

**From Research to Policy and Care:  
Exploring Opportunities for Autism Spectrum Disorders  
Research Networks in Western Canada**

**PROGRAM**

**Richmond, British Columbia  
March 18-19, 2004**

# **From Research to Policy and Care: Exploring Opportunities for Autism Spectrum Disorders Research Networks in Western Canada**

## **PURPOSE OF THE MEETING:**

To bring together policy makers, researchers, program administrators, funders, and family representatives to:

1. Stimulate and support coordinated action on autism research that will address service provision and policy issues facing government and service providers;
2. Exchange information on current initiatives in autism research, policy, and service provision across Canada;
3. Provide an opportunity for participants
  - a. to share perspectives on autism issues in their provinces; and
  - b. to determine how their priorities and concerns might shape a collaborative autism research network initiative across the region;
4. Explore immediate opportunities for regional collaboration, including but not limited to, agreement in principle to collaborate on the development of a regional data network, based on a minimum set of common core variables; and
5. Agree on next steps towards longer term development of a collaborative autism research network initiative across the region.

## **BENEFITS TO PARTICIPANTS:**

- Information sharing on latest research, service delivery and policy trends in Canada's western provinces and territories.
- Update on benefits of research networks and factors for their success.
- Identification of common issues, research questions, and/or opportunities for collaboration.
- Potential development of a plan for a shared regional data network.
- Contribute to plan for a regional autism research network.

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Networks in Western Canada**

Facilitator: Ms. Lillian Bayne	
<b>Thursday March 18, 2004</b>	Time
Continental breakfast and registration	0800-0900
Welcome and overview of the purpose of the day	0900-0915
<i>Cross Ministry Cooperation in Assessing Children's Intervention Needs in Ontario: Assessing Functional Needs and Monitoring Progress.</i> Speakers: Dr. Wendy Roberts, Associate Professor of Pediatrics, University of Toronto/Hospital for Sick Children; Dr. Jessica Brian, Co-director, Autism research network, Hospital for Sick Children	0915-1015
Nutrition break	1015-1030
<i>Autism Intervention Outcomes in B.C.: How Are the Children Doing, and How Can We Tell?</i> (Speaker: Dr. Pat Miranda, Associate Professor, Education, University of British Columbia)	1030-1130
Group discussion and Q&A to morning session speakers	1130-1200
Lunch	1200-1300
Three separate discussion breakout groups will convene, each with a nominated recorder and rapporteur (policy, service, research/research funding). Each group will discuss issues among themselves, and agree on key themes from their discussions to report out to the group as a whole	1300-1430
Reporting out: <b>Policy makers'</b> priority issues to inform a research agenda	1430-1450
Nutrition break	1450-1505
Reporting out: <b>Program administrators' and family representatives'</b> priority issues to inform a research agenda	1505-1525
Reporting out: <b>Researchers' and research funding agencies'</b> priority issues to inform a research agenda	1525-1545
Summary of main themes – implications for network collaborations	1545-1615
Wrap up and looking ahead to the next day	1615-1630
Dinner in Four Points Sheraton restaurant, hosted by the BC Ministry of Health Services	1800-1930

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<b>Friday March 19, 2004</b>	Time
Continental breakfast and networking	0815-0830
Welcome - context and background to the day, large issues in summary, round table introductions	0830-0845
<i>The Power of Research Networks</i> Speaker: Nancy Reynolds, Executive Director, Alberta Centre for Child, Family and Community Research	0845-0915
Research organization reports, including Q&A	
<ul style="list-style-type: none"> <li>• <i>Presentation of the December 2003 inventory of Autism Research in Canada</i> Speaker: Patricia Evans, Senior Advisor to the President, Michael Smith Foundation for Health Research, Vancouver</li> </ul>	0915-0945
<ul style="list-style-type: none"> <li>• <i>Activities of the Canadian Autism Intervention Research Network (CAIRN)</i> Speaker: Sherry Thompson, Director, Research Liaison, Community Strategies, Alberta Children's Services</li> </ul>	0945-1015
Nutrition break	1015-1030
<ul style="list-style-type: none"> <li>• <i>Activities of the Autism Spectrum Disorder-Canadian American Research Consortium (ASD-CARC)</i> Speaker: Dr. Jeannette Holden, Principle Investigator and overall Project Leader, ASD-CARC; medical geneticist, Queens University</li> </ul>	1030-1130
<i>The BC Autism Assessment Network Database</i> Speaker: Dr. Stephen Wellington, Co-director of the BC Autism Assessment Network, Provincial Health Services Authority, Vancouver, BC	1130-1230
Luncheon with guest speaker – Dr. Shoo Lee, Founder and Director, The Canadian Neonatal Intensive Care Network	1230-1330
Introduction to the afternoon – review main themes from day one and two, focus group discussions.	1330-1345
Mixed small breakout groups: Vision for success of a regional autism research network	1345-1445
Nutrition Break	1445-1500
Groups report out – 5 minutes each x 4 groups	1500-1520
Summary of vision and discussion of next steps	1520-1600
Wrap up and adjourn	1600-1615