



# **CAIRN: A guide through difficult terrain**

Canadian Autism  
Intervention Research Network  
Conference  
October 2, 2009  
Toronto, Ontario

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## **Key Messages**

At the 2009 CAIRN Conference over 100 parents, practitioners, people living with ASD, policy makers, and researchers met to discuss the most pressing research issues in ASD. These were their suggestions:

- The need to develop and evaluate the effectiveness of lifespan supports.
- The need to identify barriers to timely access to early intervention services.
- How can we provide the training teachers need to support students with ASD?
- What is the most cost effective means of identifying ASD across the life span?
- The need for evidence-based interventions for children identified through early screening that are appropriate both in terms of chronological age and developmental level to ensure timely access in communities across Canada.
- What gene-environment interactions predispose children to develop ASD?
- How do we provide researchers and practitioners with training and support to engage in knowledge translation activities?
- How do we provide policy-makers and practitioners with the most reliable research evidence to support evidence-informed decision-making for children with ASD?
- There is an urgent need for Canadian research, relevant to policy development, on the major life transitions experienced by people with ASD. These include life stages (e.g., adolescence, adulthood) or those occurring between service sectors (e.g., entry into school, from school to community).
- Lifespan and family systems perspectives on transitions are essential, incorporating both factors that may be specific to persons living with ASD and what is known from studies of developmental disabilities, in general.



## **Background**

Since its inception in 2001, CAIRN has brought together parents, practitioners, researchers and policy-makers from across the country to address issues related to Autism Spectrum Disorder (ASD). To date, three national CAIRN conferences have been held in Toronto focusing on bridging the gaps between evidence and practice, and fostering collaboration to inform the research agenda. The culmination of the 2004 conference was the establishment of a national ASD research agenda. (For details see <http://www.cairn-site.com/en/nra.html>.)

In our funding proposal to Health Canada submitted in October 2008, we described a project in which the main goal was to generate and disseminate evidence-based knowledge on ASD and to enhance awareness and collaboration among a variety of stakeholders such as parents, professionals, researchers, policy-makers, and people with ASD.

To reach that goal, we set four objectives. The first of these was to develop and post an online national survey of research priorities in ASD to be completed by parents, professionals, researchers, policy makers, and people with ASD. The second was to hold a national ASD conference in the fall of 2009 to bring together members of all stakeholder groups from across Canada to share the findings from the national survey of research priorities in ASD, and share and discuss the initial findings of the Pathways in ASD research project. The Pathways project, funded by the Canadian Institutes of Health Research and Autism Speaks, includes both a national longitudinal study of children with ASD and a study of current ASD policies in Canada. The third objective was to enhance the CAIRN Web site ([www.cairn-site.com](http://www.cairn-site.com)) making it the primary Canadian bilingual source for disseminating evidence-based information about ASD. The final objective was to synthesize the information obtained from Objectives 1 and 2 to develop an updated ASD research agenda.

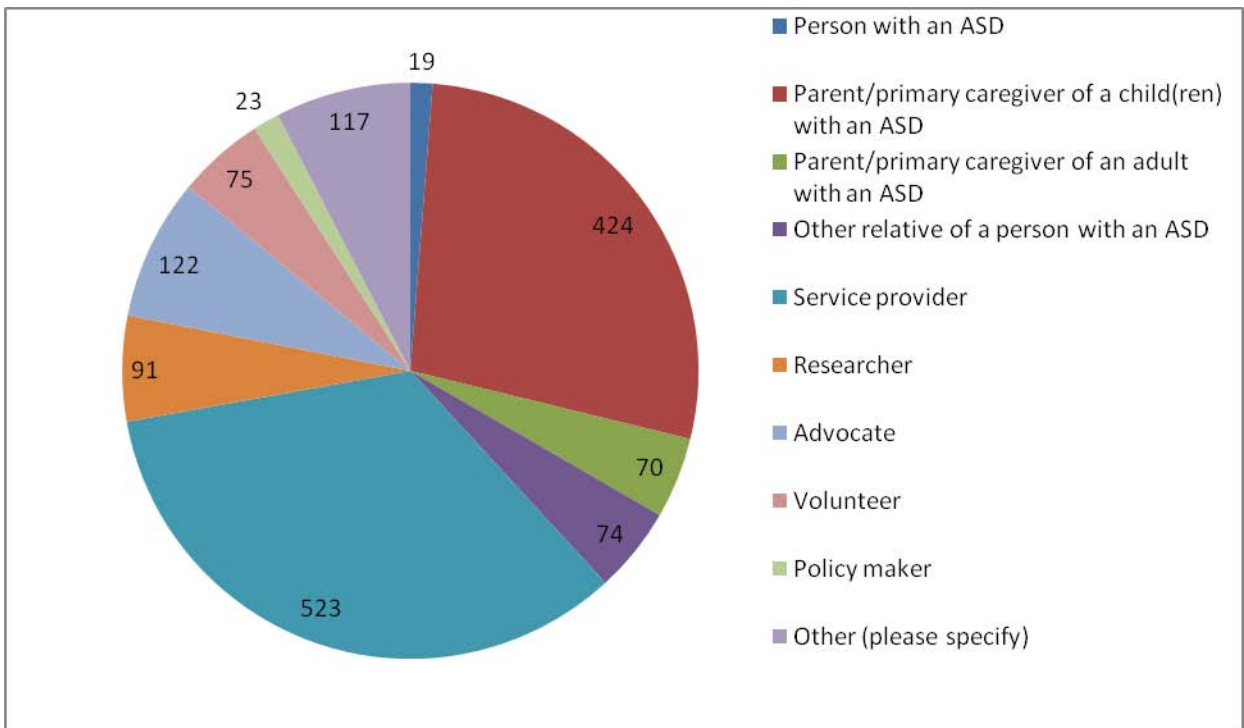
### **The Online Survey**

We identified the research priorities of 1003 survey participants (both English and French). Wide distribution of the survey instrument was accomplished by contacting members of CAIRN's web site subscription list and posting it on the CAIRN, Autism Speaks Canada (AS), and Autism Society Canada (ASC) Web sites. Personal contacts with professional associations, student groups, and

other parent organizations were made by CAIRN, ASC, and AS representatives. The survey was also distributed through a list serve by a parent representative on the CAIRN Steering Committee. The priority research topics/questions identified through the survey were (number of responses in parentheses):

- Treatment (839)
- Education (610)
- Transitions (531)
- Causes (428)
- Knowledge translation (402)
- Diagnosis/screening (397)
- Health Issues (374)
- Outcomes (365)
- Policy (328), and
- Epidemiology (243)

Categories of survey respondents (more than 1 category could be selected)



For further information about the findings, please go to [www.cairn-site.com/en/conference/2009/cc.html](http://www.cairn-site.com/en/conference/2009/cc.html)

## **The Conference**

On October 2, 2009, we held our 4<sup>th</sup> national ASD conference in Toronto. One hundred and four people attended the conference, with representation from parent groups, Autism Speaks Canada, researchers, clinicians, other service providers, Autism Research Training program students, policy makers from all provinces, and, for the first time, members of Autism Society Canada's Advisory Committee of Adults on the Spectrum. The inclusion of the adults living with ASD was met very positively by all the participants, who remarked on the fulfillment of a previously unmet need to hear the voices of this constituency, and by the Advisory Committee's members, themselves, who felt heard and welcomed to the conference.

In the course of this conference we were able to share and discuss a) the findings from the national survey of research priorities in ASD, and b) the initial findings of Pathways in ASD, a national study examining the developmental pathways of children with ASD and current ASD policies in Canada.

### **Conference Activities**

The group of 104 participants was welcomed by Dr. Peter Szatmari, and Senator Jim Munson. Ms Lillian Bayne of L. Bayne & Associates, Victoria, British Columbia, outlined the day's format and activities, which included presentations on various aspects of the Pathways in ASD project by Dr. Charlotte Waddell, Mr. Cody Shepherd, Dr. Susan Bryson, Dr. Eric Fombonne, and Dr. Peter Szatmari. Ms Patricia Colton presented the online survey findings.

(Slides may be viewed at [www.cairn-site.com/en/conference/2009/cc.html](http://www.cairn-site.com/en/conference/2009/cc.html)).

The small group work sessions followed. Participants were assigned to six groups based on their pre-selected topic preferences. All of the groups, each based on the top choices as indicated in the online survey, had a mix of professionals, parents, and adults living with ASD.

Each of the small group sessions was facilitated by researchers with special expertise in the topic. The Treatment group was facilitated by Dr. Susan Bryson, Education by Dr. Pat Mirenda, Transitions by Dr. Isabel Smith, Causes by Dr. Peter Szatmari, Screening/Diagnosis by Dr. Lonnie Zwaigenbaum, and the Knowledge Translation session was facilitated by Dr. Charlotte Waddell and Mr. Cody Shepherd.

The facilitators introduced each topic using a template composed of four questions: Why is this an important topic? What do we currently know about it? What have we learned in recent years (i.e., new developments of which everyone will not necessarily be aware)? and What don't we know?

Each participant was asked to identify why this topic area was of interest to them, and what in particular they wanted to know in this area. Participants were asked to reflect and share their thoughts on the following:

- Why does this question matter to me?
- What will an answer to this question tell us?
- How will the knowledge generated be used?
- Are there other research topic areas to which this needs to be linked? Why?

Participants were encouraged to make diary entries based on these questions:

- What did I learn in this session?
- What did I agree with? Disagree with?
- What will I take away?
- What will I talk to others about?



### **Small Group Session Reports**

## **Treatment**

**Facilitator: Dr. Susan Bryson**

**Note takers: Steven Gentles and Emma Duerden**

Discussion focused on ASD treatment research priorities, prefaced by a brief overview of existing research on both the efficacy and effectiveness (as implemented in communities) of treatment/intervention in ASD. Existing findings, derived largely from studies conducted in highly controlled university settings, have established the efficacy of several approaches, particularly those that employ behavioural/ABA techniques and focus on specific targets (e.g., language/communication, social and other adaptive skills; see, e.g., report of the “National Autism Centre” in the United States, 2009, for review of several treatment/ intervention approaches rated as “established”). We know relatively

little about the effectiveness of community-based treatment programs, and even less about the relative effectiveness of different treatments or service delivery models. Within our groups, there was wide recognition of the paucity of research in Canada on effective treatments/interventions or service delivery models for ASD, in part due to the lack of available services. The major exceptions are community-based early intervention programs, implemented across the country, but, except for a few studies, there are no data on their effectiveness. Among the questions raised are: Do we have evidence that treatment delivered in a given province/community is effective? Or, do we even know that the treatment is being implemented properly? In this context, it was emphasized that care needs to be taken in drawing any conclusions about a given treatment in the absence of appropriate quality control. Community-based early intervention programs in Canada are being delivered by paraprofessionals, but little is known about the quality of programming or supervision. Moreover, virtually nothing is known about treatment models that span into adulthood and the senior years. What would a viable, cost-effective lifespan service delivery look like? Finally, concern was expressed about the untenable quality of life experienced by families living with a family member with severe behaviour problems, many of whom are severely disabled without a functional communication system.

Major themes explored include the need for:

- A clear sense of the over-arching goals of treatment research, notably to support and enable children and adults with ASD so that they can function more effectively (e.g., vs. striving to change them into “neurotypicals”, at the risk of losing their personal identity) and experience a better quality of life; related goals are to:
  - facilitate access to regular social, recreational and spiritual opportunities, as appropriate;
  - enhance understanding of the diversity and cultures among those with ASD;
  - be careful not to over-medicalize ASD, risking the emotional and social well-being of individuals, while recognizing the need for appropriate medical care; and
  - seek ongoing input from individuals with ASD and other key stakeholders.
- Development and evaluation of lifespan supports and interventions/

treatments in communities, with a particular focus on older children and adults, and individuals with severe behaviour problems, some with limited, if any, speech, and including support for parents.

- Major research efforts aimed at establishing the effectiveness of various forms of intervention/treatment (across disciplines), with a focus on those that are most promising, feasible, sustainable and cost-effective, and including information on:
  - the relative effectiveness of different treatments and service models
  - which treatments are most effective for particular children and adults
  - “acceptable” minimal interventions (vs. “all or none”, although some viewed this as potentially discriminatory vs. standard practices with other disorders)
  - critical family variables and readiness for treatment
  - the specifics of what treatment was delivered
  - possible confounding variables (e.g., co-existing medical problems or treatments, or parental stress, that might account, even partially, for the effects of the treatment under study)
  - treatment fidelity
  - whether behavioural/ABA treatment makes a difference with older children
  - more socially valid, quality of life outcome measures
  - sex differences
  - the characteristics of non-responders
  - both short-term and long-term outcomes
  - biomedical treatments that have best evidence for effectiveness, recognizing that we need more understanding of the biology of ASD before we can propose appropriate biomedical treatments
- Research aimed at ensuring more timely access to appropriate intervention/treatment, recognizing all of the above and that:
  - timely access to diagnostic assessments is critical (e.g., otherwise the early “window of opportunity” is lost and parents can lose hope)
  - treatment needs to be individualized, and, where appropriate, focused on language/communication
  - sensory issues may need to be considered (and may reflect a physical condition, or a particular learning history, thus underscoring the need for care in deciding what treatment is most appropriate)
  - good standard medical care is essential (notably, physical problems might interfere with learning/progress; several examples were provided of everyday medical conditions, which, when treated, led to considerable improvement)

- Research on effective parent training programs (e.g., parents often are unsure about what to do, and have limited or no resources, or are overwhelmed by the mass of information, some of which is contradictory; the need for training sessions and education on basics of ABA and other evidence-based teaching strategies, and opportunities to talk to other parents and to individuals with ASD in order to see the positive qualities of people with ASD).
- Research on effective training programs for direct service providers in the community; and, more generally, research on effective ways of educating physicians and other clinicians, teachers and other school personnel, and community care providers about ASD.
- Effective knowledge transfer of advances in treatment research, including:
  - success stories about older individuals with positive outcomes
  - information on how to manage the message (e.g., strong claims from untrained people, and a lot of people are trying to push some interventions, diets for example, as if they are good for everyone, while others are trying to scare everyone away from some interventions)
- Effective knowledge transfer aimed at informing funders that:
  - the priority for families is research on treatment and support
  - a variety of methods are warranted and have merits, depending on the status of evidence and the context (e.g., RCTs may neither be possible in community contexts, nor necessarily warranted until there are positive findings using other methods, and other experimental methods have distinct strengths)
- Enhanced shared (common) knowledge regarding efficacious/effective treatments/intervention (e.g., via a website); general recognition that families need to be informed to make good decisions; suggestion that CAIRN might do this.

Consider the relative merits of establishing a national standards report for the support and treatment /intervention of children and adults with ASD.

## **Education**

**Facilitator: Dr. Pat Mirenda**

**Note taker: Jillian Filliter**

Most individuals with autism spectrum disorders spend the majority of their formal learning time at school; however, school attendance does not necessarily result in learning in many cases. While some schools are successful at meeting the educational needs of students with ASD, many are not. Examination of

issues related to educational success and best practices is necessary in order to improve the current situation for all learners with ASD.

Currently, we have research supporting a number of elements that are critical for school success for learners with ASD. These include the use of a wide range of environmental and curricular modifications, general education classroom supports, specific instructional methods, and attitudinal and social supports. In a recent report by the National Autism Centre in the United States (2009), several school-appropriate intervention approaches were rated as “established,” including: antecedent interventions that are designed to reduce the likelihood that problem behaviours will occur and behavioural treatment packages that include strategies for teaching alternative replacement behaviours. Additional interventions rated as “established” include video modeling, naturalistic teaching strategies, peer-mediated interventions, visual schedules, self-management skills, and story-based scripts. We also know that a coordinated team commitment, recurrent evaluation, and home-school collaboration are essential.

We have learned that, with the appropriate supports in place, many students with ASD can learn important skills in general education classrooms. We have also learned that, without such supports, learning is unlikely to occur in EITHER general or special education settings.

We know very little about how to manage the transition of young children with ASD (both those who receive early intensive intervention services and those who do not) into the school system; how parents, teachers, and students with ASD themselves define “success;” what core competencies are required for educational personnel to be successful; and how to support adolescents and adults as they transition from school to work. Some key questions identified were:

#### Core Personnel Competencies

- ▶ What are the core competencies that school personnel (e.g., teachers, administrators, speech language pathologists, educational assistants, etc.) require to support students with ASD?
- ▶ How do these competencies differ depending on student age or grade?
- ▶ How are school personnel currently trained and how can we design training programs that better equip these individuals to work with students with ASD?
- ▶ How can we best match the competencies of school personnel to the needs of the students that they are working with?

## Definition of Success

- ▶ How do we define success within the school system? For example, do we consider success to be academic progress, social networks, student and family happiness, etc.?
- ▶ Do different stakeholders (e.g., parents, children, teachers, etc.) define success in the same way?
- ▶ In what ways do cultural factors influence how individuals define success?
- ▶ How do individuals with ASD define success (including within the social domain)?

## Best Practices

- ▶ What are the practices employed by the schools that are considered to be “the best” with respect to peer support, programming, etc.?
- ▶ What factors contribute to the emergence of these schools as leaders in the education of individuals with ASD?
- ▶ How can we ensure that school philosophies and curricula reflect the importance of fostering social functioning and community relationships?
- ▶ How do we identify the schools and people that are championing best practices?
- ▶ How can we use parents’ knowledge of their children to learn how to best support individuals with ASD within the school system?
- ▶ What are the best practices for helping individuals with ASD to deal with bullying, conflict resolution, community awareness, sexual health education?
- ▶ Once we know which competencies and characteristics are present within schools that best support individuals with ASD, how can we move other schools, personnel, etc. in the same direction?

## Adults & Post Secondary Students

- ▶ What are the needs of, and established treatments for, adults and post-secondary students with ASD?
- ▶ How can we provide adults with ASD with the social, vocational, independent-living, self-management, and self advocacy skills, as well as post-secondary supports, that they require?
- ▶ What are the barriers that adults with ASD face in pursuing educational opportunities?

## Differences across Jurisdictions

- ▶ What are the different provinces in Canada doing regarding ASD education and treatment?
- ▶ How can we create more equality across and within provinces with respect to the services that are available?

## Transitions

**Facilitator: Dr. Isabel Smith**

**Note takers: Emma Duerden and Carley Piatt**

There is sparse literature that addresses issues related to lifespan transitions specifically for persons with autistic spectrum disorders (ASD). There is, however, a substantial literature in the more general field of developmental disability. Although much can be learned from this research (for example, in terms of predictors of independent living outcomes), there is also reason to suppose that there may be unique aspects to the experience of persons with ASD and those who support them. For instance, a distinction is made between “horizontal” transitions (i.e., relatively micro-level transitions between activities or settings) and “vertical” transitions (i.e., those macro-level transitions such as between stages of life, or with reference to major systems such as health or education). There is broad recognition that persons with ASD have particular difficulty with horizontal transitions, and it is common to consider specific supports related to these differences. This might lead to the assumption that navigating vertical transitions might also present particular challenges in ASD. However, empirical evidence on this issue is only beginning to emerge. Since transitions frequently refer to relationships between systems, it seems likely that some findings might not be readily transferable from one country to another. Thus, there is a particular need for Canadian data relevant to this topic. As an example of recent Canadian research, Levy and Perry (2008) studied professionals’ perspectives on the transition of children with ASD from Ontario’s IBI program to the public school system.

Participants in the two small group sessions were highly engaged in the topic. One powerful aspect of both sessions was hearing the language of families as they discussed their experience of lifespan transitions: “falling off a cliff”, “hitting the wall”, “dropping off the table”, entering the “void”, “starting all over at each transition”. Another over-arching observation that emerged over the

day was that often, transitions were defined in relation to formal systems – usually the education system – rather than individual developmental experiences or needs. That is, transitions -- such as preschool to school, junior high to high school, after high school – that are relevant only to 12 or so of the child’s/family’s first 17-18 years. Participants identified a variety of other milestones and contexts that involve important transitions for individuals and their families, such as from the stage of parental “concerns” regarding a young child to diagnosis, from pediatric to adult health care, or from living within a family context to alternative living arrangements. The following themes emerged from the two group discussions: (1) the necessity of a lifespan view of transitions; transitions are a fact of life, not an anomaly, and (2) the importance of family systems perspectives; this might include effects on the individual, on sibling, parents, and extended family, as well as the relationships between and among these family members.

With respect to research needs, one suggestion was to build on what is known from other related research literature (e.g., re: persons with intellectual disabilities). Issues of definition and measurement were regarded as crucial: e.g., how to determine what are the most challenging transitions and how to define them; what constitutes a successful transition outcome, and how does one measure this?

One research approach that was suggested was to begin with a needs assessment, that is, to identify where gaps exist in transition services. This approach presupposes that “transition services” exist or that these are built into other services, and that the search for same will reveal gaps. One novel re-interpretation of this issue was the suggestion to look for opportunities to eliminate unnecessary transitions (that is, the idea of “seamlessness” conceived as an absence of noticeable transitions).

Another approach was to identify models of what seem to be successful programs or practices promoting transitions (that is, exemplars of ‘best practices’) and to “shine a light” on these. That is, to systematically examine the factors that might contribute to successful transitions. Once the success of small-scale programs was identified and analyzed, research efforts could shift to replication and expansion of models built on the successful template.

Recognizing the pervasiveness of transitions across contexts and over the lifespan, one participant suggested that all research projects should incorporate a component that examines transitions (where possible and

appropriate). Underlying such a strategy was the idea that knowledge about transitions would accrue incrementally.

Other stakeholders and participants need to become involved in research discussions concerning transitions – funders were an important example. Employers are also important players in research surrounding the needs of adults with ASD. Perhaps issues of accountability for programs are highlighted when stakeholders such as employers are included.

In addition to funders, there is a need for input from health policy experts. What are the drivers of policy change that might influence the development of enhanced transition services? These perspectives are needed at all levels from local and provincial to national policy- and decision-makers. Contributions by health economists would be appropriate additions to research teams addressing such issues.

## **Causes**

**Facilitator: Dr. Peter Szatmari**

**Note takers: Stephanie Patterson and Sharon Smile**

A complete understanding of the causes of autism is still lacking but we have made a lot of progress in the last few years. Now there is good evidence that ASD is a biological disorder, but one which can be affected by experience such as treatment interventions and extreme deprivation. For instance, Romanian adoptees have been shown to have some ASD characteristics that tend to dissipate with good care and affection.

Brain imaging studies have also made major contributions to our understanding of ASD. For example, many children with ASD have a larger head compared to their same age peers. It is likely that this increase in head size can be accounted for by an increase in white matter, the tissue in the brain through which messages pass between different areas of gray matter or neurons. Functional imaging has also shown important differences in local vs. long range communication in the brain. Long range communication (front to back of brain) is not as efficient in individuals with ASD compared to people without ASD.

What have we learned in recent years?

There has been an incredible growth in our understanding of the genetics of ASD. In the last five years, a great deal of evidence has accumulated that ASD

is associated with dozens of different rare structural variants in DNA termed 'copy number variants' (CNVs). The genes implicated in these CNVs appear to have a common purpose; they affect how nerve cells communicate with each other. This fits nicely with imaging studies on how parts of the brain communicate.

In contrast to evidence for rare genetic variants, there is not much evidence for more common changes in genes acting as risk factors. Epigenetics, a process through which gene expression is altered without changes to the DNA, may play a causal role as well. There are no definite findings at present on epigenetics as a causal mechanism in non-syndromic ASD (e.g., autism and Prader-Willi syndrome), but advances in technology will open up the possibility of learning more.

Environmental risk factors are attracting more and more attention. It has been known for quite some time that when valproic acid, a drug used to control epilepsy is given to pregnant mothers, there is an increased risk of ASD in their offspring. New evidence suggests that there is also an increased risk of ASD if the mother or father (or both) are over 40 years of age at the birth of the child with ASD. The mechanism for this effect is unknown. Other evidence implicates pesticides: new studies show that those living closer to farms with organochlorine pesticides appear to carry a higher risk for ASD symptoms or disorder

There is still quite a bit of interest in understanding the role of autoimmune disorders in causing autism. Some studies have reported that a family history of an autoimmune disorder, or a parent with type 1 diabetes, indicates an increased risk of ASD. The mechanism for this is also unknown but may be through effects on the developing foetus. Pregnancy and birth complications are the subject of new studies looking at low birth weight as a risk factor for ASD.

Why is a search for causes important?

It is now clear that a better understanding of underlying mechanisms can lead to advances in treatment. For example, there are strong associations between ASD and both Rett's syndrome and Fragile X syndrome. Animal studies are underway to reverse the molecular abnormalities seen in Fragile X and Rett syndrome. There is no reason why similar breakthroughs are not possible in ASD once we have a better understanding of biochemical abnormalities.

What are we interested in learning about? What do we want answered? What don't we know?

The morning and afternoon groups proposed a number of different areas and cross-cutting themes that included focusing on mirror neurons (involved in imitation), the subgroup of people with ASD with co-morbid intellectual disability or sensory processing problems, the concept of a family of phenotypes (that is, that other conditions such as schizophrenia are related by means of a common genetic pathway); the concept of heterogeneity of causes (in which different subsets of ASD may have different causes); a systems model of ASD, and developmental timing.

There was a consensus that there needs to be a change in the way research is conceived and used. For instance, while curiosity-driven research is the norm, what is needed is applied, interdisciplinary work – that is, research that crosses both disciplines and disorders. This would require more complex model building approaches that break down the ASD phenotype into its components when looking at causation. Nothing should be “off the table” in terms of understanding mechanisms, as long as there is a sophisticated understanding of where we have come from and where we are now.

Group participants thought that study of genetic factors in autism should continue to be a priority, recognizing that the etiology of ASD is multifactorial and may include environmental factors, exposure to toxins, and manipulation of epigenetic environment (such as *in vitro* fertilization). A need for regulation of the use of genetic findings was expressed; for example, prenatal testing should not be used to discover “genetic abnormalities” in a fetus. It was suggested that researchers look at inter- and intra-family inheritance and elucidate why ASD occurs sporadically in so many families.

The group also thought it was important to disseminate the right information about new findings regarding causal agents. In this area, knowledge translation is important as information could be misunderstood if not explained accurately and in plain language. There is also a need to help families understand research findings, that is, to improve their science/health literacy to reduce anxiety and fear around their children's conditions.

Other suggestions were

- More research should focus on the profile and different presentation of autism in girls. There may be a different genetic predisposition and causation pathway.
- Focus of possible causes of ASD in various cultural or ethnic groups.
- Look at co-morbidities and ASD and see if the association gives us clues to causes
- Look at commonalities within populations.
- Good surveillance is needed to identify possible environmental causes
- Look at the total ‘toxin burden’ in older mothers and its possible impact on the neonate

Members of these small group sessions defined as their top priorities:

- Genetics
- Environment
- Gene-environment interactions
- Knowledge translation aspect: getting the correct information to parents and decreasing the lack of trust within the community.
- Move away from comparing ASD and controls but move to look at the differences within ASD
- Multidisciplinary approach

Research opportunities

- Look at mothers during pregnancy
- Population surveillance and incidence studies in clusters of individuals
- Epigenetics
- IVF/ parental age as a risk factor
- Culture/ ethnicity/ regions/ medical populations

## **Knowledge Translation and the Policy Process**

**Facilitators: Dr. Charlotte Waddell and Cody Shepherd**

**Note takers: Carley Piatt and Steve Gentles**

We opened the session with a general orientation to knowledge translation and the policy process for children’s health and development.

Knowledge translation can be defined simply as the use of research evidence in policy and practice. However, a more complete definition of knowledge translation is the reciprocal exchange of ideas among the different groups

involved in the policy process, including researchers, service providers, families, advocates and policy-makers themselves.

The policy process is complex. Policy-making encompasses multiple levels (legislative, administrative and clinical), jurisdictions (national, provincial, regional and local) and sectors (health, education, children’s services and community services). It is also important to consider the major influences on policy-making: managing *institutional* constraints (e.g., budget cuts), reconciling competing *interests* (e.g., public spending versus tax cuts), and advancing new *ideas* (e.g., investing in children).

When it comes to ideas about autism spectrum disorders (ASD), there are some longstanding differences between the various groups involved, resulting in ongoing court cases and public inquiries about intervention funding. We presented several scenarios to illustrate the problem of knowledge translation from the diverse perspectives of parents, researchers and policy-makers. We then asked participants to discuss their own perspective on knowledge translation and to identify priorities for improving the exchange of ideas in the field of ASD.

#### Participants’ Perspectives on Knowledge Translation

- Participants in this session spoke as parents and family members of children and adults with ASD, as service providers and managers, as researchers in clinics and universities, and as policy-makers from various provinces.
- Many participants were comfortable speaking from multiple perspectives. For instance, some parents had returned to university once their children were older, in order to educate themselves about autism and to help other families — they’ve gone through the journey and now they’re in a position to share. Several policy-makers had service backgrounds, while service providers often had some research training.
- Participants emphasized that ASD is a complex condition. No two children with ASD are exactly alike. When it comes to policy and services for children with autism, there are no “magic bullets” or “quick fixes.”
- One of the biggest challenges for knowledge translation in ASD is that research rarely provides simple answers. Researchers work in specialized fields and published research is often uncertain or ambiguous. But there are many advocacy groups who are willing to give seemingly simple answers to families, to the media and to policy-makers.

- Service providers, in particular, felt that it was often challenging to reconcile research evidence with other information and ideas about ASD, in order to provide the best advice to families.
- Policy-makers also wondered how to identify good research. How do you know when research is reliable enough to take action? How do you make recommendations to senior policy-makers based on research that is always in progress and ever changing?
- Participants emphasized that knowledge translation was especially important during critical periods in the development of ASD. At the time of diagnosis, for instance, many parents are desperate to learn as much as they can about ASD and appropriate interventions. Service providers and policy-makers are also concerned about being able to provide reliable information to parents during this period.

#### Participants' Priorities for Knowledge Translation

- There was a general desire for more communication and collaboration between the various groups concerned with childhood ASD. Why are researchers, service providers and policy-makers still working in isolation? In a “fantasy world,” everyone would come together to ask questions and identify shared priorities.
- Many participants talked about the need for additional training and support for the people who see children with ASD every day — parents, service providers, teachers, support workers, physicians and pediatricians.
- Participants also identified a need for training in knowledge translation itself. In other words, how do you most effectively share your experiences and views with others? How do you influence the policy process for ASD? There is no agreed-upon way to do these things.
- In particular, many researchers and service providers felt that they needed more support to engage in knowledge translation. Universities could provide researchers with incentives to spend more of their time on knowledge translation activities; and service providers are often overwhelmed by the demand for interventions, so they don't always have the capacity for knowledge translation.
- Several participants felt that everyone should be more comfortable “working with shades of gray.” In other words, we need to accept a degree of uncertainty and ambiguity when it comes to ASD research.

- Others suggested that we should tell more positive stories about children with ASD, because there are too many “scare stories” in circulation. Family members can be very influential in the policy process, because their personal stories about ASD are particularly powerful.

## **Screening/Diagnosis**

**Facilitator: Dr. Lonnie Zwaigenbaum**

**Note takers: Sharon Smile and Stephanie Patterson**

Although the American Academy of Pediatrics has issued guidelines about screening for ASD, their uptake has been limited. In Canada there are no formal guidelines (and no professional group has recommended universal screening). As well, Canadian physicians are generally apprehensive about the use of standardized tools to screen for ASD, preferring more of a surveillance approach. They believe that their clinical skills are good enough to detect children at risk and they are also concerned about the effects of a false positive result. It is apparent that there is an ongoing need for further dialogue and consensus-building regarding best practice for ASD screening in Canada, given the potential implications for age of diagnosis, timing of intervention and other services, family experiences, and long-term developmental course.

Researchers are making progress in the development of screening tools, and clinicians are gaining experience in the use of tests for 18 to 24 month children. However, it may be that a multistep screening process needs to be put in place to ensure that appropriate and early referrals are made for diagnosis. Canadian studies have identified 2 patterns of trajectory. One group of children is less communicative and withdrawn between 6 and 18 months. A second group has clear symptoms in the first year but less rapid change between 1-2 yrs of age. Some of these children may later have a profile of children with Asperger disorder, who are usually diagnosed later than children with other ASDs.

Clearly, there are many factors that contribute to the age at which children with ASD are diagnosed and receive services, and there is a need for further research on many fronts. We’re interested in hearing more about the various perspectives on research priorities in this area.

Participants’ Perspectives

Parents live with their concerns about their child's development long before a diagnosis is made. Parents are quite accurate in what they describe as being symptoms of ASD, but getting the diagnosis is the critical point for opportunities to intervene. Early diagnosis is also viewed as leading to improved quality of life, access to school supports, and also helping persons with ASD understand their own behaviours (e.g. perseverative interests) so they "don't have to feel guilty about it" and because "it has helped me navigate through society"

Group members stated that they believe that early intervention works and that high-risk children should be diagnosed early and intervention commenced in a timely fashion. However, there were concerns expressed about the variability in physician practice around diagnosis and treatment recommendations. They believe that a national population level screening program should be carried out. They also identified the need for tools to definitively diagnose autism because it is unacceptable for parents to wait for long periods for a definitive diagnosis after the child has been identified as 'possibly having a pervasive developmental disorder'. Delays in diagnostic process lead to undue stress and anxiety for families. However, physicians should be clear about their decision to refer a child -- A physician should never give a 'possible ASD' diagnosis. The terms around the autism should be specific and not ambiguous. Other comments included:

- Recognizing that there are many older youth and adults with ASD who have not been able to access an appropriate diagnosis, assessment research supporting improved diagnosis should involve participants across the life span. This should include assessment of screening in childhood, adolescence and adulthood.
- The practicality of screening: who, what, where and when. Can a single measure be used to identify a child at risk, or is a more sequential approach needed?
- Due to the lengthy delays that commonly occur between first concerns and definitive diagnosis, research should focus on the identification of early signs and the development of economical interventions (e.g., effective but potentially less intensive) for very young children with early signs, regardless of diagnosis.
- There must be safeguards to misdiagnosis and initiating interventions inappropriate to a child's needs.
- Access to intervention (and eligibility for treatment research) should not be based solely on diagnosis. We should evaluate different therapies and

see which is best suited for specific constellations of symptoms. Policy/ mandates must be more flexible to ensure that children and adults can access interventions based on functional needs e.g. starting social skills groups.

- Who is the authority on diagnosis? Parents vs. professionals? Some participants commented that parents know their children best, and thus are the authority when it comes to identifying atypicalities in development but expert clinical judgement is needed to evaluate how these atypicalities relate a specific diagnosis such as ASD. More collaboration is needed.
- Is being termed “high functioning” a burden on the child? Is this label inappropriate? Does it lead to inadvertent inappropriate expectation laid down for parents?
- Are there different critical phases for different individuals with ASD? Are there different critical junctures depending on trajectory?
- Challenge of moving these children into services. Is the system ready to take on early screening when there is a considerable wait time for diagnosis and then an additional wait for service? Thus we need capacity building in the system- but how do we do this?
- Need for diagnostic staff to have understanding of what supports are available in the community that they are working in, better understanding of what you are sending families out into. Diagnosis and service provision are especially important in adult system.
- Ethical obligations: if you screen for ASD, what other diagnoses are you going to screen for? Approximately 30% of Canadian children enter the school system with developmental vulnerabilities. Perhaps a general screen with an autism algorithm could be used. Regardless, researchers (and the health system as a whole) must be prepared to address the needs of the broader range of children with developmental differences who are flagged by screening programs.
- How do families understand the information that is given to them? What kind of translational process needs to occur here? Can we communicate more effectively and how?
- What happens when the diagnosis changes over time? Need to have children (and variation in developmental trajectories) better described in the research literature so we know exactly who is responding and not responding to interventions or how to interpret when trajectories shift/diverge?
- How well do current screening and diagnostic tools scale down to very young age groups (i.e., does sensitivity and specificity vary by age and developmental level)?

- Will this lead to over or under diagnosis until we have a better understanding of ASD in infants?
- Is it really early intervention that brings about the change or is it natural trajectory?
- We should begin to listen to adults who are living with autism and talk about concerns about research. Need to change policies around research.

#### Proposed Research Questions

- How do we go about understanding and determining what is important for a family and child who is diagnosed with autism. How can we empower families to articulate their needs?
- How can we utilize parent reports and known characteristics of ASD to promote early/timely diagnosis of autism? This should be approached at three levels: dissemination of tools for parents, professional education and greater focus on the need for screening tools across the lifespan (including adults).
- What will work in a rural setting where there is lack of resources? Should we be utilizing public health nurses as initial contact persons who will initiate screening if there are a concerns about a child's development? How might different systems of care (as opposed to different screening tools) perform in various settings?
- Is there a role for prenatal education about red flags for ASD in early child development?
- How can we identify children who are higher functioning earlier, especially girls, whose profile is often atypical or more subtle compared to boys? This influences opportunities for early intervention and may possibly change outcome.

#### **Themes Derived from the Small Group Reports**

##### ***Life Span Focus***

The focus on early intervention and early years has served CAIRN and Pathways well in its work to date, however, there is great interest among stakeholders, especially “persons on the spectrum” and family members, to ensure a life span focus in research and intervention that considers people’s experiences and needs across a lifetime. In exploring the topic of screening/diagnosis, for example, in addition to initial diagnosis of ASD, such an approach would be sensitive to the co-morbidities that might emerge, or decline, over the life of a person on the spectrum.

### ***Broad Conception of Transitions***

Participants noted that critical transitions occur at many points over the life span of persons on the spectrum and include the impacts of transitions experienced by their family members (e.g. birth, initiation of intervention/treatment, school entry, school exit, as well as parent's retirement, parent's job loss, parent's death). Rather than thinking of transitions as a discrete topic area, it may be fruitful to consider transitions as a theme with discernible impacts on other areas - treatment/intervention strategies, education, causes, screening/diagnosis and knowledge translation.

### ***Knowledge Transfer/Translation***

Similar views were expressed about the need to integrate knowledge transfer/translation into all other topic areas in order to ensure effective communication and uptake of new knowledge by the wide range of players who could benefit.

### ***Multi-Disciplinary Inquiry***

Given the multiple possible experiences and impacts of ASD on individuals, family members, the public and service systems, and society, research teams should be as multi-disciplinary as possible. Economic considerations, for example, may be a critical dimension of study and the inclusion of economists and other social scientists as part of a research team is an important direction for future research.

### ***Broad Partnerships***

Participants welcomed the opportunity to be engaged in developing a research agenda for ASD and encouraged the expansion of research partnerships and teams to include partners from a range of sectors, such as employers as well as policy makers, persons on the spectrum, family members and clinicians.

### ***Need for Environmental Scans and Inventories***

Participants expressed an interest in knowing what is going on across the country with respect to each of the topics under consideration. Participants wanted to know, for example, what policies govern education in each province and territory? What educational programs, with what eligibility criteria, are offered? What clinical interventions, with what eligibility criteria, are funded in each province and territory?

As well, participants sought access to a reliable, trustworthy, evidence-informed, and, ideally, synthesized source of information and knowledge on effective interventions, as well as information on the specific, expected outcomes of these interventions. There was considerable interest in

undertaking more structured environmental scanning and in creating related accessible databases or information resources for stakeholders.

### ***Education and Training***

Related to the need for information, stakeholders expressed a need to better educate and/or train the range of players involved in effective ASD intervention. Articulation and communication of desired or expected outcomes of interventions was seen as an important element of the education process.

### ***Health Services Research***

It was noted that a greater emphasis on health services research may be needed to generate knowledge on how and why the behaviours and practices of health service and policy decision makers change. Expanding enquiries so as to link new knowledge generated at the 'bench' with its application to interventions, and even further, to policy and funding decisions, would create a more comprehensive approach to studying ASD.

### ***Differences Related to Gender and Sex***

Participants noted the need to study possible differences in all aspects of ASD and all topic areas as they relate to both sex (the state of being male or female) and gender (the social and cultural constructions of masculinity and femininity).



### **Formulation of the Research Agenda -- The Scientists' Meeting**

The stakeholder meeting provided participants with an opportunity to work in small groups to identify priorities for research in six topic areas: treatment, education, transitions, causes, knowledge transfer, and diagnosis/screening.

Then, during the evening of October 2, 2009, a group of scientists, many of whom were new to CAIRN, came together in a meeting funded by the Canadian Institutes of Health Research (CIHR). There, the themes that emerged from the small group sessions were discussed and distilled to the research areas that need to be addressed in Canada.

Further objectives of the Scientists' Meeting were to generate strategies to move these priority research areas forward, and to identify the initial steps in the process.

The following research areas were identified for further action:

### ***Compiling an Inventory of Education Programs***

Despite tremendous interest, there is no reliable and comprehensive information on current ASD-related policy, programming and services available in Canada. Focusing on education policies and programs was identified as a good starting point, because reliable, linkable data exist in several regions (i.e., school-based data linked to health services and potentially other data).

### ***Experience of First Nations and New Immigrants***

The difficulty in collecting data from some sub-populations means that little is known about the experience of members of these groups with ASD. Questions about prevalence, and availability of and access to services, as well as how disability and need are conceived in these sub-populations are all under researched. Ensuring ethnic diversity in the research team would increase the likelihood that the right questions are identified and would support the development of culturally sensitive research methods.

### ***Environmental Risk Factors and Genes***

There was considerable interest in exploring the causal roles or links in ASD of environmental risk factors such as in vitro fertilization, *in utero* exposure to contaminants such as pesticides, age of birth parents, premature birth, or the presence of an immune disorder. The interaction of environmental risk factors and genetic vulnerability was highlighted as especially important.

### ***Biological Measures and Interventions***

Related to the interest in exploring causes and links, there was interest in studying biological factors that could be used to measure the impact of interventions. If a set of biological markers could be identified, these could be measured both pre- and post-treatment to determine whether basic biological mechanisms underlying ASD have been altered.

### ***Evidence-Informed Interventions Related to ASD***

Participants desired a reliable source of information on all topic areas discussed during the CAIRN conference and Scientists' Meeting. It was noted

that funding support from CIHR might assist with the development of a Web site where synthesized knowledge could be shared with the wide range of potential users/audiences. The task of creating and maintaining a Web site of current knowledge, including current information on available treatment services throughout Canada, was considered a high priority for the CAIRN network.

### **Follow up to the Scientists' Meeting**

Scientists interested in pursuing each of the research areas were identified, groups formed, and a lead for each was identified. To date, three of the working groups have held conference calls facilitated by CAIRN, and the process of formulating and refining research questions is underway.

In exploring further next steps, the groups will bear in mind the themes emerging from the stakeholder meeting. For example, each group will ensure that consideration is given to exploring sex differences as well as different experiences across the lifespan.

### **Next Steps**

- Creating strategies for disseminating the ideas and decisions arising from the conference
- Assisting the evolution of the work groups formed during the Scientists' Meeting that followed the CAIRN Conference
- Developing government, private, and public partnerships for applied research in ASD
- Enhancing the CAIRN Web site ([www.cairn-site.com](http://www.cairn-site.com)) as the primary Canadian bilingual source for evidence-based information about ASD by disseminating pre-publication data, summaries of evidence, and other documents related to the themes identified in the CAIRN conference.

## **Appendix A: Conference Evaluation**

One hundred and four people participated in the forum. Forty-four (44) evaluation forms were completed (42% response rate). The majority of respondents thought that the forum objectives were met.

- Participants appreciated the short, focused overviews of research findings presented. They particularly appreciated efforts to make the findings accessible by limiting the use of technical terms and speakers' engagement in question-and-answer and dialogue with members of the audience.
- Participants appreciated the diversity of the group, with representation of key stakeholders from across the country. They felt the atmosphere created facilitated engagement and inclusion of the many perspectives represented. The large group sessions and the lunch provided good occasions for highly valued networking.
- Participants found great value in the small group discussions, which were seen to be both informative and engaging. The round table format gave participants opportunities to contribute meaningfully to the discussion and to ensure a good balance of the range and mix of perspectives represented.
- Some participants did not get to participate in groups on the topics of their choice, and others wished there was an opportunity to participate in more than two topic-based discussions.
- Given the depth and breadth of the topics discussed, some participants wished for more time for this kind of engagement.
- Ground rules that set the tone for engagement are an important aspect of meetings such as this. Engagement of a wide range of stakeholders, including parents and persons "on the spectrum" is highly valued. Greater efforts to engage policy-makers may be required.
- Small group discussions, guided by clear process instructions, offered highly valued opportunities for sharing and learning.

Here is a selection of participants' opinions of the presentations and small groups:

“This [conference] reflected how things have changed since 2001. Then, parents were very much on the side and researchers and clinicians were the focus. Now, there is a much stronger sense that we all need to work together.”

“Very good. Made efforts to present results in such a way that “non-researchers” could understand.”

“Good discussions (two-way). Presenters were experts but also good listeners. Important issues [were] tackled with objectivity.”

The young adults living with ASD who attended appreciated the opportunity, usually denied them, of having their experiences, perspectives, and opinions heard by those with the authority to influence policies and practices affecting them.

“I really liked the equal opportunity for sharing my views and hopefully offer my insights into my ASD.”

Other participants clearly appreciated the presence of the young adults with ASD in the discussion groups, too.

“Especially enjoyed hearing from individuals on the spectrum -- helped keep the focus.”

“Great dialogue and strategies and perspectives. Very interesting “on the spectrum” participants.”

The views of participants will provide guidance for planning and organization of future meetings of this kind that seek to engage a wide range of stakeholders in ASD research, from researchers and clinicians, to policy-makers, persons “on the spectrum” and family members.