# WORKSHOP PROCEEDINGS

## AUTISM SPECTRUM DISORDERS SURVEILLANCE IN CANADA

The Workshop was held in Ottawa, Ontario on May 9, 2011.

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**Please be advised that this report is best viewed on the screen or printed in colour.**

# Table of Contents

# List of Abbreviations

| | |
|---|---|
| ADI | Autism Diagnostic Interview |
| ADOS | Autism Diagnostic Observation Schedule |
| AHCIP | Alberta Health Care Insurance Plan |
| ASD | Autism Spectrum Disorders |
| ASD-CARC | Autism Spectrum Disorders–Canadian-American Research Consortium |
| BCAAN | British Columbia Autism Assessment Network |
| CD | Census division |
| CIHI | Canadian Institute for Health Information |
| CIHR | Canadian Institutes of Health Research |
| CMA | Census Metropolitan Area |
| CRDITED | Centre de réadaptation en déficience intellectuelle et troubles envahissants du développement |
| CSD | Census subdivision |
| CT | Census tract |
| DA | Dissemination area |
| DAD | Discharge Abstract Database |
| DPL | Designated place |
| DSM | Diagnostic and Statistical Manual |
| FRSQ | Fonds de recherche en santé du Québec |
| FSA | Forward sortation area |
| ICD | International Classification of Diseases |
| ICES | Institute of Clinical Evaluative Sciences |
| MCHP | Manitoba Centre for Health Policy |
| MELS | Ministère de l'Éducation, des Loisirs et du Sport |
| MESS | Ministère de l'Emploi et de la Solidarité sociale |
| MIMS | Manitoba Immunization Monitoring System |
| MOMBABY | Mother-Baby Linked Database |
| MSSS | Ministère de la Santé et des Services sociaux |
| NACRS | National Ambulatory Care Reporting System |
| NEDSAC | National Epidemiologic Database for the Study of Autism in Canada |
| OHIP | Ontario Health Insurance Plan |

| | |
|---|---|
| PHAC | Public Health Agency of Canada |
| PHIN | Personal Health Identification Number |
| PIA | Privacy Impact Assessment |
| RAMQ | Régie de l’assurance maladie du Québec |
| RPDB | Registered Persons Database |
| RRQ | Régie des rentes du Québec |
| SAMIN | Social Assistance Management Information Network |
| SICDI | Système d’information clientèle : Déficience intellectuelle |
| SIPAD | Système d’information des personnes ayant une déficience |
| TRA | Threat Risk Assessment |
| UA | Urban area |

# Background

The National Epidemiologic Database for the Study of Autism in Canada (NEDSAC; www.nedsac.ca) was established in 2001 with funding from the Canadian Institutes of Health Research to monitor autism spectrum disorders (ASD) among Canadian children. As part of NEDSAC's commitment to provide effective surveillance of ASD, the improvement of its existing surveillance system is critical. NEDAC is also committed to ongoing relationship building to expand the scope of its surveillance to other provinces in Canada.

The *Autism Spectrum Disorders Surveillance in Canada* workshop held on the 9th of May, 2011 in Ottawa, was organized by NEDSAC (with financial support from the Public Health Agency of Canada). This workshop was attended by 21 participants, representing BC, Alberta, Manitoba, Ontario, Prince Edward Island and Newfoundland & Labrador. The Agenda for the workshop can be found in Appendix A and the list of participants in Appendix B.

This workshop facilitated the engagement of experts across Canada with the ability to exchange knowledge of surveillance of ASD in their respective provinces, engage in discussion of the infrastructure support for surveillance of ASD and exchange resources/ protocols on how administrative datasets from various sectors can be used in ASD surveillance.

# Opportunities and Challenges

As part of the objectives of the day, the opportunities for and challenges in using administrative datasets for ASD surveillance were noted. Research completed in Manitoba on the use of administrative datasets in ASD surveillance was presented, as well as current NEDSAC protocols to collect data in Prince Edward Island and in Newfoundland & Labrador. Current surveillance strategies and/or the infrastructure in place for potential surveillance were also presented for Alberta, British Columbia, Québec and Ontario.

The participants engaged in discussions and provided information and resources that could be used to enhance surveillance strategies. Several discussion sessions allowed for thorough compilation of opportunities and challenges regarding the use of administrative data for surveillance.

The workshop participants identified three key opportunities or benefits of using administrative data:

1. utilizing existing data reduces cost
2. an administrative data approach can provide the opportunity to combine data from various sources like education, health and social services

3. because administrative datasets are typically owned by provincial government departments, use of such data in national surveillance results in the engagement of important stakeholders (federal and provincial governments).

A number of challenges inherent in using administrative data for surveillance were also identified:

1. administrative data are not collected with surveillance or research in mind
2. finding effective linkages of data from multiple sectors (health, education, social service or community services)
3. privacy, confidentiality concerns
4. approvals to access data
5. sustainability and verification of data
6. ability to control for population change and age
7. data verification
8. inclusion of First Nations communities

# Presentation Summaries

In this section, we summarize the various presentations made by participants. Power point slides for each are found in Appendix C.

## Administrative data for ASD Surveillance in Canada – An Opportunity & a Challenge

*Hélène Ouellette-Kuntz*

The presentation was an overview of the creation of NEDSAC and the last 10 years of contributions to ASD surveillance and establishing relationships with provinces. A grant from CIHR enabled NEDSAC to be established in 2001. The current partnership with the Public Health Agency of Canada under the Enhanced Surveillance of Chronic Diseases Program has supported research to explore administrative data as an improved method of surveillance.

An overview was presented on the use of administrative data, and the various challenges and opportunities experienced. NEDSAC receives data for surveillance purposes from Newfoundland & Labrador, Prince Edward Island, Southeastern Ontario and Manitoba. A brief overview of the data collection methods in each was provided.

## NEDSAC: Challenges and Opportunities in Three Provinces

### 1. Newfoundland and Labrador

*Paulette Jackman & Paula Hennessey*

Newfoundland and Labrador has a large geographical area and a high rural to urban population. The Department of Education is a valuable source of information on children with ASD. In 2000, ASD consultants were hired to coordinate the number of children with ASD known to the Department of Education. Challenges exist in tracking the number of children and obtaining data for younger children that are not in the school system, in which case, data from the Department of Health and Community Services become important. Concerns were raised about duplicate and triplicate data entries which resulted in improved data verification methods. No information is collected from private schools.

The Department of Health has 4 regional health authorities where ASD diagnoses are made. The province provides universal developmental screening for children at two months and 18 months. Delays are found for screening and diagnostic assessments that can take from 3 to 9 months. Efforts are underway to train physicians in the diagnosis of ASD. ASD falls under the pervasive spectrum disorders diagnosis coding and can be difficult to discern from other disorders found under this category from the Health data.

The collaboration of the Department of Health and Community Services with the Department of Education is vital for effective data collection and continued surveillance efforts.

### 2. Prince Edward Island

*Marlene Breitenbach*

In Prince Edward Island, the Department of Education and the Department of Social Services and Seniors have merged such that today information of ASD in this province is available from one source (the Department of Education and Early Childhood Development). Data collected since 2008 is provided by an Autism Coordinator through the Department of Education and Early Childhood Development. A large database is in place, and is able to capture the majority of cases of ASD in the province. Challenges were encountered in merging the data from the two departments as privacy concerns had to be addressed.

At present, most preschool children are diagnosed by the Autism Diagnostic Team, including a pediatrician and a psychologist. The assessment used is the ADI/ADOS. Wait times for diagnosis and IBI services may be up to one year and some families choose to go out of province for the diagnostic evaluation. There are few public resources for the diagnosis for school age children. Varied diagnostic practices are being utilized with these children, and may not include formal assessment or direct observation. More training in "gold standard" assessment and minimum requirements reflecting best practices are needed to optimize service provision and

available funding. Information on First Nations students with ASD in band operated schools is generally not available; however, private school and home schooled students are included in the PEI data.

Some suggestions for future improvements for ASD surveillance in PEI is increasing the frequency of data collection, examining methods for improving data quality, and unifying diagnostic and educational teams for ASD diagnosis and services.

### 3. Manitoba

*Dickie Yu presented by Shahin Shooshtari*

In Manitoba, NEDSAC partnered with Children's Special Services, a program of Manitoba Family Services and Consumer Affairs. Children's Special Services provides services and supports to families who may need assistance with caring for a child with disabilities. Once a child is deemed eligible for the program, a Family Services Worker is assigned to the family and works in partnership to develop a Service Plan.

Manitoba has 7 regional Children's Special Services centres that coordinate and collect the data for NEDSAC. A case worker in each region completes the NEDSAC Demographic and Diagnostic Information Form. The encrypted database is updated every few months and sent to NEDSAC.

Challenges have presented in the form of privacy and confidentiality agreements to access data, high staff turnover and communication barriers that have resulted in gaps in data. There are concerns about how data is collected by Children's Special Services. Aboriginal children living on reserves are not captured in the databases. Improving on processes to use medical claims would provide better linkage and case capture for all residents in Manitoba.

## Manitoba Centre for Health Policy: an Opportunity

*Marni Brownell*

The Manitoba Centre for Health Policy (MCHP) is an independent research centre that maintains a population data health repository that includes data from health, education, registries, and social services. MCHP provides the highest standard of security, privacy and confidentiality for the data held. Access to the data requires approvals from a University-based research ethics committee, the provincial health privacy commission and the data holders (that is, different government departments).

Data linkage occurs with appropriate approvals on a project-by-project basis. Data is available from prenatal to adulthood on everyone that is registered for health care, through hospitalizations, physician visits, receipts of income assistance, child welfare, residence and family composition. MCHP, by using a Personal Health Identification Number (PHIN) which is unique for each individual, can link data more easily and can create a clearer picture of the development of each individual.

### Manitoba Centre for Health Policy's ASD Data: Lessons Learned (the Challenges)

*Helen Coo*

This presentation provided the results of research completed in Manitoba, using administrative data, in partnership with the Manitoba Centre for Health Policy (MCHP). Helen Coo presented the challenges encountered and the future steps needed to address linkage of data, the selection of indicators and the current case ascertainment methods. In preparation of the data set for study, 75% linkage of data was obtained, and the results confirmed that NEDSAC may be missing a substantial number of cases in Manitoba.

Some potential recommendations from this research would be to utilize the Health and Education datasets at the MCHP, as a supplement or replacement, for the current case ascertainment methods used by NEDSAC. Further validation studies of the data are required and understanding the full scope of how well the 299 code identifies ASD cases is essential. In continuing further work with the Manitoba Centre for Health Policy's data, expansion of the list of reportable indicators would need to be considered and the optimal way to capture these indicators.

## Explorations in two more provinces: Québec and Ontario

*Virginie Cobigo*

This was an overview of the potential opportunities for surveillance in Québec and Ontario. In Québec multiple sources exist that have potential for ASD surveillance. The *Régie de l'Assurance maladie du Québec* (RAMQ) administers the public health and prescription drug insurance plans. This provides a repository for population-based health information but no structure is in place to support researchers.

The *Ministère de l'Éducation, du Loisir et du Sport* (MELS) collects data for children between the ages of 6 and 16. The *Régie des Rentes du Québec* (RRQ), *Ministère de la Solidarité sociale, Supplément pour enfant handicapé* (Supplement for handicapped children*)* provides financial assistance for parents who have children with a handicap. Information is available on children up to age 18.

The *Centres de réadaptation en déficience intellectuelle et troubles envahissants du développement Système d'information clientèle – Déficience intellectuelle* (SIC-DI) was established in 2000 and replaced in 2010/2011 by the *Système d'information pour les personnes handicapées* (SIPAD). This information system collects data on all individuals who receive specialized services in the province.

Although all these agencies exist, obtaining approvals to access data is complicated and authorization would need to be asked of many stakeholders. No structure is in place that can facilitate data linkage and access to the data.

In Ontario, the Institute for Clinical Evaluative Sciences (ICES) provides population-based health information. ICES is an independent organization that conducts health services research by utilizing information demographics, health services utilization,

and diagnoses. The data available is limited to health, and data from multi sectors are required for ASD. Data sharing agreement would need to be formulated between ICES and other entities. The process would require 1 to 2 years to complete, and would be dependent on the willingness of all stakeholders to share data.

## Opportunities in Alberta

Xinjie Cui

The Child and Youth Data Lab (CYDL) in Edmonton is a not-for-profit research centre that is funded by the government. This centre supports priority research through research funding and provides knowledge mobilization and builds research capacity through data sources. Information is integrated from government administrative data across nine child serving ministries across the province.

Data Sharing Agreements between ministries and CYDL which fulfill legislative requirements of data use for research purposes are being developed. Legislative requirements are those outlined in the Health Information Act (HIA), the Freedom of Information and Privacy Act (FOIP) and Personal Information Protection Act (PIPA). The centre provides the highest security standards and has a "state of the art" Anonymous Identify Resolution System (Crosswalk/AIRS) that enables personal information to be completely anonymous. The linkage of various data is complex but results have been positive.

For ASD surveillance, sectors and organizations that could contribute to data collection are Health and Wellness, Education, Children and Youth Services, Autism Follow-up Clinics, Glenrose Rehabilitation Hospital, Children's Hospital, and Community Mental Health services.

At present, the Education data are not reliable for ASD surveillance as coding is not based on clinical diagnoses. Codes reflect the impact of a child's difficulties on his or her learning (mild, moderate, or severe difficulty), and ASD can occur in any of these categories.

## Opportunities in British Columbia

*Steve Wellington and Karen Kalynchuk*

The team in British Columbia has created the largest database of children with an ASD in North America, which describes children not only in terms of their ASD diagnosis, including their ADOS and ADI results, but also in terms of their functional needs and strengths, which gives flexibility to their data and is useful for research. Their database is also web accessible which allows easier linking and recentralization. In addition, they are working towards a uniform case definition which would give their data longitudinal stability. There is concern that some children, such as those from immigrant families, may be missed.

Challenges associated with collecting data in British Columbia have to do mostly with missing data. The team does not receive any information from the private sector and they must rely on funding agencies to collect data. Also, they have no access to data about children served through First Nations programs. The spread of regional districts also causes some problems when linking data. British Columbia is constantly undergoing review of data quality and has found that 25% of their cases are missing clinical information.

## Opportunities with PHAC

*Lisa Belzak*

Lisa Belzack outlined the Public Health Agency of Canada (PHAC)'s mandate and approach to surveillance, noting that the Agency was established to provide oversight and a government structure for public health surveillance. It provides six core functions:

1. public health surveillance,
2. population health assessment,
3. disease and injury prevention,
4. health promotion,
5. health protection, and
6. emergency preparedness and response.

In these core functions PHAC monitors trends in health, detects any emerging issues, provides assessment of the risks, and provides a response in the form of information and tools.

In terms of a national autism strategy, the lead is Health Canada and funding is provided to PHAC to do surveillance and CIHR to coordinate research. Part of the first steps in working towards a national strategy was to perform an environmental scan examining administrative data (which was done with NEDSAC), Registries, Population-based surveys, clinical databases/repositories, NGO and professional networks (CPS, CAPH-C, CASDA, etc.) as well as looking at other successful models.

The next steps would be to formulate an Expert Advisory Committee which would include researchers, practitioners, and other stakeholders and a Scientific Expert Working Group to determine the best strategy and methods for surveillance.

## Future considerations

In conclusion, participants of the workshops identified some important solutions and future steps for ASD surveillance and the future of NEDSAC:

1) Raising awareness among various government departments in respective provinces. It was suggested that some provinces would be particularly interested if surveillance activities were broadened to include all developmental disorders, including Fetal-Alcohol Syndrome Disorders (FASD).

2) Surveillance strategies may vary from one province to another as the best way to capture information about affected children may differ.

3) There is some capacity to build synergistic database systems in at least 3 provinces (Alberta, British Columbia, Manitoba).

4) Developing multilateral data sharing agreements between provincial privacy officers will need to be considered.

5) The provision of national standards for case definition will be critical.

6) The Public Health Agency of Canada has a key role to play toward the development of a national system for ASD surveillance.

7) Time should be taken to explore lessons learned and experience of different countries: Australia (registries), UK (surveys), USA (admin data), Denmark, Finland and Sweden.

# APPENDIX A: Agenda

| Time | Meeting Agenda | Presenter |
|---|---|---|
| **7:00-8:00** | Breakfast<br>Central Break Area or Meeting room | |
| **8:00** | Welcome and Introduction | Helene Ouellette-Kuntz |
| **8:15** | Administrative data for ASD Surveillance in Canada – An Opportunity & a Challenge | Helene Ouellette-Kuntz |
| **8:40** | NEDSAC:<br>Challenges and Opportunities in three provinces | Paulette Jackman & Paula Hennessey (NFLD & Lab)<br>Marlene Breitenbach (PEI)<br>Shahin Shooshtari (Manitoba) |
| **9:40** | Manitoba Center for Health Policy: an Opportunity | Marni Brownell (MCHP) |
| **10:00** | coffee/tea break interactive break | |
| **10:15** | Manitoba center for health policy: Lessons Learned (the Challenges) | Helen Coo (NEDSAC) |
| **10:35** | Explorations in two more provinces: Québec and Ontario | Virginie Cobigo (Queen's University) |
| **11:00** | Opportunities in Alberta | Xinjie Cui (Alberta) |
| **11:30** | Opportunities in British Columbia | Steve Wellington & Karen Kalynchuk (BC) |
| **12:00** | Lunch- Served In Trio Restaurant | |
| **13:15** | Review of Challenges and Opportunities | Helene Ouellette-Kuntz |
| **13:45** | Opportunities with PHAC | Lisa Belzak |
| **14:00** | Administrative Data for ASD Surveillance in Canada – An Opportunity or Too Much of a Challenge? | Virginie Cobigo to facilitate discussion |
| **15:30** | Final Wrap up<br>Continue networking | Hélène Ouellette-Kuntz |

# APPENDIX B: List of Participants

| Name | Position and Affiliations | City, Province |
|---|---|---|
| Lisa Belzak | Manager/ Epidemiologist, MHSc., Developmental Disorders Surveillance Unit<br>Health Surveillance and Epidemiology Division, Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada | Ottawa, Ontario |
| Marlene Breitenbach | Special Education Autism Coordinator, Department of Education and Early Childhood Development | Charlottetown, Prince Edward Island |
| Marni Brownell | Senior Research Scientist Manitoba Centre for Health Policy (MCHP) and Associate Professor, Department of Community Health Sciences, Faculty of Medicine, University of Manitoba | Winnipeg, Manitoba (via Southern Ontario) |
| Beata Chledowski | Master's in Applied Health Services Research Candidate Atlantic Regional Training Center (ARTC) Health Services Research, University of New Brunswick | Kingston, Ontario |
| Virginie Cobigo | Postdoctoral fellow, Queen's University | Kingston, Ontario |
| Helen Coo | Project Coordinator, National Epidemiologic Database for the Study of Autism in Canada (NEDSAC), Queen’s University | Kingston, Ontario |
| Angela Cornick | Director, ABA Program & Psychological Services, St. Amant Centre, Winnipeg, MB | Winnipeg, Manitoba |
| Xinjie Cui | Director, Child and Youth Data Laboratory, Alberta Centre for Child, Family and Community Research | Edmonton, Alberta |
| Deborah Dewey | Director, Behavioural Research Unit, Alberta Children's Hospital and Professor, Departments of Paediatrics & Community Health Sciences, University of Calgary | Calgary, Alberta |
| Deborah Gorski | NEDSAC Research Assistant , Queen’s University | Kingston, Ontario |
| Allan Hendrickson-Gracie | CSS Program Specialist, Community Service Delivery | Winnipeg, Manitoba |
| Paula Hennessey | Director, Early Childhood Learning Division, Department of Education | St. John’s, Newfoundland and Labrador |
| Jeanette Holden | Professor, Autism Research Program, Depts. Psychiatry and Physiology, Queen's University | Kingston, Ontario |
| Paulette Jackman | Professional Development Consultant-Autism Division of Student Support Services, Department of | St. John’s, Newfoundland |

| Name | Position and Affiliations | City, Province |
|---|---|---|
| | Education | and Labrador |
| Karen Kalynchuk | Program Director BC Autism Assessment Network | Vancouver, British Columbia |
| Suzanne Lewis | Clinical Professor, Department of Medical Genetics, University of British Columbia and Adjunct Professor, Department of Psychiatry, Queen's University | Vancouver, British Columbia |
| Tara Longpre | MSc (candidate), Epidemiologist, Developmental Disorders Surveillance Unit, Health Surveillance and Epidemiology Division, Centre for Chronic Disease Prevention and Control , Public Health Agency of Canada | Ottawa, Ontario |
| Michelle Loranger | NEDSAC Research Assistant, Queen's University | Kingston, Ontario |
| Marianna Ofner | Senior Advisor/Epidemiologist, MSc, PhD (Candidate), Directors Office/ Developmental Disorders Surveillance Unit , Health Surveillance and Epidemiology Division, Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada | Toronto, Ontario |
| Hélène Ouellette-Kuntz | Director, National Epidemiologic Database for the Study of Autism in Canada, Epidemiologist at Ongwanada, and Associate Professor, Department of Community Health & Epidemiology, Queen's University | Kingston, Ontario |
| Maureen Seguin | Manitoba Family Services and Consumer Affairs, Disability Programs and EIA and Disability Programs | Winnipeg, Manitoba |
| Shahin Shooshtari | Assistant Professor ,Department of Family Social Sciences, Department of Community Health Sciences, University of Manitoba | Winnipeg, Manitoba |
| Stephen Wellington | Medical Director, B.C. Autism Assessment Network, Developmental Paediatrician, and Clinical Assistant Professor, Division of Developmental Paediatrics, University of British Columbia | Vancouver, British Columbia |

# APPENDIX C: Power Point Slides

## Hélène Ouellette-Kuntz's Presentation

### ASD Surveillance in Canada WORKSHOP

May 9, 2011

Ottawa

### Surveillance

- "tracking and forecasting any health event or health determinant through the ongoing collection of data, the integration, analysis and interpretation of that data into surveillance products and the dissemination of that resultant surveillance product to those who need to know."

Health Canada, Office of National Health Surveillance. Partnering for quality, timely surveillance leading to action for better health. Proposal to Develop a Network for Health Surveillance in Canada. Ottawa, May 1999.

### Public Health Surveillance & ASD

source: http://www.maine.gov/dhhs/reports/ASD_SurveillanceOptions.pdf

- case definition and case finding procedures must remain constant over time
- the system must control for population changes, and focus on an age by which one would expect most children to have been diagnosed
- selected surveillance option(s) must be sustainable, with the expectation that needed resources will continue to be available for many years

### Public Health Surveillance & ASD

source: http://www.maine.gov/dhhs/reports/ASD_SurveillanceOptions.pdf

- All surveillance systems should be evaluated periodically, and modified as needed, so that the data they yield can be accurately interpreted[21]
- Quality control procedures are also needed[22]
- Some of the options **utilize existing data** (e.g., education administrative data, clinical administrative data, survey data); others would require the collection of new data

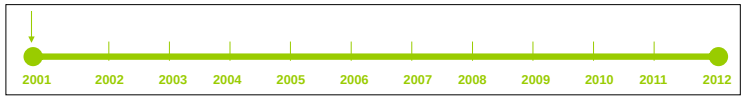
[21] Doyle TJ, Glynn K, Groseclose SL. Completeness of notifiable infectious disease reporting in the United States: an analytical literature review. *American Journal of Epidemiology.* 2002;155(9):866-874.
[22] National Birth Defects Prevention Network (NBDPN). *Guidelines for conducting birth defects surveillance.* Atlanta, GA: National Birth Defects Prevention Network, Inc.; June 2004.

ASD Surveillance in Canada
10 years of preliminary activity

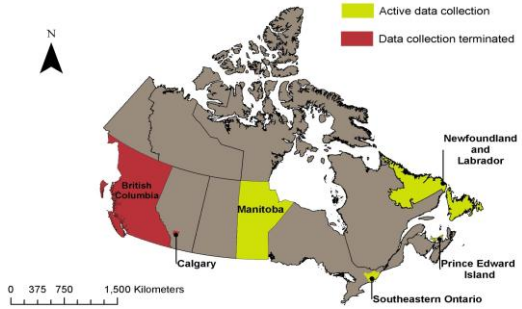
## In the beginning…

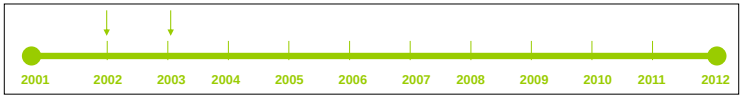
CIHR IHRT Team Grant (2001-2006)

- Genetics
- Dysmorphology
- Early identification
- Epidemiology
  - Prevalence
  - Services/family impact
  - Etiology



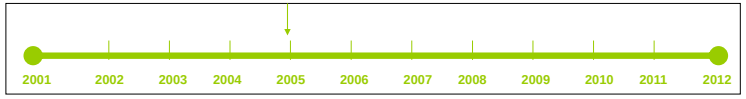

## NEDSAC: Prevalence of ASD



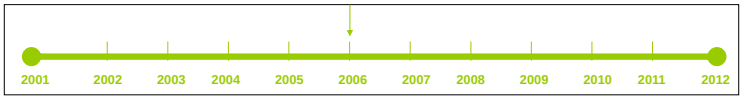

## Edudata (BC)

- Research agreement with BC Ministry of Education/Edudata to obtain information on children with a special education code of autism
- Meant to supplement NEDSAC data collection in BC, but lack of identifiers meant could not accurately match to records collected through other sources
- Instead, examined diagnostic substitution and effect of earlier identification on prevalence estimates



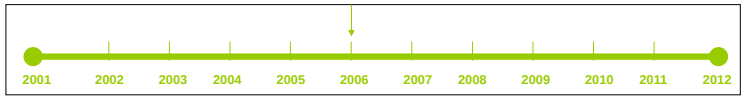
## Federal Government involvement

- Minister of Health announces intention to enhance **monitoring**, research, knowledge-sharing, and best practices in the field of ASD



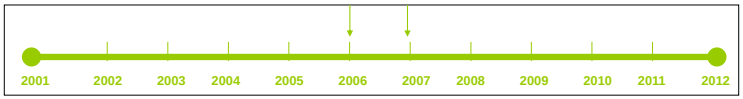

## NEDSAC Phase II (2006-2011)
### -CIHR Programmatic Operating Grant

- Continue work from initial grant
- Confirm diagnosis using gold-standard tools
- Study effectiveness of parent and teacher questionnaires in differentiating children with autism from children with other developmental disorders



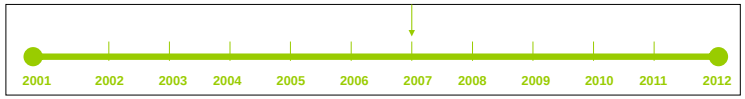

## NEDSAC coverage diminishes

- Data collection terminated in BC and Alberta due to lack of certainty around denominator for calculating prevalence




## PHAC takes a leadership role

- forms external Steering Committee to guide development of business case
- conducts Environmental Scan and Identification of Key Stakeholders
- sponsors technical workshop resulting in list of priority indicators for ASD Surveillance
- announces Enhanced Surveillance for Chronic Disease Program RFA

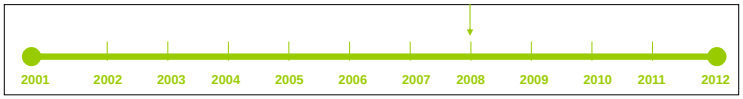


## PHAC takes a leadership role

- commissions Stakeholder Consultation re: indicators to ASC, CAIRN, ASD-CARC

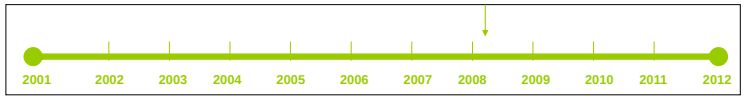
Tracking ASDs in Canada
Surveillance des TSA au Canada

- commissions descriptions of options for ASD Surveillance in Canada
  - Queen's submits report on Administrative Databases as an Option for ASD Surveillance to PHAC (2008, March)



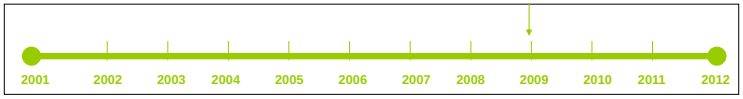

## Using Administrative Datasets to Examine Environmental Risk Factors for Autism
### -CIHR Meeting Grant

- CHARGE Study
  - Childhood Autism Risk from Genetics and the Environment
- Environment Canada
  - Canada's National Pollutant Release Inventory
  - National Air Pollution Surveillance Network
  - National Atmospheric Chemistry Database and Analysis System



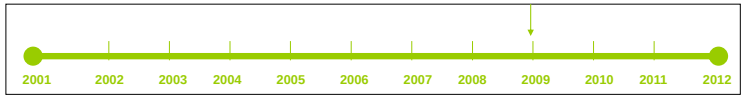

## Post doctoral fellow: V. Cobigo (2009-2012)
### -Fonds de Recherche en Santé du Québec

- Developing protocols and agreements for linkage of data
  - Health Surveillance in Intellectual Disabilities
  - ASD Surveillance



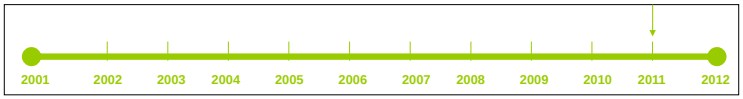

## Enhancing ASD Surveillance (2009-2011)
### -PHAC Contribution Agreement

- Specifically, to evaluate how well we identify cases of ASD in Manitoba
- More generally, to explore the use of administrative data for ASD surveillance



## ASD Surveillance in Canada Workshop

- Continue to identify provincial systems and protocols whereby administrative data may be used in autism surveillance.
- Discuss further collaborations for expanding the scope of current activities led by NEDSAC.



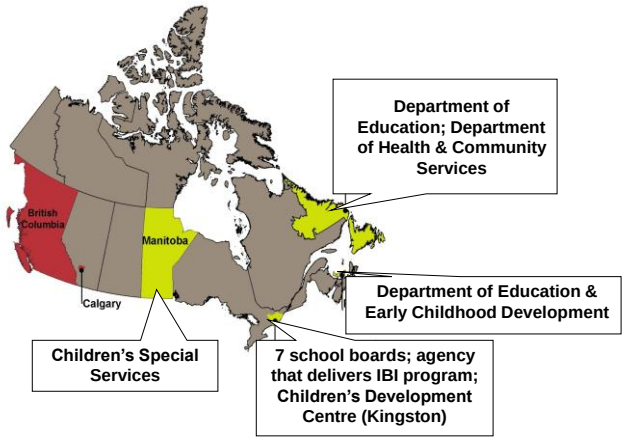

## Administrative Data: An opportunity and a challenge

## *Data collected for the purpose of carrying out various non-statistical programs*

- Present a number of advantages
  - reduced cost and respondent burden
- Requires initial as well as continuous/periodic assessment
  - Coverage, content, concepts and definitions, quality and control procedures, frequency of updates, timeliness, stability over time
- Often valuable to combine sources
- Must overcome concerns about privacy
- Changes in administrative considerations may distort time series!

source: http://www.statcan.gc.ca/pub/12-539-x/steps-etapes/4147786-eng.htm

## NEDSAC data sources and data collection



# Consent Tracker

| Surname of child | First name of child | Family ID | Child ID | DOB (DD-MMM-YY) | Sex (M/F) | Prevalence year | Dx Subtype | Current date (DD-MMM-YY | Discharge date (DD-MMM-YY | Reason discharged |
|---|---|---|---|---|---|---|---|---|---|---|
| | | 1 | 1 | | M | 2002 | Autistic Disorder | 10-Apr-02 | 13-Oct-04 | Graduated |
| | | 2 | 1 | | M | 2002 | Autistic Disorder | 10-Apr-02 | 2-Nov-06 | Moved |
| | | 3 | 1 | | M | 2002 | Autistic Disorder | 10-Apr-02 | | |
| | | 4 | 1 | | M | 2002 | Autistic Disorder | 10-Apr-02 | | |
| | | 5 | 1 | | M | 2002 | Autistic Disorder | 10-Apr-02 | | |
| | | 6 | 1 | | M | 2002 | Autistic Disorder | 10-Apr-02 | | |
| | | 7 | 1 | | M | 2002 | Autistic Disorder | 10-Apr-02 | | |
| | | 8 | 1 | | M | 2002 | Autistic Disorder | 10-Apr-02 | | |
| | | 9 | 1 | | M | 2002 | Autistic Disorder | 5-Apr-03 | | |

# Data collection

- Telephone interviews with parents in Newfoundland & Labrador, PEI, Southeastern Ontario
- Agency completes form in Manitoba

# Data elements

- # of siblings
- # of siblings with confirmed or suspected ASD
- Where mother lived when pregnant with child
- Maternal/paternal ages at birth of child
- Ethnicity

- Type of professional who made diagnosis
- Tests used to make diagnosis
- Diagnostic subtype
- Date of diagnosis
- Where living when diagnosed

## Paulette Jackman & Paula Hennessey's Presentation

### NEDSAC
### Challenges and Opportunities

Newfoundland and Labrador

2011

### Newfoundland and Labrador Education – Demographics (2010-11)

- 272 schools; 68, 729 students
- 4 English School Districts, 1 French School District
- 37.5% Urban Schools ( >10,000) vs. 62.5% Rural (<10,000)

### Newfoundland and Labrador Education Data on Students with ASD

- History
- In 2000, provincial ASD consultant positions were created at Department of Education. There were approximately 100 identified students with ASD (K-12).
- In 2005, this number was approximately 300.
- In 2010, this number was approximately 700.

### Newfoundland and Labrador Education Data on Students with ASD

- How were these numbers obtained?

  - Provincial ASD Consultants

  - District Level Personnel responsible for Student Support Services

  - Annual General Report (AGR)- Recent Years (2010-11: 716)

## Newfoundland and Labrador Education Data on Students with ASD

- In 2007, issues with data were identified.
- Larger numbers of students with ASD was resulting in less accurate data (i.e. unidentified students with ASD, failure to report transfers in and out of school and districts, etc.)
- NEDSAC hired an individual to contact every school in the province ( 2009 ).
- Opt Out/Privacy

## Newfoundland and Labrador Education Data on Students with ASD

- School district level autism specialist positions began in the 2010-11 school year.
- To update 2009 data collection, these specialists have been requested to collect information on students with ASD that schools became aware of in the past two years (i.e K and Grade 1; transfers; recent diagnosis).

## Further Discussion

- Collaboration with Department of Health and Community Services
- How are the reports/stats used by Department of Education?
- Challenges
- Opportunities

## ASD Surveillance in Canada: Prince Edward Island

May 9, 2011
Marlene Breitenbach,M.S.Ed.,BCBA

## PEI - Context

September, 2011 (ASD estimates)

- In school 200
- Private or home school <10
- Receiving IBI or Intensive Kindergarten Support 36
- Wait list for IBI 4
- Wait list for diagnosis 35

## NEDSAC-PEI

- Collaboration since 2001
- Two departments-Social Services and Seniors (SSS) and Education (EDUC)
- Departments merged in 2008
  *Department of Education and Early Childhood development*

## Data Sources

2001-2007

- Data for preschoolers provided by IBI Coordinator (SSS)
- Data for school age children provided by Autism Coordinator (EDUC)

2008-2011

- Data for all provided by Autism Coordinator (EDUC)

## Diagnosis - Preschool

- Majority of preschool diagnoses provided by Autism Diagnostic Team (psychologist/pediatrician) using ADI/ADOS, clinical judgment
- Cognitive/communication assessment generally not included

## Diagnosis-School

- Few public resources for school age diagnosis
- Majority of school diagnoses provided by private practitioner (comprehensive psycho-educational assessment) or pediatrician (clinical judgment)

## PEI Database

- All newly diagnosed preschoolers are referred to the Department Autism Coordinator by Diagnostic Team
- All newly diagnosed school age children or transfers from out of province are reported to the Department by school board Autism Consultants

## Issues with Diagnosis

Changing trends

- Use of "ASD" for all
- Provisional diagnosis
- Different diagnostic practices across professionals ("gold standard", standardized assessment, DSM criteria, clinical judgment, statement only)

## Issues

- Transfer of information challenges
- Ethics approval
- Diagnosis tied to accessing services and funding
- Different criteria to access autism specific services IBI/school

## Case ascertainment

- Confidence level – preschool vs school age
- Increasing numbers of very able children identified

## NEDSAC

- NEDSAC Data/reports primarily used for disseminating accurate information to parents, the public and NGOs
- Results from related study on unmet needs (Brown & Ouellette-Kuntz, 2010) was very useful and supported current policy development

## Future

- More frequent updates?
- Disseminate more widely?
- Clarification regarding differing diagnostic practices?
- How will new DSM criteria affect NEDSAC?

## Reference

Brown, H. K., & Ouellette-Kuntz, H. (2010, September). *Examining the needs of families of school-aged children with an autism spectrum disorder: Summary of results from the Family Needs Study. Kingston, ON: Queen's University Department of Community Health & Epidemiology.*

# National Epidemiologic Database for the Study of Autism in Canada (NEDSAC)

## Manitoba

**Shahin Shooshtari,** Ph.D.

## NEDSAC in Manitoba

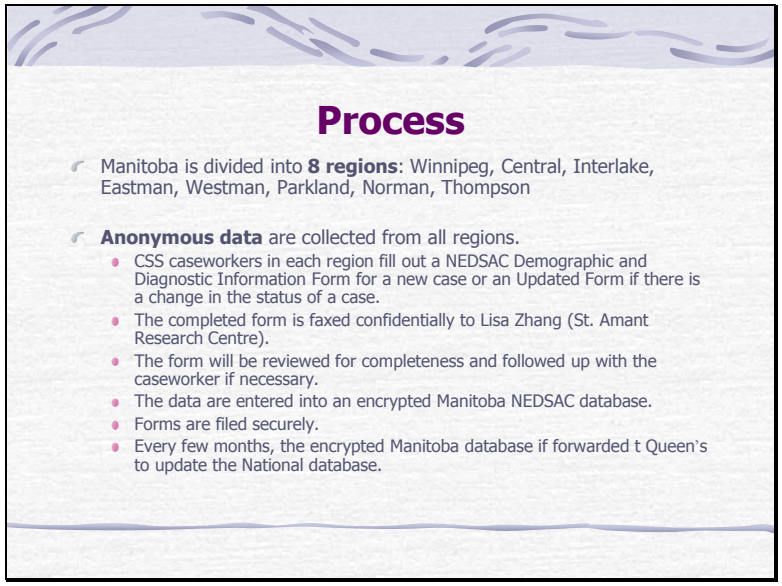
- Partnership with Children's Special Services (CSS), department of Manitoba Family Services and Consumer Affairs
- Partnership with CSS began in 2002
  - Ms. Eleanor Chornoboy (Director of CSS)
  - Mr. Allan Hendrickson-Gracie
  - Continuing support and cooperation of all regional supervisors and CSS caseworkers

## Funding

- NEDSAC is supported by research grants from CIHR (H. Ouellette_Kuntz, PI, Queen's U)
- In-kind contributions from St. Amant Research Centre
  - Dr. Dickie Yu (Lead person for Manitoba site)
  - Ms. Lisa Zhang (technical Support Staff at St. Amant Research Centre)

## Case Definition

- A child with a specific diagnosis corresponding to ICD-9, ICD-10, DSM-III, DSM-IIIR or DSM-IV classifications for pervasive developmental disorders (PDD) is included.
- PDD is a group neurodevelopmental disorders that include Autism, Asperger, PDD-NOS (Not Otherwise Specified), Rett, and Childhood Disintegrative Disorders.
- A child is included if (s)he has received a diagnosis of ASD or PDD.
- Children with a diagnosis of "suspected" PDD are excluded.


Process
Manitoba is divided into 8 regions: Winnipeg, Central, Interlake, Eastman, Westman, Parkland, Norman, Thompson
Anonymous data are collected from all regions.
CSS caseworkers in each region fill out a NEDSAC Demographic and Diagnostic Information Form for a new case or an Updated Form if there is a change in the status of a case.
The completed form is faxed confidentially to Lisa Zhang (St. Amant Research Centre).
The form will be reviewed for completeness and followed up with the caseworker if necessary.
The data are entered into an encrypted Manitoba NEDSAC database.
Forms are filed securely.
Every few months, the encrypted Manitoba database if forwarded t Queen's to update the National database.

# The Manitoba Centre for Health Policy: An Opportunity for ASD Surveillance?

Marni Brownell, PhD

ASD Surveillance in Canada Workshop
Ottawa, ON
May 9, 2011

## Manitoba Centre for Health Policy

- University of Manitoba
- unit of the Department of Community Health Sciences, Faculty of Medicine
- 1991 … but a long history pre-dates this
- Five-year contracts with Manitoba Health; 6 deliverables per year
- Independently funded research

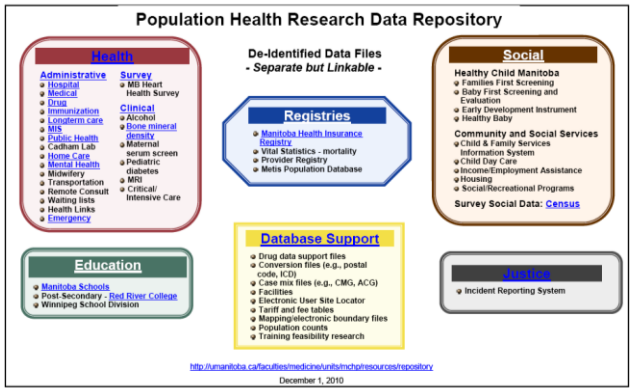
## Manitoba Centre for Health Policy

**MISSION**

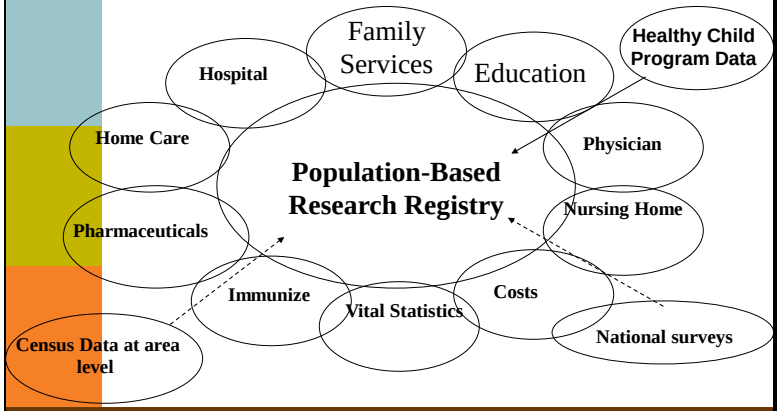
***MCHP is a research centre of excellence that conducts world class population-based research on health services, population and public health, and the social determinants of health. MCHP develops and maintains the comprehensive population-based data repository on behalf of the Province of Manitoba for use by the local, national and international research community. MCHP promotes a collaborative environment to create, disseminate and apply its research. The work of MCHP supports the development of policy, programs and services that maintain and improve the health of Manitobans.***

**VISION**

***MCHP sets the international standard for using population-based secondary data to create new knowledge that informs health policy, social policy and service delivery.***

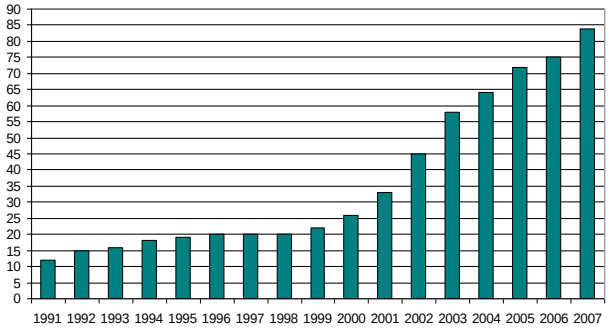


## Manitoba Population Health Research Data Repository




Key health databases start in 1970

## Total Number of Data Files in MCHP Repository




Continual expansion of databases -
CFI funding 1999-2003 ($2.7 million)

## MCHP: Respect for Privacy

- Highest standards of security, privacy & confidentiality of data (PHIA, FIPPA)
  - No names, no addresses; “scrambled” identifier numbers
  - MCHP feasibility/mandate, Ethics review committee, Health Information Privacy Committee, other stakeholder groups as required
  - Limited access on project-specific basis; data stored in unlinked files
  - Suppression for 5 or fewer persons/events
  - Data for research not for administrative use

## How does MCHP get de-identified data from providers that can be linked to other data sets?

Manitoba Centre for Health Policy

## How does MCHP get de-identified data from providers that can be linked to other data sets?

**Provider**

**De-identification Process between Trustee (Provider), MH and MCHP**

Program Data | Scrambled ID | Identifying Information: Name, Address, DOB



Manitoba Centre for Health Policy

**Provider**

① Program Data | Scrambled ID | Identifying Information: Name, Address, DOB

**De-identification Process between Trustee (Provider), Manitoba Health (MH) and MCHP**

**MH**

(MH attaches a Scrambled PHIN and strips Identifying Information) ②

③ Scrambled ID | Scrambled PHIN (Crosswalk File)

④ **MCHP Data Repository**

Program Data | Scrambled ID

Scrambled ID | Scrambled PHIN (Crosswalk File)

⑤ (Data linkage occurs only with appropriate approvals on project by project basis)



Manitoba Centre for Health Policy

## Using linked data to build a picture of development throughout childhood

**Prenatal:**
FF screen
Prenatal care
Maternal serum screen

**At birth:**
Birth weight
Gestational age
Apgar scores
Breastfeeding
Complications
FF screen

**Early Years:**
Immunization
Child care

**School Entry:**
EDI
School enrolment
Early literacy
Special needs

**Middle Years (~7-11):**
Grade 3 assessment
School enrolment
Grade retention
Special needs

**Middle Years (~12-14):**
Grade 7/8 assessments
School enrolment
Grade retention
Special needs

**Youth (~15-19):**
Grade 12 assessments
High school marks
Special needs
High school completion

Prenatal | birth | Early years | School entry | Middle years | adolescence

**At all stages: health status (hospitalizations, doctor visits, medications prescribed, FASD), receipt of income assistance, involvement with child welfare, residence (area-level income, number of moves), family composition (marital status, number of siblings)**



Manitoba Centre for Health Policy

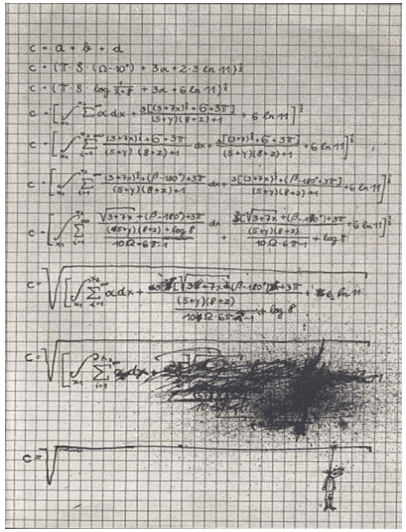
# Manitoba Centre for Health Policy

Marni_Brownell@cpe.umanitoba.ca

**www.umanitoba.ca/medicine/units/mchp/**

# Evaluating case ascertainment and expanding surveillance indicators for autism spectrum disorder using administrative data

Presented by Helen Coo
NEDSAC Project Coordinator

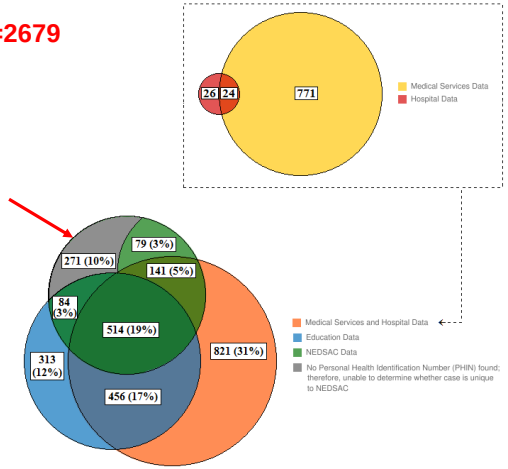


## Preparing the study dataset

- Decoding identities at Children's Special Services — 1146
  – 52 – 5
- Preparing crosswalk file at Manitoba Health
  1089
  – 271 (75% linkage)
- Merging datasets at Manitoba Centre for Health Policy — 818

## Study dataset

N=2679



## I. Evaluating NEDSAC's case ascertainment

**When surveillance programs rely on passive case ascertainment, the completeness of case ascertainment depends to a large degree on the number and types of data sources used to identify cases and on the consistency of reporting from those data sources. The use of measures to evaluate the completeness of case capture is essential (National Birth Defects Prevention Network, 2004).**

## Objectives

**Objective 1: Evaluate our current case ascertainment in Manitoba through NEDSAC**

**Objective 2: Assess whether the 299 code in physician billing claims is specific enough to identify cases of ASD**

## Objective 1 Findings

| Among 8 year olds in 2006, 1 in X have ASD | |
|---|---|
| 110 | Centers for Disease Control and Prevention |
| 100 | Health and education data at Manitoba Centre for Health Policy |
| 153 | National Epidemiologic Database for the Study of Autism in Canada |

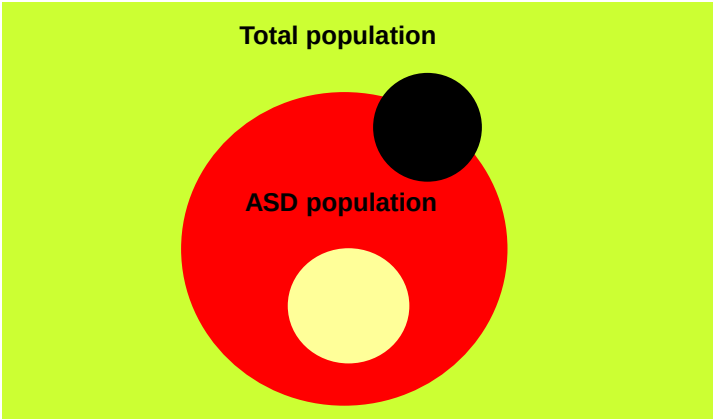
## Objective 1 Findings

| | NEDSAC | Not in NEDSAC |
|---|---|---|
| **Total n** | 863 | 1171 |
| **Boys** | 701 (81.2) | 905 (77.3) |
| **Age group in years** | | |
| 0-4 | 91 (10.5) | 455 (38.0) |
| 5-9 | 387 (44.8) | 517 (44.2) |
| 10-14 | 385 (44.6) | 209 (17.8) |
| **Health region** | | |
| Winnipeg | 543 (62.9) | 749 (64.0) |
| Central | 69 (8.0) | 89 (7.6) |
| Interlake | 48 (5.6) | 67 (5.7) |
| North/South Eastman | 73 (8.5) | 95 (8.1) |
| Assiniboine/Brandon | 99 (11.5) | 81 (6.9) |
| Parkland | 20 (2.3) | 33 (2.8) |
| Burntwood/Churchill/Norman | 11 (1.3) | 57 (4.9) |
| **MCHP dataset where first identified with ASD code** | | |
| Medical Services | --- | 882 (75.3) |
| Hospital Discharges | | 23 (2.0) |
| Education | | 266 (22.7) |

## Objective 2

- Assess whether the 299 code in physician billing data is specific enough to identify cases of ASD

## The 299 diagnostic code



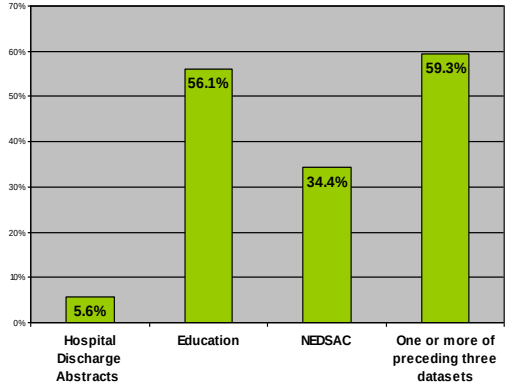

## Objective 2

- Assess whether the 299 code in physician billing data is specific enough to identify cases of ASD

→ Could allow us to partially evaluate our case ascertainment in Southeastern Ontario using data from the Institute of Clinical Evaluative Sciences

## Objective 2 Findings

**Based on 1894 records identified in Medical Services Database**



## Conclusion

- NEDSAC *may* be missing a substantial number of cases in Manitoba
- The Health and Education datasets at the Manitoba Centre for Health Policy may be a good supplement to, or replacement for, our current case ascertainment methods, but…
- Further validation studies of the data are needed, which would also…
- Provide more information about how well the 299 code identifies ASD cases

## II. Expanding Surveillance Indicators

**Objective:** To identify indicators relevant to the surveillance of ASD that can be collected through the Manitoba Centre for Health Policy datasets, and to examine measurement issues (missing values, other data quality issues)

## Findings

Using the Manitoba Centre for Health Policy's data would expand the list of reportable indicators considerably

- Comorbidities
- Obstetric factors
- Special education funding
- Receiving social assistance
- Mental health of mother and siblings
- Movement patterns
- Immunizations

## Findings

There are some potential, and known, issues with these data

- The validity of indicators that depend on an ICD code is unknown
- Some indicators depend on the establishment of a mother-child link, which is not available for all individuals
- Some indicators, such as paternal age and marital status, have known measurement issues
- Can date of initial diagnosis be reliably captured?

## Findings

**Some potentially important indicators may not be fully captured through data at the Manitoba Centre for Health Policy**

- **Ethnicity**

## Conclusion

- **Need to identify which indicators, at a minimum, should be collected as part of a surveillance program**
- **Then decide optimal way to capture them, taking into account data quality, feasibility (cost, time, etc.),**
  - **A hybrid model may be necessary**

**Recommendations based on the work done with the Manitoba Centre for Health Policy**

**Recommendation 1: Develop an algorithm to define ASD cases status using the health and education data at the Manitoba Centre for Health Policy (and possibly Children's Special Services data?).**

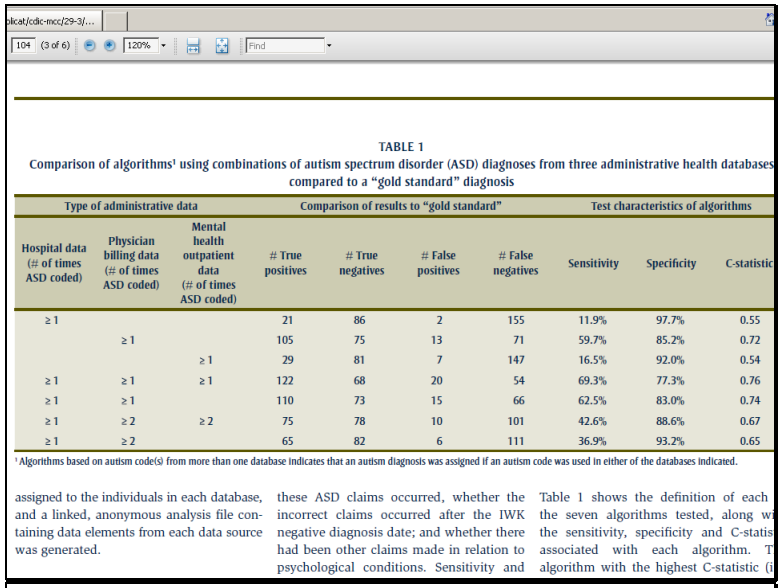


TABLE 1
Comparison of algorithms[1] using combinations of autism spectrum disorder (ASD) diagnoses from three administrative health databases compared to a "gold standard" diagnosis

| Type of administrative data | | | Comparison of results to "gold standard" | | | | Test characteristics of algorithms | | |
|---|---|---|---|---|---|---|---|---|---|
| Hospital data (# of times ASD coded) | Physician billing data (# of times ASD coded) | Mental health outpatient data (# of times ASD coded) | # True positives | # True negatives | # False positives | # False negatives | Sensitivity | Specificity | C-statistic |
| ≥ 1 | | | 21 | 86 | 2 | 155 | 11.9% | 97.7% | 0.55 |
| | ≥ 1 | | 105 | 75 | 13 | 71 | 59.7% | 85.2% | 0.72 |
| | | ≥ 1 | 29 | 81 | 7 | 147 | 16.5% | 92.0% | 0.54 |
| ≥ 1 | ≥ 1 | ≥ 1 | 122 | 68 | 20 | 54 | 69.3% | 77.3% | 0.76 |
| ≥ 1 | ≥ 1 | | 110 | 73 | 15 | 66 | 62.5% | 83.0% | 0.74 |
| ≥ 1 | ≥ 2 | ≥ 2 | 75 | 78 | 10 | 101 | 42.6% | 88.6% | 0.67 |
| ≥ 1 | ≥ 2 | | 65 | 82 | 6 | 111 | 36.9% | 93.2% | 0.65 |

[1] Algorithms based on autism code(s) from more than one database indicates that an autism diagnosis was assigned if an autism code was used in either of the databases indicated.

assigned to the individuals in each database, and a linked, anonymous analysis file containing data elements from each data source was generated.

these ASD claims occurred, whether the incorrect claims occurred after the IWK negative diagnosis date; and whether there had been other claims made in relation to psychological conditions. Sensitivity and

Table 1 shows the definition of each the seven algorithms tested, along wi the sensitivity, specificity and C-statis associated with each algorithm. T algorithm with the highest C-statistic (i

## How would we do this?

- **Methodologically**
  - **Can we assume that "cases" with an ASD code in the physician billing data and one other data source (Education, hospital discharges, NEDSAC) are true positives, and focus on validating case status of those identified in physician billing claims only?**
  - **Two-way validation?**
  - **Is there any way to validate status of "cases" that appear in Education data only?**
- **Logistically**
  - **Funding source?**

**Recommendation 2: Determine whether the date an ASD code first appears in the Manitoba Centre for Health Policy data accurately reflects the date of initial diagnosis.**

**Recommendation 3: Decide the scope of ASD surveillance in terms of what indicators NEDSAC should collect, and establish whether those indicators are readily available in regional administrative datasets or whether they would be better captured through other measures.**

## Exploration in Quebec & Ontario


Dr. Virginie Cobigo
ASD Surveillance in Canada Workshop, Ottawa, May 9th, 2011

## Exploration in Quebec


- Second most populous province in Canada
- 7.5 million habitants
- Multiple sources of data
- Postdoctoral award from the Fonds de recherche en santé du Québec (2009 – 2012)

## Exploration in Quebec

- **Régie de l'Assurance maladie du Québec (RAMQ)**
  - Administers the public health & prescription drug insurance plans
  - Repository for population-based health information ONLY
  - All ages
  - No structure to support researchers

## Exploration in Quebec

- **Régie de l'Assurance maladie du Québec (RAMQ)**
  - Diagnoses, age at diagnosis and sequence of diagnoses
  - Utilization of medical services (before and after diagnosis)
  - Demographics
  - Deprivation index (neighbourhood): current address and place of birth.
  - If linkage possible with the mother's file: obstetric factors, age of the mother, etc.

## Exploration in Quebec

- **Ministère de l'Éducation, du Loisir et du Sport (MELS)**
  - School-aged children
    - Mandatory from 6 to 16 yo
    - Potentially data on children 4 to 21 yo.
  - Only 1 diagnosis recorded per school year.

## Exploration in Quebec

- **Ministère de l'Éducation, du Loisir et du Sport (MELS)**
  - School attendance
  - Support required at school
  - Age, sex
  - Language spoken at home
  - Place of birth

## Exploration in Quebec

- **Régie des Rentes du Québec (RRQ)**
  **Ministère de la Solidarité sociale**
  **Supplément pour enfant handicapé (Supplement for handicapped children)**
  - Financial assistance for parents of a children with handicap.
  - One per children with handicap.
  - 0 to 18 yo

## Exploration in Quebec

- **Régie des Rentes du Québec (RRQ)**
  **Ministère de la Solidarité sociale**
  **Supplément pour enfant handicapé (Supplement for handicapped children)**
  - Sequence of diagnoses
  - Age at diagnosis
  - Sex
  - Living with family or placement, marital status, age of parents
  - Siblings with ASD

## Exploration in Quebec

- **Centres de réadaptation en déficience intellectuelle et troubles envahissants du développement**
  **Système d'information clientèle – Déficience intellectuelle (SIC-DI)**
  **Système d'information pour les personnes handicapées (SIPAD)**
  - Persons who receive specialized services
  - All ages
  - SICDI: 2000 to 2010
  - List of variables included in the SIPAD unknown at the time of inquiry.

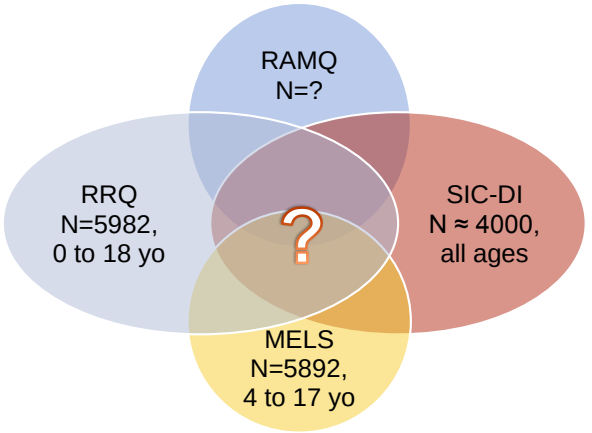
## Exploration in Quebec

- **Centres de réadaptation en déficience intellectuelle et troubles envahissants du développement**
  **Système d'information clientèle – Déficience intellectuelle (SIC-DI)**
  - Demographics
  - Intellectual and adaptive functioning (diagnosis of intellectual disability)
  - Challenging behaviours and some other comorbidities
  - Waiting time for specialized services, including early intervention

## Exploration in Quebec

- **Centres de réadaptation en déficience intellectuelle et troubles envahissants du développement**
  **Système d'information clientèle – Déficience intellectuelle (SIC-DI)**
  - Services received, including early intervention
  - Living with family or residential services received

## Exploration in Quebec



## Exploration in Quebec

- **Obtaining approvals to access data:**
  - SICDI/SIPAD: authorization from each service agency: more than 20 in Québec.
  - RAMQ: authorization from the *Régie de l'assurance maladie*.
  - MELS: authorization from the Ministry
  - RRQ, *Supplément pour enfant handicapé*: authorization from the *Ministère de la solidarité sociale*.
  - Authorization from the *Commission d'accès à l'information*

## Exploration in Quebec

- **Linkages**
  - SICDI/SIPAD ↔ RAMQ using Personal Health Insurance Numbers
  - MELS ↔ RRQ: no information on the method and success of the linkage.
  - Probabilistic linkages
  - No structure such as MCHP which facilitates access to data and linkages for research purposes. RAMQ: to proceed with linkages

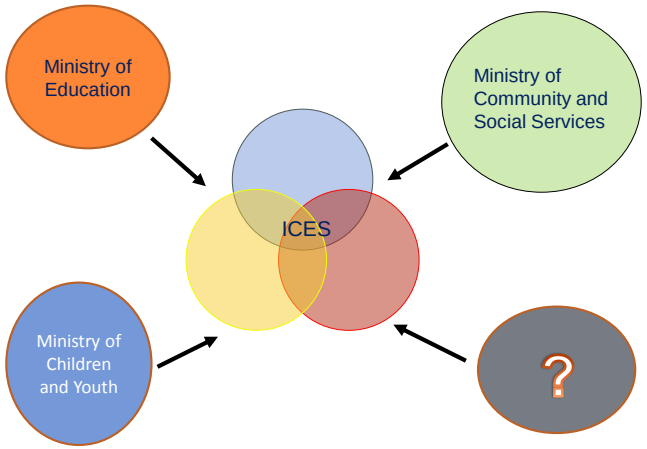
## Exploration in Ontario


- Most populous province in Canada
- 13 million habitants
- NEDSAC in South Eastern Ontario
- Repository for Population Health Data

## Exploration in Ontario

- **Institute for Clinical Evaluative Sciences (ICES)**
  - Population-based health information
  - Independent organization conducting health services research: ICES scientists et fellows
  - Demographics, health services utilization, diagnoses
  - Possible link with the mother's file
  - Information limited to health, need for data from other sectors

## Exploration in Ontario




## Exploration in Ontario

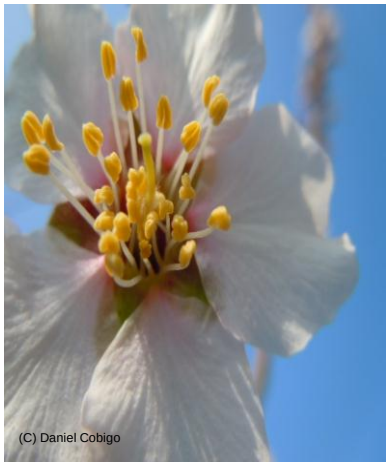
- **Linkages**
  - Data Sharing Agreement between ICES and other entities
  - Privacy Impact Assessment
  - Threat Risk Assessment
  - 1 to 2 years to complete the process
  - Strong collaborations and commitment from relevant entities required.

## Exploration in other provinces: Conclusion

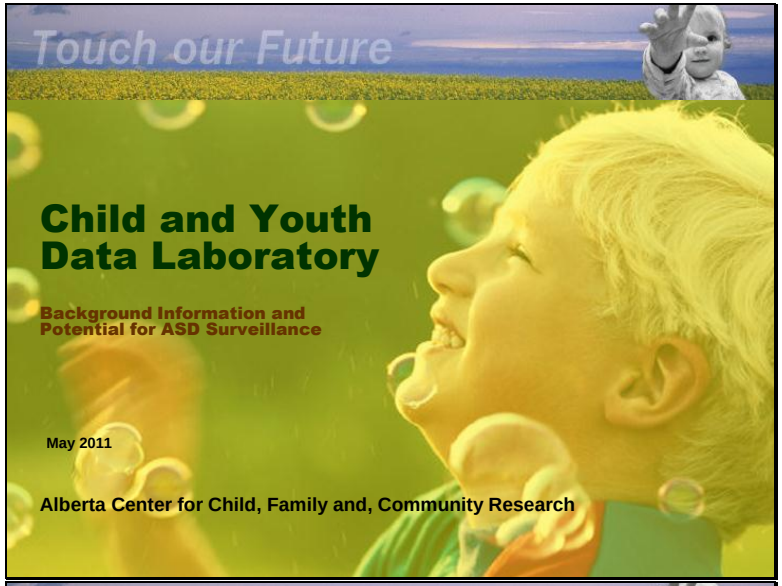
- Multisectoral efforts for a better case ascertainment and comprehensive data collection: Health, Education, Social services, etc.
- Sources of data differ from one province to another
- When a structure such as MCHP does not exist, allow sufficient time to obtain required authorizations to access and link data
- Build strong collaborations with dataholders

**Questions or comments**

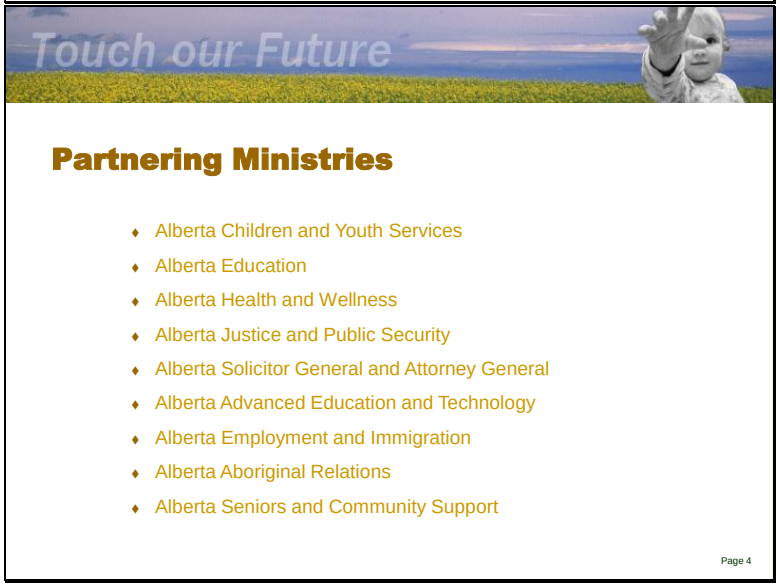
?



## Xinjie Cui's Presentation





Touch our Future

# Roles and Responsibilities

- **Ministries**
  - Provide funding
  - Identify research priorities
  - Involve in project development, data element identification, and feasibility examination
  - Develop PIAs and information sharing agreements
  - Establish data linkage
  - Provide data
    - Including relevant info on data (metadata) and databases
    - Assist researchers to understand data and ministry specific data collection processes
    - Conduct data quality assessment and support data and data linkage validation
    - Support data interpretation
  - Involve in dissemination
- **CYDL**
  - Build infrastructure that meets the technical and security requirements to support research activities
  - Develop research questions based on government priorities
  - Develop projects – conceptualization, methodology, and analysis plan
  - Support and facilitate CYDL related processes
  - Verify data and perform data analysis
  - Generate reports and other information products
  - Develop knowledge mobilization plan and disseminate research results



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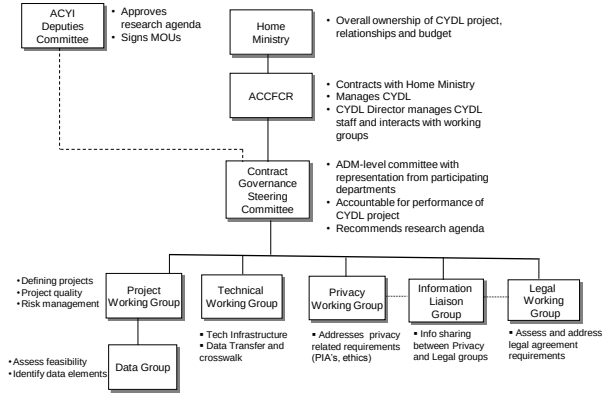
# CYDL Governance Structure



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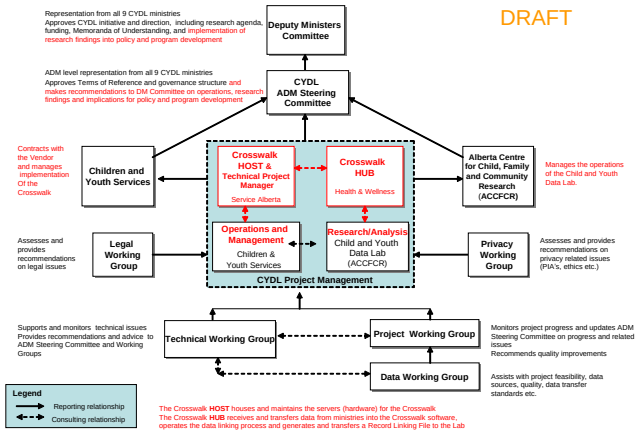
Updated January 13, 2011

# Child and Youth Data Lab (CYDL) Initiative Governance Structure

DRAFT



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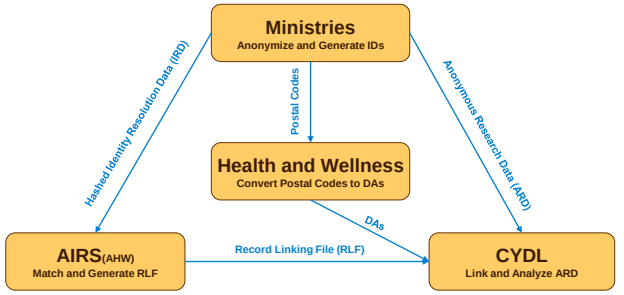
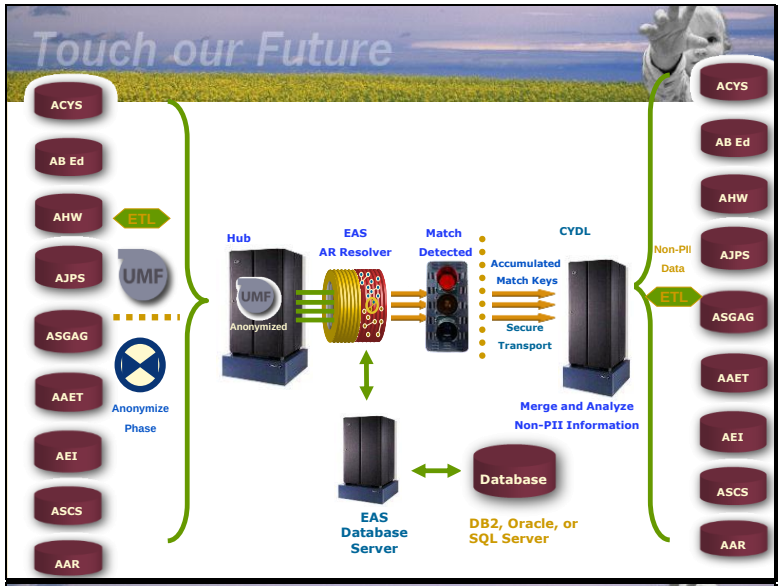
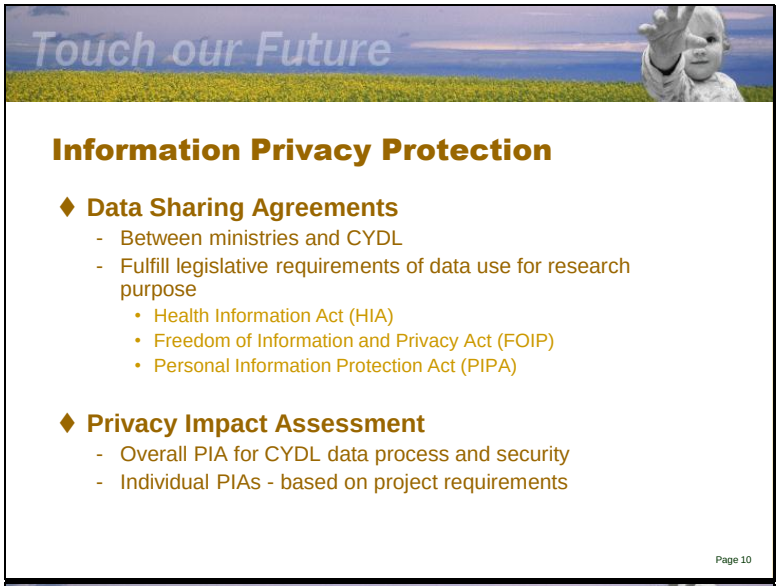
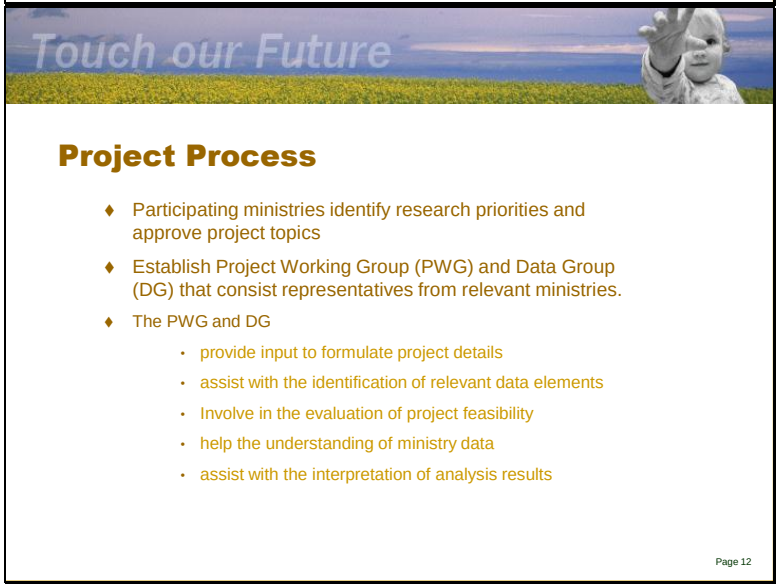
# Data Flow




Touch our Future
ACYS
AB Ed
AHW
ETL
AJPS
UMF
ASGAG
AAET
Anonymize
Phase
AEI
ASCS
AAR
Hub
UMF
Anonymized
EAS
AR Resolver
Match
Detected
CYDL
Accumulated
Match Keys
Secure
Transport
Merge and Analyze
Non-PII Information
Non-PII
Data
ETL
EAS
Database
Server
Database
DB2, Oracle, or
SQL Server


Touch our Future
Information Privacy Protection
Data Sharing Agreements
- Between ministries and CYDL
- Fulfill legislative requirements of data use for research purpose
  - Health Information Act (HIA)
  - Freedom of Information and Privacy Act (FOIP)
  - Personal Information Protection Act (PIPA)
Privacy Impact Assessment
- Overall PIA for CYDL data process and security
- Individual PIAs - based on project requirements
Page 10


Touch our Future
Security
The highest security standards are followed
- Alberta government shared data facility security standards
- Statistics Canada data center security standards (check list)
- ISO 27001/27002 attestation on infrastructure and process
Physical and technical
- Access cards, motion detectors, security monitoring and etc.
- Multilayer network design
- Data stored in separate tables
- Anonymized data is joined only when project analysis is required
Restricted access
- Physical space
- Data access
Page 11


Touch our Future
Project Process
Participating ministries identify research priorities and approve project topics
Establish Project Working Group (PWG) and Data Group (DG) that consist representatives from relevant ministries.
The PWG and DG
- provide input to formulate project details
- assist with the identification of relevant data elements
- Involve in the evaluation of project feasibility
- help the understanding of ministry data
- assist with the interpretation of analysis results
Page 12


## Project Process

- Develop information sharing agreements (ISAs) between ministries and CYDL, and ministries with HUB
- Develop Privacy Impact Assessments
- Transfer data following designed data flow processes
- Perform data linkage for each project
- Analyze data and generate reports for participating ministries
- Review and release of final research products




## Progress

- **Approved and signed MOAs April 2007**
- **IT infrastructure and staff in place**
- **First two projects approved and design developed**
- **Data sharing agreements – signed**
- **Crosswalk/AIRS (Anonymous Identify Resolution System) implementation close to finish**
- **PIAs reviewed by Office of the Information Privacy Commissioner – under revision**
- **All research data for project one except one ministry has been received**




## Autism Spectrum Disorder Data in Alberta

- Where is data collected in Alberta?
  - Health and Wellness
  - Education
  - Children and Youth Services
  - Autism Follow-up Clinics
    - Glenrose Rehabilitation Hospital
    - Children's Hospital
  - Community mental health services?
  - …




## Alberta Health and Wellness

- Data bases
  - Physician Claims
  - Hospital Discharge
  - Ambulatory Care
- Issues associated with these
  - Diagnostic criteria
  - Under estimation
  - …
- 'Incidence rates' generated
  - Based on Physician Claims only
  - Case definition simple
  - No validity test done


## ASD 'Incidence'

- Physician Claims - ICD9 Diagnosis Codes (1st, 2nd or 3rd) with first three digits of "299"
- The year of incidence is taken as the first year the Alberta Resident had a claims record with a diagnosis of 299 from 1983 to present
- Data before 1994 only has one diagnosis field




## Education

- Special Education Codes
  - Codes developed by the ministry to manage
    - Program Unit Funding (Early Childhood Services)
    - Special Education for severe disabilities (G1 - G12)
    - Funding for Mild and Moderate (including Gifted and Talented)
  - Based on a comprehensive, individualized assessment (a diagnosis is not enough)
  - Focuses on the impact of the condition on the child's **functioning** in an educational environment
    - the number of areas of functioning affected
    - the extent to which functioning is affected in each area
    - the effect on others
    - the amount of support required




## Special Education Codes

- **Mild/Moderate**
  - Cognitive
  - Emotional/Behavioural
  - Leaning disability
  - Visual
  - Hearing
  - Communication
  - Physical or Medical
  - Multiple
- **Severe**
  - Cognitive
  - Emotional/Behavioural
  - Multiple
  - Physical or Medical
  - Deafness
  - Blindness
  - Severe delay involving language
- **Not very useful for ASD surveillance?**




## Children and Youth Services

- **Family Services for Children with Disability**
- **Services Provided**
  - **Information and Referral Support**
    - Information about federal and provincial government programs and services, community supports and local resources
    - Assistance obtaining and coordinating supports and services
    - Referral to community support and advocacy resources, such as parent support groups, disability associations or advocacy organizations
    - Information and support to empower parents to advocate for their child


## FSCD Services

- **Family Support Services**
- Based on the family's needs and circumstances,
  - Individual and family counseling
  - Assistance with the cost of clothing and footwear related to the child's disability
  - Assistance with the cost of attending medical appointment or when the child is in hospital, such as parking, mileage, meals and accommodation
  - Respite services

Page 21


## FSCD Services

- **Child-Focused Services**
- A child's disability **significantly limits** his or her ability to function in normal daily living activities, and are based on the child's and family's individually assessed needs.
- Child-focused services include:
  - Respite services
  - Child care support
  - Aide supports
  - Health-related supports, such as assistance with some of the extraordinary cost of prescription drugs, formulas and diets
  - Specialized services, such as support and consultation from occupational or physical therapists, speech language pathologists or psychologists
  - Out-of-home living arrangements, if necessary, to support a child when all other alternatives for in-home supports have been explored.

Page 22


## Data Collected at FSCD

- Diagnostic codes
  - Primary
  - Secondary
  - Tertiary
- Families are encouraged to use services offered by Health and Education
- Capture mostly severe cases

Page 23


## Follow-Up Clinics

- Glenrose
  - Currently has 18,000 patient records in database
  - Very detailed diagnostic and treatment information
  - Has been used for research
  - Linkability
    - not clear
    - likely need patient consent
- Children's Hospital
  - Similar
  - Less extensive

Page 24


Touch our Future
Potential
• Alberta Health and Wellness
– Already doing some analysis
– May have better comparability with other provinces
– Limitations
• Validity
• Underestimation
• Priority
• Education
– Current Special Education Codes - Not specific enough
– New coding system – Inclusive Education
– Maybe – new opportunity
• Children and Youth Services and Follow-up Clinics
– Only those with complex needs
• CYDL
– Linking Health, FSCD, community mental health..
– Better picture for ASD
– Priority and funding
Page 25

# ASD Surveillance Workshop: Opportunities in British Columbia

Stephen Wellington, MD, MHSc, PhD, FRCP(C)
Karen Kalynchuk, BSc, PMP
(May 9, 2011)

## Overview

- Introduction to BCAAN
- BC Provincial Policy on ASD
  - Standards & Guidelines
  - Funding & Implications for data quality
- STAR BC Database
- BC Strengths/Challenges to Epidemiology Studies

## Summary

- Policy can potentially benefit research:
  - 'best evidence' standards help create uniform case definitions (avoids 'garbage-in-garbage-out' phenomenon)
  - Documentation requirements for funding promotes comprehensive data acquisition (minimizes volunteer/reporting bias)
  - Harmonization of case definitions between different provincial agencies

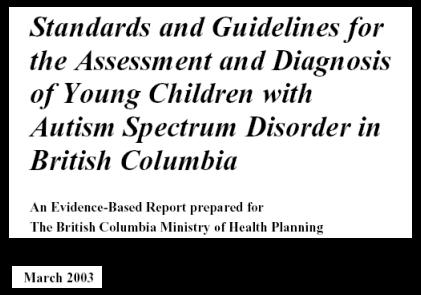
## Summary

- STAR BC Database offers
  - Supports all aspects of clinical operations
  - Secure web-accessible data entry
  - Comprehensive provincial 0 – 19 yr reporting
  - Collects both positive and negative cases (effectiveness of screening)
  - Reporting of co-morbid conditions (ICD)
  - Report test outcomes & functional data (ICF)
  - Linkage of family to government funding

## Creation of BC Autism Assessment Network October 2002

- Provincial Health Service Authority's Response to Government's Requests for Improved Autism Assessment Services:
  - develop standards for service
  - develop regional capacity
  - increase the number of assessments
  - reduce waitlists for assessments

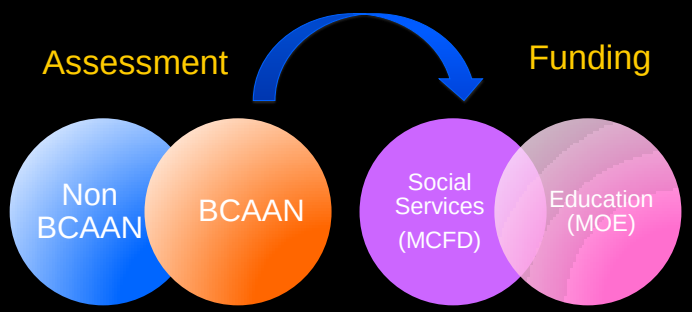
## Clinical Standards for Service


*Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in British Columbia*

An Evidence-Based Report prepared for
The British Columbia Ministry of Health Planning

March 2003

http://www.healthservices.gov.bc.ca/cpa/publications/asd_standards_0318.pdf



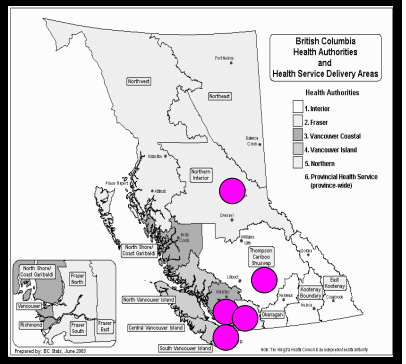

## Administrative Standards for Service

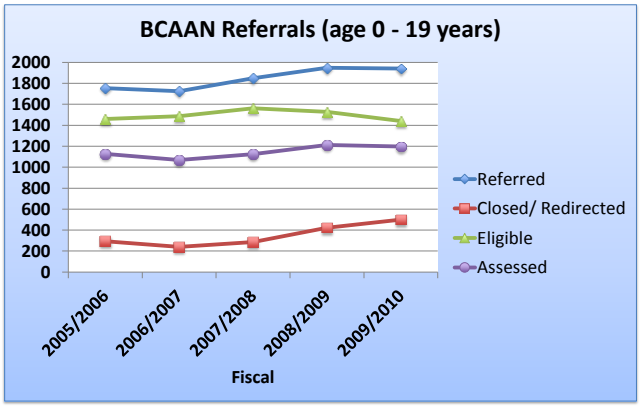
Province-Wide Measurement Definitions:

- Receipt of Referral/Date of Diagnosis
- Wait times
- Collaboration with Ministries of Health, Child/Family Development, and Education on synchronizing ASD definitions

# BC Autism Assessment Network

- Regional Service Teams
  - Accept referrals from physicians
  - Unified Intake system
  - Standardized Assessment/Diagnosis
  - Data collection & reporting
  - Serve as liaison with local resources & treatment supports




# Program Evaluation

- Decentralized clinical assessments but need centralized data
- Development of provincial web-accessible database


# Data acquisition linked to government policy

- Government intervention funding application process linked to STAR BC web form completion (for BCAAN assessments)
- Regional funding linked to data delivery

## STAR BC*

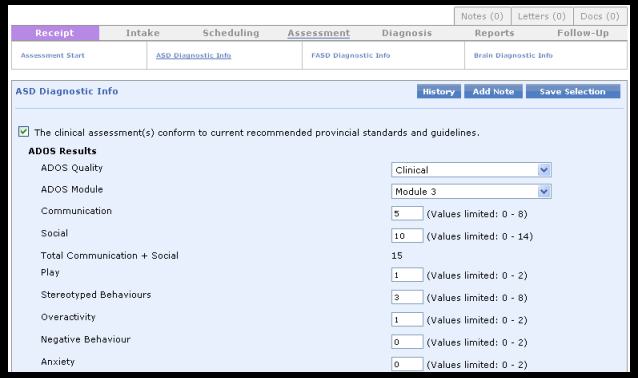
- System for
- Tracking
- Assessments and
- Referrals

*Note: STAR BC supports the BCAAN and CDBC programs

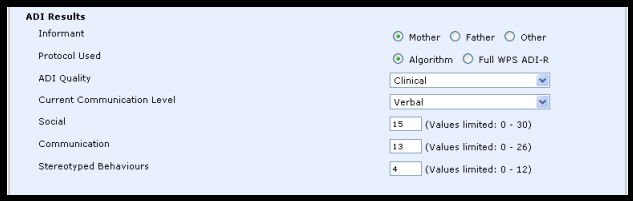
## Summary

- STAR BC Database offers
  - Supports all aspects of clinical operations
  - Secure web-accessible data entry
  - Comprehensive provincial 0 – 19 yr reporting
  - Collects both positive and negative cases (effectiveness of screening)
  - Reporting of co-morbid conditions (ICD)
  - Report test outcomes & functional data (ICF)
  - Linkage of family to government funding

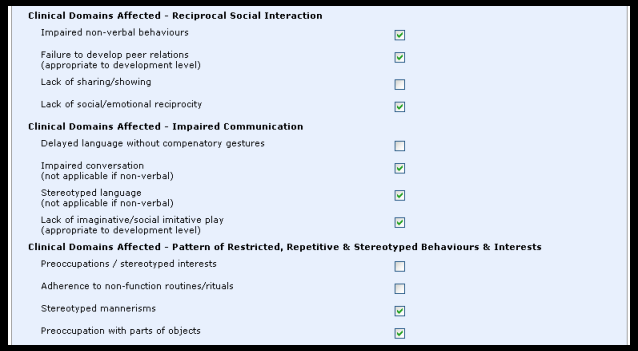
## ADOS Results




## ADI Results

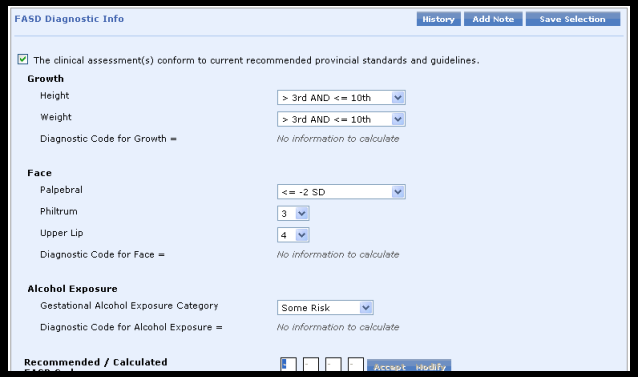


# DSM results (DSM V compatible)

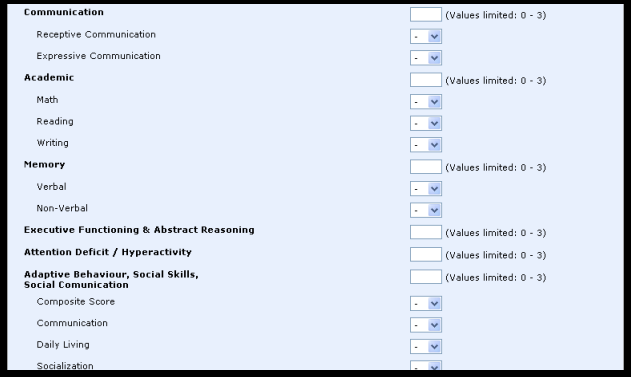



# Other ASD Clinical Domains


# Fetal Alcohol Spectrum Disorder (Canadian Guideline Algorithms)

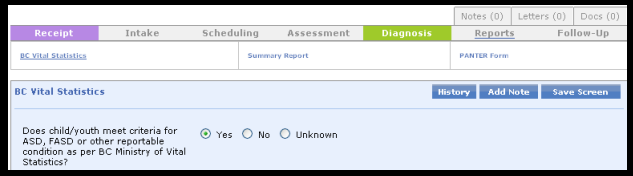



# Standardized Test Outcomes

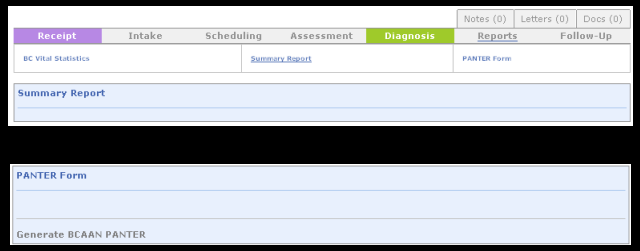


## ICD/ICF Outcomes

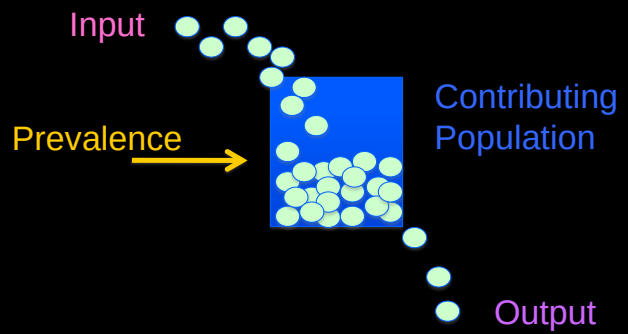

## BC Vital Statistics Reporting




## Funding Application Forms




## Measuring Occurrence

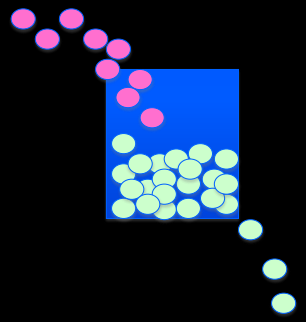


## Input

- Incidence

☑Case Definition

- Comprehensive Ascertainment?
  - Finding
  - Recording
- Selective Migration



## 909,000 children/youth in B.C. age 0 – 18 yr

- B.C. provides funding to more than 6,000 children and youth diagnosed with ASD and their families*
- But predict ~ 9,000 with ASD based on current prevalence data
- (where are the other potential 3,000?)
- (plus ~ 440 new cases/yr born in B.C.)
- Undiagnosed? Prevalence overestimate?

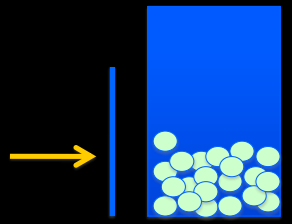
*MCFD February 2010: Autism and Medical Benefits Analysis Tracking (AMBAT)

## Comprehensive Data Reporting?

- Within BCAAN – YES
  - Reporting requirements linked to funding and government policy
- Non-BCAAN Assessments - NO
- Funding Agencies? – Unsure?
  - Social Services (MCFD)
  - Education (MOE)

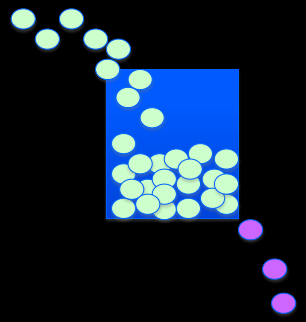
## Contributing Population

- Selective Undercounting in populations?

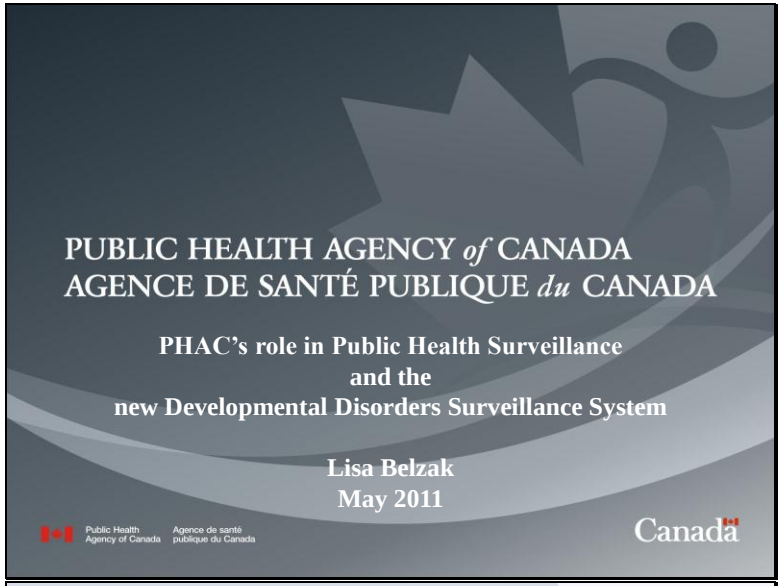


## Output

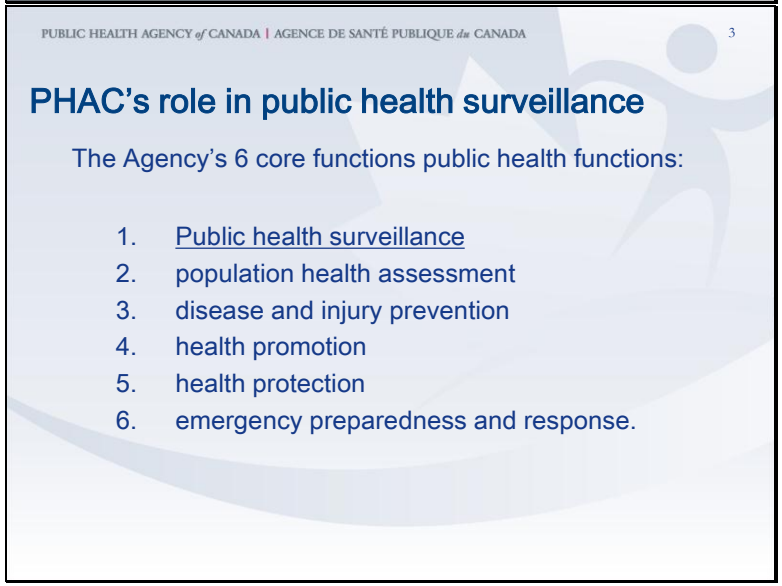
- Age-out of surveillance window
- Selective Migration
- Shift in Diagnosis?
  - Need longitudinal follow-up to determine

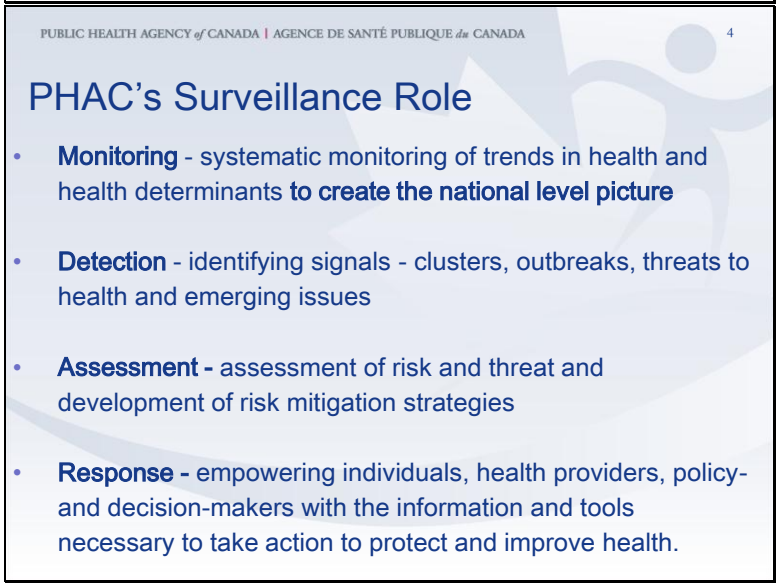


## Lisa Belzak's Presentation

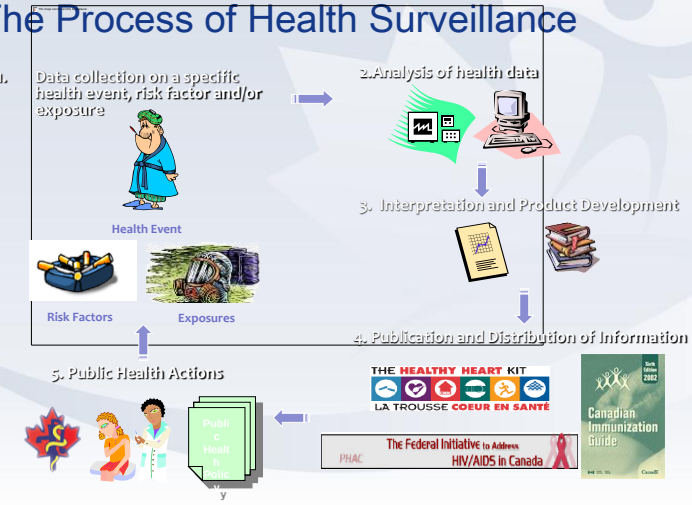






# The Process of Health Surveillance





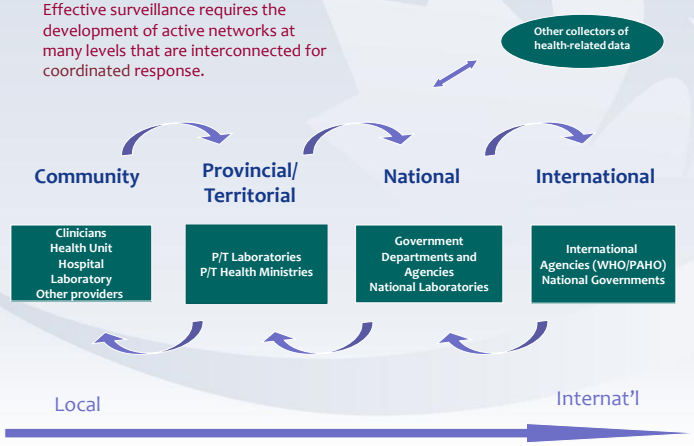

# PHAC's Core Surveillance Areas

- Adult chronic disease surveillance (e.g. cancer, arthritis, diabetes, respiratory, mental illness, cardiovascular, risk factors)
- Maternal and child surveillance systems (e.g. injury, abuse, perinatal, diseases and *NEW* developmental disorders)
- Infectious and zoonotic disease surveillance and immunization (e.g. HIV, Influenza, hepatitis, hospital-acquired infections)
- PHAC operates world-class laboratories in Winnipeg and Guelph that support national surveillance capacity.



# Actors in Health Surveillance

Effective surveillance requires the development of active networks at many levels that are interconnected for coordinated response.






# Developmental Disorders Surveillance

## Overview

- The Public Health Agency of Canada (PHAC) is establishing a national surveillance system to monitor developmental disorders with an initial focus on Autism Spectrum Disorders (ASDs)

## Purpose

- To estimate national prevalence and incidence rates for developmental disorders
- To better understand the impact of developmental disorders on the individual, family and society
- To inform research, to improve diagnosis, prevention and treatment methods, and to provide evidence to support policy

# Developmental Disorders Surveillance

Background

- Health Canada is the lead for the Autism file
- Funding provided to PHAC for surveillance and CIHR to coordinate research
- PHAC held consultations in 2007 where a series of options were presented and discussed

First steps

- Perform an environmental scan on advances made on the proposed options:
  - Registries
  - Population-based surveys
  - Clinical databases/repositories
  - Administrative data (NEDSAC; health and education)
  - NGO and professional networks (CPS, CAPH-C, CASDA, etc.)
  - Other successful models (BCCAN, AADM in the US, etc.)
- Establish an oversight and governance structure



# Developmental Disorders Surveillance Governance

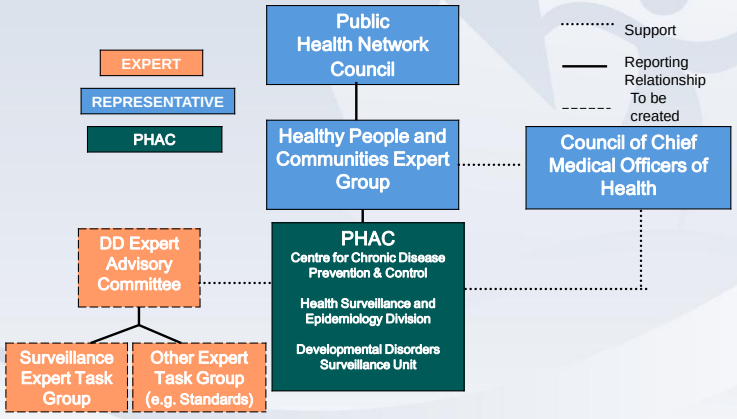
**Expert Advisory Committee (Researchers, practitioners, PT reps and other stakeholders)**

- Provide ongoing leadership, advice and recommendations on surveillance of DDs and other issues impacting people living with DDs (e.g. ASDs) in Canada

**Scientific Expert Working Groups**

- Provide PHAC and the Advisory Committee with timely expert advice relating to ASD and other DD issues based upon the best current available scientific knowledge (time-limited)
- E.g.; Surveillance, Standards, Special Studies,etc.






**Proposed Structure of Governance of National Developmental Disorders (DD) Surveillance System**



# Developmental Disorders Surveillance

Plans for 2011-2012:

- Consult with provincial and territorial partners, stakeholders, national and international experts
- Create an expert advisory committee and surveillance working group
- Host a 2-day meeting to review options to determine the most efficient and reliable surveillance option(s) *(Sept 2011)*
- Design a framework for surveillance of DD focusing on ASDs
- Propose standards (data, case definition & reporting )
- Identify and establish pilot projects in one or two sites

# Developmental Disorders Surveillance

- Proposed 2-3 year work plan:
- Implement pilot projects and evaluate/lessons learned
- In partnership, select sites and implement sentinel surveillance centres across the country
- Track prevalence and incidence starting with children and expanding to include the adult population
- Broaden surveillance to include other DDs
- Conduct special studies to assess impact and risk factors
- Publish routine surveillance reports



# Developmental Disorders Surveillance Program

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**Health Surveillance and Epidemiology Division**
**Centre for Chronic Disease Prevention and Control**
**Public Health Agency of Canada**



## Routine surveillance of rare developmental disorders in children

**Proposed Priority Indicators**

- o Age at diagnosis
- o Ethnicity
- o Sex
- o Parental age
- o Presence of affected siblings
- o Severity of disability
- o Co-morbidities
- o Educational factors (school attendance, special needs)
- o Status of case (suspect, confirmed diagnosis)
- o Type of treatment & services provided or recommended
- o Disease specific risk factors (demographic/health)