Journey to the Janeway’s Autism Clinic: Let’s Start with the Birth and Perinatal Clinic story.

March 29, 2016  -  Elaine Dobbin Centre – Autism Research Exchange Group

Phil Murphy, MSc
Data Consultant / Analyst – Perinatal Program NL
Professional Associate – Memorial University (Ob/Gyn & Peds)
I am not an expert in Autism, please don’t ask me any hard questions : - )
Outline

- Birth statistics
- About the NLPPP
- High-Risk Follow-Up Clinic
- Referrals to Autism
- Autism Database
- Link to Perinatal Database
- Risk Factors/Research
- Final Thoughts
Birth Statistics

- Multiple Sources:
  - Live Birth Notification Form (LBNF) – Vital Statistics
  - Discharge Abstract Database (In-Hospital Admissions)
  - Provincial Perinatal Surveillance Program (PPSP)
This database contains demographic, administrative and clinical data related to all live births that occur in the province of Newfoundland and Labrador. Both resident and non-resident live births are reported in the system. It is used primarily for research and to provide aggregate statistical information. It is also used to cross reference other databases for quality assurance and verification purposes.
### Live Birth Notification Form

#### Part A - Mandatory for Registration of Birth (Required within 48 hours of delivery)

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surname</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Given Name(s)</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Sex</td>
<td>M</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>[MM/DD/YYYY]</td>
</tr>
<tr>
<td>Locality of Birth</td>
<td>Hospital</td>
</tr>
<tr>
<td>Hospital Code</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Place of Occurrence</td>
<td>City / Town</td>
</tr>
<tr>
<td>Infant's Alien #</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Infant's Hospital City</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Maiden Name and Initials</td>
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</tr>
<tr>
<td>Health Care Number</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>[MM/DD/YYYY]</td>
</tr>
<tr>
<td>Age at Delivery</td>
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</tr>
<tr>
<td>Birth Place (Province/Territory / Country / Outside Canada)</td>
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</tr>
<tr>
<td>Usual Home Address</td>
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<tr>
<td>Postal Code</td>
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<td>Date of Birth</td>
<td>[MM/DD/YYYY]</td>
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<tr>
<td>Age</td>
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#### HEALTH HISTORY AND MEDICAL CERTIFICATION OF BIRTH

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
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<tbody>
<tr>
<td>Total Number of Children Ever Born</td>
<td>[Blank]</td>
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<tr>
<td>Number of Stillbirths During This Mother's Pregnancy</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Number of Infants in Last Delivery (Incl. Live &amp; Stillborn)</td>
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</tr>
<tr>
<td>Number of Stillborn in Last Delivery</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Number of Single Births in Last Delivery</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Gestational Age</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Was this Birth Due to Medical Termination of Pregnancy?</td>
<td>Yes</td>
</tr>
<tr>
<td>Birth Weight</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Delivered by (Surname, Given Name) - Identify Only One Person</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Designation of Attendant (Specify)</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Smoking</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Cigarettes per day</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Physician Specialist for Perinatal Care (Including Family Doctor/Obstetrician/Other)</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Labour Onset (check only)</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Other (Specify)</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Delivery Presentation</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Method of Delivery</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Delivery Complications</td>
<td>[Blank]</td>
</tr>
<tr>
<td>Major Congenital Anomalies</td>
<td>[Blank]</td>
</tr>
</tbody>
</table>

#### Notes

- Please fill in all required fields.
- Use the appropriate codes for medical information.
- Ensure all dates and numbers are accurate.
**Discharge Abstract Database**

- Contains demographic, clinical and administrative data collected at hospitals when patients are discharged from inpatient and surgical day care services. This information is used to support health system policy development, planning, management, evaluation and research.

- The DAD captures information regarding hospitalization to both residents of Newfoundland and Labrador and non-residents receiving care in Newfoundland and Labrador.
Discharge Abstract Database

Small-for-Gestational-Age Rate: The Picture Across Canada, * 2006–2007 (Figure 4 in the report)
The Perinatal Program Newfoundland and Labrador (PPNL) collects, summarizes, interprets and reports on perinatal events, outcomes, and care processes at the provincial, regional and community level. This information is used for surveillance activities, for maternal / infant health program and policy development, and to facilitate and support research and quality assurance initiatives in perinatology and developmental outcomes.
Established in 1979, the Perinatal Program Newfoundland and Labrador (PPNL), evolved from the need to improve the quality of perinatal (around the time of birth) care in the province.

The PPNL’s mandate, as directed and supported by the Provincial Perinatal Advisory Committee, is to strive to improve pregnancy outcomes and provide a follow-up clinic to infants at high risk for developmental delay.
Presently, the PPNL collects maternal and neonatal data from the four Regional Health Authorities:

- Eastern Health (since April 2001 STJ and October 2007 rest of EH)
- Labrador-Grenfell Health (since January 2005)
- Western Health (since April 2010)
- Central Health Authority (since August 2012)

The collection, maintenance, analysis and dissemination of this data are essential in the evaluation of obstetrical and newborn care and in making recommendations for best practice.
## Data Collection: Follow-up, Surveillance Program, HBC, Congenital Anomalies

<table>
<thead>
<tr>
<th>FOLLOW-UP CLINIC ADMISSION CRITERIA</th>
<th>PERCENTAGE OF 2014-15 CLINIC INTAKE</th>
<th>PERCENTAGE OF 2013-14 CLINIC INTAKE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal Substance Use</td>
<td>38.2%</td>
<td>40.6%</td>
</tr>
<tr>
<td>Birth Weight ≤1500 grams</td>
<td>24.4%</td>
<td>27.1%</td>
</tr>
<tr>
<td>Ventilated for 48 hours or more</td>
<td>28.5%</td>
<td>18.0%</td>
</tr>
<tr>
<td>Specific Physician Request</td>
<td>10.6%</td>
<td>12.0%</td>
</tr>
<tr>
<td>Complex Surgery</td>
<td>8.1%</td>
<td>9.8%</td>
</tr>
<tr>
<td>Seizures in 1st 28 days of life</td>
<td>10.6%</td>
<td>4.5%</td>
</tr>
<tr>
<td>APGAR Score ≤ 3 for ≥ 5 minutes</td>
<td>7.3%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Cord Blood pH &lt; 7</td>
<td>6.5%</td>
<td>3.8%</td>
</tr>
<tr>
<td>Intraventricular Hemorrhage (IVH)</td>
<td>0.8%</td>
<td>1.5%</td>
</tr>
<tr>
<td>Meningitis in 1st 28 days of life</td>
<td>3.3%</td>
<td>3.8%</td>
</tr>
<tr>
<td>Periventricular Leukomalacia (PVL)</td>
<td>0.8%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Extracorporeal Membrane Oxygenation (ECMO)</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>
About PPNL – Projects & Issues

- Data Collection: Follow-up, Surveillance Program, HBC, Congenital Anomalies
About PPNL – Projects & Issues

- Surveillance Reports
About PPNL – Projects & Issues

- Research: diversion costs, diabetes, maternal obesity, GWG/GWL, methadone, <29wks, prenatal class, vitamin D, teenage, 2nd Hand Smoke Exposure & Newborns, breastfeeding

- Education: FHS, NRP, ACoRN, Obstetretrical updates & Colaborative Neonatal Education
About PPNL – www.ppnl.ca
Demographics

- 526,977 population
- 4,496 live births in 2015
- 56% capture at St. John’s site
The Program provides a special clinical service for young children and their families to ensure their best possible growth and development. The goal of the Clinic is to assess the children at 4 months, 8 months, 12 months, 18 months and 3 years of age.
Children Referred - Some infants, including those who are very premature, of low birth weight or have breathing problems after birth are automatically referred to the clinic before they are discharged from hospital.

Infants who have other medical conditions or who have had major surgery may also be referred to the clinic.

Most of the infants who are referred to the clinic have been admitted to the NICU or Special Care Nursery following birth.

Physicians or nurses in other regions of the province may also make referrals.
Admission Criteria (updated Sept 2015)

1. Birth weight less than or equal to 1500 grams or GA < 32 weeks

2. Mechanical ventilation for 48 hours or more

Central Nervous System:
3. Seizure confirmed by abnormal EEG, or as a result of metabolic etiology
4. Hypoxic Ischemic Encephalopathy
5. Stroke
6. Meningitis/Encephalitis/Intrauterine virus infection (eg, CMV)
7. Hydrocephalus
8. Intraventricular hemorrhage, grade 3 or greater
9. Periventricular leukomalacia (PVL)

Complex Surgery:
Admission Criteria (updated Sept 2015)

Cardiac:
13. Cyanotic Congenital Heart Disease
14. Cardiac surgery requiring bypass less than 30 days of age
15. Prolonged hypoglycemia greater than 3 episodes of blood glucose less than 2.6 mmol/L in a 24 hour period
16. History of prenatal exposure to alcohol as a result of maternal alcohol intake characterized by substantial, regular intake or periodic binge drinking during pregnancy
17. History of prenatal exposure to illicit substances, such as amphetamines, cannabis, club drugs, stimulants, opioids and solvents, as a result of maternal habitual use during pregnancy
18. Prenatal exposure to Methadone, as a result of maternal participation in a Methadone Maintenance Treatment Program during pregnancy
19. Physician request, specify
Perinatal Clinic Admissions

PPNL Clinic Admissions

- 2007/08
- 2008/09
- 2009/10
- 2010/11
- 2011/12
- 2012/13
- 2013/14
- 2014/15
# Admission Criteria

## Follow-Up Clinic Admission Criteria

<table>
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<tr>
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Clinic Outcomes

Innovations in Patient Care: A Framework for a Clinical & Decision Support Partnership to Improve Best Practice
Phil Murphy, MSc1,2, Christine Winters, RN2 and Lorraine Burrage, RN, MSc1.
1Newfoundland and Labrador Provincial Perinatal Program, Eastern Health, St. John's, NL, Canada and 2Faculty of Medicine, Memorial University, St. John's, NL, Canada.

www.nlppp.ca

Abstract
In the traditional hospital organization, the clinicians gather patient data on a routine basis but the use of this information is often delayed or not utilized at all. Given this reality, collaboration between clinicians, decision support and management is essential for efforts to enhance the quality of care and improving health practice. The presentation describes how the Newfoundland and Labrador Provincial Perinatal Program (NLPPP) has established a framework that will foster this partnership. The model involves a process of standardized data capture, analysis & dissemination. The model fosters processes of quality improvement and decision support to interpret, design and implement an action plan with Neonatal Intensive Care Unit (NICU) staff and their clients follow-up information.

About the NLPPP
Established in 1979, the NLPPP is a collaborative effort between neonatologists and other healthcare professionals, aimed at improving the care of newborns in the province of Newfoundland and Labrador. The NLPPP focuses on evidence-based care and continuous improvement in the delivery of perinatal care.

Who’s Referred
Some infants, including those who are very premature, of low birth weight or have breathing problems after birth, are automatically referred to the clinic before they are discharged from hospital. Most of the infants who are referred to the clinic have been admitted to the NICU or Special Care Nursery following birth.

A Typical Clinic Visit
Children are seen at approximately 4, 8, 12, 18 months and 3 years of age. Developmental screening, Neurological and Physical assessments are done at each visit and child is appropriately referred should additional intervention be necessary (Physiotherapy, Speech Pathology, Audiology, OT, etc.).

At age 3 years, Bayley III Scales of Infant Development performed by psychologist. Following the 3-year visit, information is sent to the Public Health Nursing Division as the history to assist the pre-school assessment.

Methods
Data from the High Risk Follow-Up database (MS Access) on babies born between 1998-2004. Data for each visit for all babies were analyzed using SPSS 15.0. Outcomes of interest were clinical concern or diagnosis of neonatal delay, developmental delay, hearing impairment, vision impairment. Summarized information was presented to NICU staff and a 10 point Yearly questionnaire was disseminated.

Criteria Averages

VLBW & Outcome

Seizures & Outcome

Ventrilated & Outcome

Knowledge Translation
37.6% felt the outcomes of those babies presented were what they expected.
62.6% felt the outcomes were better than expected.
100% felt getting feedback from the NLPPP will improve their insight into long term outcomes of the babies they care for.
82.6% felt that this information will alter their philosophy/values towards caring for artificially ill neonates.
76% felt their interest in neonatal research was increased.

Outcomes – Visit Concerns

78.4% of babies followed had NO concerns or diagnosis of disability

Conclusion
Administrative databases such as the NLPPP’s follow-up database provide a rich source of information that can be utilized to improve quality of care and services. The key is through collaboration among clinicians, decision support and quality and risk management that allows easy data capture and analysis that will lead to better decision making.

Discussion with front line caregivers is crucial.
Clinic Outcomes – 2005-2012 summary

- Counterpart Barbara Young developed an internal report for some recent years.
**PPNL Clinic Assessment Form**  
*(Visit Outcomes and Referrals)*

**Client Information**  
- **Client Key:** 24  
- **Client Key:** 29  
- **Visit:** 1

**Clinic Location**  
- **St. Anthony**

**Visit Date:**  
- **Chronological Age:**  
- **Corrected Chronological Age (up to 2 years):**

**Weight (kg):**  
- **%ile:**

**Height (cm):**  
- **%ile:**

**Head Circumference (cm):**  
- **%ile:**

**Fontanelles:**

**CAT/CLAMS**  
- **Language (Receptive):**
- **Language (Expressive):**
- **CLAMS DQ:**
- **CAT DQ:**
- **FSDQ CAT/CLAMS:**

**Bayley III**  
- **Cognitive:**
- **Language:**
- **Motor:**

---

**Issues/Concerns for Present Visit**

- **None:**
- **Hearing:**
- **Vision:**
- **Language:**
- **Visual Fine Motor:**
- **Gross Motor:**
- **Cerebral Palsy:**
- **Learning:**
- **Behaviour:**
- **New Congenital Anomaly:**
- **Hypo Tone:**
- **Hyper Tone:**
- **Other:**

**Details of Issues/Concerns, specify:**
### Clinic Outcomes – new version

#### Referred Today

<table>
<thead>
<tr>
<th>Service</th>
<th>Service</th>
<th>Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Audiology</td>
<td>Social Work</td>
<td>Genetics</td>
</tr>
<tr>
<td>ENT</td>
<td>Psychology</td>
<td>Cardiology</td>
</tr>
<tr>
<td>Speech/Language</td>
<td>Child Youth Family Services</td>
<td>Endocrinology</td>
</tr>
<tr>
<td>Ophthalmology</td>
<td>Direct Home Services</td>
<td>Urology</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>Janeway Family Centre</td>
<td>Surgery</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>Dietitian</td>
<td>Orthopedics</td>
</tr>
<tr>
<td>Rehab</td>
<td>Public Health Nurse</td>
<td>Plastics</td>
</tr>
<tr>
<td>Neurology</td>
<td>Behavioural/Child Management</td>
<td>Dentistry</td>
</tr>
<tr>
<td>Development</td>
<td>Pediatric</td>
<td>Other, specify</td>
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<tr>
<td>Blood Work</td>
<td>BF Clinic</td>
<td>U/S</td>
</tr>
<tr>
<td></td>
<td>RSV</td>
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</tr>
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</table>

#### Follow-Up Status (eg, if refuse follow-up enter status in last visit)

<table>
<thead>
<tr>
<th>Status</th>
<th>Status</th>
<th>Status</th>
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<tbody>
<tr>
<td>Continue Follow-Up</td>
<td>Discharge to Rehab/Development</td>
<td>Discharge to Other Prov/Territory</td>
</tr>
<tr>
<td>Finished Program - complete Final Assessment Below</td>
<td>Died</td>
<td>Missing</td>
</tr>
<tr>
<td></td>
<td>Refuse Follow-Up</td>
<td></td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Hearing Loss</th>
<th>Mild (25-40dB)</th>
<th>Moderate (41-55dB)</th>
<th>Moderate Severe (56-70dB)</th>
<th>Severe (71-90dB)</th>
<th>Profound</th>
<th>H. Aid</th>
<th>C. Implant</th>
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</thead>
<tbody>
<tr>
<td>None:</td>
<td>✗</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left:</td>
<td>✗</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Right:</td>
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<td></td>
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<td>✗</td>
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<td>Sensorinourel:</td>
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<td>✗</td>
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<td>Conductive:</td>
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</table>

<table>
<thead>
<tr>
<th>Vision Problems</th>
<th>None:</th>
<th>Hyperopia:</th>
<th>Myopia:</th>
<th>Astigmatism:</th>
<th>Strabismus:</th>
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<tbody>
<tr>
<td>Cortical blindness:</td>
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<tr>
<td>Retinal detachment:</td>
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<tr>
<td>Retinal detachment:</td>
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</tr>
<tr>
<td>Function</td>
<td>Had ROP:</td>
<td>Resolved:</td>
<td>Not resolved:</td>
<td>Other Issue:</td>
<td></td>
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<tr>
<td>Normal:</td>
<td>Normal with p. glasses:</td>
<td>Unilateral Impairment:</td>
<td>Bilateral Impairment:</td>
<td>Unknown:</td>
<td></td>
</tr>
</tbody>
</table>

| Speech/Language Problems | None: | Expressive Delay: | Receptive Delay: |

<table>
<thead>
<tr>
<th>Developmental Delay</th>
<th>None:</th>
<th>Language:</th>
<th>Visual Fine Motor:</th>
<th>Gross Motor:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral Palsy:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Autism:</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Behavioural:</td>
<td></td>
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</tr>
<tr>
<td>Social Skills:</td>
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<td></td>
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</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Additional Comments:
Let's work backwards for a min
Autism Database

- ID
- LAST NAME
- FIRST NAME
- MCP
- DOB
- GENDER
- ADDRESS REGION
- REFERRAL SOURCE
- PHYSICIAN
- DIAGNOSIS
- CO-DIAGNOSIS
- DATE DX
- DTAC
- EXTRA CLINIC
- ADOS DATE
- ADOS MODULE
- ADIR DATE
- AGE AT DX
- ABA THERAPY
- MEDICATION
- GENETICS
The database consists of approximately 20 data elements and includes children with autism aged 0-14.

It currently has 9 calendar years of data with up to 150 cases per year. This database can be improved by adding ICD10 codes. A general consensus is that this database could be a great asset for us and that steps should be taken to make it more comprehensive.
Autism Database

- Clients are seen by four Physicians
- Information is maintained by Connie Bursey (Clinic Nurse).
- Clients have to have the cognitive ability of 15-18 month olds in order to perform the **Autism Diagnostic Observation Schedule (ADOS)**
- Diagnosis: Autism, ASD, ASPERGERS
ADOS: At a Glance
**ADOS: At a Glance**

- **Purpose:** Allows you to accurately assess and diagnose autism and pervasive developmental disorder across ages, developmental levels, and language skills.

- **Ages / Grade:** Toddlers to adults

- **Administration Time:** 30 to 45 minutes

- **Format:** Standardized behavioral observation and coding

- **Score:** Cutoff scores for both a narrow diagnosis of autism and a broader diagnosis of pervasive developmental disorder.
The ADOS includes four modules, each requiring just 35 to 40 minutes to administer. The individual being evaluated is given just one module, depending on his or her expressive language level and chronological age. Following guidance provided in the manual, you select the appropriate module for each person.

- Module 1 is used with children who do not consistently use phrase speech
- Module 2 with those who use phrase speech but are not verbally fluent
- Module 3 with fluent children
- Module 4 with fluent adolescents and adults.
Autism Database – ADOS/Diagnosis

ADOS Assessments and Autism Diagnosed
Janeway Clinic Cases


ADOS  DX

2009: ADOS 150, DX 100
2010: ADOS 160, DX 110
2011: ADOS 170, DX 120
2012: ADOS 180, DX 130
2013: ADOS 210, DX 140
2014: ADOS 240, DX 150
2015: ADOS 250, DX 160
AUTISM Diagnosis RATE following ADOS Assessment @ Janeway
Autism Database - Gender

- 2007-2015: 82% were male clients
## Autism Database – Region (update)

<table>
<thead>
<tr>
<th>REGION</th>
<th>2013</th>
<th>2014</th>
<th>2015</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>CENTRAL</td>
<td>7.6%</td>
<td>4.1%</td>
<td>3.8%</td>
<td>5.0%</td>
</tr>
<tr>
<td>EASTERN</td>
<td>87.4%</td>
<td>91.3%</td>
<td>93.3%</td>
<td>90.9%</td>
</tr>
<tr>
<td>NORTHERN</td>
<td>3.0%</td>
<td>3.2%</td>
<td>2.1%</td>
<td>2.7%</td>
</tr>
<tr>
<td>WESTERN</td>
<td>2.0%</td>
<td>1.4%</td>
<td>.8%</td>
<td>1.4%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
Autism Database – Referral Source

- SCHOOL
- SPEECH LANG PATH
- PUBLIC HEALTH NURSE
- DEVEL BEHAV PRAC
- FAMILY DOCTOR
- PEDIATRICIAN

Yearly referral percentages from 2007 to 2012.
Autism Database – Referrals update

- FAMILY DOCTOR
- PEDIATRICIAN
- PUBLIC HEALTH NURSE
- COMMUNITY HEALTH NURSE
- SPEECH LANGUAGE PATHOLOGIST

*IF CLIENT SEEN BY TWO PEOPLE THE SECOND ONE GETS RECORDED*
Linking to the PPNL Clinic’s Database
How Many are in Autism Database?

![Graph showing the percentage of individuals in the Autism Database from 2007 to 2012.](image-url)
40 of 892 seen during 2007-2012 were initially followed by perinatal (mean of 4 visits)
31 of the 40 from perinatal were diagnosed with autism
- 45% - Autism
- 42% - ASD
- 13% - Aspergers
Reasons Followed by Perinatal

- LESS THAN 1500 GRAMS (45% of those given Autism Dx)
- VENTILATED (19% of those given Autism Dx)
- SPECIFIC PHYSICIAN REQUEST
- ANTENATAL SUBSTANCE MISUSE
- SEIZURE
- PERSISTENT NEURO
- APGAR
- CORD PH
- HYPOGLYCEMIA
Autism & Type of Delivery

2007-2012

48.4% CSECTION
51.6% VAGINAL
Autism & Type of Delivery

2007-2012

77.4% SINGLETONE
22.6% MULTIPLE
Autism & Perinatal Outcomes

2007-2012

Developmental Delay: 54.8%
Other: 25.8%
None: 19.4%
Autism & Gestational Age

2007-2012

38.7% PRETERM
61.3% TERM
Autism & Maternal Age

2007-2012

- 86.7% under 35 years
- 13.3% 35+ years old
Autism & First Time Mothers

2007-2012

34.5%  

65.5%  

PRIMIPS  

MULTIPS
Other Autism Research Links

Birth Complications Linked to Autism
Study: Factors Related to Oxygen Deprivation, Fetal Growth May Be Associated With Autism
By Perriene Goodman, MA
WebMD Health News
Reviewed by Louise Cheng, MD

The Association of Maternal Obesity and Diabetes With Autism and Other Developmental Disabilities
Mengying Li, M. Daniele Fadlan, Anne Riley, Rebecca Lande, Sheila O. Walker, Michael Silverstein, Deanna Caruso, Colleen Pearson, Shannon Kiang, Jamie Lyn Dahm, Xinmei Hong, Guoying Wang, Mei-Cheng Wang, Barry Zuckerman, Xiaobin Wang

Mental Health in Children Born Extremely Preterm Without Severe Neurodevelopmental Disabilities
Sijie Karine Elgen Fenvang, Mari Hysing, Trond Markestad, Kristian Sommerfelt

Abstract

BACKGROUND: Preterm birth and maternal obesity and diabetes are the leading causes of neonatal complications in the United States. We evaluated the independent and combined effects of maternal gestational age and maternal complications on the risk of autism spectrum disorder (ASD) and neurodevelopmental disabilities (NDD) in infants born prematurely (PT).

METHODS: This study is based on 27,444 infants (excluding 1,897 ASD cases), a subset of the Boston Birth Cohort who completed the first postnatal study visit at Boston Medical Center between 1995 and 2016. ASD and other NDDs were based on physician diagnosis.

OBJECTIVE: To describe the prevalence and gender characteristics of mental health problems in extremely preterm/extremely low birth weight (ELBW) children without intellectual disabilities, blindness, deafness, or severe cerebral palsy compared with a reference group at 11 years of age.

METHODS: In a national cohort of ELBW children, mental health was assessed by parental and teacher report, using the Autism Spectrum Screening Questionnaire, the Swanson, Nolan, and Pelham Questionnaire IV (attention-deficit/hyperactivity disorder), the Strengths and Difficulties Questionnaire, and the Child Behavior Checklist.

For each measure, children were compared with a reference group at 11 years of age.
Other Links of Interest

- genetic factors predominate (complicated)
- environmental factors (e.g., certain foods, infectious disease, heavy metals, solvents, diesel exhaust, PCBs, phthalates and phenols used in plastic products, pesticides, brominated flame retardants, alcohol, smoking, illicit drugs, and vaccines)
- prenatal risk factors - advanced age in either parent, diabetes, bleeding, and use of psychiatric drugs in the mother during pregnancy, Infectious processes (congenital rubella syndrome), Environmental agents (embryo to thalidomide, valproic acid, or misoprostol),
A fresh perspective on autism research with the developing "Bacterial Theory" of autism. The fastest-growing developmental disorder in the industrialized world, autism has increased an astounding 600 per cent over the last 20 years, and science cannot say why. Some say it's triggered by environmental factors and point to another intriguing statistic: 70 per cent of kids with autism also have severe gastrointestinal symptoms. Could autism actually begin in the gut? *The Autism Enigma* looks at the progress of an international group of scientists studying the gut's amazingly diverse and powerful microbial ecosystem for clues to the baffling disorder.

Dr. Derrick MacFabe, Director of Kilee Patchell-Evans Autism Research Group, University of Western Ontario
Read an interview with Dr. MacFabe and others involved in this film on the [filmmaker's website](http://www.cbc.ca/natureofthings).
Trends in 4 Disorders

The ASD surveillance cases must satisfy the following three criteria:

1. The diagnosis of ASD is provided or confirmed by a licensed physician, psychologist, or nurse practitioner, whose scope of practice includes ASD diagnosis*. The diagnosis of ASD is based on the clinical criteria in the Diagnostic and Statistical Manual for Mental Disorders or the International Classification for Diseases.

2. The individual is a Canadian resident.

3. The individual is aged two to 18 years at time of diagnosis (or up to 21, if available in data source).
NASS  The National ASD Surveillance System

Working Together to Track Autism Spectrum Disorder across Canada
Working Together to Track Autism Spectrum Disorder in Canada

• **NASS** is a collaboration of federal, provincial and territorial governments, working together with other stakeholders, to build a comprehensive picture of ASD in Canada.

• **NASS** will track the demographic profile of ASD, including key characteristics, patterns and trends, by collecting and analyzing data from multiple sectors such as health, education and social services.

• **NASS** will provide the evidence based numbers to inform critical planning of programs, services and research that impact Canadians living with ASD, as well as their families and caregivers.
The Need to Know

ASD poses a significant health, social and financial impact.

» Public concern over increases in the number of Canadian children and youth with ASD

» Lack of national information and surveillance infrastructure to accurately report on ASD prevalence in defined Canadian populations

» Research has shown that early intervention has a positive impact on longer-term outcomes

» Estimated lifetime cost up to $5.5M per individual with ASD
The Path to NASS

- 2006 - Federal Minister of Health announced measures to help Canadians with ASD and their families
- 2007 - Senate Report: Pay Now or Pay Later
- 2009 - Treasury Board Submission: Action plan to protect human health from environmental contaminants
- 2010 - PHAC assumed responsibility for the ASD initiative
- 2011 - Program launch: staffing, meetings w/ P/T, nomination committee for ASD-AC
- 2012 - ASD Advisory Committee with Surveillance and KT Working Groups
- 2012/13 – Program preparation: environmental scans, feasibility projects, Letters of Invitation sent to P/Ts
- 2014 - Program Operation: Collaborative Surveillance Agreements, data flow begins
- March 2016 - Program Findings: First report on ASD in Canada released
Project Structure

- Letters of Invitation to P/Ts
- P/T Letters of Intent (to PHAC)
- PT Proposals (methodology, funding given)
- Collaborative Surveillance Agreements (CSAs)
  - Negotiate CSAs to build required infrastructure
  - Target the development of jurisdictional ASD surveillance systems
- Formation of a Liaison Team/Facilitated Support (Agency – P/Ts)
  - Skills: Information technology; epidemiology; project management
  - Assist in the development of ASD surveillance solutions
- Project Implementation
  - Collate data centrally
  - Review data quality
  - Produce preliminary reports
**Program Implementation: Timelines**

**Phase I: Launch of Implementation**
- Letters of invite to PTs
- Site visits and webinars to outline Program goals, scope and obtain feedback

**Phase II: Capacity Support**
- Ascertain which PTs are interested in going forward and what is needed
- Begin to negotiate Collaborative Surveillance Agreements (CSAs)

**ASD Surveillance Data**
- Collate data centrally
- Review data quality
- Produce preliminary reports
- Evaluate process to form basis of second round of CSAs

**Timelines**
- June 2013
- Dec 2013
- Mar 2016
First Years of Data Collection 2014 - 2016

- NASS will collect data and deliver evidence-based analysis (2014-2016).

- **Overall Objective** - to provide the most accurate estimate of the total number of children and youth diagnosed with ASD (prevalence) in Canada.

- It will share its findings through multiple channels to stimulate discussion and raise awareness about ASD in Canada.

- The NASS will in turn support the advancement of ASD initiatives and research across the country.
Working Together

Education and health data sources

Data Collection via record linkage or other means

P/Ts transfer collected data to Public Health Agency of Canada - NASS

Requires:
- a) Agreement on core data elements, particularly case definitions
- b) Adaptation of PT data set(s)
- c) Agreements to support infrastructure and capacity development
Key Data Sources

Health
» Collected through PT Depts. of Health (such as physician billing, hospital admission/discharges), regional health authority, specialized health care centres/hospitals, or private practice psychologists.

Education
» Collected through Dept/Ministries of Education through Student Information Systems identifying students with ASD using criteria which may include evaluation or letter of diagnosis from a physician, psychologist, psychologist, or psychiatrist.

Social Services
» Collected through Social Services records on individuals who participate in targeted programs, receive financial contributions or services for their condition or to support their employment

Multisectoral Research Teams
» Some universities in Canada lead multisectoral surveillance research projects that involve the linking of administrative data sets from different sectors
Key Data Elements

**CORE (MINIMAL)**
date of birth, sex,
geographic locator, date of record capture

**CORE (PROPOSED FULL)**
date of diagnosis, country of 1st diagnosis,
diagnostic tests used, other assessment tools,
source of diagnosis, country of birth, other geographic locators, ethnicity,
co-morbidities

**TARGETED**
P/T specific data needs
Focused surveillance projects
Data Confidentiality

- ASD surveillance work seeks to “count heads” at the population level and is not concerned with attaching names, addresses or social insurance numbers to data.

- P/Ts anonymize data prior to transfer to Public Health Agency of Canada.

- Privacy Impact Assessments conducted to identify and minimize potential privacy risks, and includes information about collection, use, disclosure, storage and ultimately destruction.

- Reviewed by the Office of the Privacy Commissioner of Canada for compliance with Canada’s Privacy Act.
Benefits at a Glance

NASS will track information over time to:

• Estimate how many Canadian children and youth are living with ASD (prevalence) and how many new cases are emerging (incidence)
• Better understand the profile and impact on individuals living with ASD, their families, caregivers and communities
• Compare patterns within Canada and internationally
• Identify potential risk factors
• Support policy, program and service development
• Share lessons learned
• Support new hypotheses/questions to direct future research
• Increase public awareness and understanding of ASD
Final Points

- Update in Local Autism Database
- Benefits of having NASS being established
- Can Impact Decision Support and Research
- Important to have a strong link with Health Care Providers, Researchers, Educators and Policy Makers
Additional Thanks

- Connie Bursey – Autism Clinic Nurse - Janeway Child Development Team

- Jay Onsyko – Manager, Childhood Cancer & Developmental Disorders
  NSASS – Public Health Agency of Canada
Thank You For Listening

Always Unique Totally Interesting Sometimes Mysterious
Questions?

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