

***From Research to Policy and Care:
Exploring Opportunities for Regional
Networking on Autism Policy and Research***

*Proceedings of a conference held March 18 and 19, 2004
Richmond, British Columbia, Canada*

*Western Canada and Territories
Autism Research Network*

From Research to Policy and Care: Exploring Opportunities for Regional Networking on Autism Policy and Research

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Executive Summary

On March 18 and 19, 2004, the Western Canada and Territories Autism Research Network, a group of policy-makers, hosted an innovative planning session, designed to explore ways to enhance research and policy relating to services for people with autism. Logistical planning and conference organizing was done by the BC Ministry of Health Services with support provided by the Michael Smith Foundation for Health Research. The meeting brought together more than 60 stakeholders from across Western and Northern Canada, with the goal of identifying opportunities for these jurisdictions to join together in efforts to build capacity for evidence-based policy and service delivery. A series of presentations were made, covering three key areas:

- Updates on major autism research activities, particularly through network groups, across Canada
- Information about the benefits of research networking
- Inventory and database initiatives of particular relevance to Western and Northern autism research capacity.

These presentations were followed by working groups, during which participants:

- Identified issues which from their perspective should be top priorities to inform a regional research agenda
- Discussed the potential benefits of regional collaboration on autism research.

In summary, these groups arrived at a broad consensus on:

- A series of common questions that infused the conference
- A series of compelling factors as to why a network is needed, and
- The opportunities and potential power of networks to enhance evidence-based policy and care.

A preliminary vision statement was drafted for the network, along with some draft measures of success and proposed next steps towards its formation. These are summarized on the next page, and it was noted that there are at least three key considerations in moving forward:

- Are we ready?
- Linked to existing research strategies?
- Learning from BC – successes of fusion.

In conclusion, attendees agreed that the following represented priority “next steps” towards creating such a network:

- Who needs to know? – right people, more than here today
- Champion or champions
- Steering Committee
- Northwest network focus – start regionally
- Annual conference
- Research linked to outcomes.

DRAFT MISSION STATEMENT:

The mission of the **Canada Northwest Autism Policy and Research Network** we envision is to identify and improve health and quality of life for people living with autism by creating a continuum of knowledge around autism to:

- Inform policy and practice for children and families across the lifespan
- Advance diagnosis, treatment and prevention strategies
- Identify gaps in service and knowledge
- Develop widespread knowledge of supports and outcomes
- Inform policy and practice
- Identify collective needs
- Increase recognition that this is part of a fabric of other developmental conditions

Broad Outcomes

- Evidence-based support
- Better integration of strategies

Measures of success

- Databases – data, research, projects, knowledge
- Identify needs
- Identify leader – single/many
- Identify resources
- Champions multiple across multiple jurisdictions – Steering Committee
- Links to existing networks
- A very diverse network – evidence of inclusive nature
- Good data, best practice data

Long term measures

- Articulated plan to address our needs
- Measures that are reliable and valid
- Integration of policy across ministries
- Access to/standards for intervention
- Value of network is revealed and recognized
- Known as a trusted source of information
- Agreements to share data
- Funding support
- Reduced isolation (professionals and family members)
- Increased funding
- Increased number of funded researchers
- Increased number of collaborative projects across jurisdictions
- Bigger “N”s (larger studies)

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Next Steps

Following the Conference, Members of the Working Group will continue discussions to assess opportunities for continued collaboration and networking with the broader autism research community. Interested parties should contact the relevant representatives in their jurisdiction for updates (see page 23 for a listing of Working Group participants).

Introduction and Background

On March 18 and 19, 2004, the British Columbia Ministry of Health Services hosted an innovative planning session, designed to explore ways to enhance research and policy relating to services for people with autism. The meeting brought together more than 60 stakeholders from across Western and Northern Canada, with the goal of identifying opportunities for these jurisdictions to join together in efforts to build capacity for evidence-based policy and service delivery. As outlined in the conference program, the purpose of the meeting was 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 to
 - a. share perspectives on autism issues in their provinces, and
 - b. 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.

Participation in this conference is essential in ensuring that efforts to stimulate concerted action around Autism Spectrum Disorders (ASD) issues receive the highest possible cross-jurisdictional support.

The proposed **Canada Northwest Autism Policy and Research Network** is the result of discussions between BC, Alberta, Saskatchewan, Manitoba, the Northwest Territories and the Yukon over the past few months. There is a pressing need to advance a research platform that will meaningfully inform families, providers and policy-makers on issues pertaining to the delivery of autism-related services.

The aims of the conference were:

- To stimulate and support coordinated action on autism research that will address health service and policy issues facing government and service providers;
- To exchange information on current initiatives in autism research, policy and service provision across Canada;
- To explore short-term opportunities for Northwest regional collaboration and reach an agreement in principle on the development of a common regional data set based on a minimal set of core variables;
- To agree on longer-term actions towards development of a collaborative autism research networking initiative across the region.

Proceedings, Day One: Thursday, March 18, 2004

Facilitator Lillian Bayne opened the meeting by welcoming all those in attendance and reviewing the Conference Objectives:

1. **To stimulate and support coordinated action on autism research** that will address service provision and policy issues facing government and service providers.
2. **To exchange information on current initiatives in autism research, policy and service** provision across Canada.
3. To provide an opportunity for representatives of various stakeholder communities to meet together **to share perspectives on autism issues** in their provinces, and to share perspectives on **how their priorities and concerns might shape a collaborative autism research networking initiative** across the region.
4. **To explore immediate opportunities (short term) for northwest regional collaboration**, including but not limited to, agreement in principle to collaborate on development of common regional data set based on minimal set of core variables.
5. **To agree on next steps longer term** towards development of a collaborative autism research networking initiative across the region.

She then introduced the morning's first speakers.

Morning Presentations

- A. **Wendy Roberts, MD and Jessica Brian, PhD, Child Development Centre, Autism Research Unit, The Hospital for Sick Children, Dept. of Pediatrics, Toronto**

Challenges in ASD Intervention: Research to Practice to Research
(http://www.msfr.org/docs/1_Roberts_Brian_Challenges_in_ASD_Research.pdf)

Families of children with autism have many challenges: coming to terms with their child's unique differences, finding professionals with the expertise needed for diagnosis and intervention, advocating and case managing as well as still being parents for their exceptional and typically developing children. Service providers similarly face many challenges: relating to different community systems, philosophies and ministries while trying to improve resources and outcomes for children with autism. Research is desperately needed to shed more light on our knowledge of what works best for whom, at what age and in what setting, all the while living within the realities of well-established systems and budgetary constraints. Sharing ideas about current projects involving integration of disciplines on community-based teams may allow fruitful discussion and planning for collaborative activities.

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Two specific examples were highlighted in this presentation. In the service delivery area, an Ontario program integrates mental health and child development assessment and service delivery. Benefits are seen in both effectiveness and timeliness. In the research area, the importance of networks was stressed, through the example of the Baby-Siblings study. This study uses methodology in Canada also employed by NIH-funded studies in the US, which will allow networking to achieve the larger numbers necessary to investigate certain aspects of ASD more effectively.

B. Pat Mirenda, PhD, Project Director, BC Autism Evaluation Project, University of British Columbia

Autism Intervention Outcomes in BC: How are the Children Doing, and How Can We Tell? (http://www.msfnr.org/docs/2_Mirenda_Autism_Intervention_Outcomes.pdf)

The presentation summarized the one-year early intervention outcomes for two cohorts of young children with autism in British Columbia. One group of children (n=39) received services through site-based programs that provide approximately 20 hours per week of home- and/or pre-school behavioural interventions. A second group of children (n=31) receive parent-managed programs that are eclectic in nature, ranging from behavioural intervention alone to a combination of other therapies. A standard set of assessment instruments was administered to all children and families at baseline and after one year of intervention. Outcomes were discussed separately for each group of children.

Afternoon Breakout Groups: Priority Issues to Inform a Research Agenda

After an informal networking luncheon, the conference reconvened into three small working groups. As outlined by Ms. Bayne, the purpose of these sessions was to address Conference Objective 3: **To share perspectives on autism issues and on how the identified priorities and concerns might shape a collaborative autism research networking initiative.**

Participants were pre-classified into one of three small groups for discussion, representing perspectives of:

- Policy-makers,
- Program administrators and family representatives, and
- Researchers and research funding agencies.

Volunteer facilitators worked with their respective groups to address the following questions:

1. From your perspective, what are the issues and concerns related to ASD?
2. Which of these are most important and why?
3. In what way can research help to address these issues? What do you “need to know”?

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Group members were asked to select the “top 3-5 issues” and then report out as a group to the subsequent plenary session so as to identify top priorities for research and begin to build a research agenda. The three groups reported out as follows:

A. Program Administrators and Families (Red Breakout Group)

This group reported that a very diverse set of issues was discussed, reflecting the really diverse mix of the group. The resulting pages of issues were summarized under the following categories:

Diagnosis

- Waits
- expertise
- access

Transitions

- of caregivers
- to/from/between schools
- retirement
- parents'/caregivers' death

Communications re

- which professionals are available
- information re treatment
- services available

Service providers

- standards
- training
- attitudes

Family connection

- mobility
- coping
- resources

Management strategies

- dealing with challenging behaviors
- aggression
- co-morbid mental health disorders, such as depression

Top issues:

- Inter-ministry responsibility, integration and planning
- Services across the life span
- Consecutive waitlists
- Quality assurance of ABA and other interventionists – standardized training and credentialing
- Family doc knowledge – no referral, arrogance

Research priorities:

- Evidence-based treatment for people over six
- Research on family resilience
- Research on autism in the teen years
- Dissemination of research with treatment recommendations or warnings
- Clarify anecdotal stories – what is reliable, what works, what is relevant
- Translation of research findings into plain language

B. Researchers and Research Funding Bodies (Blue Breakout Group)

WHAT:

Key issues, all of them dealing with effectiveness of intervention strategies over the lifespan:

1. Dose response for interventions:
 - For which children do the interventions work best
 - What are the strength of the interventions
 - Subtype, context
 - Which children need more/less for good outcomes
 - When do we need to stop or reassess intervention outcomes
 - Continuum of service over the lifespan
 - Health economic utility models
2. Basic Science:
 - What are the foundations of autism?
 - Cell models, genetic analysis, tissue – genetic foundations of the disorder

WHO:

Noted were the difficulties of knowing who is doing autism research, from which backgrounds/disciplines – and what will be needed in future (to inform training).

HOW:

1. Multidisciplinary teams across sites
2. Longitudinal studies
3. Inclusive process involving stakeholders and considering context

Observations:

Much of the learning we gain in the autism field can be beneficial to children with other diagnoses (i.e. other developmental disabilities). What we do in terms of providing services for individuals with ASD may be a template for other children with other disabilities. It will be important to look at whether or not effective interventions/service provision strategies should be restricted in the absence of a formal diagnosis.

There is an urgent need to educate the public about the impact of ASD on the families of affected children, to increase the understanding of their reality and lived experience, as well as acceptance of the need for the additional cost support.

In response to a question regarding whether or not there is a real increase in the incidence of autism – is it an epidemic? – Dr. Wendy Roberts referred participants to a recent scholarly article that provides valuable insight on this topic: Eric Fombonne's article *Modern Views of Autism* in the September 2003 Canadian Journal of Psychiatry (<http://www.cpa-apc.org/Publications/Archives/CJP/2003/september/sep2003.asp>)

C. Policy-makers (Green Group)

1. Effectiveness of interventions for children:
 - What, how much, by whom?
 - For what outcomes (and for short/long term)?
 - For how long (duration)?
 - For function – how measured?
 - What outcomes have meanings for society?
2. Effectiveness of interventions for families:
 - What outcomes have meaning for families, and for how long?
 - Are expectations reasonable (i.e. cure versus improvement/chronic)?
 - Consideration for families whose children “just miss” the diagnosis of ASD but nonetheless have real functional needs that require support?
3. Lifespan issues: how do needs shift over time
 - How do we measure them?
 - How do we know we are helping?
 - Entitlement – efficacy and change of needs being met over time?
4. How do services for children and youth with ASD link/mesh/overlap with services for other children with disabilities and in fact for all children?
5. What are the issues for children and families at the transition to school, to adults, how do we support them?
6. How do we measure cost-effectiveness?
7. Are there systemic approaches that are better than others (linking government, non-profit, for profit) – work together, who’s responsible for what? Benefit of sectors working together for continuum of care and to manage expectations around appropriate transitions, so that parents can gain increased confidence about the evidence-base of services in each age.
8. Ecology of the intervention: What is the effect of service provision on the system of service, re cost, to support providers, to integrate into care for other needs? What are the unintended effects of focusing care for a particular cohort of children, on the services provided to other cohorts?
9. Are there community interventions that would make a difference (socio-ecological approach)?

An additional issue raised during the conference question period: Given the current trend to increasing numbers of people with the diagnosis, what education will the public need to cope – how will society change as a result (workplaces, housing, etc.)?

Summary of Themes – First Day's Sessions

To wrap up the first day's proceedings, common themes and priorities identified by the various breakout groups were compared and summarized in a brief presentation by Nancy Reynolds (Executive Director, Alberta Centre for Child, Family and Community Research) and Heather Davidson (Director, BC Ministry of Health Services, Strategic Policy and Research):

We get a sense of the potential power of bringing together all of the different players (families, policy-makers, service providers, researchers) in one room – the issues are all the same. As we moved from room to room, the language and points of emphasis varied but there were very common issues and themes. So clearly there is a desire to work together and move forward, specifically on:

1. There was a clear consensus around the need for evidence, and for research, re:
 - Intervention effectiveness
 - Intervention integrity across the lifespan, particularly around transitions
 - The need to include families, both parents and siblings
 - Building the evidence on how best to support parents
 - Outcomes.
2. Economic issues, funding both research and service
 - Health economic analysis – better efficiency for the system
 - Shared capacity and how we can work together to eliminate duplication.
3. Knowledge transfer
 - Research to users (parents) who can trust the information
 - Professionals to receive timely information and be up to date
 - To get information effectively to policy decision-makers
 - Video as a powerful tool to help build understanding
 - Researchers need to know what others are doing, what questions policy-makers have
 - Need for reciprocal understanding (research/policy) and for everyone to understand the needs of parents and communities
 - Broader knowledge and understanding in the general public.
4. Importance of data – common database needs, longitudinal outcome analysis.
5. A cross-ministry/cross-sector systems approach is essential.

The amount of concurrence and consensus in the room around these issues is really significant. To move these issues forward, a common language and understanding are essential to effectively explore our shared opportunities and challenges.

Proceedings, Day Two: Friday, March 19, 2004

Facilitator Lillian Bayne congratulated attendees on a productive and successful first day, and introduced the first speaker.

Morning Presentations

A. Nancy Reynolds, Executive Director, Alberta Centre for Child, Family and Community Research

The Power of Research Networks

(http://www.msfhr.org/docs/3_Reynolds_Power_of_Research_Networks.pdf)

The World Health Organization (WHO) defines a network as “A grouping of individuals, organizations and agencies organized on a non-hierarchical basis around common issues and concerns which are pursued proactively and systematically, based on commitment and trust.” These innovative organizations have emerged to deal with complex problems and the increasing interdependence required to respond effectively. To help ensure relevance to health and social science policy and practice, there has been an increased interest and requirement for interdisciplinary and cross-sectoral approaches to research. Networks are increasingly being considered as a vehicle for researchers, service providers, and policy-makers to collaborate and advance knowledge. This presentation explored the potential power of research networks and lessons learned from examples of existing networks.

The presentation used the example of the Southern Alberta Child Youth Health Network to illustrate how networks can succeed. The example showed how networks increase the political power in the system, by recognizing that policy-makers need help from the research community. Two defining factors were stressed for the early priorities of any emerging research network – the need to develop a research agenda with clear deliverables quickly, and then to show early results to build confidence and momentum.

B. Patricia Evans, Senior Advisor to the President, Michael Smith Foundation for Health Research

An Inventory of Autism Research in Canada

(http://www.msfhr.org/docs/4_Evans_Inventory_of_Autism_Research.pdf)

In early 2004 MSFHR completed an analysis of autism-related health research funding and activity in Canada, looking at research supported by major national and international granting agencies, as well as activity supported by funding agencies and/or governments in Canada’s West and North. The analysis indicates that the majority of currently funded activity focuses on understanding the biological and genetic causes of autism, and that most ASD research in Canada occurs outside the Northwest. This presentation reviewed highlights of the inventory’s findings, and discussed implications for current and future efforts by Northwest regional governments to build their jurisdictions’ capacity for ASD research.

C. Sherry Thompson, Director, Research Liaison, Alberta Children's Services

Canadian Autism Intervention Research Network (CAIRN): Opportunities to Partner
(http://www.msfnr.org/docs/5_Thompson_CAIRN.pdf)

This presentation provided an overview of the Canadian Autism Intervention Research Network, and suggested opportunities for partnerships in the future. The overview outlined who is currently involved in the network, how the network developed, and its current goals and activities. Examples from the CAIRN website were shared, to provide the flavour of the current work of the CAIRN network. Potential areas for partnerships in the future were presented.

The presentation stressed the strength of intervention research in the West, and noted the presence of policy-makers in the North and West who are seeking advice from researchers – an unusual circumstance and an important opportunity.

D. Jeannette J.A. Holden, PhD, Autism Spectrum Disorders Canadian-American Research Consortium (ASD-CARC), Queen's University

Unraveling the Mystery of Autism Spectrum Disorders
(http://www.msfnr.org/docs/6_Holden_Unraveling_Mystery_of_ASD.pdf)

Both genetic and environmental factors contribute to the etiology of ASD. In order to “Unravel the Mystery of ASD”, we have formed the ASD-CARC, comprising >60 researchers, clinicians, and parents. The program of research includes several projects: 1) Epidemiology of ASD in Canada; 2) A Research Registry and on-line Research; 3) Genetics of ASD; 4) Phenotypic subgrouping of families based on physical, clinical, and behavioural differences; 5) Retrospective and Prospective Studies to identify the earliest signs of autism; 6) A Very Early Intervention Study; and 7) Mouse and Cell Models for Autism-related genes. The structure of the team and the projects were discussed as a model of interdisciplinary research and training.

Dr. Holden's experience underscores the extent to which ASD research requires an interdisciplinary approach (something for which many researchers are not adequately trained), action and projects in diverse areas, and the involvement of many families to have enough affected individuals/families to be able to identify and understand the full spectrum of the disorder. A network approach is the logical way to go since operational dollars, infrastructure dollars and equipment are required to do research at multi-sites and in multi-situations. Also, dollars for transdisciplinary training are essential to prepare the next generation.

Autism also needs to be seen within the larger context of developmental disabilities and as an adult as well as a childhood disability.

- E. Stephen Wellington, MD, PhD, FRCP(C), BC Autism Assessment Network (BCAAN) Co-Director, Division of Developmental Pediatrics, University of British Columbia, BCAAN Database, Provincial Health Services Authority (BC)**

The BC Autism Assessment Network (BCAAN) Database – Autism Spectrum Disorders Research Networks in Western Canada

(http://www.msfr.org/docs/7_Wellington_BCAAN_Database.pdf)

The presentation focused on the design and research potential of the integrated BC Autism Assessment Network database. The strength of the database is derived from both a uniform case definition of autism spectrum disorders (facilitated through the use of validated clinical diagnostic instruments), as well as comprehensive data acquisition across the province (which includes both positive and negative case-reporting and co-morbidities), and recording of DSM-IV domains. A brief review of how the BC provincial government has linked Autism Assessment Standards and Guidelines to funding applications was provided as part of the introduction. The presentation also provided a “walk-through” of the web-based forms.

Luncheon Keynote Address

Shoo K. Lee, MBBS, PhD, FRCP(C), The Canadian Neonatal Intensive Care Network, Director, Centre for Healthcare Innovation and Improvement, Associate Professor of Pediatrics, University of British Columbia

State of the art in outcomes evaluation and quality improvement in the Canadian Neonatal Network (http://www.msfr.org/docs/8_Lee_Canadian_Neonatal_Network.pdf)

The Canadian Neonatal Network is a national network of Canadian clinicians, researchers and decision-makers who collaborate on research to improve health and health care for infants in Canada and elsewhere. Since its inception in 1995, the network has grown rapidly to include all 30 institutions providing tertiary neonatal care in Canada. Currently, over 50 researchers and 20 trainees participate in eight peer review funded research projects in the network. The network maintains a standardized national database of all infants admitted to neonatal intensive care units (NICU) in Canada and members of the network have published over 100 peer reviewed articles in the last five years.

Highlights of their work include a) description of variation in outcomes and practices among Canadian NICUs, b) evaluation of practice guidelines, c) development of patented illness severity risk adjustment instruments, d) comparison of outcomes among Canadian NICUs, e) development of scientific evidence based systems for quality of care improvement, and f) use of network data for provincial health policy and planning. In addition to research in Canada, members of the network actively participate in efforts to train health workers and improve health care for infants in developing countries around the world.

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What makes a network successful?

1. Leader(s)/champion(s) who believe in the power of networking, can bring people together and maintain momentum until success is viable;
2. Distributed so everyone takes ownership, everyone has opportunities to participate and benefit – a structure to support this;
3. Willingness to share/work together – belief that the whole is stronger than the parts.

Afternoon Breakout Groups: Priority Issues to Inform a Research Agenda

Following Dr. Lee's presentation, the conference reconvened into four small working groups. For the afternoon's activities, participants were pre-classified into one of four small groups for discussion; each group consisted of participants from across the full spectrum of interests, to ensure a diverse mixture of perspectives.

As outlined by Ms. Bayne, the purpose of these sessions was to address Conference Objectives 4 and 5: **To explore immediate opportunities (short term) for Northwest regional collaboration and to agree on next steps longer term.**

Working in small groups with volunteer facilitators and recorders, participants were asked to develop a vision for success for a regional ASD research network, by addressing the following questions:

1. What is your vision for a regional network?
2. How would you measure success of the network in one year's time? Three to five years' time?
3. What steps are needed to achieve the vision?

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A. Group One

First looked at real-world outcomes:

- We want all children with autism to have evidence-based support
- We want clarification of which department does what and work together on the same definition
- Better information on strategies to support families
- Service providers with up to date information

1. *What is your vision of a regional network?*

To identify and improve outcomes for children, youth and adults with ASD and their families by building capacity ... with links nationally and internationally.

Capacities:

- Research on best practices for intervention
- Cause and possibly prevention of ASD
- Speed up movement from knowledge to practice
- Most effective distribution of funding
- Addressing needs of families

Who do we want in the network?

- Parents
- Adults with autism
- Researchers
- Service teams
- Funders
- Policy planners
- Politicians
- Community foundations
- Others

2. *How would you measure success for the network in one year's time? Three to five years?*

- A strong champion for networking to improve outcomes for children, youth and adults with autism and their families
- Diverse networks including all stakeholders
- Solid operating funding for networks
- Database
- Network coordinator
- Accessibility: web strategy, Telehealth
- Subgroups by interest (local groups, cross-ministerial, subsystems, conferences)

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- Outcomes:
 - Support and evidence-based training for professionals and parents supporting those with autism
 - More effective interventions
 - Better research and identification of best practices

3. *What steps are needed to achieve the vision?*

- Research linked to up to date best practice intervention
- Develop a Northwest network and funding
- Develop a volunteer Steering Committee to gather members, develop working guidelines, seek network funding
- Annual conference or working group meeting

B. Group Two

1. *What is your vision of a regional network?*

A continuum of knowledge around autism to inform policy and practice for children and families across the life span to:

- Identify gaps
- Develop widespread knowledge of supports and outcomes
- Collective identification of needs

Components required to achieve that:

- Membership from all stakeholders
- A flexible and evolving structure
- A research and information network that will inform practice
- Collaborative
- Results oriented
- Accessible
- Would involve a central registry of researchers, practitioners and policy-makers

2. *How would you measure success for the network in one year's time? Three to five years?*

One year:

- A website with a broad knowledge of research of projects
- Identify needs and prioritizing
- Identify stakeholders (roles, contribution)
- Identify the leader
- Identification of resources – who the network serves
- Establishment of a steering committee

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Five years:

- A well-developed plan to address those needs
- Measures that are valid, reliable, both broad-based and specific
- Change would be realized in terms of integration of policy across ministries
- Full value of the network would be realized
- Access to good information about standards for service delivery

3. *What steps are needed to achieve the vision?*

(None offered by this group)

C. Group Three

Had some challenges identifying/determining whether there was a specific role for a Western and Northern network in contrast to well-established networks CAIRN and ASD-CARC. Concern was expressed about whether this would be reinvention of the wheel or not.

That being said, gaps were identified in research goals from the West and North that are not necessarily embodied in some of the eastern-based research networks, and so an opportunity/niche exists to complement those existing platforms. So in addition to the things suggested by Group 2 (which captured the majority of the Group 3 discussion)

1. *What is your vision of a regional network?*

Whether or not it might be more fruitful to try and strive for local excellence that can be built upon and adopted as need be by other partners.

Can we build and learn and grow from the BC experience in terms of the fusion across stakeholder groups – to try and get that program working well before casting a wider net for larger links?

Big vision: some form of linked network of information regarding child developmental conditions in general, not just specific to autism, that could serve the national good due to the great deal of overlap.

2. *How would you measure success for the network in one year's time? Three to five years?*

(Per other groups)

3. *What steps are needed to achieve the vision?*

(Per other groups)

D. Group Four

1. What is your vision of a regional network?

To improve health and quality of life for persons with autism and their families:

- To advance diagnosis, treatment and prevention strategies
- To inform policy and practice
- To better support families

2. How would you measure success for the network in one year's time? Three to five years?

- Generating outputs of "immediate utility" to users, participants, funders
- "Quick wins" at the outset to prove the usefulness of the network model to various stakeholders
- Support/enable development of good data on incidence
- Generate "best practice" data to hold jurisdictions to account
- Champions in a variety of areas (topic, geography)
- Evidence that the network is inclusive: multiple ministries, professions, stakeholders and a mix of program types
- Enhanced ability to work across program sites, provinces/territories
- Enhanced ability to compare interventions by outcome to inform policy
- Links established with existing autism-related networks (network of networks, not one super network)
- Short term: regional, small, some research projects under way with collaboration evident
- Longer term: build on success and become known as a trusted source of information
- "US wants to buy"
- Increase in number of funded PIs, in federal/international research dollars, in projects funded re issues prioritized by network stakeholders
- Involvement of a broad range of stakeholders from Northwest Canada with sufficient resources for meaningful participation
- Number of jurisdictions that have agreed to share their data in a way that's usable
- Ability to craft and ask researchable questions that result in usable evidence
- Degree of cross jurisdictional funding

3. What steps are needed to achieve the vision?

- Get information on this meeting to those who weren't here but could/should have been
- Generate a bigger list – who else should have been invited
- Find a champion(s) to own and move the next steps forward
- Need a Steering Committee to develop a plan and next steps for implementation

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- Stakeholders in each region to further discuss/buy into shared database using BC's as a model – agreement on what to capture, consistently
- Western “champion” team – volunteers from each province, territory, ministry or with links to their networks, including parents, service providers, program administrators, clinicians, researchers and funding agencies

Summing Up

Facilitator Lillian Bayne noted that as an observer, family member, Regional Officer of the Canadian Health Services Research Foundation and former policy-maker, she is both knowledgeable and “completely uninformed about autism research, so I’ve learned a ton over these two days.”

From that perspective, she identified the following as key themes that she had observed during the course of the two-day meeting:

1. There are a series of common questions that have infused the conference:
 - What is autism? (Need for a common definition)
 - What works? (How do we define success?, What is a meaningful outcome? Quality of life measures)
 - For whom?
 - When?
 - Where?
 - Why do these things work and why don't they?
 - How much do we need to do and for how long?
 - What to measure and how to measure these things?
2. There are a series of compelling factors as to why we need a network:
 - This is a truly multidisciplinary field that can benefit from sharing perspectives and work together
 - There is a diffuse group of people with common/overlapping concerns – and who else, who is missing? (e.g. family practitioners, educators, social workers)
 - We have competing resource pressures (for research funding, for researchers, for infrastructure such as databases, for services and programs) that underscore the need for information for policy-makers (what works and where should we be putting our limited resources?)
3. Opportunities and power of networks:
 - All key players have a role to play
 - The network has the potential to be much more inclusive than conventional models, with a rich group of people involved
 - Facilitating research collaborations
 - Creating a critical mass in spite of geography and can influence the national agenda
 - Pooled resources – lots of opportunities
 - A natural public relations platform
 - Natural program advisory platform
 - Rapid and efficient knowledge transfer, particularly to counter poor information on the Internet

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4. Where are we going? – A vision statement:

To identify and improve health and quality of life for people living with autism by creating a continuum of knowledge around autism to:

- Inform policy and practice for children and families across the lifespan,
- Advance diagnosis, treatment and prevention strategies
- Identify gaps in service and knowledge
- Develop widespread knowledge of supports and outcomes
- Inform policy and practice
- Collective identification of needs
- Recognition that this is part of a fabric of other developmental conditions
- Starting with building capacity here in the northwest, but being open to involvement in a network of networks

5. Measures of success:

- Databases – data, research, projects, knowledge
- Identify needs
- Identify leader – single/many
- Identify resources
- Champions multiple across multiple jurisdictions – steering committee
- Links to existing networks
- A very diverse network – evidence of inclusive nature
- Good data, best practice data

6. Long term measures:

- Articulated plan to address our needs
- Measures that are reliable and valid
- Integration of policy across ministries
- Access to/standards for intervention
- Value of network is revealed and recognized
- Known as a trusted source of information
- Agreements to share data
- Funding support
- Reduced isolation (professionals and family members)
- Increased funding
- Increased number of funded researchers
- Increased number of collaborative projects across jurisdictions
- Bigger “N”s (larger studies)

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7. Network requirements/features:

- Flexibility
- Collaborative
- Results-oriented
- Accessible
- Central registry of researchers, policy-makers, provinces
- Immediately useful
- Inclusive – all those here plus business, community foundations, many others

8. Next steps:

- Who needs to know? – right people, more than here today
- Champion or champions
- Steering Committee
- Northwest network focus – start regionally
- Annual conference
- Research linked to outcomes

9. Outcomes:

- Evidence based support
- Better integration of strategies

10. Challenges:

- Are we ready?
- Linked to existing research strategies?
- Learning from BC – successes of fusion.

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Canadian Northwest Autism Policy Research Working Group

British Columbia	Heather Davidson (Chair of teleconference) Director, Strategic Policy and Research BC Ministry of Health Planning	Alberta (cont)	Fern Miller Project Team Leader Population Health Strategies Alberta Ministry of Health and Wellness
	Victoria Schuckel Manager of Research BC Ministry of Health Planning	Saskatchewan	Terry Blackmore Program Consultant Community Care Branch Saskatchewan Health
	Steve Noyes Senior Policy Analyst BC Ministry of Health Planning		Wanda Lyons Director Special Education Unit Saskatchewan Learning
	Del Nyberg Director, Integrated Health Promotion Planning BC Ministry of Health Planning		Bob Neufeldt Senior Consultant Community Living Division Saskatchewan Community Resources and Employment
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	Christine Ferbey Manager/ Senior Analyst Resources for Children with Disabilities Alberta Children and Family Services		

From Research to Policy and Care – Conference Committee

- BC Ministry of Health Services:
 - Heather Davidson, Director, Strategy Policy and Research
 - Victoria Schuckel, Manager of Research, Strategic Policy and Research
 - Steve Noyes, Senior Policy Analyst, Strategic Policy and Research
 - Del Nyberg, Director, Child and Youth Health
 - Barb McDonald, Administrative Assistant
- Michael Smith Foundation for Health Research:
 - Patricia Evans, Senior Advisor to the President
 - Debra Car, Executive Assistant
 - Rumi Ogura, Executive Assistant
 - Helen Evans, Research & Analysis Assistant
- Facilitator:
 - Lillian Bayne, Lillian Bayne and Associates

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Attending the Conference

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Elkin	Lynn	Family Representative; Autism NWT
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Evans	Helen	Michael Smith Foundation for Health Research
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Westbury	Robert	Alberta Centre for Child, Family and Community Research
Wong	Bibiana Ka Yan	University of British Columbia, PhD Candidate

Resources and References

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Michael Smith Foundation for Health Research inventory of autism research: **Building through Collaboration: An Inventory and Analysis of Implications for Building Autism Research Capacity in Canada's Northwest Region** [http://www.msfr.org/docs/Autism Research in Canada.pdf](http://www.msfr.org/docs/Autism%20Research%20in%20Canada.pdf)

Common Functional Abilities

http://members.shaw.ca/cmmties_children/Final_report_june19_03.PDF

This is a study carried out by **Community-University Institute for Social Research (CUISR)**. CUISR is a partnership between a set of community-based organizations (including Saskatoon District Health, the City of Saskatoon, Quint Development Corporation, the Saskatoon Regional Intersectoral Committee on Human Services) and a large number of faculty and graduate students from the University of Saskatchewan. The CUISR website is <http://www.usask.ca/cuisr/>

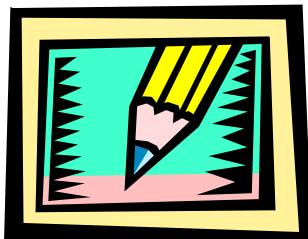
The **Canadian Institutes for Health Research (CIHR)** Institute of Health Services and Policy Research (IHSPR) is partnering with the Canadian Health Services Research Foundation (CHSRF) and four other national organizations in a second round of its **Listening for Direction** consultations, aimed at identifying research priority themes in applied health services and policy research <http://www.cihr-irsc.gc.ca/e/institutes/ihspr/20638.shtml>

Autism Genetic Resource Exchange, "the world's first collaborative gene bank", sponsored by End Autism Now <http://www.agre.org/>

Canadian Autism Research Network (CAIRN), a consortium of researchers, parents, professionals, and policy makers from across Canada <http://www.cairn-site.com/>

Autism Spectrum Disorder-Canadian-American Research Consortium (ASD-CARC), a group of more than 60 researchers, clinicians, and parents from across Canada and the US <http://www.autismresearch.ca/>

A moment of your time



The British Columbia Ministry of Health Services and the Michael Smith Foundation for Health Research request your assistance in improving our efforts to share information with our broader stakeholder community. Please take the time to complete and return a brief evaluation of this document. The evaluation is available online at (<http://survey.msfr.org/ASDConference/ASDConference.htm>).

Thank you.

For more information

To obtain further information on this document or on efforts to develop a collaborative autism research network initiative in Northwest Canada, please contact:

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Strategic Policy and Research Branch

5-1, 1515 Blanshard Street

Victoria BC V8W 3C8

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Please join us

If you are interested in receiving information on future meetings or initiatives designed to further explore development of a collaborative autism research network initiative across Northern and Western Canada, please fill in the following:

YES, please send me more information:

NAME			
TITLE			
MAILING ADDRESS			
EMAIL			
PHONE			
FAX			
SECTOR	Please indicate which of the following best describes your background/interest in autism spectrum disorders:		
	<input type="checkbox"/> Researcher	<input type="checkbox"/> Family Representative	<input type="checkbox"/> Health Research Funder
	<input type="checkbox"/> Policy Maker/Analyst	<input type="checkbox"/> Program Administrator	<input type="checkbox"/> Other (please specify)

Complete this form and return to:

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