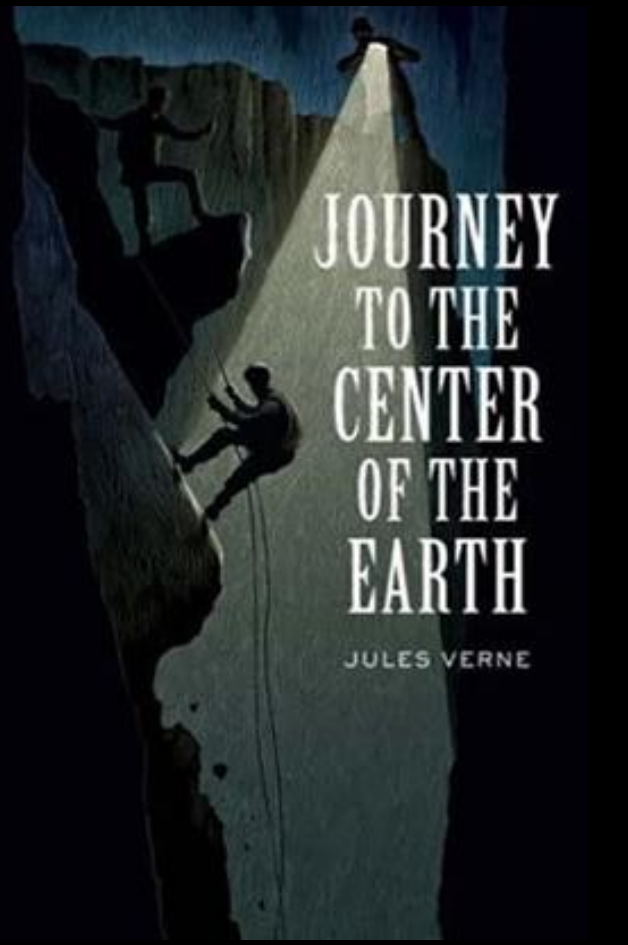
# Journey to the Janeway's Autism Clinic: Let's Start with the Birth and Perinatal Clinic story.




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)

Perinatal Program
Newfoundland
Labrador

# Disclaimer

- 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)




# Live Birth Notification System

- 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.

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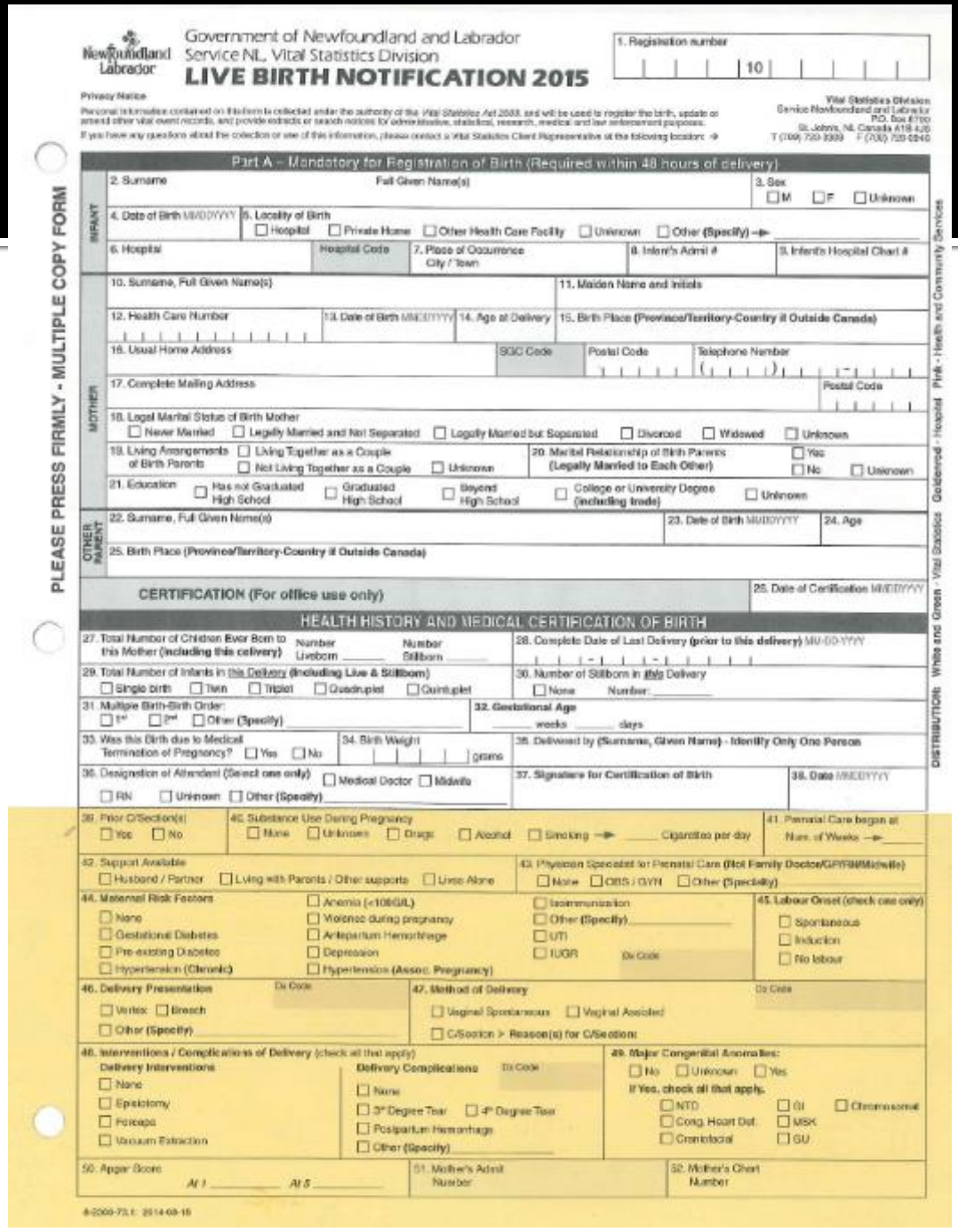

Government of Newfoundland and Labrador
Service NL, Vital Statistics Division

# LIVE BIRTH NOTIFICATION 2015

1. Registration number: | | | | 10 | | | | |

Privacy Notice

Personal information contained on this form is collected under the authority of the *Vital Statistics Act 2009*, and will be used to register the birth, update or amend other vital event records, and provide extracts or search notices for administrative, statistical, research, medical and law enforcement purposes.

If you have any questions about the collection or use of this information, please contact a Vital Statistics Client Representative at the following location: →

Vital Statistics Division
Service Newfoundland and Labrador
P.O. Box 8700
St. John's, NL Canada A1B 4J6
T (709) 729-3309 F (709) 729-0946

PLEASE PRESS FIRMLY - MULTIPLE COPY FORM

DISTRIBUTION: White and Green - Vital Statistics Goldenrod - Hospital Pink - Health and Community Services

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

**INFANT**

2. Surname | Full Given Name(s) | 3. Sex ☐ M ☐ F ☐ Unknown

4. Date of Birth MM/DD/YYYY | 5. Locality of Birth ☐ Hospital ☐ Private Home ☐ Other Health Care Facility ☐ Unknown ☐ Other (Specify) →

6. Hospital | Hospital Code | 7. Place of Occurrence City / Town | 8. Infant's Admit # | 9. Infant's Hospital Chart #

**MOTHER**

10. Surname, Full Given Name(s) | 11. Maiden Name and Initials

12. Health Care Number | 13. Date of Birth MM/DD/YYYY | 14. Age at Delivery | 15. Birth Place (Province/Territory-Country if Outside Canada)

16. Usual Home Address | SGC Code | Postal Code | Telephone Number

17. Complete Mailing Address | Postal Code

18. Legal Marital Status of Birth Mother ☐ Never Married ☐ Legally Married and Not Separated ☐ Legally Married but Separated ☐ Divorced ☐ Widowed ☐ Unknown

19. Living Arrangements of Birth Parents ☐ Living Together as a Couple ☐ Not Living Together as a Couple ☐ Unknown

20. Marital Relationship of Birth Parents (Legally Married to Each Other) ☐ Yes ☐ No ☐ Unknown

21. Education ☐ Has not Graduated High School ☐ Graduated High School ☐ Beyond High School ☐ College or University Degree (including trade) ☐ Unknown

**OTHER PARENT**

22. Surname, Full Given Name(s) | 23. Date of Birth MM/DD/YYYY | 24. Age

25. Birth Place (Province/Territory-Country if Outside Canada)

**CERTIFICATION (For office use only)** | 26. Date of Certification MM/DD/YYYY

## HEALTH HISTORY AND MEDICAL CERTIFICATION OF BIRTH

27. Total Number of Children Ever Born to this Mother (including this delivery) Number Livebom ____ Number Stillborn ____

28. Complete Date of Last Delivery (prior to this delivery) MM-DD-YYYY

29. Total Number of Infants in this Delivery (including Live & Stillborn) ☐ Single Birth ☐ Twin ☐ Triplet ☐ Quadruplet ☐ Quintuplet

30. Number of Stillborn in this Delivery ☐ None Number: ____

31. Multiple Birth-Birth Order: ☐ 1st ☐ 2nd ☐ Other (Specify) ____

32. Gestational Age ____ weeks ____ days

33. Was this Birth due to Medical Termination of Pregnancy? ☐ Yes ☐ No

34. Birth Weight ____ grams

35. Delivered by (Surname, Given Name) - Identify Only One Person

36. Designation of Attendant (Select one only) ☐ Medical Doctor ☐ Midwife ☐ RN ☐ Unknown ☐ Other (Specify) ____

37. Signature for Certification of Birth

38. Date MM/DD/YYYY

39. Prior C/Section(s) ☐ Yes ☐ No

40. Substance Use During Pregnancy ☐ None ☐ Unknown ☐ Drugs ☐ Alcohol ☐ Smoking → ____ Cigarettes per day

41. Prenatal Care began at Num. of Weeks →

42. Support Available ☐ Husband / Partner ☐ Living with Parents / Other supports ☐ Lives Alone

43. Physician Specialist for Prenatal Care (Not Family Doctor/GP/FP/Midwife) ☐ None ☐ OBS / GYN ☐ Other (Specialty) ____

44. Maternal Risk Factors
☐ None
☐ Gestational Diabetes
☐ Pre-existing Diabetes
☐ Hypertension (Chronic)
☐ Anemia (<100G/L)
☐ Violence during pregnancy
☐ Antepartum Hemorrhage
☐ Depression
☐ Hypertension (Assoc. Pregnancy)
☐ Isoimmunization
☐ Other (Specify) ____
☐ UTI
☐ IUGR
Dx Code

45. Labour Onset (check one only)
☐ Spontaneous
☐ Induction
☐ No labour

46. Delivery Presentation Dx Code
☐ Vertex ☐ Breech
☐ Other (Specify) ____

47. Method of Delivery Dx Code
☐ Vaginal Spontaneous ☐ Vaginal Assisted
☐ C/Section > Reason(s) for C/Section:

48. Interventions / Complications of Delivery (check all that apply)

Delivery Interventions
☐ None
☐ Episiotomy
☐ Forceps
☐ Vacuum Extraction

Delivery Complications Dx Code
☐ None
☐ 3rd Degree Tear ☐ 4th Degree Tear
☐ Postpartum Hemorrhage
☐ Other (Specify) ____

49. Major Congenital Anomalies:
☐ No ☐ Unknown ☐ Yes
If Yes, check all that apply.
☐ NTD ☐ GI ☐ Chromosomal
☐ Cong. Heart Def. ☐ MSK
☐ Craniofacial ☐ GU

50. Apgar Score At 1 ____ At 5 ____

51. Mother's Admit Number

52. Mother's Chart Number

8-2000-73.1: 2014-08-15

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Newfoundland Labrador

# Discharge Abstract Database

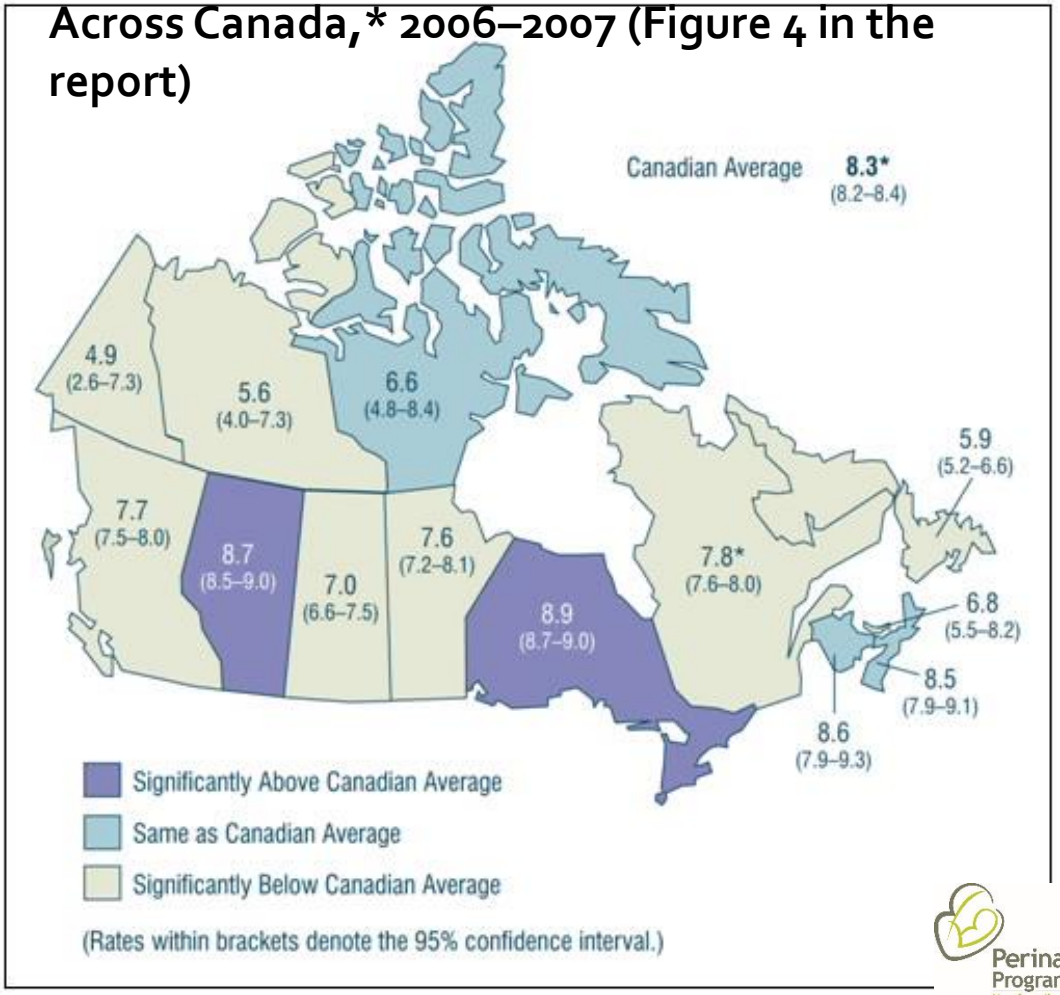
- Contains demographic, clinical and administrative data collected at hospitals when patients are discharged from inpatient and surgical day care services. This information is used to support health system policy development, planning, management, evaluation and research.

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

Perinatal Program
Newfoundland Labrador

# Discharge Abstract Database


**Small-for-Gestational-Age Rate: The Picture Across Canada,* 2006–2007 (Figure 4 in the report)**




Perinatal Program Newfoundland Labrador

# Provincial Perinatal Surveillance Program (PPSP)

- 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.

Perinatal Program Newfoundland Labrador

# About PPNL – vision/mandate

- 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.

Perinatal Program Newfoundland Labrador

# About PPNL - PPSP

- Presently, the PPNL collects maternal and neonatal data from the four Regional Health Authorities:
  - Eastern Health (since april 2001 STJ and oct 2007 rest of EH)
  - Labrador-Grenfell Health (since jan 2005)
  - Western Health (since april 2010)
  - Central Health Authority (since aug 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.

Perinatal Program
Newfoundland Labrador

# About PPNL – Projects & Issues

- Data Collection: Follow-up, Surveillance Program, HBC, Congenital Anomalies

| FOLLOW-UP CLINIC ADMISSION CRITERIA | PERCENTAGE OF 2014-15 CLINIC INTAKE | PERCENTAGE OF 2013-14 CLINIC INTAKE |
|---|---|---|
| Maternal Substance Use | 38.2% | 40.6% |
| Birth Weight ≤1500 grams | 24.4% | 27.1% |
| Ventilated for 48 hours or more | 28.5% | 18.0% |
| Specific Physician Request | 10.6% | 12.0% |
| Complex Surgery | 8.1% | 9.8% |
| Seizures in 1st 28 days of life | 10.6% | 4.5% |
| APGAR Score ≤ 3 for ≥ 5 minutes | 7.3% | 3.0% |
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| Intraventricular Hemorrhage (IVH) | 0.8% | 1.5% |
| Meningitis in 1st 28 days of life) | 3.3% | 3.8% |
| Periventricular Leukomalacia (PVL) | 0.8% | 0.0% |
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Perinatal Program
Newfoundland Labrador

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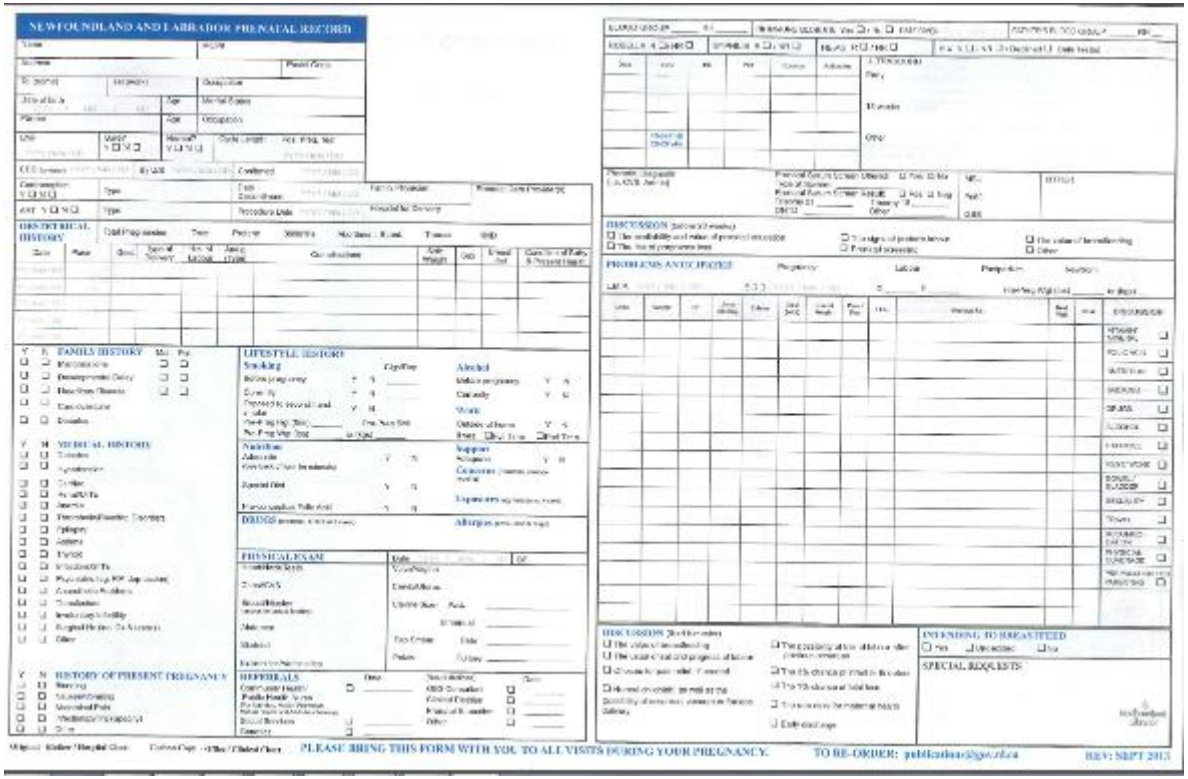
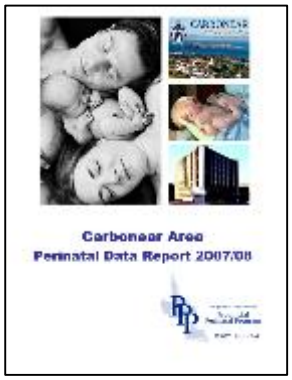
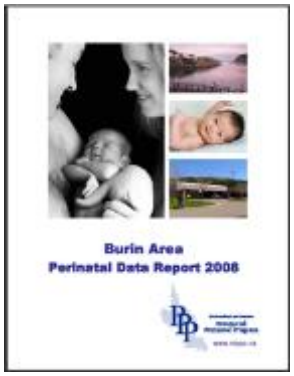


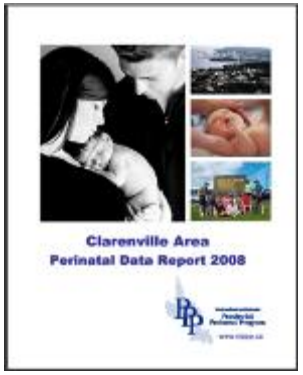

Perinatal Program Newfoundland Labrador

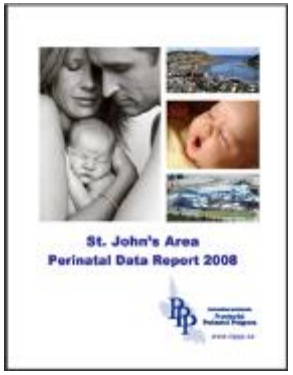
# About PPNL – Projects & Issues

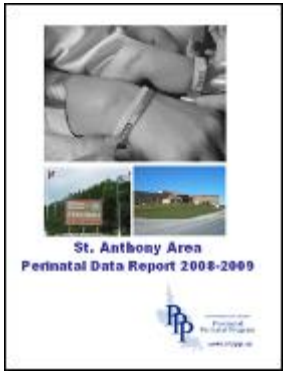
- Surveillance Reports

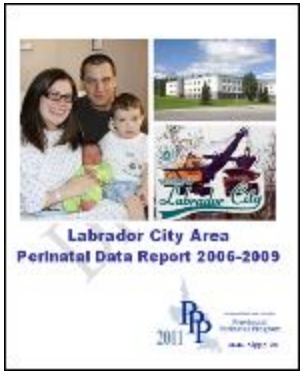


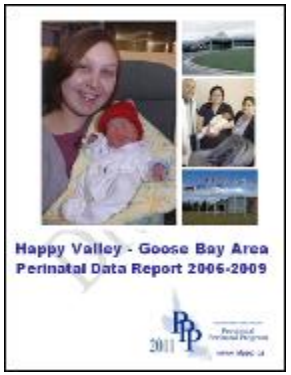



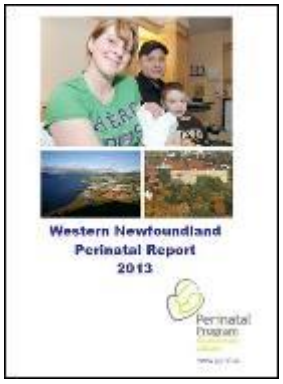





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# About PPNL – Projects & Issues

- 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, Obstretrical updates & Colaborative Neonatal Education

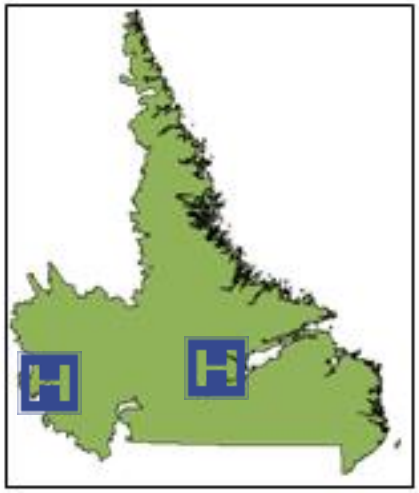
Perinatal Program
Newfoundland Labrador

# About PPNL – www.ppnl.ca


Perinatal Program Newfoundland Labrador

# Demographics

- 526,977 population
- 4,496 live births in 2015
- 56% capture at St. John's site



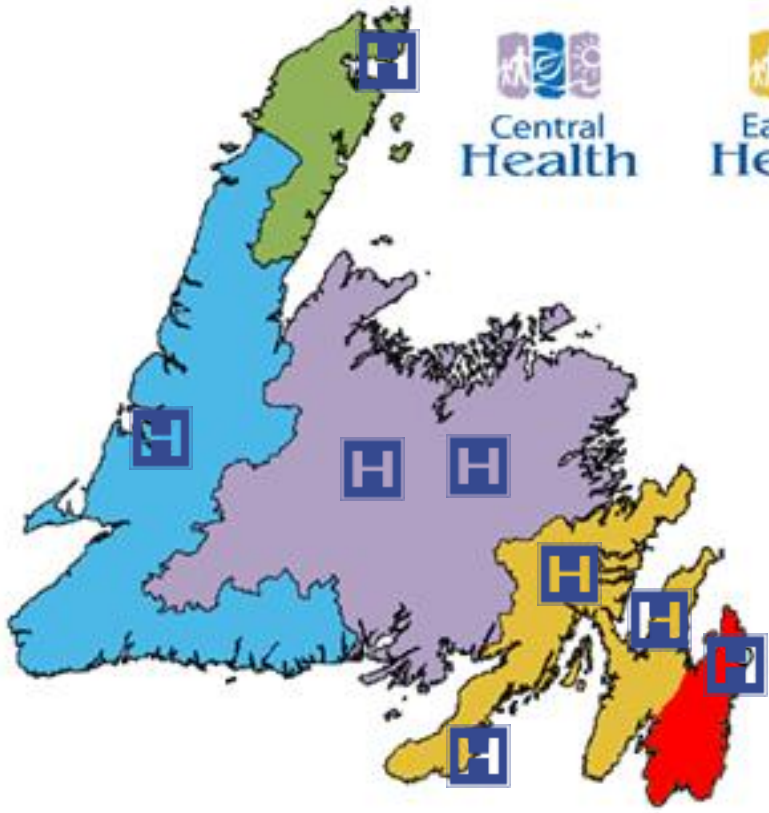
Newfoundland Labrador

Labrador-Grenfell Health

Western Health

Central Health

Eastern Health




Perinatal Program Newfoundland Labrador

# High-Risk Follow-Up Clinic

- 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.

Perinatal Program
Newfoundland Labrador

# High-Risk Follow-Up Clinic

- 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.

Perinatal Program
Newfoundland Labrador

# 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:
10. Thoracic 11. Gastrointestinal (GI) 12. Genital Urinary (GU)

Perinatal Program
Newfoundland Labrador

# 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

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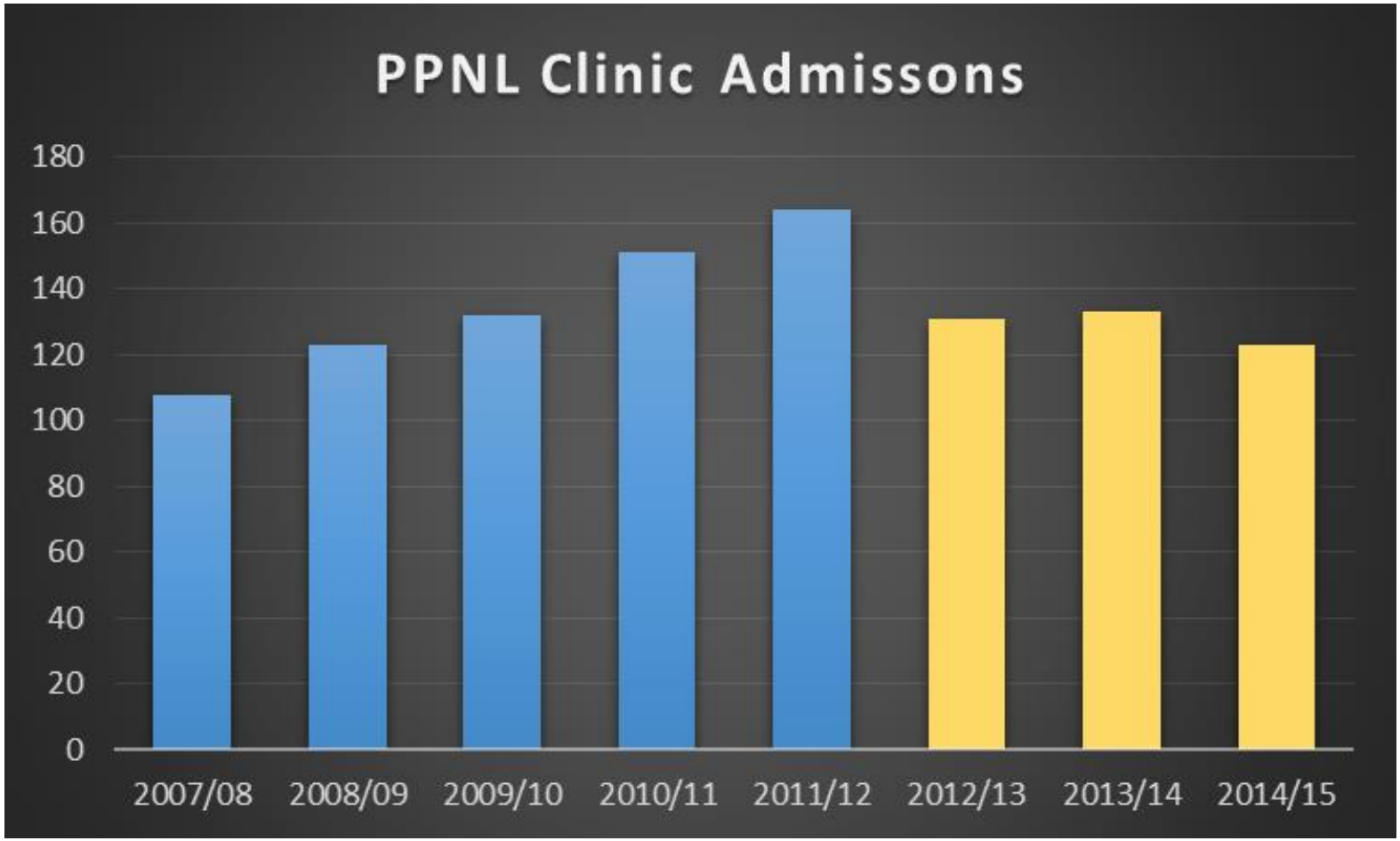
# Perinatal Clinic Admissions




Perinatal Program
Newfoundland Labrador

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Perinatal Program
Newfoundland Labrador

# Clinic Outcomes

## Innovations in Patient Care: A Framework for a Clinical & Decision Support Partnership to Improve Best Practice

*Phil Murphy, MSc[1,2], Christine Winters, RN[1] and Lorraine Burrage, RN, MSc[1].*
*[1]Newfoundland and Labrador Provincial Perinatal Program, Eastern Health, St. John's, NL, Canada and [2]Faculty of Medicine, Memorial University, St. John's, NL, Canada.*

Provincial Perinatal Program
www.nlppp.ca
Labrador-Grenfell Health · Western Health · Central Health · Eastern Health · Memorial University

### Abstract

In the traditional hospital organization, the clinicians gather patient data on a routine basis but the use of its 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 best 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: simplified data capture; analysis & dissemination; then, collaboration with clinicians and decision support to interpret, design and implement an action plan with Neonatal Intensive Care Unit (NICU) staff and their clients' follow-up information.

A ten year summary of outcomes of infants at high risk for developmental delay is presented. The result of this interdisciplinary initiative has allowed clinicians and staff to become more informed of their clients' developmental outcomes and improve their daily clinical practice and patient care.

To improve quality of reproductive care and pregnancy outcomes in the province, the NLPPP aims for an collaborative approach in translating the knowledge of patient data back to the clinicians who initially captured the information.

### About the NLPPP

Established in 1979.

Mandated to improve quality of reproductive care and pregnancy outcomes in Newfoundland and Labrador.

Provide a province wide follow-up clinic to infants at high risk for developmental delay (~3% of annual 4500 live births).

Surveillance of provincial deliveries, decision support role for Eastern Health and applied health research with Memorial University.

### 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 1995-2004.

Data for each visit for all babies were analyzed using SPSS 15.0.

Outcomes of interest were clinical concern or diagnosis of cerebral palsy, developmental delay, hearing impairment, vision impairment.

Summarized information was presented to NICU staff and a 10 point Yes/No questionnaire was disseminated.

### Results

1102 were followed (61 or 5.5% went on to other follow up)

814 (73.8%) were born in St. John's

57.3% were males

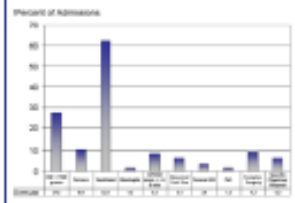
93.8% were singletons

66.0% were born preterm

▼ Cerebral Palsy (referred to Rehab)

▲ Developmental Delay in recent years

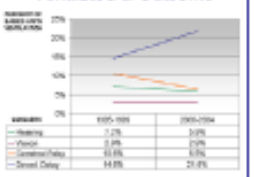
### Criteria Averages



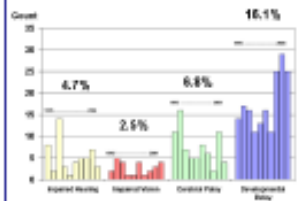
### VLBW & Outcome

### Seizures & Outcome

### Ventilated & Outcome



### Outcomes – Visit Concerns




### Knowledge Translation

- ✓ 37.6% felt the outcomes of those babies presented were what they expected.
- ✓ 82.6% 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 critically ill neonates.
- ✓ 75% felt their interest in neonatal research was increased.


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

### Conclusion

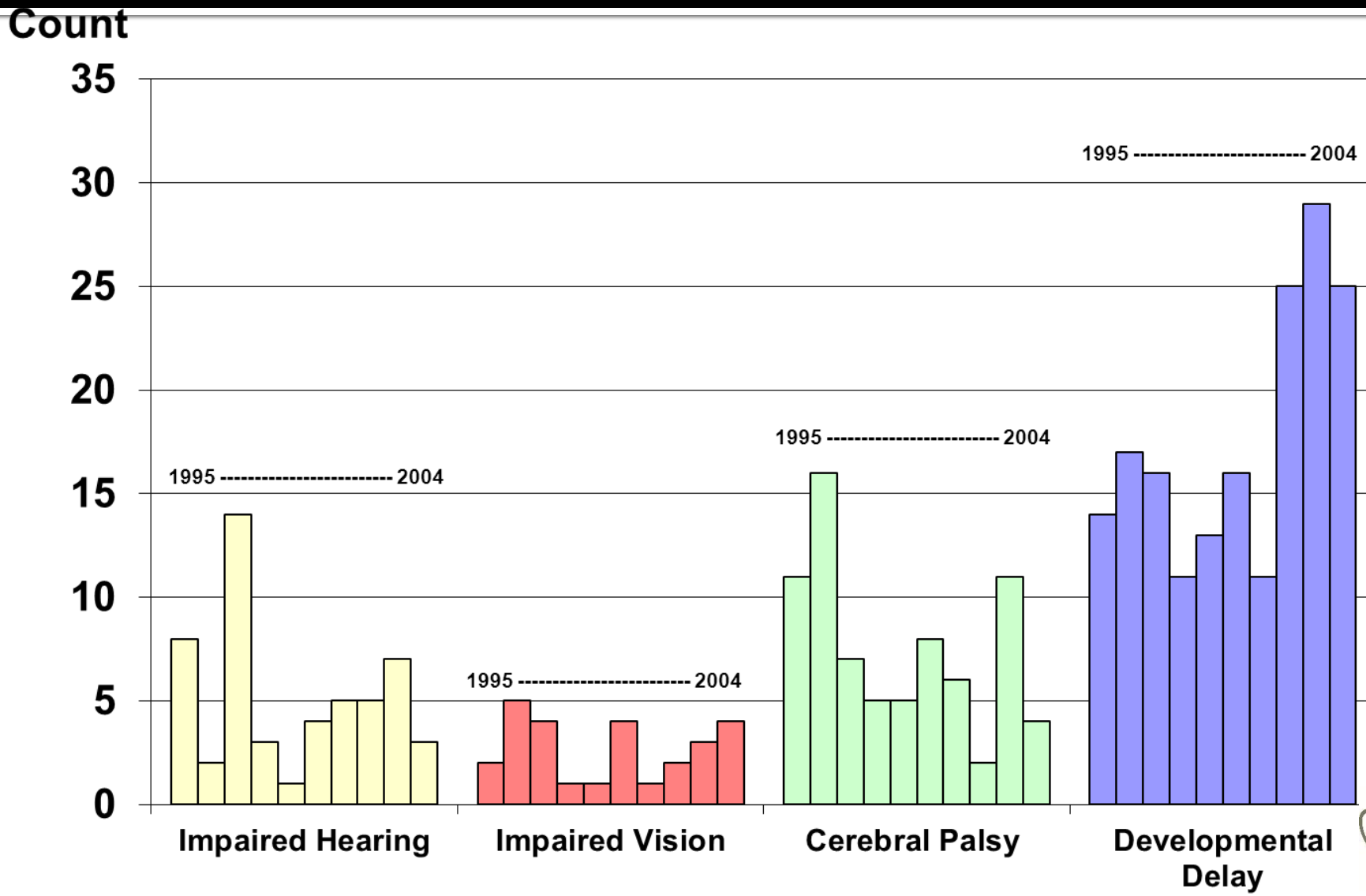
Administrative databases such as the NLPPP's follow-up database provide a rich source of information that can be utilized to improve quality of care and services.

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.

Perinatal Program Newfoundland Labrador

# Clinic Outcomes – 10 year analysis

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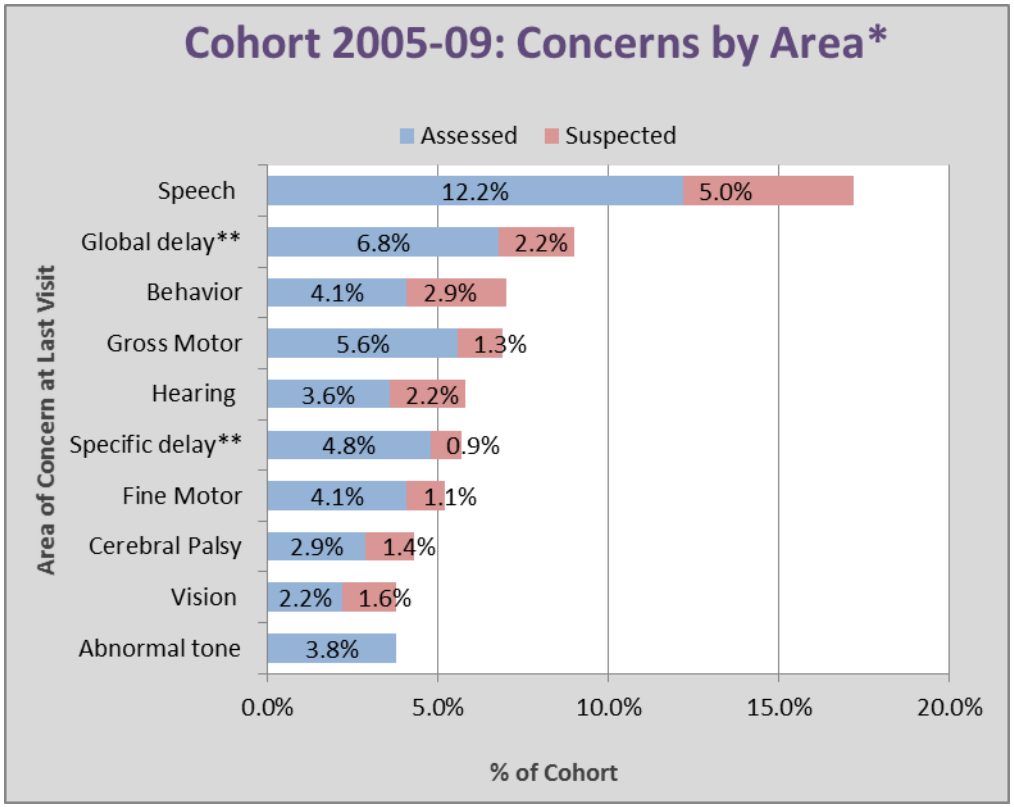
# Clinic Outcomes – 2005-2012 summary

- **Counterpart Barbara Young developed a internal report for some recent years.**

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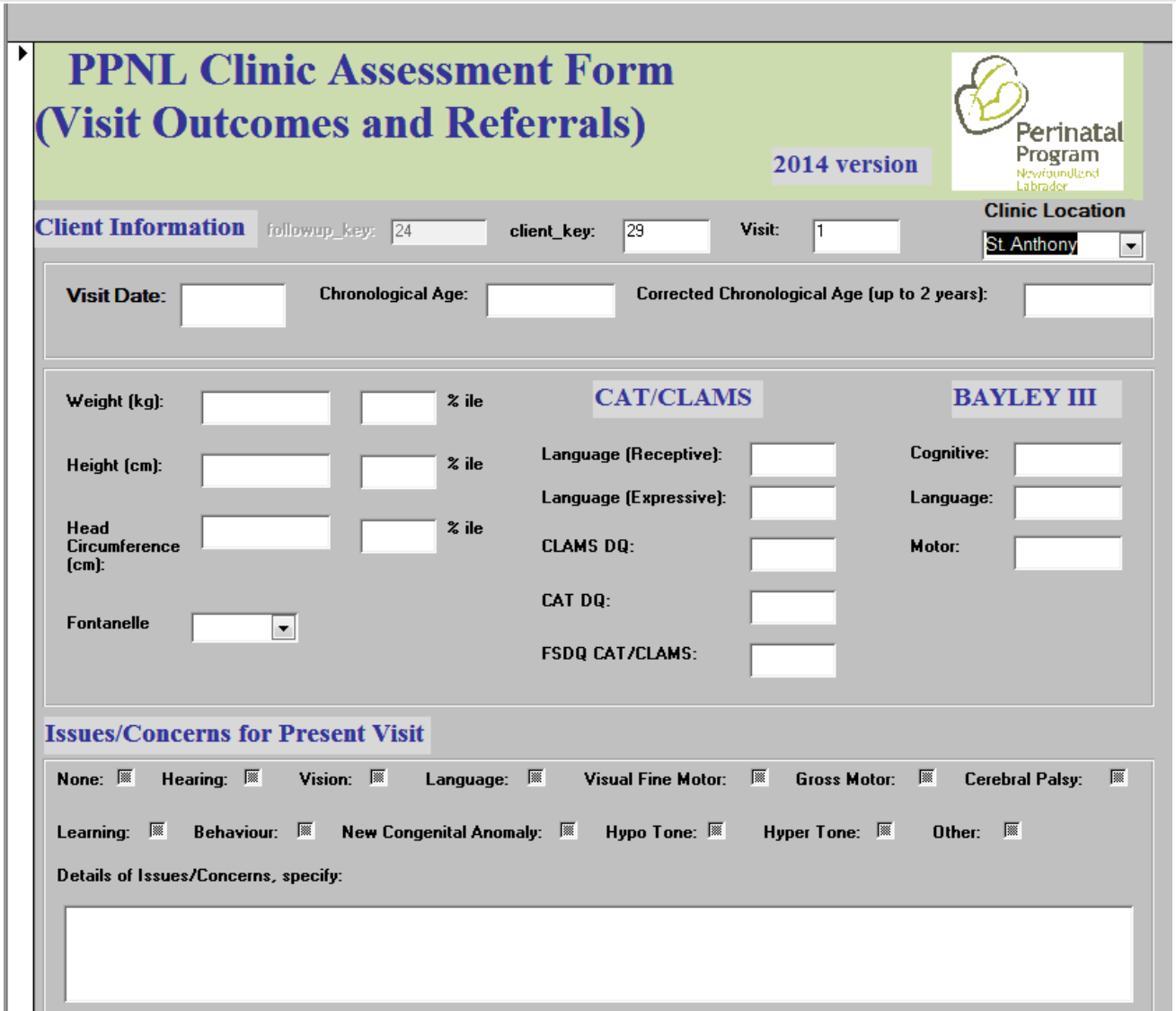
# Clinic Outcomes – new version



## PPNL Clinic Assessment Form (Visit Outcomes and Referrals)

2014 version

Perinatal Program Newfoundland Labrador

**Client Information** followup_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

Fontanelle

**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:

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# Clinic Outcomes – new version

**Referred Today**

| | | |
|---|---|---|
| ☐ Audiology | ☐ Social Work | ☒ Genetics |
| ☐ ENT | ☐ Psychology | ☒ Cardiology |
| ☐ Speech/Language | ☐ Child Youth Family Services | ☒ Endocrinology |
| ☐ Ophthalmology | ☐ Direct Home Services | ☒ Urology |
| ☐ Physiotherapy | ☒ Janeway Family Centre | ☒ Surgery |
| ☐ Occupational Therapy | ☒ Dietitian | ☒ Orthopedics |
| ☐ Rehab | ☒ Public Health Nurse | ☒ Plastics |
| ☒ Neurology | ☒ Behavioural/Child Management | ☒ Dentistry |
| ☐ Development | ☐ Pediatrician | ☒ Other, specify |
| ☒ Blood Work | ☒ BF Clinic ☒ U/S ☒ RSV | |

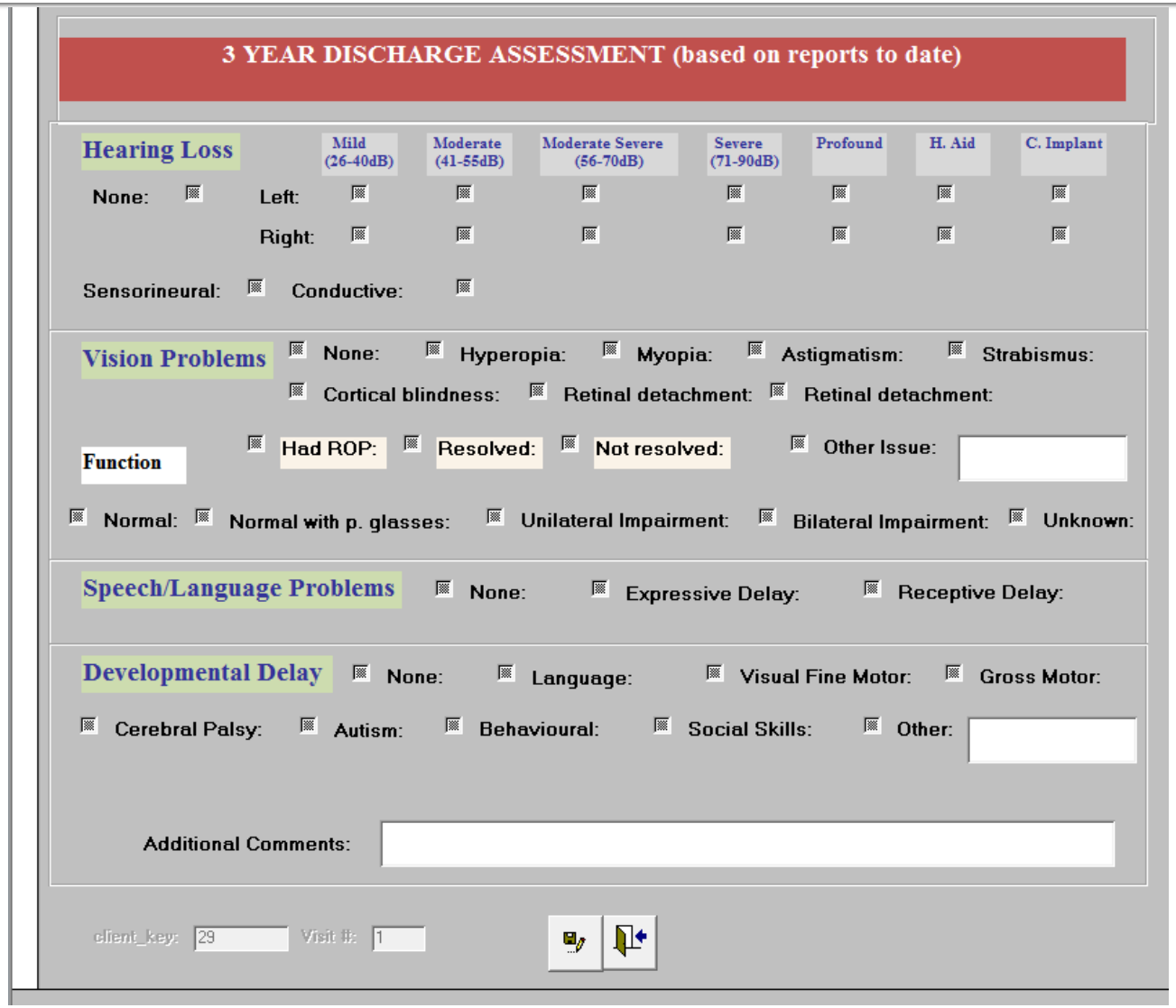
**Follow-Up Status (eg, if refuse follow-up enter status in last visit)**

☒ Continue Follow-Up ☒ Discharge to Rehab/Development ☒ Discharge to Other Prov/Territory

☒ Finished Program - complete Final Assessment Below ☒ Died ☒ Missing ☒ Refuse Follow-Up

Perinatal Program Newfoundland Labrador

# Clinic Outcomes – new version



3 YEAR DISCHARGE ASSESSMENT (based on reports to date)

**Hearing Loss**

| | Mild (26-40dB) | Moderate (41-55dB) | Moderate Severe (56-70dB) | Severe (71-90dB) | Profound | H. Aid | C. Implant |
|---|---|---|---|---|---|---|---|
| None: | | | | | | | |
| Left: | | | | | | | |
| Right: | | | | | | | |

Sensorineural: Conductive:

**Vision Problems** None: Hyperopia: Myopia: Astigmatism: Strabismus:
Cortical blindness: Retinal detachment: Retinal detachment:

**Function** Had ROP: Resolved: Not resolved: Other Issue:

Normal: Normal with p. glasses: Unilateral Impairment: Bilateral Impairment: Unknown:

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

**Developmental Delay** None: Language: Visual Fine Motor: Gross Motor:

Cerebral Palsy: Autism: Behavioural: Social Skills: Other:

Additional Comments:

client_key: 29 Visit #: 1

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# Lets work Backwards for a min

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# 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

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# Autism Database

- 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.

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# 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

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# ADOS: At a Glance

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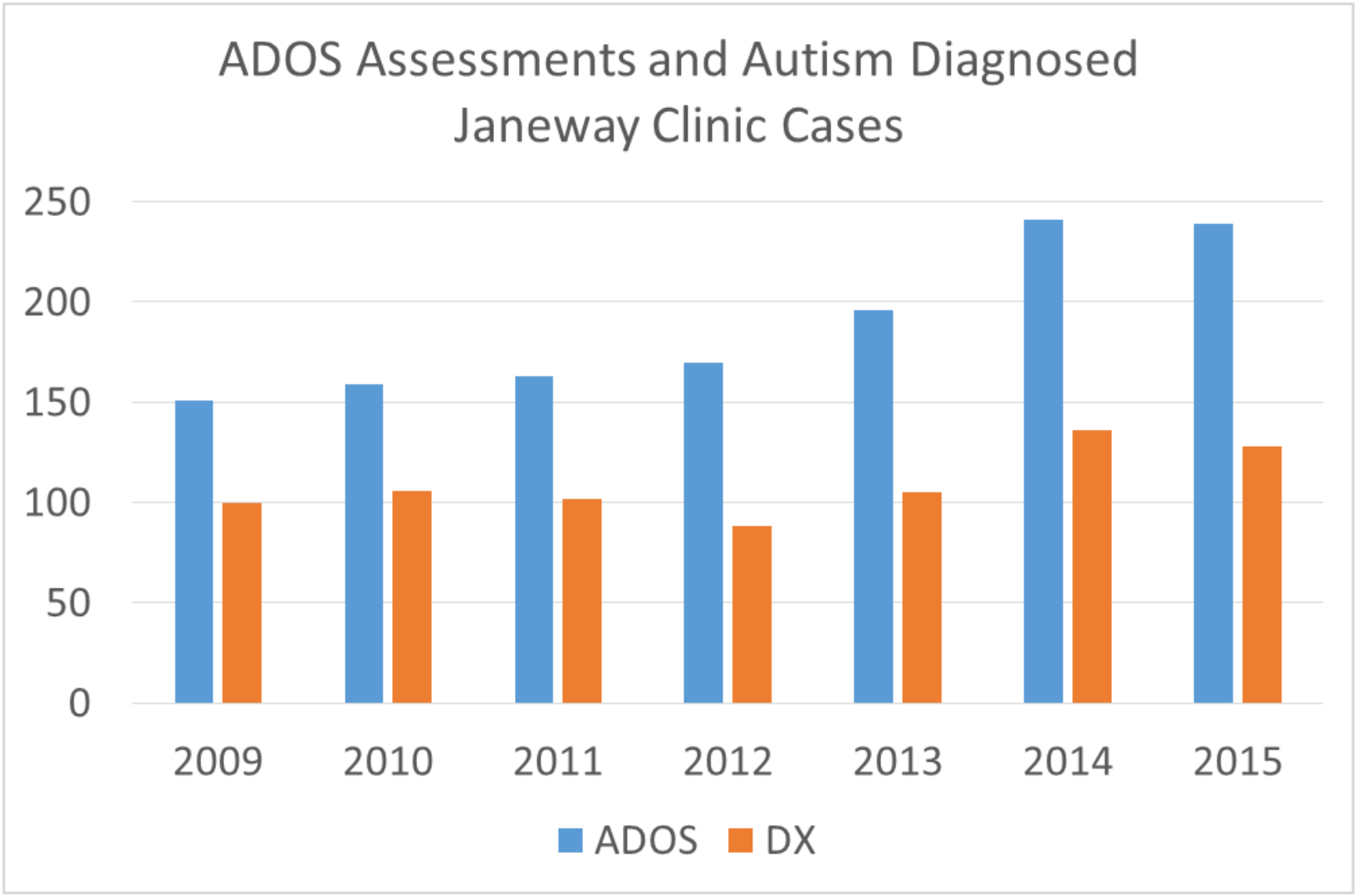
# ADOS: At a Glance

- 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

# ADOS: At a Glance

- 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

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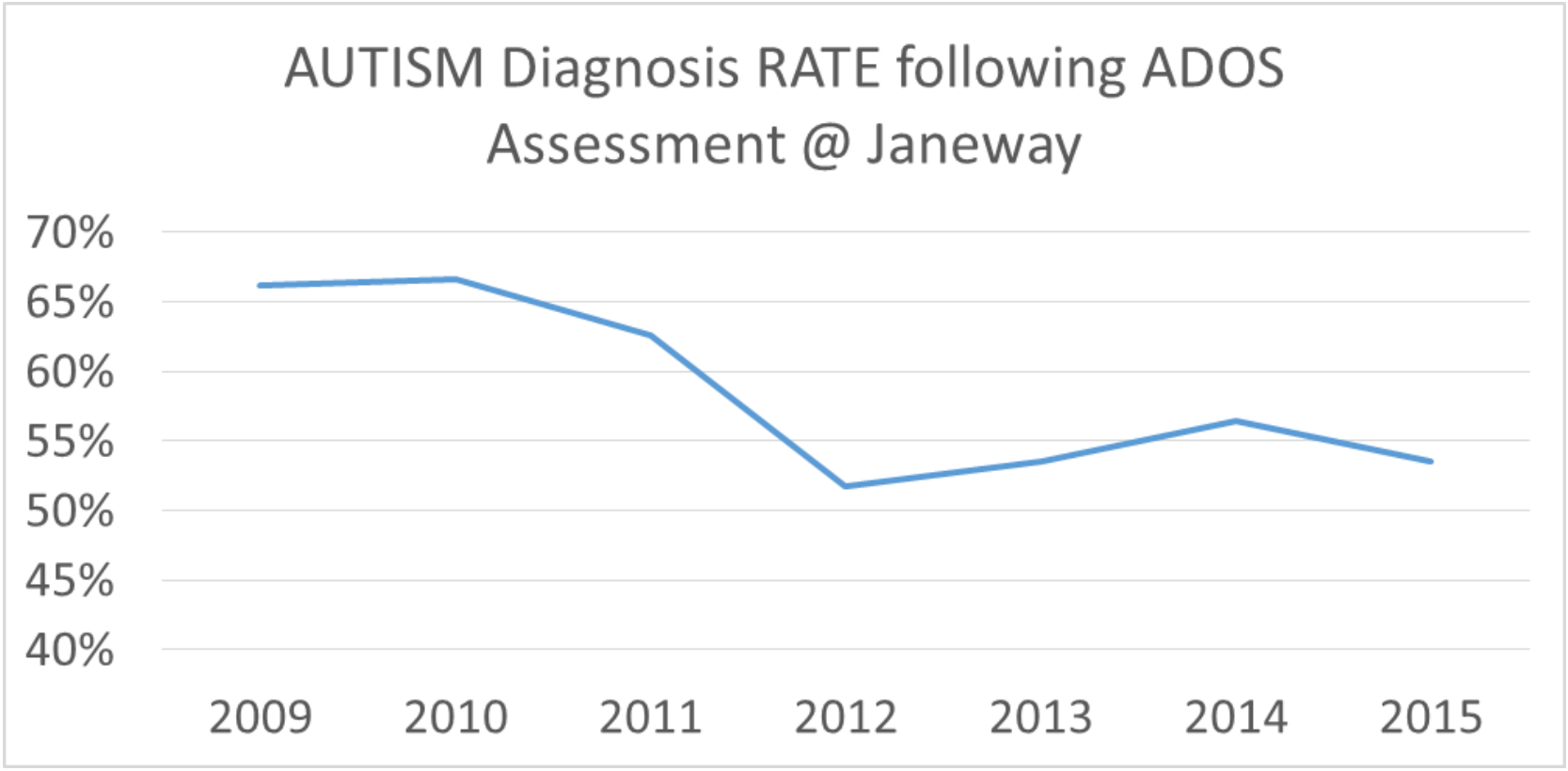
# Autism Database - Diagnosis

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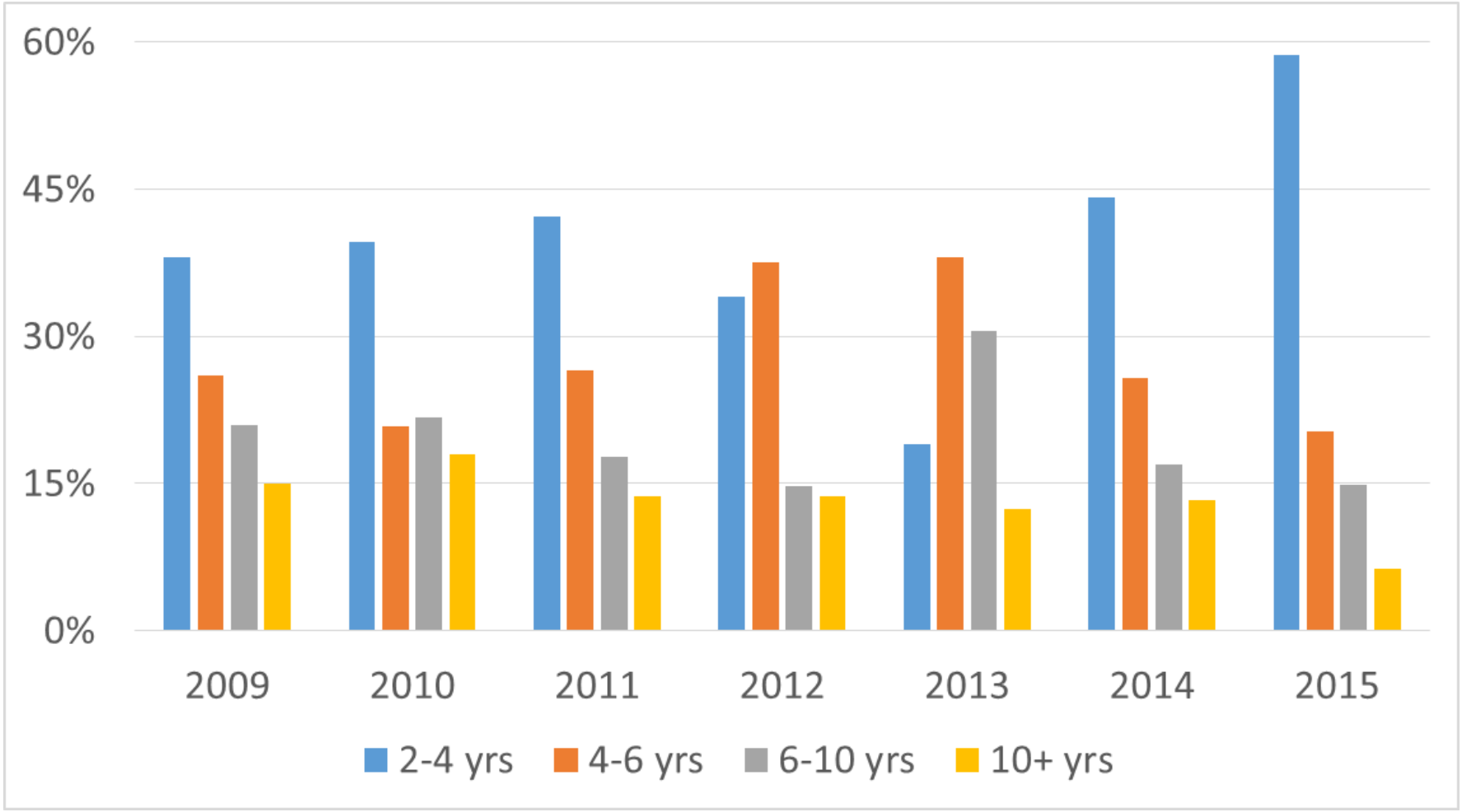
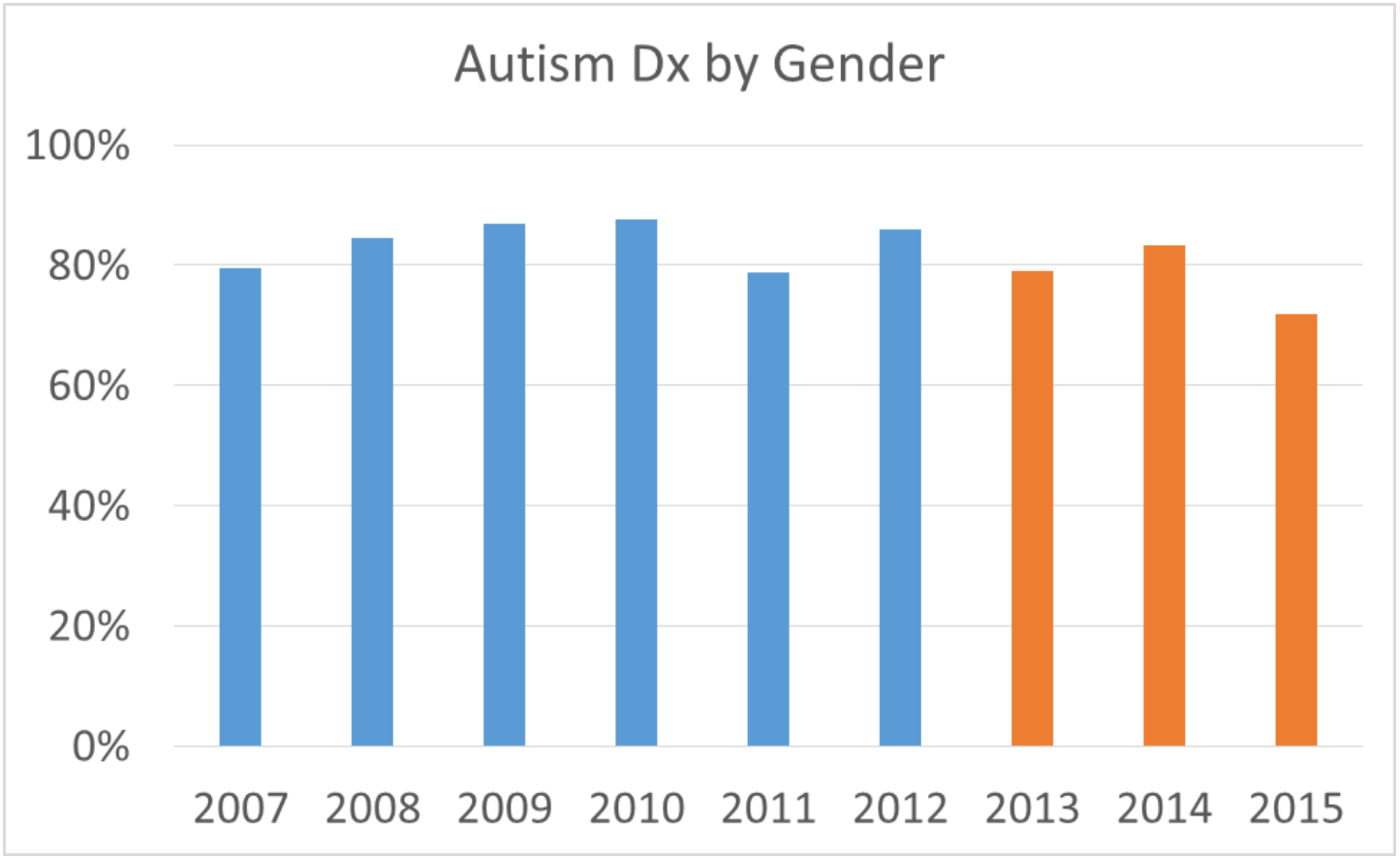
# Autism Database – Age At Dx



# Autism Database - Gender

- **2007-2015: 82% were male clients**





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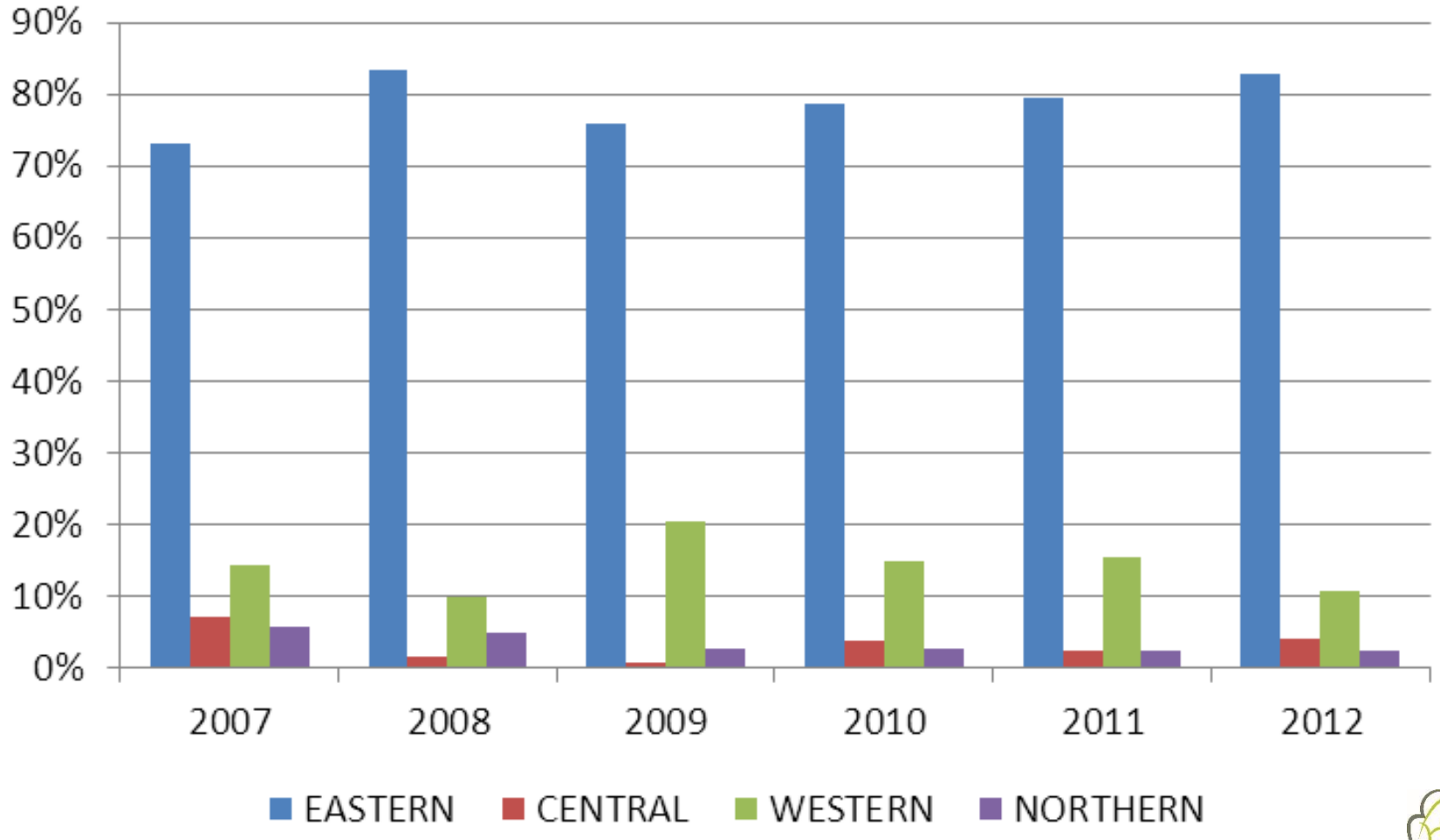
# Autism Database - Region

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# Autism Database – Region (update)

**Crosstab**

% within YearSeenatAutismClinic

| | | YearSeenatAutismClinic | | | |
|---|---|---|---|---|---|
| | | 2013 | 2014 | 2015 | Total |
| REGION | CENTRAL | 7.6% | 4.1% | 3.8% | 5.0% |
| | EASTERN | 87.4% | 91.3% | 93.3% | 90.9% |
| | NORTHERN | 3.0% | 3.2% | 2.1% | 2.7% |
| | WESTERN | 2.0% | 1.4% | .8% | 1.4% |
| Total | | 100.0% | 100.0% | 100.0% | 100.0% |

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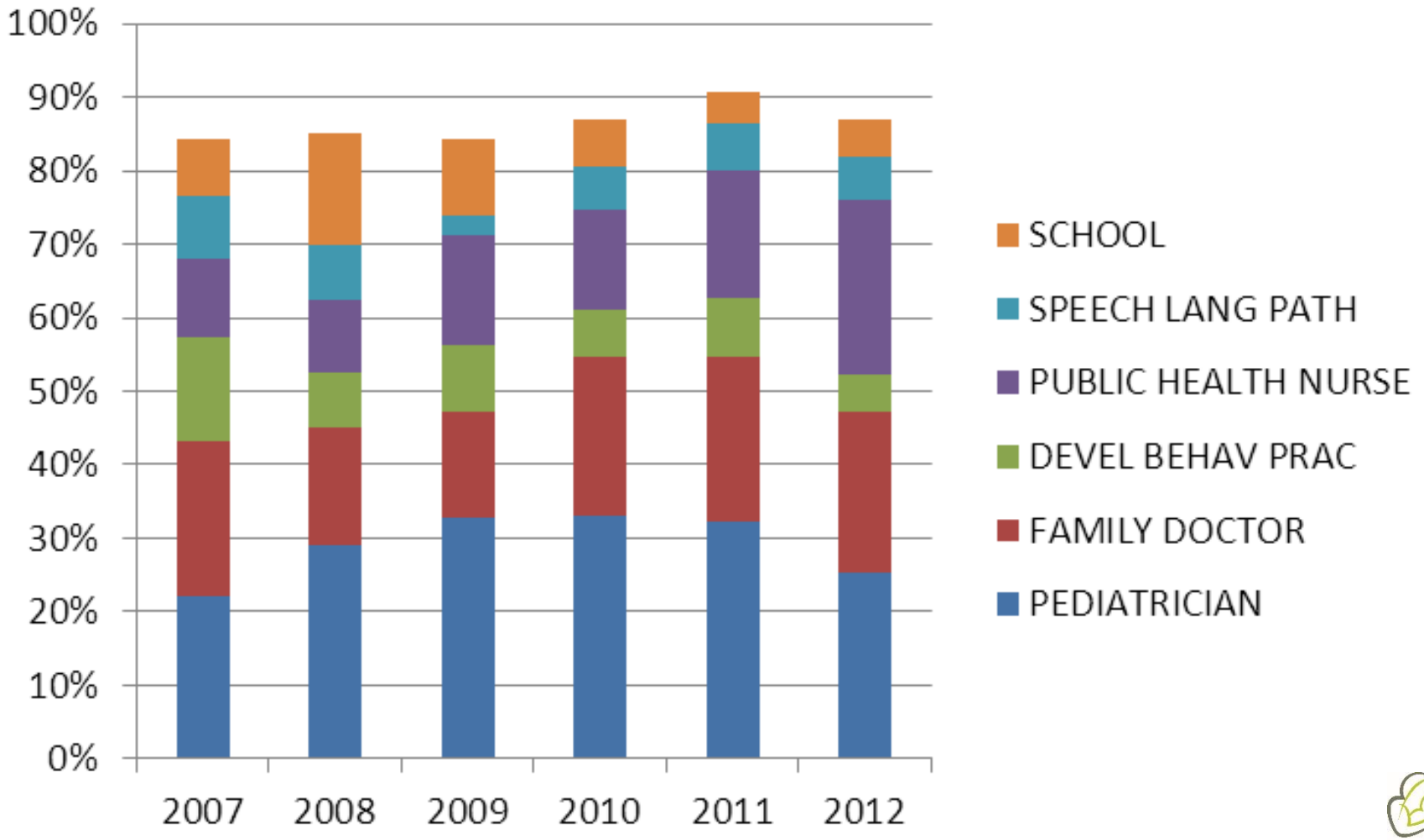
# Autism Database – Referral Source

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# 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

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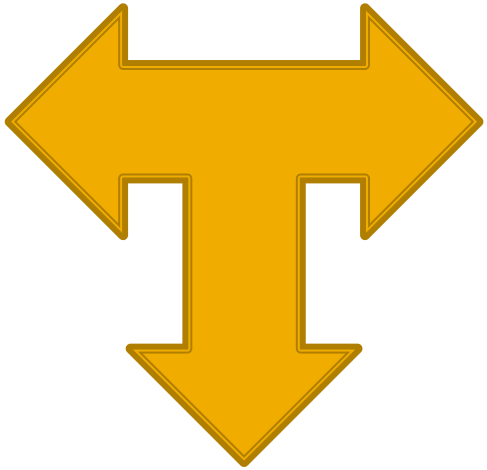
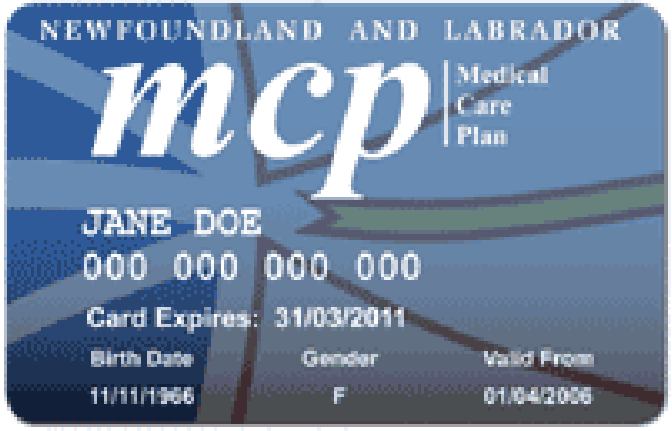
# Linking to the PPNL Clinic's Database

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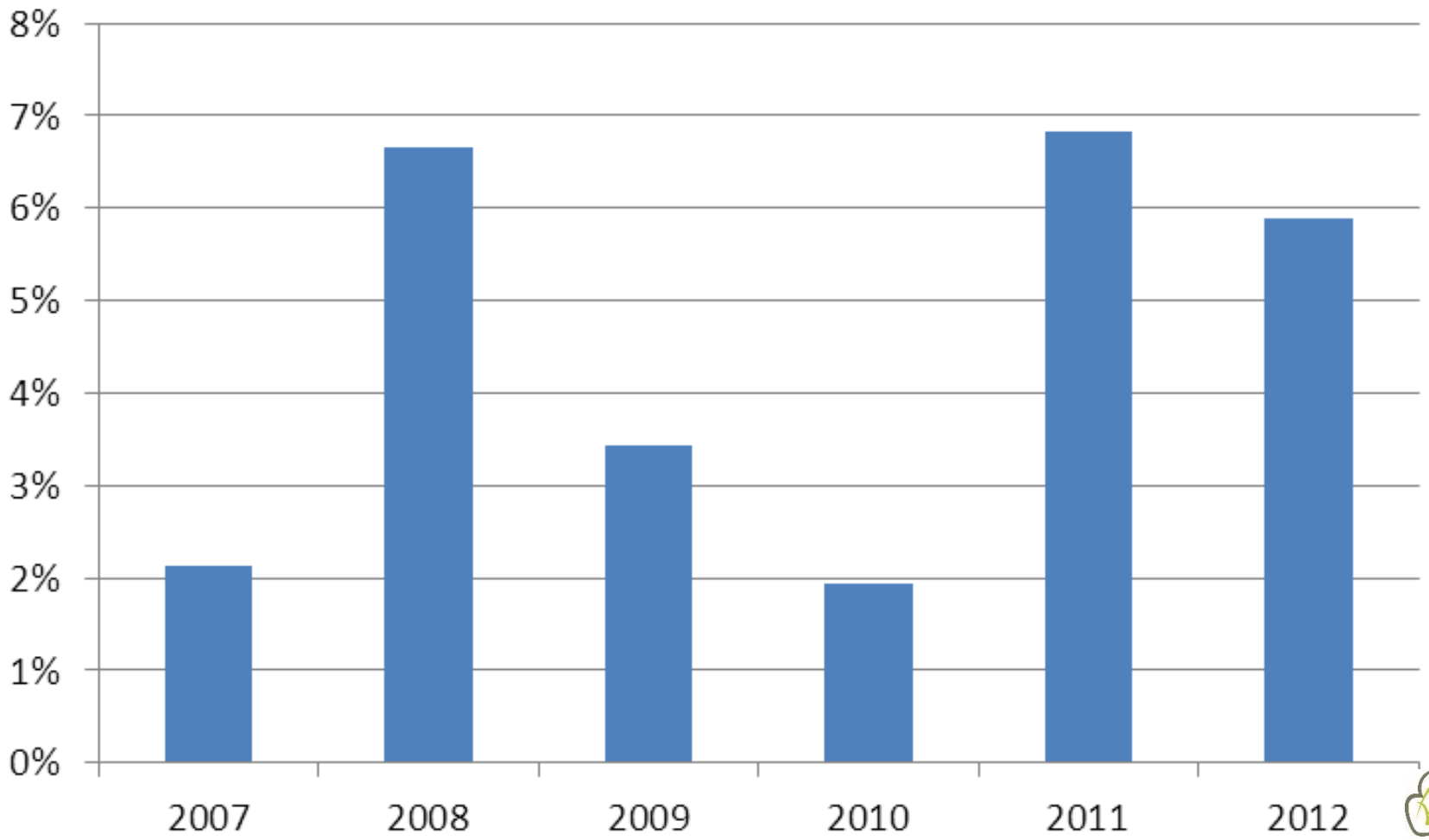
# How Many are in Autism Database?

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# How Many are in Autism Database?

- 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

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# 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

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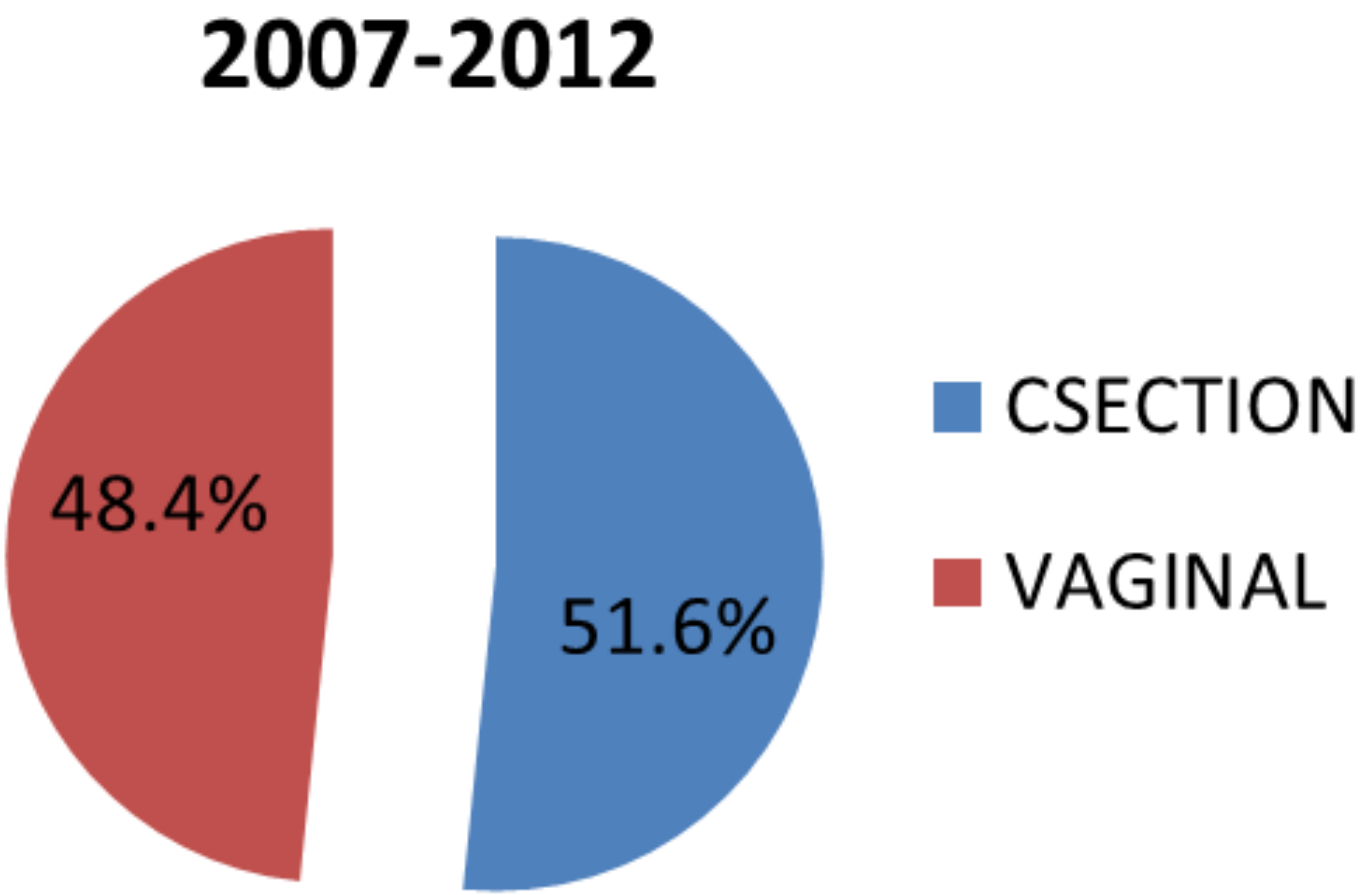
# Autism & Type of Delivery

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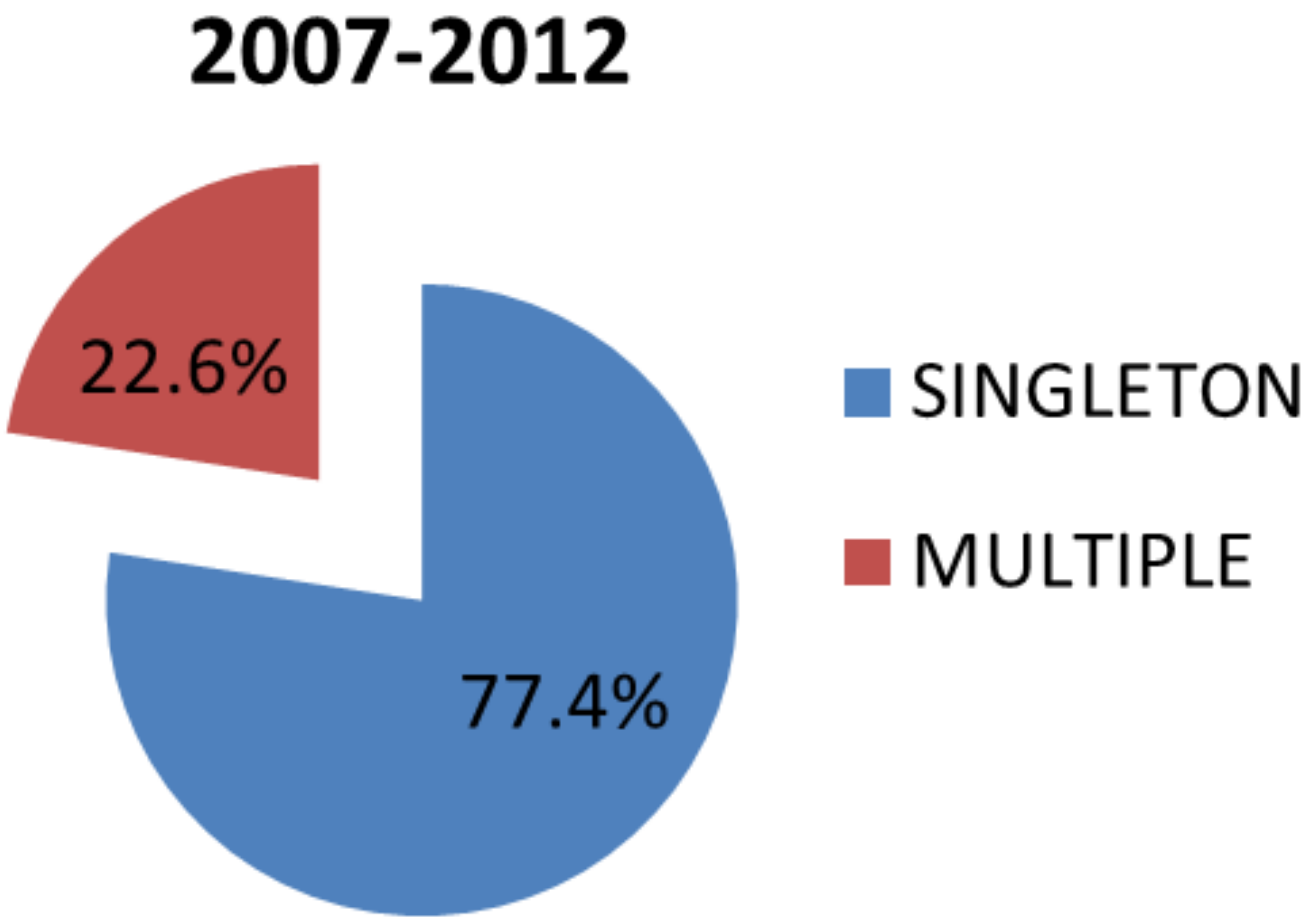
# Autism & Type of Delivery

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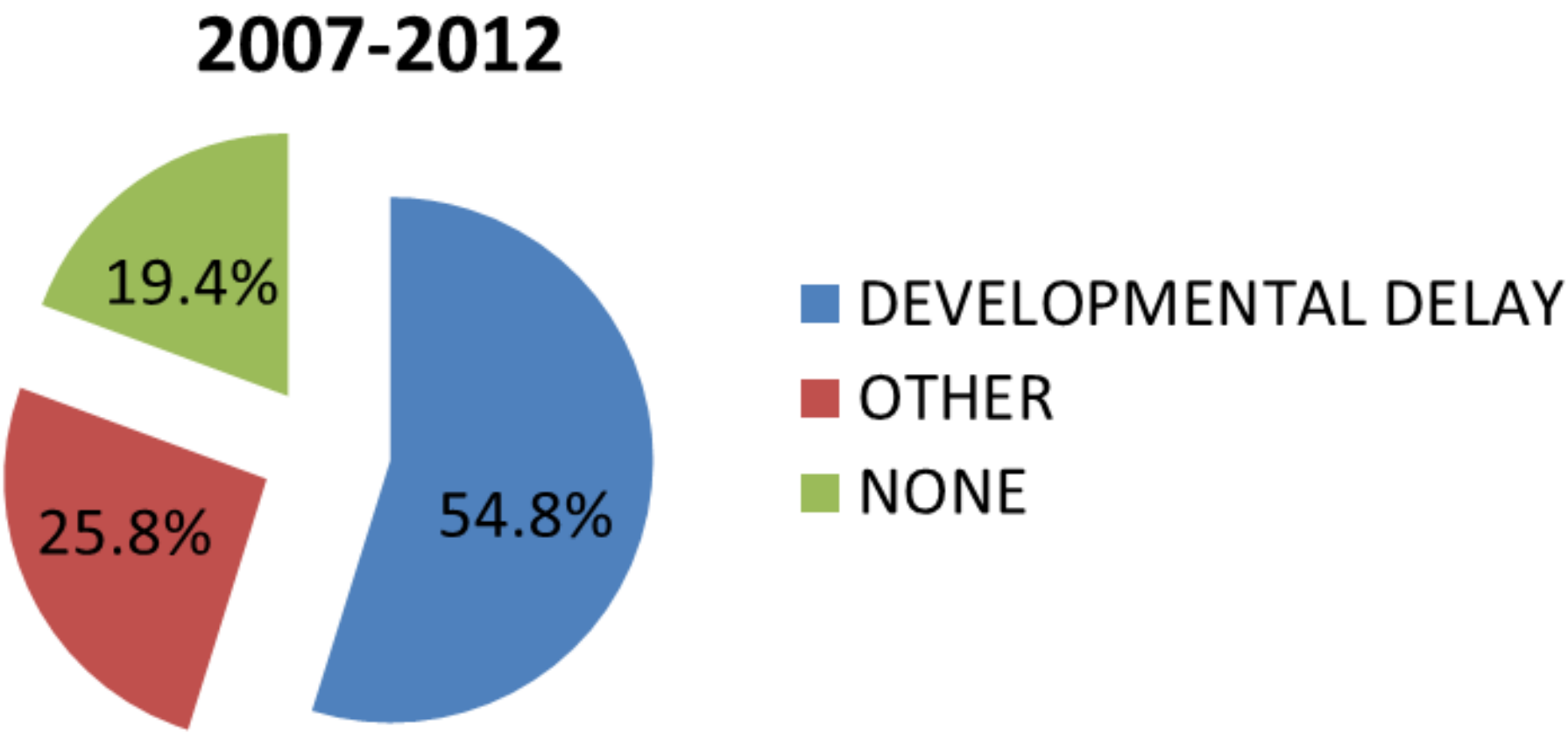
# Autism & Perinatal Outcomes

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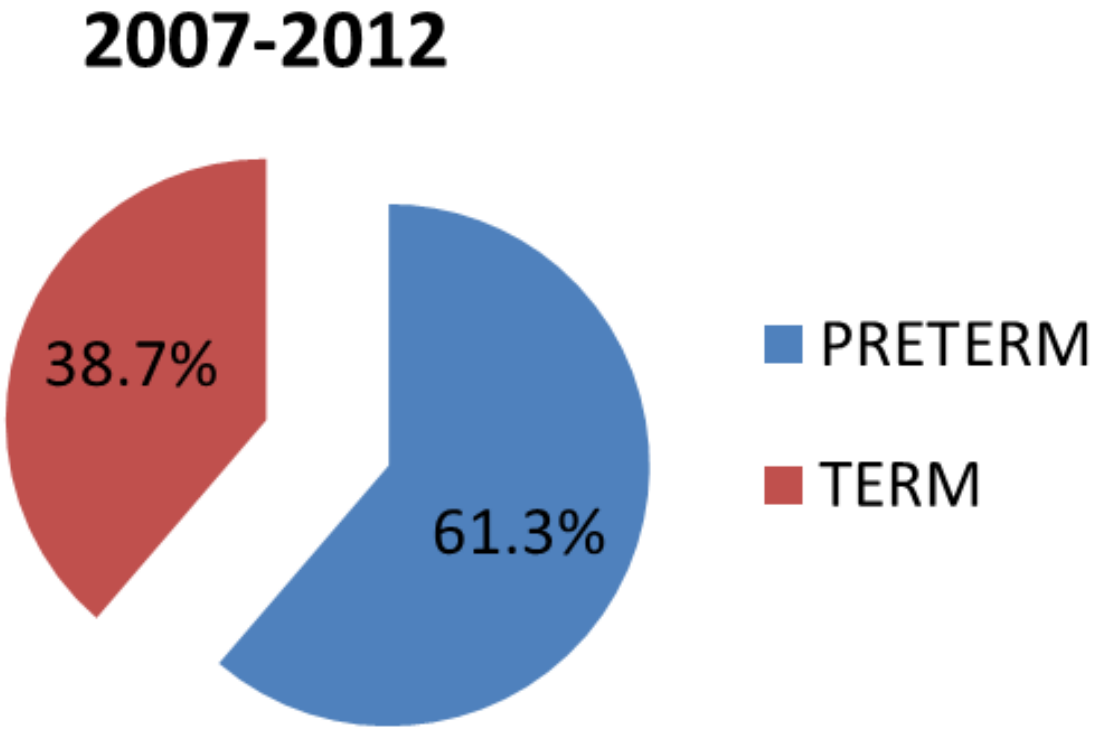
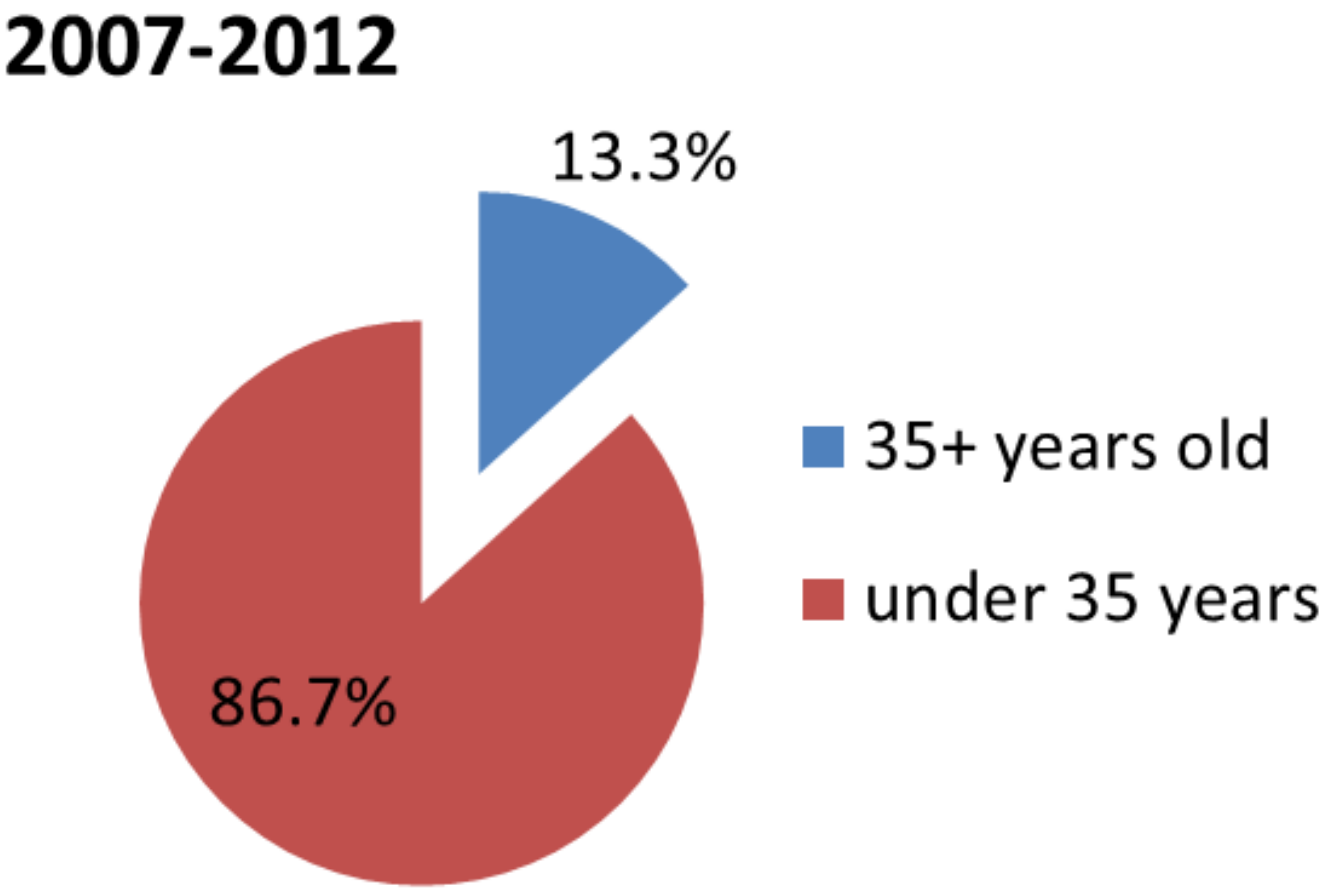
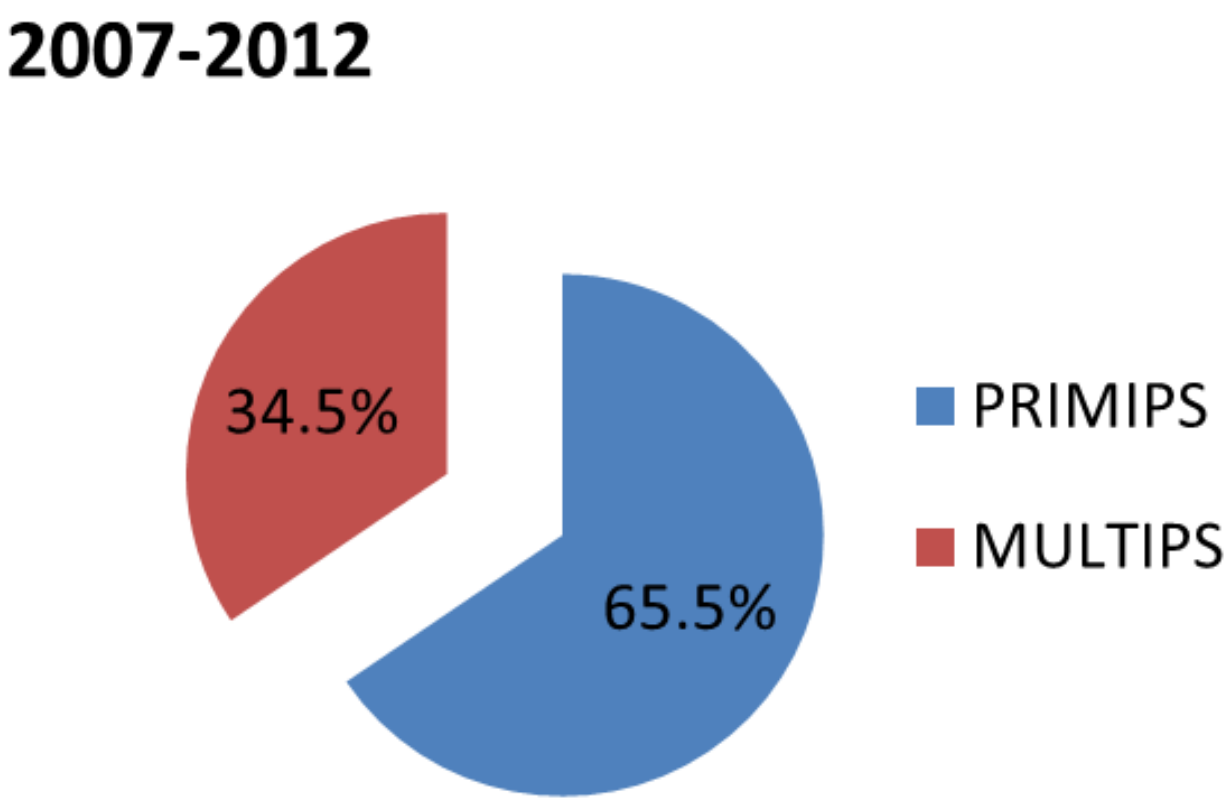
# Autism & Gestational Age



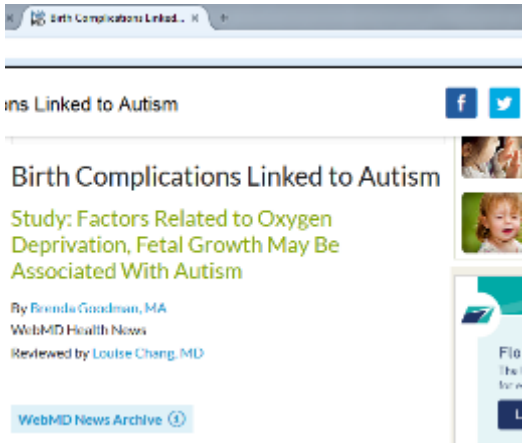
# Autism & Maternal Age



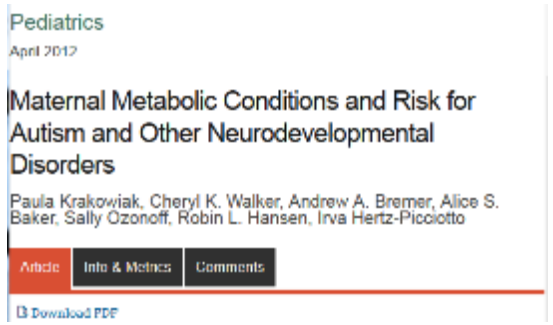
# Autism & First Time Mothers



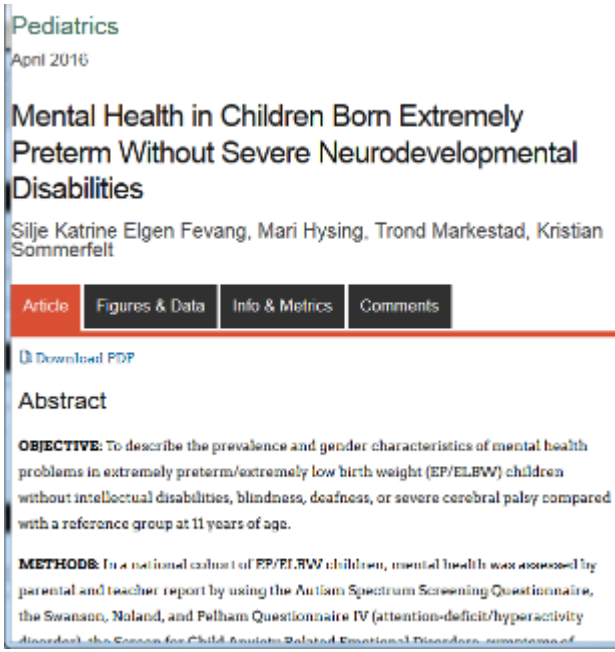
# Other Autism Research Links











# 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),

Building an Autism Spectrum ... | The Autism Enigma - The ...

www.cbc.ca/natureofthin

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the nature of things
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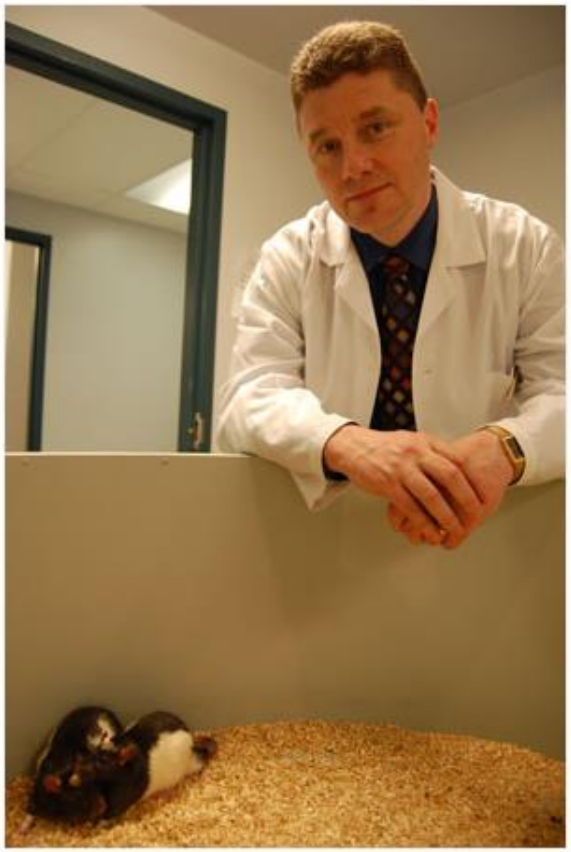
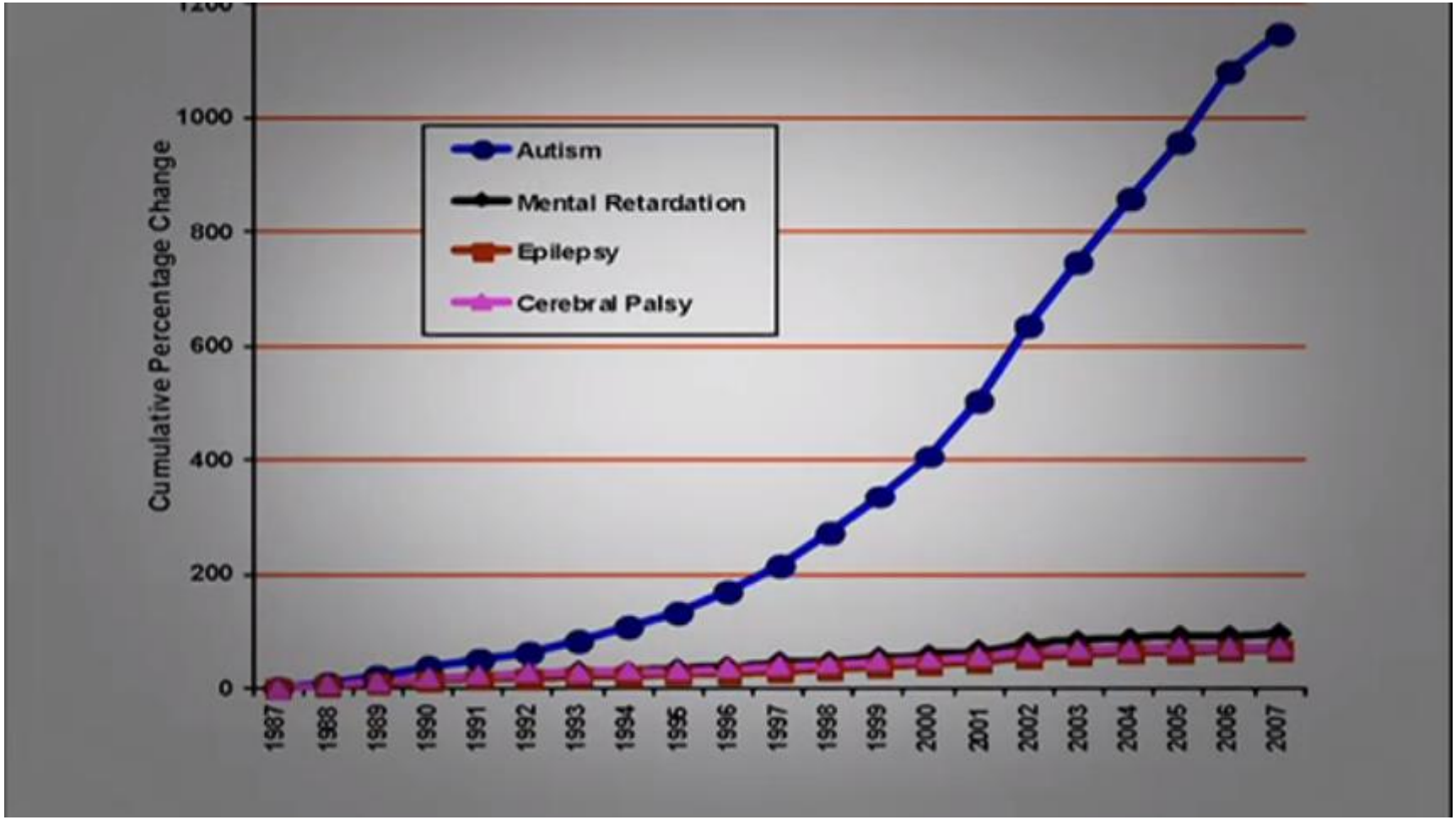


A fresh perspective on autism research with the developing "Bacterial Theory" of autism. The fastest-growing developmental disorder in the industrialized world, autism has increased an astounding 600 per cent over the last 20 years, and science cannot say why. Some say it's triggered by environmental 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**.

# Trends in 4 Disorders




- **Source: Nature of Things, CBC 2016**

# ASDSS – case definition

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

PROTECTING CANADIANS FROM ILLNESS

Public Health Agency of Canada | Agence de la santé publique du Canada

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

# 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.

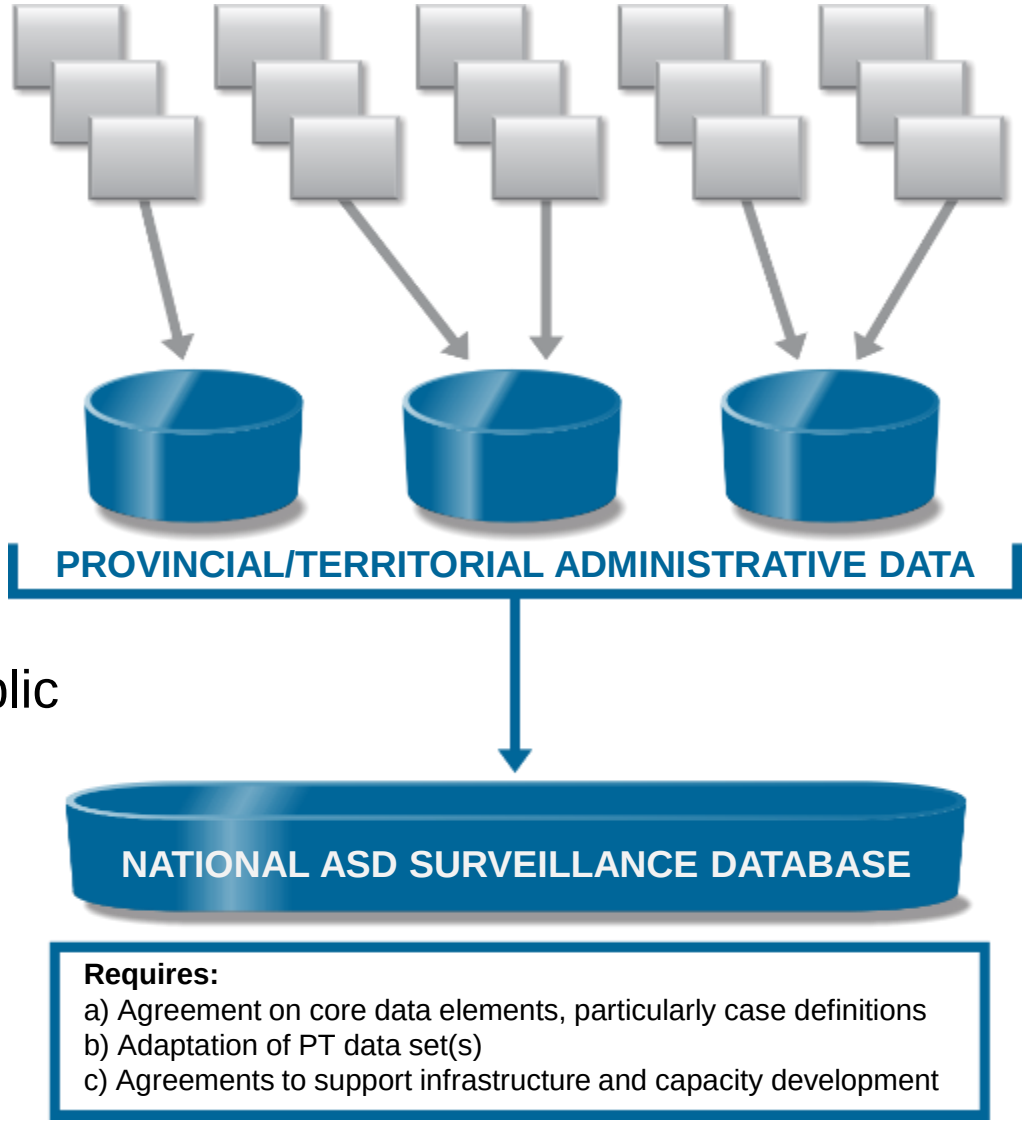
- The NASS will in turn support the advancement of ASD initiatives and research across the country.

# 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*



# 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.

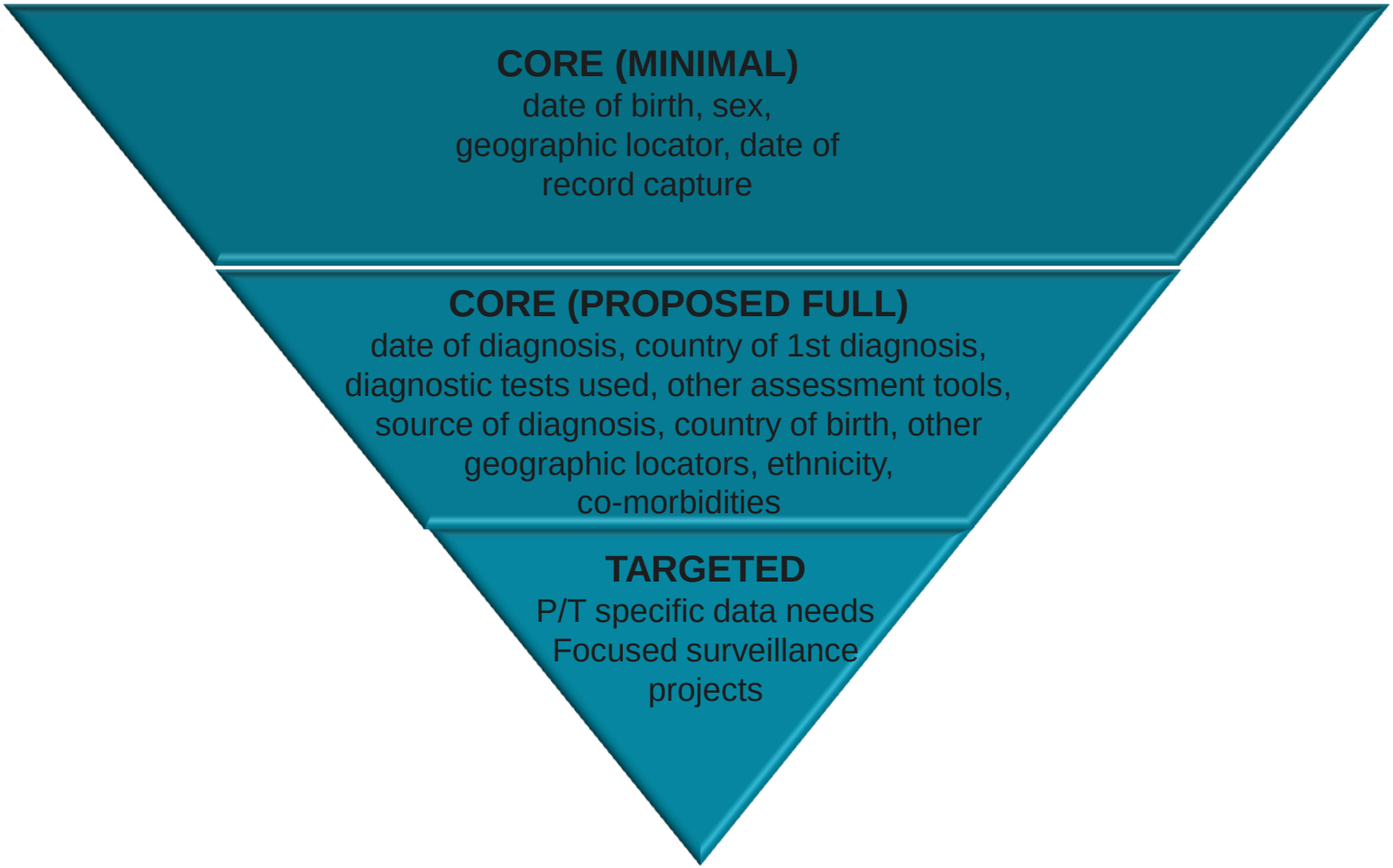
**Social Services**

- 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



# 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

# Questions?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Data Consultant / Analyst - Perinatal Program NL
Professional Associate - Memorial University (Ob/Gyn, Pediatrics)

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