

Report on the 2009 CAIRN Conference

Executive Summary

Since it began in 2001, the Canadian Autism Intervention Research Network (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 to allow all of these groups to work together. A major result of these meetings was a national ASD research agenda developed in 2004 (for details see <http://www.cairn-site.com/en/nra.html>).

The major goal of CAIRN's 2009 Health Canada-funded project, **Generating and Disseminating Evidence-Based Knowledge on Autism Spectrum Disorder**, was to enhance awareness, knowledge, and collaboration among a variety of stakeholders to inform the development of a national research strategy for ASD. We achieved this goal by carrying out the following activities.

1. An online survey of research priorities, provided in both English and French, was distributed by CAIRN, Autism Speaks, Autism Society Canada, and individual members of these organizations. The survey was filled out by 1003 parents, researchers, clinicians, policy makers, and people living with ASD. Of ten topics proposed to the survey participants, the most frequently chosen were Treatment, Education, Transitions, Causes, Screening/Diagnosis, and Knowledge Translation. (For more information about the survey, go to .)
1. A national ASD Conference, held in Toronto on October 2, 2009, was attended by 104 parents, policy makers, practitioners, researchers, and, for the first time, people living with ASD. At the conference, the online survey results were presented and preliminary results of the [Pathways in ASD](#) study were shared. The conference speakers' slides can be viewed at
1. Improvements to the CAIRN Web site (www.cairn-site.com) were made that included translating all documents into French so that Francophone communities in Canada and across the globe could use them. During the 2009/10 period, many new summaries were written, translated into French, and posted on CAIRN's mirrored English/French Web sites. These studies looked at such topics as gastrointestinal symptoms in children with ASD, hyperbaric oxygen therapy, drug therapy for children with ASD and high levels of repetitive behavior, developmental regression in children with ASD, and medication and parent training in children with ASD and serious behavior problems.

Now plans are underway to publish information from some studies before they have been published in scientific journals. The site will also contain summaries of evidence and other documents about ideas coming out of the CAIRN conference.

1. Beginning with the 6 topics chosen by online survey participants (see 1 above), the conference program was developed. Small group discussion sessions were facilitated by CAIRN researchers. In these sessions, parents, practitioners, researchers, and policy makers, and people living with ASD worked together to decide what it is important to focus on in ASD policy and practice. Several [themes](#) came out of these discussions, which were reported back to the large group in the afternoon. 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 then distilled down to research areas that need to be addressed in Canada. For an overview of these, go to [\[LINK TO SCIENTISTS' REPORT\]](#) . This meeting should eventually lead to these scientists working together on studies based on the opinions of members of all stakeholder groups represented at the CAIRN Conference. By bringing together information obtained from Objectives 1 and 2, a new research agenda that could change

ASD programs and policies across Canada was developed in the course of the CAIRN Conference.

Overall, the participants were very pleased with the organization and content of the conference day. They only wished it had been a two-day conference, instead!

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."