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

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JULES VERNE

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)



Government of Newfoundland and Labrador Service NL, Vital Statistics Division LIVE BIRTH NOTIFICATION 2015



Canadian Institute for Health Information



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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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



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.



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.



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.



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

FOLLOW-UP CLINIC	PERCENTAGE OF	PERCENTAGE OF
ADMISSION CRITERIA	2014-15 CLINIC INTAKE	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 1 st 28 days of life	10.6%	4.5%
APGAR Score ≤ 3 for ≥ 5 minutes	7.3%	3.0%
Cord Blood pH < 7	6.5%	3.8%
Intraventricular Hemorrhage (IVH)	0.8%	1.5%
Meningitis in 1 st 28 days of life)	3.3%	3.8%
Periventricular Leukomalacia (PVL)	0.8%	0.0%
Extracorporeal Membrane	0.0%	0.0%



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

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Surveillance Reports















Happy Valley - Goose Bay Area Perinatal Data Report 2006-2009

and March 14







- 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



About PPNL – www.ppnl.ca





Demographics

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



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.





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.



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)



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





Admission Criteria

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 1 st 28 days of life	10.6%	4.5%
APGAR Score \leq 3 for \geq 5 minutes	7.3%	3.0%
Cord Blood pH < 7	6.5%	3.8%
Intraventricular Hemorrhage (IVH)	0.8%	1.5%
Meningitis in 1 st 28 days of life)	3.3%	3.8%
Periventricular Leukomalacia (PVL)	0.8%	0.0%
Extracorporeal Membrane Oxygenation (ECMO)	0.0%	0.0%



Clinic Outcomes

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

Phil Murphy, MSc1,2, Christine Winters, RN1 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.

Provincial Perinatal Program www.nippp.ca



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 diniciana. 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 cepture: analysis & desermination: then, collaboration with clinicians and decision support to interpret, design and implement an action plan with Neoratel Intensive Care Unit/NICUI staff and their clients' follow-up Information

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

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 automatical referred to the clinic before they are clackarge from hospital. Most of the infants who are where d to the clinic have been admitted to the NICU or Special Care Numery 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 t

the Public Health Nursing Division as the history to assist the pre-school assessment.

		Pecant 20 - 40 - 20 - 20 - 10 -
	Methods	0
	Data from the High Risk Follow-Up database (MS Access) on bables born between 1995-2004.	Ou
	Data for each visit for all babies were analyzed using SPSS 15.0.	Geunt 25 -
d	Outcomes of interest were clinical concern	- 21
•	developmental delay, hearing impairment, vision impairment.	3-
	Summarized information was presented to NICU staff and a 10 point Yea/No	8
	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	Con
	83.8% were singletons	Admin
ь	Cambral Dates (referred to Batach)	The la makin

Developmental Delay in recent years



Seizures & Outcome Ventilated & Outcome And the second s 1.10 Knowledge Translation DATA CAPTURE 37,5% felt the outcomes of those bables presented were what EXTENSION ANNE YOR 62.6% feit the outcomes were better than expected. DISCEMBATION 100% felt getting feedback from the NLPPP will improve their INTERPRETATION Insight into long term outcomes of the babies they care for. ACTION PLAN 4 82.5% feit that this information will alter their MPLEMENT/THOW philosophy/values towards caring for ortifically III neonates. 75% feit their interect in neonatal research was increased. 78.4% of babies followed had NO concerns or diagnosis of disability A DESIGNATION OF

Health

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nclusion

istrative 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. wy is through collaboration among clinicians, decision support and quality and fak management that allows easy data capture and analysis that will lead to better decision Discussion with front line caregivers is crucial.

> Perinatal Program

Clinic Outcomes – 10 year analysis



Clinic Outcomes – 2005-2012 summary

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





Clinic Outcomes – new version

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PPNL Clin	ic Assessme	ent Form		
Visit Outco	mes and Ref	ferrals)		Perinatal
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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	
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Follow-Up Status (eg, if refuse fo	llow-up enter status in last visit)	
Continue Follow-Lin	scharge to Behab/Development 🖉 Discharg	e to Other Prov/Territory
Finished Program - complete Fi	inal Assessment Below 🛛 🖾 Died 🖾 Missing	Refuse Follow-Up



Clinic Outcomes – new version

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Lets work Backwards for a min



Perinatal Program

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
- ABATHERAPY
- MEDICATION
- GENETICS



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.



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 <u>Autism Diagnostic Observation</u> <u>Schedule (ADOS)</u>
- 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

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



Autism Database - Diagnosis





Autism Database – Age At Dx



Autism Database - Gender

• 2007-2015: 82% were male clients







Autism Database - Region



Program

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%		



Autism Database – Referral Source



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?



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



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





Autism & Type of Delivery

2007-2012



SINGLETON





Autism & Perinatal Outcomes





Autism & Gestational Age



Autism & Maternal Age



Autism & First Time Mothers



Other Autism Research Links

🕼 Birth Complications Linked. . H 🔄

ins Linked to Autism

Birth Complications Linked to Autism

Study: Factors Related to Oxygen Deprivation, Fetal Growth May Be Associated With Autism

By Brenda Goodman, MA WebMD Health News Reviewed by Louise Chang, MD

WebMD News Archive ①

Pediatrics

February 2016, VOLUME 137 / ISSUE 2

The Association of Maternal Obesity and Diabetes With Autism and Other Developmental Disabilities

Mengying Li, M. Daniele Falin, Anne Riley, Rebecca Landa, Sheila O. Walker, Michael Silverstein, Deanna Caruso, Colleen Pearson, Shannon Kiang, Jamie Lyn Dahm, Xiumei Hong, Guoying Wang, Mei-Cheng Wang, Berry Zuckerman, Xiaobin Wang

Article Figures & Date Supplemental Info & Metrics Comments

(). Download PDP

Abstract

EACINGEOUND: Obsering and diabetes are highly prevalent among programs women in the United States. No study has examined the independent and combined effects of maternal proprogramsy obesity and maternal diabetes on the risk of autism spectrum disorder (ASD) in parallel with other developmental disorders (DDA).

METHOD® This study is based on 2734 children (including 102 ASD races), a subset of the Boston Birth Cohort whe completed at least 1 postnatal study visit at Boston Medical Center between 1990 and 2014. Child ASD and other DDs were based on physician

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US National Library of Medicine National Institutes of Health			

Abstract +

J.Autism Dev Disord, 2012 Nov;42(11):2431-9. doi: 10.1007/s10803-012-1501-4.

The effect of gestational age on symptom severity in children with autism spectrum disorder.

Advanced

Movsas TZ¹, Paneth N

Author information

Abstract

Between 2005 and 2010, two research-validated instruments, Social Communication Questionnaire (SCQ) and Social Responsiveness Social (SRS) were filled out online by 4,188 mothers of Autism Spectrum Disorder (ASD) children, aged 4-21, as part of voluntary parental participation in a large web-based registry. Univanite and multivante linear regression analysis (adjusted for child's sex, ability to verbalize, categorical IQ score, and fetal growth rate) demonstrated significantly higher SCQ and SRS scores for ASD children of both preterm (<37 weeks) and post-term (>42 weeks) gestational age (GA) compared to ASD children of normal GA, thus indicating that both preterm and post-term children manifest increased ASD symptomatology. Normal GA at birth appears to mitigate the severity of autistic social impairment in ASD children.

PMID: 22422339 [PubMed - indexed for NEDLINE]

A 🌛 🕅

Pediatrics

April 2012

Send to: +

Maternal Metabolic Conditions and Risk for Autism and Other Neurodevelopmental Disorders

Paula Krakowiak, Cheryl K. Walker, Andrew A. Bremer, Alice S. Baker, Sally Ozonoff, Robin L. Hansen, Irva Hertz-Picciotto

Arbde Into & Metrics Comments

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Pediatrics

April 2016

Mental Health in Children Born Extremely Preterm Without Severe Neurodevelopmental Disabilities

Silje Katrine Elgen Fevang, Mari Hysing, Trond Markestad, Kristian Sommerfelt



D Download PDP

Abstract

OBJECTIVE: To describe the prevalence and gender characteristics of mental health problems in extremely preterm/extremely low birth weight (EP/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 colour of EP/ELBW children, mental health was assessed by parental and teacher report by using the Autism Spectrum Screening Questionnaire, the Swanson, Noland, and Pelham Questionnaire IV (attention-deficit/hyperactivity disorder), the Screen for Child Annior Related Emotional Disorders, supersona of



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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),





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**. 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.

Trends in 4 Disorders



Source: Nature of Things, CBC 2016

ASDSS – case definition

The ASD surveillance cases must satisfy the following three criteria:

- 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.
- 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





Working Together to Track Autism Spectrum Disorder in Canada

- NASS is a <u>collaboration of federal</u>, provincial and territorial governments, working together with other <u>stakeholders</u>, to build a comprehensive picture of ASD in Canada.
- NASS will <u>track</u> the demographic profile of ASD, including key characteristics, patterns and trends, by collecting and analyzing data from multiple sectors such as <u>health</u>, education and social services.
- NASS will provide the <u>evidence based numbers</u> 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 <u>Senate Report</u>: Pay Now or Pay Later
- 2009 <u>Treasury Board Submission</u>: Action plan to protect human health from environmental contaminants
- 2010 <u>PHAC</u> assumed responsibility for the ASD initiative
- 2011 <u>Program launch</u>: staffing, meetings w/ P/T, nomination committee for ASD-AC
- 2012 <u>ASD Advisory Committee</u> with Surveillance and KT Working Groups
- 2012/13 <u>Program preparation</u>: environmental scans, feasibility projects, Letters of Invitation sent to P/Ts
- 2014 <u>Program Operation</u>: 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

NASS

Program Implementation: *Timelines*

Phase I: Launch of Implementation						
* Letters of invite to	Phase II: Capacity Support					
PIS * Site visits and	* Ascertain which PTs	ASD Surveillance Data				
webinars to outline Program goals,	going forward and what is needed	 * Collate data centrally * Review data quality 				
scope and obtain feedback	* Begin to negotiate	* Produce preliminary				
	Surveillance Agreements (CSAs)	* Evaluate process to form basis of second				
		round of CSAs				
June 2013	Dec 2013	Mar 2016				
	×	\mathbf{X}				

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First Years of Data Collection 2014 - 2016

- NASS will <u>collect data and deliver evidence-based analysis</u> (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

PROVINCIAL/TERRITORIAL ADMINISTRATIVE DATA NATIONAL ASD SURVEILLANCE DATABASE **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 Umique Totally nteresting SOMETIMES YZTERICUZ

Questions?



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