

## Scientists' Meeting

### Emerging Research Areas:

In a later meeting funded by CIHR, scientists from across the country discussed the following areas that had been identified for further attention during the CAIRN conference stakeholders' meeting:

#### **Education Programs Inventory**

While there is tremendous interest in knowing “what is going on” in terms of ASD-related policy, programming and services across the lifespan, across sectors, and in jurisdictions across the country, it was acknowledged that collecting reliable, comprehensive information in this regard is a huge challenge. Differences in nomenclature, policy and program scope, jurisdictional oversight, among many other things, make the collection of meaningful, comparative information extremely difficult. Frequent changes to program features (funding, eligibility, scope, oversight, etc) and staff turnover among those who could validate the information collected from each jurisdiction compound the problem of acquiring and collating useful information. Robust (sustained, trusted) relationships with relevant policy and program leaders within each jurisdiction, agreed upon definitions and terms, as well as a commitment to continuous updating to ensure the currency of the information collected are required to support a useful “inventory” exercise.

Participants agreed that a focus on education policies and programs, where reliable, linkable data (i.e. school-based data linkable to health services and potentially other data) exist in several jurisdictions, could be a starting point. Participants identified the following questions for consideration:

- **What is the profile of services delivered through the schools for people with ASD (and, where relevant, their families)?**
- **What do families think about these services?**

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

The difficulty in collecting data from certain sub-populations means that there is little known about the experience of these groups with ASD. Questions about prevalence, access to services, availability of services, as well as conceptions of disability and need in these sub-populations are all under-researched. It was acknowledged that diversity in the research team would increase the likelihood that the “right” questions regarding these sub-populations were identified as well as supporting the development of appropriate (culturally “sensitive” and “safe”) research approaches and methods.

Participants identified the following question for consideration:

- **What are the experiences of First Nations and new immigrants with ASD?**

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

There was considerable interest in exploring the relationship between a wide range of “environmental factors”, from in-vitro fertilization, in utero exposure to contaminants, age of birth parents, genetic vulnerability, or premature birth, to presence or absence of an immune disorder or exposure to pesticides, as causes or correlates of ASD.

- **What is the relationship between environmental risk factors and genes?**

### **Biological Measures and Interventions**

Related to the interest in exploring causes and correlations, there was interest in studying biological factors that could point to impacts of intentional (or unintentional?) interventions. If a set of biological markers could be identified these could be measured both pre- and post-treatment to determine whether and what effect the intervention had had.

Participants identified the following question(s) for consideration:

- **Are there discernible impacts of treatment on biological measures?**
- **What biological impacts could/should we anticipate from a given (set of) interventions?**
- **How might these be measured?**
- **When measured, do they demonstrate hypothesized impacts?**

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

Participants noted the desire of conference participants for a reliable source of information on all “topic” areas discussed during the conference. It was acknowledged that the creation of such an information source requires considerable investment of time, expertise and money. It was noted that funding support from CIHR might assist with the development of a Website where synthesized knowledge could be shared with the wide range of potential users/audiences. The task of creating and maintaining a Website of current knowledge was considered a prospect for the CAIRN network.

The stakeholder and scientists’ meeting led to the expansion of the scientific group beyond Pathways. There was wider national representation in this group and more disciplines represented. In addition, more junior investigators were present and a broad range of topics was discussed.

However, it was made apparent that the Canadian ASD research community is not adequately trained in knowledge translation and health services in ASD.

An established Web site could be utilized as an information sharing outlet for prepublication information/data, summaries of evidence; the four main themes emerging from the scientists’ conference could be disseminated through this web site as well, e.g., an Education Programs Inventory.