

# Improving the Transitioning of Children with Autism Spectrum Disorders (ASD) to Adult Care

**Roger Chafe, PhD**  
**Director of Pediatric Research**  
**Assistant Professor, Memorial University**

Autism Research Affinity Group Meeting  
February 17, 2012

# Outline

1. Introduce the Janeway Pediatric Research Unit.
2. Identify some of the issues that can arise around transitioning young adults with ASD into the world of adult care.
3. Outline a wider program of research aimed at developing the evidence-base for better understanding the health services issues involved in transitioning young adults with ASD to adult care.
4. Present the plan for pursuing the first part of the research program.

# Janeway Pediatric Research Unit (JPRU)

- Established in 2011, the *Janeway Pediatric Research Unit* (JPRU) serves as a nexus for pediatric research being conducted at Eastern Health's Janeway Hospital and Memorial University of Newfoundland's Faculty of Medicine.
- Support research activities of the faculty associated with the Janeway, with the aim of building greater research capacity and activity in the area of child health in the province.

# Colonel Harland Sanders Pediatric Research and Family Resource Centre



# Janeway Pediatric Research Unit (JPRU)

- Faculty and staff associated with the unit conduct clinical and applied health research, with over 40 active projects on a range of childhood diseases including in the areas of:

- Autism
- Rheumatology
- Emergency Medicine
- Neonatology
- Diabetes
- Pediatric Crohns' Disease
- Infectious Diseases
- Health Services Research
- Childhood Obesity
- Oncology
- Gastroenterology
- Genetics
- Neurology
- Medical Education
- Adolescent Medicine

# Transitioning from Pediatric to Adult Care

- Late adolescence can be a tumultuous period for people, yet it is during this period that patients with chronic conditions transition from the pediatric to adult health care environment.
- As the patient gets closer to the age of majority, family caregivers usually have less control of their child's care.

# Transition from Pediatric to Adult Care

- Often patients are encouraged/expected to take more responsibility for arranging or managing their care.
- For some diseases, there are disease-specific programs for pediatric patients (e.g., Cystic Fibrosis) that do not follow into adult care, which can lead to less coordination of care.
- Children's hospitals and programs are perceived as being more resource-rich than adult programs and allowing for easier access to care.

# Transition from Pediatric to Adult Care

- The continuance of high quality care for young adults requires that there are proper measures and supports put in place to bridge the transfer.
- Sadly, there is evidence that many patients do not have a smooth transition to adult care.

# Transition from Pediatric to Adult Care - ASD

- Complicated disease with significant variations in the care needs.
- Service needs change as a child with ASD reaches young adulthood (e.g., job programs, assisted living).
- Care is delivered through a number of departments and programs, which complicates the transition.
- Issues around the availability, training and retention of staff who work with adults with ASD.

# Transition from Pediatric to Adult Care - ASD

- Children leave the education system, which can impact their access to services.
  - The Individual with Disabilities Education Act (US)
- Lack of a clear clinical care pathway from developmental pediatric programs into adult care.

# Transition from Pediatric to Adult Care - ASD

- Perception that care is most effective when it is delivered early in life.
- Some parents with adult aged autistic children report that they are no longer able to provide the necessary experiences and care that their children require.

# Adult ASD Services

- In the US, reports of significant variations in access to services between states and (likely) even within states.
- Also, reports of variations in the criteria for eligibility across state Medicaid programs.
- In Canada, ?
- But demographics do not lie, **we need to prepare for large increases in the number of adult patients with ASD requiring care and services.**

# Previous Work on the Topic

- In 2003, the Health Research Unit and its partners released a report “**Adults with Autism Spectrum Disorders in Newfoundland and Labrador.**”
- Little is known of the prevalence, age and sex distribution of adults with ASD in Newfoundland and Labrador.
- Little has been documented as to the needs and gaps in service to adults with ASD.

# Previous Work on the Topic

The study consisted of the three main components:

1. Two telephone surveys of families with children with autism over the age of 15;
2. Focus groups and interviews with key informants;
3. A literature/internet search was conducted to scan for available services for adults with autism both within and outside the province.

# Health Research Unit's Findings

- Dissatisfied with certain aspects of the education and support received during the school years, including difficulty accessing services, lack of awareness and training for teachers and student assistants.
- Satisfaction with schooling often resulted from the actions of individual teachers and school principals.
- Assistance in daily living activities was provided either by parents or through the Department of Health and Community Services.

# Health Research Unit's Findings

- Appropriate recreational activities were considered to be unavailable or inadequate especially outside the capital region.
- “Most services presently available in the province for children and adults with special needs (including persons with ASD) are generic programs and supports for persons with disabilities.”

# Health Research Unit's Proposed Model

- **Individualized Programming:** The ISSP should be adopted as a planning process for the lifelong support of individuals with ASD including consideration of needs in education, employment and recreation as well as the future challenges for those with limited or no parental support.
- **Coordination of Health Services:** In view of the recognized range of co-morbidities among adults with ASD, there is a need to closely monitor the various health needs of these adults.
- **Living Arrangements:** A variety of living arrangements from full supportive environments to independent living should be available for adults with ASD based upon their individual strengths and needs.

# Program of Research

- **Part 1:** A survey of the publicly-funded services currently available for adults with ASD across Canada.
- **Part 2:** A survey of the publicly-funded services currently available for adults with ASD in other countries (US, UK, NZ...).

# Program of Research

- **Part 3:** A survey (or interviews) of pediatricians and adult physicians who see patients with ASD about medical service needs and transition support.
- **Part 4:** Compare the clinical care pathway of children transition out of pediatric care for different conditions.

## Part 1: A survey of the publicly-funded services currently available for adults with ASD across Canada.

### Objectives:

- To determine which the publicly-funded services are currently available to adults with ASD in each province.
- To identify any variation in the publicly-funded services available to adults with ASD in each province.

# Part 1: Eligibility

- Services funded or provided directly by a provincial department or agency;
- Services that are mostly funded (> 50% funding) by public funds, but delivered by a third-party;
- Services available for people over 18 years of age.
- Questions: Clinically diagnosed cases of ASD or not?  
Whole spectrum or focus on more sever cases?

# Part 1: Types of Services

- Specialized Medical Services / Programs
- Education Programs
- Employment Programs
- Communication and Social Interaction Services
- Behavioural Management Services
- Assisted Living Arrangements
- Recreational Options
- Community Services for Families
- Programs Focused Specifically on Children with ASD Transitioning to Adult Care

# Part 1: Data Collected

- Specialized ASD Programs vs. Generic Program for People with Disabilities
- Program Eligibility Criteria (e.g., means-tested, level of disability)
- Limits to service provision (e.g., caps on number of participants)
- Location availability (e.g., rural, remote, urban)
- Number of people with ASD accessing the program

# Part 1: How to Collect Data

- Literature search, internet searches (with a particular focus on provincial governments and ASD-related agencies)
- Surveys of Provincial Departments / ASD Societies
- Key informant interviews in all ten provinces

# Work Plan – Part 1

Activity	Date
Complete literature review on transitioning from pediatric care / adult autistic services	Feb / March 2012
Google search of current services offered in Canada / Identify recipients of survey questionnaire	Feb / March 2012
Application to Memorial's Medical Research Fund Research	March 2012
Develop Survey Instrument	March 2012
Apply for Research Ethics Approval	March 2012

# Work Plan – Part 1

Activity (cont.)	Date
Survey Mailing	April 2012
Resend surveys / Analysis results	May / June 2012
Identify individuals to interview	May 2012
Conduct Interviews	June / August 2012
Transcribe and analyze interviews	August / October 2012
Disseminate Results	October - December 2012