances.

Several questions concerned how to address the needs of children who are more severely developmentally delayed – a group that is neglected both in terms of services available and in terms of the research. Dr. Szatmari referred to a clinical trial at McMaster University that is offering some children a life-skills programs in addition to IBI, to see whether this component may also benefit cognitive skills.

Dr. Mirenda noted that data from British Columbia showed that many children did not really “take-off” until they had received six months of treatment. This observation is also supported by the Nova Scotia data. She therefore urged caution in applying benchmarks that might cut children off from treatment if they did not show progress after six months.

A final group of questions concerned methodologies, including what conclusions could be drawn from studies without comparison groups (i.e. studies that evaluate progress without control groups that would provide data on expected individual developmental trajectories, or on the development of typical children). Panellists noted that comparisons can be made within groups in terms of the effectiveness of intervention, and that major funding is required for large scale treatment studies.

Dr. Szatmari added in closing: “I think this country has experienced a traumatic event over the last number of years around the field of early intervention. There has been so much acrimony, so much conflict, so many bad feelings that has been generated by this topic. This country has reverted to the legislature and to the courts to come up with clinical decisions as opposed to science. And I think this country needs to see that science – it's not perfect, but it's an iterative process – can inform policy and decision-making and legislation. The science has to come first, but there has to be conversation and dialogue ongoing among scientists, parents and policy makers. And I just hope that this country continues to put money into this kind of research and supports it.”

2.4 Screening, Alternative Treatments, Youth, Adults and Asperger Syndrome

This portion of the symposium, addressed a number of topics of special interest to Canadian families, researchers, and professionals in the autism field. Summaries of presentations by five Canadian experts on the above-noted issues are provided in the following sections.

2.4.1 Screening and Diagnosis of ASD: Best Practice, Recent Advances and What does it Mean for Canadian Families?

Dr. Lonnie Zwaigenbaum, Glenrose Rehabilitation Hospital, Department of Pediatrics, University of Alberta

With new practice guidelines from the American Academy of Pediatrics recently recommending universal ASD screening at the ages of 18 and 24 months, Dr. Lonnie Zwaigenbaum's presentation assessed these guidelines against current best practices and available evidence, while identifying challenges and opportunities for earlier diagnosis of ASD in Canada. "We're at the point in Canada where we need to formulate our thoughts and put our cards on the table and make some recommendations based on what we feel is best for Canadian children and families," he said.

Noting that there is, unfortunately, very little systematic data on the average age of diagnosis of autism in Canada, Dr. Zwaigenbaum said research from the United States and particularly one large recent Center for Disease Control and Prevention study is "very sobering" since it indicates that children are not diagnosed on average until they reach four to five years. The data suggest, he said, that a large group of children is missing out on opportunities to benefit from pre-school interventions.

It is important to remember, he said, that the U.S. guidelines recommending universal screening are framed by other components, such as talking to parents and other care providers, responding on an ongoing basis to concerns as soon as they are identified, encouraging referrals to community interventions and pre-school services, getting more assessment, ensuring that other concerns such as hearing deficits are dealt with promptly, and ongoing follow-up and evaluation beyond the pre-school period, "to ensure that children don't slip between cracks."

Dr. Zwaigenbaum explained that much of what is known about early signs of autism comes from parents and the average age that parents first pick up on concerns is at 18 months or younger. The symptoms that parents identify include:

- Impaired communication
- Atypical social behaviors, such as a lack of response to parent's voice and difficulty in engaging in interactive play
- Atypical play behaviours with an unusual focus on tactile and visual aspects
- Lack of visual tracking, basic imitation skills, eye contact, social smiling and vocalization
- Decreased social interest and sharing of positive emotion
- Preoccupations and repetitive behaviours
- Difficulties with self-regulation extending to feeding and sleeping difficulties
- Extremes of temperament – the passive "perfect baby" or the opposite, a baby who is easily distressed, intensely irritable and difficult to soothe

Dr. Zwaigenbaum noted that "most of what we know about early development in autism comes from parents".

According to Dr. Zwaigenbaum, in recent years, researchers have also had opportunities to "study autism early in life" by tracking the progress of siblings of children with autism, most notably in the Canadian Infant Sibling Study that has followed 150 children from six months to three years old. This has led to the development of the first observational scale designed to detect early behavioral signs of autism in children younger than 18 months old. He warned, however, that none of these signs are universally present and there is no unique profile that characterizes children with ASD.

In reviewing data on existing screening tools, Dr. Zwaigenbaum observed that data is limited and that the two best documented tools have a relatively low rate of success in predicting autism, though the success of one of these is improved significantly when accompanied with follow-up interviews. He said research also shows that higher functioning children with autism and those with PDD-NOS and Asperger's Syndrome tend to be diagnosed later.

In conclusion Dr. Zwaigenbaum emphasized the importance of honest communication about the interpretation and limitations of diagnostic and screening measures. He said it is important to link early detection with effective intervention and that advances may need to occur in parallel, both in a clinical and research context. Dr. Zwaigenbaum concluded that “We have to work collaboratively and make it as easy as possible for families to access specialized assessment and treatment services.”

Dr. Zwaigenbaum was asked what families should do while waiting for services after identification and diagnosis of their children. He responded that it’s important to maximize involvement in community interventions (e.g. preschool programming). He stated that these may not be focused on autism *per se*, but have potential to stimulate social, emotional and communicational development. Dr. Zwaigenbaum noted that there is ongoing research into what interventions are most effective in very young children (12-24 months) with early signs of autism. He also stated that there is remarkable consensus among leading autism interventionists around some of the priorities, including the importance of parents as the main partners in intervention, and the importance of early work on communications skills and social development. He noted the need for recognition in the health system and by policy makers that there is a group of children with ASD that can be diagnosed at an earlier age and we need to be prepared to provide effective, developmentally-appropriate interventions to these children in a timely way.

Dr. Zwaigenbaum was also asked whether screening measures should be implemented even earlier or by different means for infants of known risk for autism. He responded that with up to 20-30% of siblings of children with an ASD diagnosis being diagnosed with ASD or another developmental disorder, there is a strong argument to be made that infant siblings should have their development carefully monitored. He also noted that a positive screen may index a wide range of developmental problems (there are many ‘false positives’; i.e., screen positive cases who do not have ASD, but rather have other developmental difficulties), and a negative screen does not necessarily rule out ASD. According to Dr. Zwaigenbaum, screening tools are best interpreted in the context of more comprehensive developmental surveillance, including ongoing discussion with families about potential concerns, and careful observation of early social and communicative behavior in the infant.

2.4.2 Screening and Diagnosis in Teens and Adults with Autism Spectrum Disorders: The Need Goes On . . .

Dr. Lillian Burke, Psychologist, Regional Support Associates, Woodstock, Ontario

Reporting on her studies and observations in screening and diagnosing teens and adults in the community, Dr. Lillian Burke addressed two key issues: why teens and adults are coming for assessment and diagnosis; and the difficulties in assessment and diagnosis of teens and adults. Dr. Burke said the reasons why some individuals are not assessed or diagnosed until their teen or adult years include:

- A lack of screening programs in schools
- A lack of community services
- An inadequate number of trained professionals; a lack of training or experience in ASD among physicians and psychologists

- Less recognition that ASD could occur in more able individuals prior to changes in the Diagnostic and Statistical Manual of Mental Disorders (DSM) ¹ in 1994 that recognized Asperger's syndrome
- A tendency for individuals to be diagnosed or labeled with other conditions or behaviour problems such as obsessive-compulsive disorder, attention deficit hyperactivity disorder, social anxiety disorder, nonverbal learning disability, or just plain lazy or unmotivated.

According to Dr. Burke, teens and adults seeking assessment include those who(se):

- Were diagnosed as children and now have new difficulties and problems obtaining support or services
- Have been maintained by families that are no longer able to do so
- Symptoms were recognized in childhood but were not formally diagnosed
- Symptoms were never recognized, but now have problems with employment, behavioural difficulties or difficulty in getting needed support
- Were previously treated in environments that emphasized treating symptoms alone rather than giving a diagnosis to guide intervention.

Dr. Burke described her agency, Regional Support Associates, which provides clinical services to people with intellectual disabilities in southwestern Ontario. Dr. Burke said the agency served 1,067 individuals in the first half of the current fiscal year and 135 of them had ASD, including 16 with PDD-NOS, 87 with autism and 32 with Asperger Syndrome. She said screening and assessment can provide people with a diagnosis, information and understanding of their condition; a guide to learning, skill development, intervention and planning; identify referral, support and service needs; and create a data base to inform funders and practitioners of service needs. She noted that there is a need for more information sharing because agencies dealing with adults tend not to specialize in autism.

Key issues that Dr. Burke identified in assessment and screening include: a need for more appropriate assessment tools for people with a wide range of intellectual, speech and language abilities; a need for more consistency across assessment sites; and better availability of professionals to do assessments which address planning and service needs. In dealing with adults, she said, the time has passed for early intervention and what is required is very clear answers to specific questions that will help the individual deal with practical problems.

"Each person with an ASD is unique. While each may share characteristics with others who have an ASD, (s)he will also have differences just as the rest of us do – in adult services we want to celebrate the individuality of the person, support the individuality of the person and help them achieve their goals " Dr. Burke said, adding that assessment can make people aware of some of the characteristics that cause discomfort or difficulty and help find appropriate resources for coping or overcoming these and achieving a better quality of life.

¹ Diagnostic Statistical Manual of Mental Disorders - an [American](#) handbook for [mental health professionals](#) that lists different categories of [mental disorders](#) and the criteria for diagnosing them, according to the publishing organization the [American Psychiatric Association](#).

Responding to a question about the frustration and stresses in the lives of parents dealing with the reality of a child with autism, Dr. Burke stressed the need for family members to take care of themselves by taking advantage of community services (e.g. respite care, circles of support, local autism society services) and natural support systems. She also noted that agencies providing autism services may try to link individuals with other supports.

2.4.3 Complementary and Alternative Therapy

Dr. Wendy Roberts, Developmental Paediatrician, Hospital for Sick Children

Focusing on Complementary and Alternative Medicine (CAM) rather than educational, behavioural or other kinds of therapy, Dr. Wendy Roberts explained that the purpose of her presentation was to “challenge our thinking about what’s a total plan of management that parents need and really think about the tremendous frustration we see day in and day out for parents who are really looking for medical answers, as well as resources to help teach their children adaptive skills as well as academic skills.” She explained that the focus of her talk would be about the most common complementary and alternative treatments that families are currently using, and how we can get research evidence about these treatments currently being used.

She defined CAM as referring to treatments that are used in addition to (complementary) or instead of (alternative) standard treatments. This may include special diets, supplements, megadose vitamins, and herbal preparations that are usually not subjected to rigorous testing for effectiveness or safety. According to Dr. Roberts, the symptoms most often targeted for CAM use include gastrointestinal tract symptoms, in addition to typical autism symptoms.

Dr. Roberts cited surveys showing that alternative and complementary medicines are adopted by a large proportion of parents of children with autism (74 % in one large Boston survey and 52 % in a smaller Montreal study)² and the majority of these are using biologically-based or dietary therapies or supplements. A key trend is that families of children with more severe disabilities tend to use alternative therapies more and their rate of use increases over time. “This makes us feel that we have to get answers, because parents feel they’re beating their heads against a brick wall, trying therapy after therapy, because those are the kids that aren’t making gains,” she said.

According to Dr. Roberts, parents are faced with an “overwhelming” array of possible therapies, but there is very little scientific evidence to guide them. Noting again that one of the most common manifestations of autism targeted with CAM is gastrointestinal symptoms, Dr. Roberts stated that some preliminary data has suggested positive results from the commonly used gluten and casein free diet (improvements in hyperactivity, level of autism and level of communication) and pointed to the need for further study in this area. While studies indicate that a subset of children with autism show gastrointestinal symptoms, “We do not have answers yet to the question of whether there are abnormalities in the gut that could

² E. Hanson et al, *Journal of Autism and Developmental Disorders* 37(4), 628-36, 2007 April; H. Wong and Smith, RG, *J. Autism Dev. Disorders* 36, 901-09, 2006

affect autism in any way,” Dr. Roberts said. She noted that one small study has suggested that omega 3 long-chain fatty acids may be helpful in alleviating autism symptoms.³

Dr. Roberts noted that other CAM treatments have little or no research to back them up. For example, she stated that there is no good evidence regarding the impact of vitamins B6 and B12, magnesium, dimethylglycine, or anti-yeast therapy on symptoms, and solid research has largely discredited some treatments (secretin, chelation therapy).

“So how do we sort out all of these biomedical treatments?” Dr. Roberts asked. “People are trying to find answers. Not all are finding that their physicians are very comfortable in talking about what they’re concerned about, what they’re reading about and what they’re trying. We need to help pediatricians feel comfortable enough with the hypotheses and conceptual bases of the good evidence-based research that is going on, so they can help parents choose from some of the buffet that’s put out in front of them. What are the healthy choices? What are the things that are safe to do? And what are the things that, if we all keep an open mind and keep talking to each other, may lead to studies that will help with finding answers regarding causes?”

Dr. Roberts responded to questions relating to the limited diet that some children may have because of extreme pickiness about their food, by noting the importance of working with a nutritionist whenever possible to ensure that diets are not nutritionally unsound. She recognized, however, this is a resource that is sometimes hard to find. Other questions related to the plethora of treatments that are available, and the lack of available help for parents in trying to determine what is the right choice for their child. According to Dr. Roberts, informed case management is a big need, not only when the initial diagnosis given, but also on an ongoing basis.

2.4.4 Adolescents and Adults: Co-morbidity and Service Needs: “What Happens When He Grows Up, Doctor?”

Dr. Peter Szatmari, Offord Centre for Child Studies, McMaster University and McMaster Children’s Hospital

In reviewing the findings of three recent studies of adults and adolescents with ASD⁴, Dr. Peter Szatmari observed that people with better cognitive skills appear to have generally better outcomes. One study of people with IQs of less than 50 indicated that 57% had very poor outcomes, 21% poor outcomes, and none good or very good outcomes. None had a high school diploma or a job, and only 3% had good language skills. A study of people with IQs mostly over 50 showed that, in terms of outcomes, 12% were very poor, 46% were poor, 10% were good and 12% were very good, with 22 % earning a high school

³ GP Amminger et al, Biol. Psychiatry 61, 551-53, 2007

⁴ Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. J Child Psychol Psychiatry. 2004 Feb;45(2):212-29; Billstedt E, Gillberg IC, Gillberg C. Autism after adolescence: population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. J Autism Dev Disord. 2005 Jun;35(3):351-60. Erratum in: J Autism Dev Disord. 2007 Oct;37(9):1822. Gillberg, Carina [corrected to Gillberg, I Carina]; Bryson S. and Szatmari P., unpublished.

diploma, 33% having a job and 10% having good language skills. Dr. Szatmari also cited A 20-year study conducted by himself and Dr. Susan Bryson which focused on people with non-verbal IQs over 70 and found that at least a third of the adolescents have social lives that involve activities such as going out with friends, joining clubs, remembering birthdays and buying gifts – and the data suggests “a good outcome is definitely possible amongst some individuals.” According to Dr. Szatmari, of this group of individuals with good outcomes, 10-12% had few or no autistic symptoms and none had received specialized services.

Dr. Szatmari reported, however, that most of the people in his study, as children and adolescents, had exhibited clinically significant challenging behaviors and that about half of them suffered from psychiatric illness (anxiety or mood disorders, aggression disorder, oppositional defiant disorder) in late adolescence. He noted that challenging behaviours, which cause a great deal of family stress and lead to greater impairment, were more commonly associated with people who had less proficient language skills and lower non-verbal IQs, while individuals with better language skills were somewhat more likely to suffer from mental illness. He stated, “It’s like you can’t win. If you have good language skills and better adaptive behaviour, you’re able to go out go in the community, but also at greater risk of having a co-morbid psychiatric disorder.”

Dr. Szatmari concluded that, with better cognitive skills, people with autism have a greater potential for better outcomes, but there is also greater variability – “a fanning out” – of outcomes over time, so that adolescents and adults with autism have a wide-range of needs in terms of independent living, medical problems and psychiatric illness. He expressed concern about high use of psychiatric medication, referring to community studies showing that about 40% of adults with Autism Spectrum Disorders are taking psychopharmacologic medication, sometimes three or four at a time, and often with very little evidence of efficacy.

Dr. Szatmari noted that the research indicates that it is very important to plan for a large increase in numbers of adolescents and young adults with ASD, and that a large cohort of children have gone through early Intensive Behavioural Intervention that will likely improve their future outcomes. He pointed out, however, that as these children grow up, they still need an integrated system of supports as adolescents and adults, including case management, psychiatric, housing, recreational, and vocational supports. “Even among the higher functioning cohorts, there is still an enormous need for intervention and support,” he said.

Dr. Szatmari predicted that IBI will shift a whole cohort of children along the spectrum so that they will look more as if they have Asperger’s and will have a greater need for mental health services. He suggested that there is a need for research into what he described as a coming paradigm shift, where the focus must change from treating adults with ASD to improving their quality of life and changing their environment. He noted that everyone should make changes to accommodate those with autism and to celebrate their gifts. He said this change will require a real sharing of resources and breaking down of silos between health, community and social services, education and children and youth services, “as the needs of these adults with Autism Spectrum Disorders are spread out over such a range of disabilities and needs.”

Dr. Szatmari was asked for the definition of Asperger Syndrome used in his studies, and whether it can be distinguished from high-functioning autism. He responded that when the study was started in 1987, “we were swimming in the dark”. Nevertheless, their definition turned out to be essentially the same as that adopted in the DSM-IV which came out in 1994, except that their study specified an IQ above 70. In contrast, most studies find out that Asperger is autism in the absence of clinically significant cognitive and language delay. In their study, the absence of language delay was defined as speaking spontaneously in phrases with a verb by 36 months of age.

In response to a question about co-occurring (“co-morbid”) psychiatric disorders, he noted that children who have better language abilities can more easily express symptoms of anxiety. He noted, however, that the assessment of a co-morbid psychiatric disorder may not involve self reporting from the child, but can be based on behavioural changes as reported by parents.

2.4.5 Interventions for Asperger Syndrome: Current Research and Future Directions

Dr. Kevin Stoddart, Social Worker

Before reviewing current research on Asperger Syndrome, Dr. Kevin Stoddart provided a summary of the diagnostic criteria for the syndrome which include: qualitative impairment in social interaction; restricted repetitive and stereotyped patterns of behaviour, interests, and activities; and no clinically significant general delay in language or cognitive development. “Very rarely do we see a so-called ‘pure case’ of Asperger Syndrome,” he said, noting that because of this and co-morbid disorders, there is a need for good cross-collaboration with professionals in other fields such as attention deficit disorder, mental health, Tourette’s, etc. He stated, “we need to help these individuals with organizational problems, life-skills deficits, sensory and perceptual differences and cognitive strengths and weaknesses.”

Dr. Stoddart outlined various challenges facing evidence-based practice for Asperger Syndrome including:

- Diagnosed controversy over how it is distinguished from high functioning autism
- A lack of studies, randomized controlled trials and few scientists or practitioners working in the field
- A wide array of interventions, but a lack of critical examination of current practice and a history of unsubstantiated treatment claims
- Poor understanding of evidence-based practice in the field
- No national or provincial guidelines for Asperger Syndrome
- Theoretically appealing interventions with little research evidence as to their efficacy

With these limitations in mind, Dr. Stoddart commented on common forms of intervention including group and individual social skill interventions, pharmacological interventions, parent and family interventions, psychotherapy and relationship skills development. He noted that there is a need for further and more systematic research in all these areas to study outcomes including generalization of skills and long-term maintenance of skills. He also cited a need for more sensitive measures of social skills development.

Dr. Stoddart offered the following conclusions:

- Unsupported *children* with Asperger Syndrome are at risk of school dropout, depression, anxiety, and long-term psychosocial problems
- Unsupported *adults* with Asperger Syndrome experience chronic mental illness, legal problems, addictions, unemployment, social isolation and marginalization requiring ongoing dependence on aging parents, social services, the healthcare system and income supports
- In order to ensure the development of comprehensive services for Canadians *of all ages* with Asperger Syndrome we need to:
 - Foster Asperger-specific practice research through national and provincial networks
 - Provide funding for lifespan Asperger-specific services (there is currently a general lack of services for which they are eligible, and frequent misdiagnosis) and research
 - Develop partnerships between national/provincial advocacy groups
 - Promote researcher-practitioner collaborations
 - Ensure best practice knowledge exchange across developmental, mental health, autism spectrum, education, and child and family service sectors.

Dr. Stoddart was asked whether social skills groups should bring Asperger Syndrome and high functioning autistic people together or group them with neuro-typical people. He responded that the literature indicates that some homogeneity of group members is advantageous in order to form a good cohesive group. He was also asked his opinion on the use of group homes. He responded that we have a lot of work to do in the area of independent living and that community resources are scarce. He noted that adults with Asperger Syndrome may have advanced degrees, but may be lacking in basic life skills and that they need support to live successfully apart from their families. He also noted that the Asperger's Society of Ontario has recently published a position paper on this topic.

3.0 Dialogue on Issues Related to Autism

During the final part of the symposium, participants were divided into groups and asked to discuss their thoughts on research priorities in relation to specific topics. The following provides a summary of the key points that emerged from each of these productive group discussions, enriched by feedback received from all symposium participants.

3.1 Knowledge Translation

The goal of this group discussion was to generate ideas on improving access to research findings and improving understanding of how research can contribute to clinical practice and policy.

Discussion highlights:

- Participants discussed the difficulties for families in making sense of all of the information available – often confusing and self-serving – suggesting a need for better integration of information and plain language summaries
- Participants identified the need for a user friendly resource for all audiences that would answer questions on treatments; provide the rationale, goals and evidence behind interventions; and provide information on where to go for help.
- The group also agreed that families need a “dictionary” on autism with a good summary of the different types of treatment.
- Participants stressed the importance that these resources be credible; accessible; non-judgmental; respectful of the needs of those with ASD; useful to varying literacy levels, languages, and cultures; and up-to-date. There was a suggestion that governments or provincial autism societies could take a lead on developing this resource.

The need for research in the following key areas was identified:

- The use and efficacy of a new information resource (as suggested above) to determine the impact of this proposed tool for various stakeholders
- The information sources currently used by parents, what they find to be credible, and why (including “the medical model”, whereby physicians are seen as the primary source of information on ASD, and consideration as to whether this model is effective)
- The provision of services, particularly relating to: how service providers make decisions about treatment, how these decisions are linked with policy, and whether more training is needed for front-line professionals
- How families make decisions related to autism and how they cope
- The state of public knowledge about autism.

Other identified needs included:

- A national autism research council
- A knowledge bridge for exchange of information between families and treatment professionals;

- Training in ASD for front-line providers and educators
- Better understanding of ASD among employers and the public in general
- A clearing house to assist smaller organizations in collecting, evaluating and interpreting research results
- The inclusion of knowledge translation in autism research programs
- Understanding of the knowledge translation tools that might help support people with ASD to better manage their own care

3.2 Interventions

The goal of this group discussion was to make suggestions that could lead to increased understanding of what makes interventions successful.

Discussion highlights:

- Discussing the evaluation of interventions, the group noted that some children have a number of concurrent interventions making it is difficult to separate out their effects; and that it is important to entertain alternative models of evaluations. The group felt that there is a need for better understanding of what interventions work for which individuals, and when.
- A number of considerations were raised with respect to researching interventions, such as: the need to look at interventions across age groups and different models across provinces, including school-based interventions; the importance of ensuring that research is not solely focussed on higher-functioning individuals with autism; the importance that research adhere to recognized standards and good experimental design to ensure quality; the need to consider real world conditions in which interventions are actually carried out; and the need to allow adequate evaluation time for programs under study to show results.
- With respect to the role of families and individuals with autism in research, the group noted that the feedback of individuals with autism on their outcomes would be essential, and that research should be done on the use of parent training as part of intervention programs. The group also considered how researchers can measure parents' opinions about what is working, and how to reflect the fact that outcomes may be different for each individual child.
- In terms of specific types of intervention, the group discussed the risks of being too satisfied with ABA and not looking at alternative interventions. They were also interested in knowing the effects of early IBI on the identity of adolescents.
- Regarding linking policy with research, the group noted that there is a need to improve uptake of research into clinical practice and policy development as well as a need to get research data more quickly, to assist policy makers in making timely decisions. The group agreed that research can provide an evidence base that would help to ensure uniform program availability across Canada.

The need for research in the following three key areas was identified:

- A broader range of evidence-based interventions that have the same standards as other research, and research that covers the lifespan
- Better definitions of good outcomes, which include the input of persons with ASD

- The cost effectiveness of interventions. “Lifespan issues” should be considered in relation to cost-effectiveness and non-financial costs, such as the toll on families, siblings and marriages, should be included.

3.3 Complementary and Alternative Treatments

The goal of this discussion was to suggest approaches leading to an increased understanding of the benefits of complementary and alternative treatments for people with Autism Spectrum Disorders and how they can be integrated with mainstream treatments.

Discussion highlights:

- The group noted that it’s easy to get information from the internet but not easy to tell if it is well researched and valid. They also commented that it is difficult to assess the potential usefulness of treatments. The group pointed to other sources of information on autism – autism associations; other parents; local, national and international conferences; and autism clinics. Concerns were expressed about “fads”, money making schemes, and the vulnerability of parents.
- They discussed the benefits to parents of partnering with a health care professional to help them: work through the maze of treatments; identify the danger, cost and efficacy of interventions; and help clarify credentials of those making claims. It was also suggested that it is important for parents to try one new thing at a time.
- It was suggested that poor funding for interventions and difficulty accessing mainstream services may be reasons why parents seek alternatives.
- Some participants were uncertain about alternative interventions, but most agreed with the value of research to evaluate them.
- Concerns were raised about research methodologies and the importance of designing studies that do not rely on anecdotal evidence. It was also noted that parents should be involved in research projects.

The need for research in the following three key areas was identified:

- Complementary and alternative treatments – more specifically:
 - A retrospective study to see what other treatments are happening at the same time as ABA – other mainstream treatments as well as complementary treatments, for the children who showed improvement
- “Gut” issues⁵ - particularly to support a better understanding of:
 - Whether there are different subsets of autism based on intestinal flora
 - Gastrointestinal function at different ages

⁵ Opinion was not unanimous regarding the importance of researching gut issues. One participant commented that many studies on gastrointestinal function and dietary interventions have been done, and that we should focus on interventions that have not been studied. Another stated that it is important to focus on other medical problems besides gut issues.

- The effects of a gluten-free, casein-free (GFCF) diet
- Whether gut problems correlate with behaviours and/or low-functioning autism
- Approaches being taken by parents – including:
 - Surveying parents to see what treatments they are using that they feel are successful and researching the top three.

3.4 Lifespan Issues

The goal of this discussion was to generate ideas on how to increase awareness and understanding of research gaps with regard to school-age children, adolescents and adults with Autism Spectrum Disorders.

Discussion highlights:

- The group agreed that there is currently a lack of research on adults and lifespan issues.
- Many noted that we need a better understanding of what societal supports, supports for parents, and educational approaches lead to successful outcomes for adults with autism. One participant commented that “we don't know how well autistics could do in a society where it is OK to be autistic”.
- The group discussed the need for school staff to have more training and information to support children so that youth with ASD are understood, supported, and included in the educational and social experience of school. It was noted that there should be transition programs for children entering their school years. Group members suggested that it is important to teach life skills, and evaluate for individuals of all levels of ability across the spectrum.
- It was also pointed out that there is a need to approach ASD research from the perspective of the individual with ASD

The need for research in the following three key areas was identified:

- Training and awareness models across the lifespan for professionals, educators, service providers, community/recreation providers and employers
- What families say they need, what the system provides, and the barriers and facilitators for what families receive
- Life, communication, social, and emotional skills needed across the lifespan for success

Additional areas for further research were also suggested, including:

- The transition from childhood to adolescence, and the effect of puberty on the physical, social and emotional development of children with ASD
- Neurological brain development across the lifespan: how this development manifests in behaviour, and identification of the critical developmental periods for the acquisition of skills
- Longitudinal studies extending into adulthood
- The effects of gender identity on individuals with ASD (e.g. friendships, what is cool and not cool: conformity and nonconformity, fads and fashion)
- The promotion of healthier families through addressing respite needs
- The effects of stereotypes on people's assumptions of individuals with ASD
- The effects of misdiagnosis of mental illness on individuals with Asperger Syndrome

- The components of successful educational supports for children with ASD at different stages across the development spectrum
- The effects of restricted autonomy on an autistic individual's mental health, societal development, and positive self identity
- The types of residential supports (models and values) that make sense for people with ASD
- The need for changing treatment and support strategies over the lifespan

3.5 Screening and Diagnosis

The goal of this discussion was to offer suggestions that could lead to better understanding of how best to do screening and diagnosis, and the role of early screening and diagnosis in outcomes.

Discussion highlights:

- Participants noted that future research should be focused on evaluating screening tools as part of an overall system of care, rather than in isolation. The endpoints shouldn't just be psychometric properties such as sensitivity and specificity, but impact on meaningful outcomes such as average age of referral, diagnosis, and initiation of ASD-specific intervention, as well as resource implications.
- From a parent's perspective, it was observed that there seems to be a lack of screening after the first initial suspicion of autism and that health caregivers need more training on screening and response to initial questions/concerns.
- With respect to relevant tools, it was noted that screening and diagnostic tools may have different uptake across the country and that they tend to be developed for research but they haven't proved to necessarily be effective, reliable or valid in community settings, where adaptation may be required. It was also pointed out that the ADOS (Autism Diagnostic Observation Schedule) and ADI (Autism Diagnostic Interview) have been suggested as gold standards, but there is not complete agreement among clinicians that this is the only model for assessment and diagnosis.
- With respect to health care providers, the group noted that healthcare professionals need to understand the importance of collecting data; of linking data information systems; and of monitoring and comparison. They also discussed the importance of establishing rules or standards for a wide variety of expertise among clinicians.
- In terms of lifespan issues, the group noted that the focus tends to be on children under six, but that older children and adults are still being diagnosed. They agreed that diagnosis, intervention and mental health issues can be more complex for older individuals and that diagnosis of adults is important in order to make provincial governments aware of their needs. The group stressed the need for early treatment following an early diagnosis.
- The group noted the importance of being firm and clear on some principles of diagnosis and assessment in order to protect resources in case of shifts in political will and different political and health care agendas across the country.
- One participant noted the need to develop Clinical Practices Guidelines encompassing individuals manifesting more complex forms of autism.
- The group cautioned against using all resources for research in the early years as learning continues and individuals need new approaches over the lifespan.

The need for research in the following three key areas was identified:

- Models of service delivery for diagnosis and assessment in Canada – including an assessment of inter-provincial differences, strengths and gaps; and the models that are most successful or effective (provincial, international) – possibly toward the use of these as models for Canadian standards and guidelines for autism screening and diagnosis
- Methods/processes that can be used to influence frontline health, educational and social service professionals to more rapidly identify and refer at-risk children, youth and adult -- possibly including the development and use of screening tools (e.g. STAT - Screening Tool for Autism in Two Year Olds) as level-2 screening tools
- The validity and reliability of diagnostic tools and their applicability in a broader mental health population (across all age ranges), addressing how to best disentangle ASD diagnoses from other DSM-IV⁶ diagnoses or co-occurring disorders

Additional areas for research were also suggested, including:

- The rate of diagnostic agreement among different types of assessments and the different diagnostic models
- Whether screening provides families with better information and choices about treatment and supports

3.6 Causes⁷

The goal of this discussion was to generate suggestions that could lead to a better understanding of genetic and environmental causes in order to develop better treatments.

Discussion highlights:

- The group noted that many human genes are involved in brain development so there are many potential candidates for autism genes.
- They noted that environmental factors can affect the genetic material (DNA) and influence gene expression (“epigenetics”). This is a mechanism through which the environment might influence individuals with genetic susceptibility.
- They noted that autism can be considered a whole body disorder, affecting, immune function, infectious processes, the gut, and other systems in some individuals. There is, therefore, a need for treatment and research in a variety of specialty areas.
- One participant noted that we cannot study genetic and environmental factors in exclusion of one another. They commented that we need to understand how all identified culprit genes relate to phenotypes and need to identify common developmental processes and correlate these with potential environmental modifiers.

The need for research in the following three key areas was identified:

⁶ Fourth version of the Diagnostic Statistical Manual of Mental Disorders

⁷ While most participants supported the suggestions, there were some reservations about focusing on this area of research, which some felt is unlikely to help those currently diagnosed with autism.

- The temporal and regional variations in the prevalence of autism across Canada
- Development of animal models of autism that could identify potential genetic causes, and investigate whether altering biochemical processes relating to possible environmental factors changes the presentation of autism associated traits in the model
- Breaking down the heterogeneity of autism symptoms (i.e., develop sub-groups of autism) in order to better understand the causal role of genes and environmental factors

Additional areas for research were also suggested, including:

- Epidemiological studies to determine whether there has been an increase and/or variation in the prevalence of ASD, and whether there are geographical and ethnic variations
- Investigation of potential environmental risk factors identified through epidemiological studies, and how such factors might interact with genetics
- Development of better measures of environmental exposures (e.g. by geographical areas)
- Investigation of the causes of the medical aspects of autism (e.g. gut and immune system)

Conclusion

Participant Comments

At the end of the day, participants were invited to communicate any parting thoughts. At this time, many interesting views were shared.

With respect to research, one participant commented on the need to better fund knowledge translation. Another stressed the need for parents and researchers to work together more closely. The value of good experimental design was also underscored, with one participant commenting, “in the autism intervention research...we are accepting much lower standards for the autistic population than we would for any other population.” The need for reliable information was also emphasized, especially in the area of treatment options, the goals of specific treatments, and evidence for their effectiveness.

From the perspective of individuals with autism, some participants commented on the importance of autistic individuals being heard, being able to advocate for themselves and being in charge of a system that affects their lives. One individual noted the difficulties that both autistics and non-autistics may have in understanding one-another – stating that the problem rests “somewhere in the middle”.

Many participants expressed their appreciation for the event, for the opportunity to learn about autism related research from across the country, and for the chance to engage in dialogue on autism related issues.

Closing Remarks

In her concluding remarks, Barbara Beckett expressed her hope that the symposium had provided everyone with “a much better concept of what we know and what we don’t know through research. Researchers, people with autism and their families, paediatricians, psychologists, social workers, occupational therapists, educators, and hopefully all of those groups whose work impacts on the lives of people and families with autism will have heard some messages that will be helpful in their professional lives. And hopefully people from the autism community will have received as well some information from research that gives them some perspective for their own lives.”

She noted that the goals of the symposium were to inform stakeholders about the current state of knowledge on autism and to assist the research community in planning for the research. “From the perspective of researchers, I would like to think that you have heard today some ideas from the various other sectors that have given you new perspectives or perhaps given you some new ideas for areas that might be researchable within your own means and current set ups and infrastructure. And perhaps it will enable you to do a little bit better research on what you are already studying or perhaps redirect a little bit into areas that you see may be of more direct interest to other stakeholders.”

Appendix A

National Autism Research Symposium

Four Points Sheraton Hotel

6257 Airport Road · Mississauga, Ontario L4V 1E4 · Canada

Phone: (905) 678-1400

Thursday November 8th 2007

Windsor room

- 6:30 PM Welcome from the organizers – Dr. Michael Kramer, Scientific Director, Institute of Human Development, Child and Youth Health, Canadian Institutes of Health Research (CIHR)
- 6:45 PM Is Anybody Really in Charge Here? A Call to Coordinate Diagnostic Procedures with School Supports for Kids with Autism Spectrum Disorders – Daniel Share-Strom, university student
- 7:00PM Autism: Now What? – Jennifer Overton, parent and playwright
- 7:15 PM Autism Spectrum Disorders: Recent Advances and Outstanding Research Questions – Dr. Susan Bryson, Dalhousie University
- 7:30 – 9:00 PM *Cash bar and reception*

Friday, Nov. 9th 2007

Kingston room

- 7:00 AM *Continental breakfast*
- 8:00 AM Welcome – Dr. Michael Kramer
- 8:05 AM Welcome – Hon. Tony Clement, Minister of Health, Government of Canada
- 8:20 AM Introduction of facilitator – Dr. Barbara Beckett, Assistant Director, Institute of Neurosciences, Mental Health and Addiction, CIHR
- 8:25 AM Overview of symposium – Susan Goodman, Facilitator, Policy Planning Plus Inc.
- 8:40 AM *State of the science*
- Autism Genetics: What We Know Now and Why It Is Important – Dr. Stephen Scherer, Hospital for Sick Children, Toronto
 - Epidemiology of Autism Spectrum Disorders: Current Rates, Time Trends and Surveillance – Dr. Eric Fombonne, McGill University
 - Cognitive neuroscience in autism: Where are we, what are the challenges? – Dr. Laurent Mottron, Université de Montréal

- 9:40 AM *Qs and As – the state of the science*
- 9:50 AM *Health break*
- 10:10 AM *Panel discussion: Research perspective on early intervention – moderated by Dr. Susan Bryson, Dalhousie University*
- The Behavioural/Developmental Continuum of Interventions for Autism Spectrum Disorders: A Systematic Review – Dr. Veronica Smith, University of Alberta
 - Outcomes for Children in the Ontario IBI Program – Dr. Nancy Freeman, Surrey Place Centre
 - Early Intervention Outcomes in British Columbia: Two- and Five-Year Follow-up – Dr. Pat Mirenda, University of British Columbia
 - Effectiveness of the Nova Scotia EIBI Model: Preliminary Data – Dr. Isabel Smith, Dalhousie University
 - Developing Clinical Practice Guidelines for Intensive Behavioural Intervention in Ontario – Dr. Peter Szatmari
- 11:40 AM *Screening and diagnosis*
- Screening and diagnosis of ASD: Best practice, recent advances and what does it mean for Canadian families? – Dr. Lonnie Zwaigenbaum, University of Alberta
 - Screening and Diagnosis in Teens and Adults with Autism Spectrum Disorders: The need goes on ... – Dr. Lillian Burke, Regional Support Associates, Woodstock, ON
- 12:15 PM *Lunch – provided*
- 1:00 PM *Complementary and alternative treatments*
- Complementary and alternative treatments: a critical review – Dr. Wendy Roberts, Hospital for Sick Children
- 1:25 PM *Adolescent and adult perspectives*
- Adolescents and adults: co-morbidity and service needs – Dr. Peter Szatmari, McMaster University
 - Interventions for Asperger Syndrome: Current Research and Future Directions – Dr. Kevin Stoddart, social worker, Toronto
- 2:10 PM *Qs and As – screening & diagnosis, complementary & alternative treatments, adolescents & adults*
- 2:30 PM *Breakout discussions – choice of 6 subject areas*
- Knowledge translation: How do we improve access to and utilization of research findings and information about Autism Spectrum Disorders?
 - Intervention: What makes interventions successful? What are the research gaps and priorities? How can research better contribute to clinical practice and policy development?
 - Complementary and alternative treatments: What do we know about the benefits of complementary and alternative treatments for people with Autism Spectrum Disorders? How they can be integrated with mainstream treatments?
 - Lifespan issues: What are the research gaps with regards to school-age children,

- adolescents and adults with Autism Spectrum Disorders?
- Screening and diagnosis: Is there a gold standard? What is the role of families, educators, community organizations etc.?
- Causes: What is the role of genetics and environmental factors? How can this knowledge inform interventions/programs and the daily lives of individuals and families with Autism Spectrum Disorders?

- 3:30 PM *Health break*
- 3:45 PM Reporting back from breakout sessions – Rapporteurs
- 4:45 PM Wrap-up – Susan Goodman, Barbara Beckett
- 5:00 PM *Adjourn*

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|------------|-----------------|
| Don | Kelly |
| Michael | Kramer |
| Mike | Lake |
| Jan | Langford |
| Suzanne | Lewis |
| Tracie | Lindblad |
| Derrick | MacFabe |
| Laurie | Mawlam |
| Jerome | McIntyre |
| Sandra | McKay |
| Danny | Melvin |
| Nancy | Milroy-Swainson |
| Pat | Mirenda |
| Laurent | Mottron |
| Jim | Munson |
| Patricia | Murray |
| Annette | Osted |
| Hélène | Ouellette-Kuntz |
| Jennifer | Overton |
| Louise | Paul |
| Susan | Perkin |
| Louise | Poulin |
| Catherine | Primeau |
| Kathleen | Provost |
| Deborah | Pugh |
| Remi | Quirion |
| Glenn | Rampton |
| Lynne | Renaud |
| Wendy | Roberts |
| Laura | Rogers |
| Mary Ellen | Ross |
| Asimina | Saikaley |
| Stephen | Scherer |
| Maxine | Share-Strom |
| Daniel | Share-Strom |
| Isabel | Smith |
| Veronica | Smith |
| Margaret | Spoelstra |
| Paula | Stewart |
| Kevin | Stoddart |
| Peter | Szatmari |
| John | Tsang |
| David | Vardy |
| Joanne | Volden |
| Kimberly | Ward |
| Sue | Wastie |
| Shannon | Watson |
| Sandra | Weizman |
| Margaret | Whelan |
| Lonnie | Zwaigenbaum |

Appendix C

Speech for The Honourable Tony Clement, Minister of Health and Minister for FedNor, CIHR ASD Research Symposium, November 9, 2007, Toronto, Ontario

Thank you Michael⁸ for your kind introduction and good morning everyone.

It's my pleasure to open this symposium – one that brings together some of our most brilliant and determined researchers.

This is a forum for you all to talk about your efforts and share your knowledge.

Of course, this is also a forum for families and individuals living with ASD to talk about *their* experiences.

In fact I think it's very appropriate that Daniel Share-Strom and Jennifer Overton started things off with their presentations yesterday.

I say so because, although this is a symposium primarily about research, your research is primarily *about* the people and families living with ASD.

It's about building the concrete knowledge base we need to support real and solid hope for the future.

And of course, this is why so many brilliant minds are being brought together here, today.

The more we share knowledge, the more we gain, and the faster we can translate discoveries into new, effective, evidence-based therapies that can provide true hope for Canadians living with ASD and their families.

And so, as I begin, I want to thank all of you for coming, and especially all of the presenters who will share their insights.

But, most of all, I want to thank Daniel and Jennifer for sharing their experiences last night.

Because, just as I gain motivation for my work by hearing directly from my constituents, I know, as researchers you must be inspired by hearing directly from the ultimate beneficiaries of your efforts.

Of course, as a Member of Parliament, I'm not alone in representing a riding in which many constituents are touched by ASD, and who are calling for action.

In fact, I'm one of more than 300.

And as I'm sure many of you may remember, on behalf of our government, last November, I announced five new initiatives to strengthen research initiatives into Autism.

- one, funding a new national Chair in Autism Research and Intervention;
- two, consulting stakeholders toward developing an ASD surveillance program;

⁸ Dr. Michael Kramer, CIHR Scientific Director, Institute of Human Development, Child and Youth Health

- three, adding a new Health Canada web page to provide Canadians with sources of reliable information;
- four, designating our Health Policy Branch as the coordinator for ASD action within the federal Health Portfolio; and
- five, holding a stakeholder symposium to discuss the latest in ASD research.

Today, I'm pleased to report on progress and results.

First of all, on October 20, our government along with the Government of British Columbia announced investments of one million dollars each, creating a national Chair in Autism Research and Intervention, at Simon Fraser University.

Second, over the last few months, our officials have been working with a steering committee to guide us forward in developing an ASD surveillance program.

And I know that a few of you here took part in a technical workshop yesterday, discussing surveillance information needs along with options on how a program could address them.

Of course, more consultations are scheduled in the coming months, and I look forward to the full and final results.

Third, in recognizing the need for Canadians to have access to trustworthy information on ASD, my Department has worked to add a new page to the Health Canada web site.

It holds useful information, including links to external sources such as the Canadian Autism Intervention Research Network, as well as information on federal action to address ASD.

And of course, we will continue to update and enhance it as information, issues and activities evolve.

Fourth, federal action to address autism has been better coordinated than ever before - and this was the goal of designating our Health Policy Branch as the lead coordinator of work on ASD happening throughout Health Canada, the Public Health Agency of Canada and the Canadian Institutes of Health Research.

Fifth and finally, we committed to holding this very symposium.

And it's here that we're bringing together the leaders in ASD research.

This is a forum for researchers and members of the ASD community to connect with one another so we can make greater headway in pursuing answers, for the benefit of Canadians and families living with ASD.

We need forums like this because we need greater collaboration, for greater knowledge to produce real results for families.

Although the past 25 years have seen a dramatic increase in ASD knowledge and awareness, I'm sure everyone here knows quite well that we still have far more questions than answers.

And of course, the questions run far deeper than "how do we best treat or prevent ASD," as many are still asking, "what causes ASD?"

Even scientists who agree that the cause is genetic are still asking: "what are the key genes?; in what way do they affect brain circuitry?;" and "to what extent do they influence the risk of developing ASD?"

And then there are still a host of questions on what role environmental factors play – if any – during pregnancy and after birth?

Yet in the face of these questions, and many more, when it comes to causes, health professionals still lack an objective means of diagnosing ASD.

If what William Shakespeare wrote in Twelfth Night is true, that “there is no darkness but ignorance,” then, by all means, research is humanity’s brightest light.

Research converts questions into answers.

Research separates fact from fiction.

And as a result, research is the backbone for all truly effective policies and therapies.

As I’ve noted, since the 1980’s, great strides have been taken and I’m proud to say that the Canadian Institutes of Health Research has supported many of them.

For example, CIHR has invested in a team of 10 Canadian researchers based at McMaster, McGill, Dalhousie, UBC and Toronto. This team is following more than 400 Canadian children with ASD for 5 years.

And they’re focussing on the critical transition between the initial diagnosis of ASD and starting school.

Their results may help shape new programs and interventions to help families during this challenging time in life and increase the likelihood of a positive transition.

Of course, CIHR is also supporting the work of a group of research stars here with us today, including Doctors Lonnie Zwaigenbaum and Susan Bryson.

Together, they are conducting research for developing the Autism Observation Scale for infants, and their work aims at identifying symptoms in children faster.

And on this note, along with Genome Canada, CIHR provided support to the Autism Genome Project, led by Doctors Stephen Scherer and Peter Szatmari, who are both here with us today.

In February, the Project made front page news in Canada with a breakthrough –one that brings us closer to understanding the genetics of autism – and that could eventually lead to earlier diagnoses.

As optimistic as I was to hear this news, I also understand the importance of not rushing to conclusions or assumptions.

I say so because, I can only imagine how high the hopes of some family members jumped upon opening the morning paper and seeing the words “autism” and “breakthrough” in the same front page headline.

Most people, when they think “news,” they think “now.”

Yet, of course, despite the fact of this breakthrough’s enormous importance, it’s difficult to tell when it will make a practical difference.

And to me, this underlines the frustrations of families living with ASD.

As any parent can and will tell you, help for children in need can never come soon enough.

The desperation being felt by so many families living with ASD today in Canada is understandable and justifiable.

But we have to guard against the urge of families to let this force them off the evidence-based path being paved by so many of the researchers here today.

As we all know, buying into false hope can have drastic consequences.

Leaping to conclusions or rushing to judgement can only lead us all off course.

For example, in addressing the Senate Standing Committee on Social Affairs, Science and Technology last year, Doctor Szatmari provided a poignant example.

Today, there are still a number of web sites promoting vaccinations against viruses like measles and mumps as a cause of ASD.

Of course, this is only a theory.

And another researcher, who will be speaking to you all here later this morning, Doctor Eric Fombonne, has conducted research finding absolutely no scientific evidence to back this theory.

Despite this, many fearful families acted on this theory of vaccination as a cause, and needlessly subjected their kids to a heightened risk of outbreaks and infection.

Fortunately, the more research advances, the more knowledge gaps get filled, the more misinformation gets dispelled and the more families can get real help.

I know that there are a wide range of different treatments for autism to which some families are very committed – and whenever any one therapy benefits any individual child, this is a great thing.

However, as Health Minister, I am keenly aware of the crucial need to support the *science* behind actions that will ultimately benefit the many – and I am confident that research is the way forward.

Through the work of so many of you here today, the answers are coming, the mysteries are being unwrapped.

But more research is needed, more collaboration is needed, and this is what today's event is all about.

Of course, our Government is supporting research efforts and supporting families.

For families, this is why Budget 2007 invested \$140 million over two years to establish a Registered Disability Savings Plan.

For research, this is why the Speech from the Throne pledged our government to supporting Canadian researchers in developing new ideas through Canada's Science and Technology Strategy.

It's why Budget 2007 invested an additional \$37 million per year for health science research through CIHR.

In addition, our Budget invested \$35 million over two years and \$27 million per year thereafter to support an additional 1,000 students through the Canada Graduate Scholarships.

And these new health research scholarships will be dedicated to the memory of leading Canadian researchers, including Nobel laureate Sir Frederick Banting and Dr. Charles Best who led the world in the development of insulin.

While the new investment is most significant, I think it's also important to recognize and publicly document the volumes of Canadian research accomplishments, which have saved thousands upon thousands of lives.

The work of Banting and Best surely belongs in this book.

So does the support Canada's Connaught Laboratories provided in making Jonas Salk's polio vaccine accessible to millions in the 1950's.

I'm confident as well, that the work of Doctor John Dick and his team on stem cells and colon cancer may one day be recognized as the start of another important chapter.

And of course, with all of the knowledge, energy and determination being shared, and being magnified here today, it's my hope, and one I share with all of you, that your work will form an important chapter as well – for the benefit of Canadian families ... and the world.

On behalf of our government, I commend all of you for the work you are doing and that you will help advance here today.

Thank you.