



Forum canadien des
experts en autisme

Canadian Autism
Leadership Summit

MINUTES

Monday, April 18, 2016

Welcome

Debbie Irish, Vice-Chair of CASDA, welcomed everyone to the 2nd Annual Canadian ASD Leadership Summit. She provided the attendees with some housekeeping items.

Opening Remarks

The Canadian ASD Leadership Summit was opened by the Honourable Jane Philpott, Minister of Health and Senator Jim Munson who both provided a few words for Summit 2016. CASDA thanked them for their participation today.

Canadian Autism Partnership Project (Cynthia Carroll and Marg Whelan)

Cynthia Carroll and Margaret Whelan, Co-Directors of the Canadian Autism Partnership Project (CAPP) provided a brief overview of the history of CASDA, the highlights of the National ASD Needs Assessment conducted by CASDA in 2014 and the identified priority issues that were part of the 2015 Canadian Autism Summit in 2015. This material formed the basis upon which the CAP Project was built. After the presentation, the Summit participants worked together to provide feedback on the proposed model for the Partnership, identified barriers and strengths, and suggested improvements to the graphic used to explain the workings of the partnership.

ASD National Surveillance Project Update (Kim Elmslie)

This presentation will touch on strategic planning & engagement, surveillance systems design, data acquisition & management, analysis & interpretation, knowledge mobilization, and public health action.

The role of public health is to monitor trends (by time, place, and person), help estimate current and future impacts, support policy and programs, facilitate planning, evaluate prevention and management measures, and identify cases for further study in order to take action.

Next Steps:

- Aiming to publish a report in late 2016
- Key preceding work requirements include completion of:
 - Data collection from participating P/Ts (as many as possible)
 - Data analysis and interpretation
 - Knowledge mobilizations products (e.g., NASS surveillance report)

- Concurrent and continued engagement of remaining P/Ts

A View from the Shoes of Autism: Know me for who I am (Erik Hedley)

Erik's video was presented. Erik will be attending Autism on the Hill tomorrow.

ASD Research Chair Stakeholder Update (Jonathan Weiss)

This presentation presented the dedication of studying ways to improve the mental health and well-being of people with ASD and their families in Canada. It will provide an update on the work of the Chair to-date in terms of accomplishments and future directions for research, knowledge translation, and training. The Chair is funded by the Canadian Institutes of Health Research in partnership with Autism Speaks Canada, the Canadian Autism Spectrum Disorders Alliance, Health Canada, NeuroDevNet and the Sinneave Family Foundation.

Ready, Willing and Able (Radha MacCulloch)

RWA is a national 3 year initiative designed to increase the labour market participation of individuals with intellectual disabilities and ASD. The initiative is a partnership between CACL and CASDA and funded through the Federal government. They have secured 650 jobs since September 2014 and are hoping for 1200 by end of project.

University of Calgary, School of Public Policy (Carolyn Dudley & Jennifer Zwicker)

This presentation presented public policy research related to the background on prevalence, transportation challenges, cost of caregiver time and improving employment outcomes.

Closing Remarks

Esther Rhee closed day 1 of the summit with a brief overview of Autism Speaks in the following 4 areas and an overview of some of the programs that are being funded by Autism Speaks.

- Research
- Advocacy and collaboration
- Awareness
- Family Services

Tuesday, April 19, 2016

Opening Remarks

Day 2 of the Canadian ASD Leadership Summit was opened by The Honourable Carla Qualtrough, Minister of Sport and Persons with Disabilities and The Honourable Mike Lake, PC, MP. CASDA thanked both of them for their participation today.

Promising Practices Panel A

A Community Approach to Housing for Individuals with ASD (John Seigner)

In 2013, The Sinneave Family Foundation (SFF) initiated a series of round tables across Alberta to engage the Autism Spectrum Disorder (ASD) community to determine how to best help them answer the question, "Who will take care of our children when we are gone?" This series of round tables resulted in the creation of a Provincial Housing committee. Through the committee, SFF conferred with agencies, caregivers, families and some levels of government to develop collaborative ideas for solutions to a broad range of ASD clients with a variety of support needs and financial resources. This presentation will provide a history as well as an update on the progress of the Provincial Housing Committee, and a broad overview of key lessons and outcomes as well as hoped for next steps.

Suicidality in ASD (Jonathan Lai)

This presentation explored the under-studied issue of risk for suicide among youth and adults with ASD and resultant responses. This includes presentation of current estimates of rates and risks of suicidality in ASD. The presentation is based on a review of the international peer-reviewed literature addressing this topic. We will present evidence related from this review including predisposing influences on suicide risk using a multifaceted framework. We draw on a multilevel orientation in considering a range of interpsychic (individual-based), contextual-relational and systemic aspects intersecting at micro, meso and macro levels of practice/experience. Recommendations for action will be discussed.

Mental Health Treatment for Individuals with ASD: Essential, Possible and Overdue (Dr. Katelyn Lowe)

This presentation focused on effective strategies and programs for mental health treatment in ASD and on the process being developed by the Sinneave Family Foundation to increase capacity in mental health services and support.

Low Maintenance, Low Resource, HIGH Impact Programming in ASD (Lauren McGuinness)

This presentation looked at two programs which launched in 2015. **The League of Extraordinary Individuals** provides social opportunities and peer support to individuals 18-24 years old who have aged out of funding supports in Alberta. **The Pantry Program** provides food and basic personal items to adults and families who struggle to maintain personal sustainability and require supports that are accessible. The Pantry provides immediate supports while we work with the individuals to find long-term solutions.

Worktopia – Improving the Employment Futures of individuals with ASD (Tanya McLeod)

This presentation provided a brief description of each of the Worktopia programs, the project evaluation and the collaborative activities of the promising practices network.

Promising Practices Panel B

Interdisciplinary Community Participation Support Program for Individuals with Challenging Behaviours (Laurie Collins & Carmela Campanella-Borraccia)

This presentation described how Geneva Centre for Autism uses the principles of interdisciplinary service provision to ensure individualization and self-determination for program participants and how an interdisciplinary model contributes to team effectiveness, improves client outcomes and improves the use of resources

Treatment Fidelity: Developing a Measure for Use in a Community-based Early Intervention Program for Children with ASD (Kimberley Ward & Shelley Booker)

Identification of effective intervention practices is a necessity and treatment fidelity, the degree to which an intervention is implemented as intended, is an essential component. A measure of treatment fidelity was developed to examine a comprehensive early intervention program for children with ASD. Members of a multidisciplinary team collaborated to determine essential intervention components to be measured using a Likert-based scale; interventionists were trained and implemented treatment; and intervention standards were verified using treatment fidelity checks.

Spectrum of Care Partnership (Mayada Elsabbagh)

Spectrum of Care (SoC) is a newly formed partnership at the intersection of research, practice, and policy. Currently connecting 18 community partners in Quebec, our goal is to develop knowledge translation strategies and tools that can in the long run minimize preventable negative consequences, disability, and exclusion for people with autism.

Catalyzing Change in Public Autism Services in Quebec: A Report from the Miriam Foundation one year into a five-year Community-Public Sector Partnership (Malvina Klag)

This presentation provided an update on the progress of, and key learning from, this project to-date, evaluation and resulting partnerships.

Promising Practices Panel C

Military Family Services

This presentation raised awareness and understanding among special needs professionals (physicians, pediatricians, developmental services workers, social workers, educators, etc.) about the unique stressors inherent with the military lifestyle, and how communities can potentially make subtle modifications to key elements of their programs and services to better address the special needs of CAF families. This presentation will also help familiarize professionals with the existing programs and services that are currently available for military families.

Unlocking the Mystery of Autism in Canada's Northwest Territories (Nancy Noseworthy)

This presentation explored the realities of living in Canada's Northwest Territories in remote First Nation communities as families strive to access diagnosis and services for their children with Autism Spectrum Disorder. The realities of the North are noted in the National Needs Assessment and are a targeted area for development and understanding.

The focus of the presentation was on the Dehcho Region encompassing eight communities and a total school population of approximately 600 students in an inclusive school environment.

Online Parent Training for Children with an ASD aged 0-5 years: Collaborative Development of a Province-wide eLearning platform for parents of pre-school aged children (Nathalie Garcin)

The Gold Centre, in collaboration with the Ministry of Health and Social Services partners in the province of Quebec, launched a bilingual eLearning platform destined for parents of children with an ASD under the age of 6. This platform, accessible by all parents of children who have been diagnosed in the province, is accessible for free on tablets, smartphones PCs, and Apple products with an internet connection. Eight (8) modules were developed by content experts including University lecturers, early intervention specialists, diagnostic clinicians and registered health professionals recognised for their in-dept knowledge of diagnosis, intervention and navigation of services for children with an ASD in the province. The project also includes outcome measures, and a research program assessing both the social validity of the program and its impact on the family was also developed. This presentation will present the 8 modules, the learning objectives and the process & deployment involved in this collaborative development.

The PLAY Project Autism Intervention Model: From Clinical Practice to Research to Statewide (USA) Implementation

PLAY Project Autism Intervention (PLAY) is an evidence-based, parent-implemented model that uses a developmental and relationship-based approach to helping young children (18months to 6 years old) with autism spectrum disorders improve in their development, and social interaction.

Breaking down barriers: Toward more flexible service delivery models for reducing program behaviours in children and youth with ASDs (Katy Albert & Justine Wiegelmann)

The Clinical Behaviour Service at Geneva Centre for Autism (GCA) provides families with behavioural support for treatment of individuals with complex needs engaging in significant problem behaviour. Responding to the growing number of families re-referred for service following relapse or failing to meet their goals, alternative service models were piloted to better support the needs of families. A review of two cases with contrasting profiles will illustrate the need for community agencies to demonstrate flexible and creative service delivery models to better serve families.

First Steps to School Success: The Ottawa Carleton District School Board's Kindergarten Intake Process (Leanne Forrest)

Due to the rising number of children diagnosed with Autism in Ontario the PPM 140 was created to support and strengthen initiatives for collaboration between parents, schools and community and to look specifically at how to address the transition challenges students with autism face.

Through this initiative the OCDSB ASD Team created the Kindergarten Intake procedure. This entry level transition process begins at the time of Kindergarten registration and follows the child throughout the transition process into school.

Promising Practices Panel D

Building Inclusive Bridges to Community through Recreational Skating for Preschool and School Aged Children (Anne Senez)

The Centre's partnership with Extreme Edge Skating provides a model for ways in which community groups can increase their capacity to include children with ASD. Through looking at the successes and challenges within the program I will provide an example of how community service providers can partner with recreation programs to overcome difficulties with inclusion.

Drama Weavers: Creating a Unique Space for Dramatic Play for Children with Autism (Karen Balcome & Jennifer Cecil)

Karen and Jennifer discussed their experience in developing and delivering a specialized drama program for children with autism and multiple learning needs. They focused on the development of social skills within their program and how it can fit within a larger continuum of arts education and learning experiences for their participants. The presentation included a short demonstration of an activity from the class to allow attendees to get a live experience of our practice.

Comprehensive Strategy for Building Capacity for Community Sports and Recreation Providers (Stephanie Jull)

The Canucks Autism Network has developed a comprehensive strategy for building capacity within community recreation providers to support both children and adults with autism. This presentation focused on lessons learned and provided strategies for engaging local recreation providers in autism training.

Project inForm: Investigating Barriers to Early Diagnosis and Intervention in Minority Communities (Priya Nadarajan)

Project inForm is a multi-partnership effort between the South Asian Autism Awareness Centre, Tamil Health Association and Ninety9Thirty to raise autism awareness amongst South Asian communities in Canada. This initiative aims to address issues related to early diagnosis and intervention with a focus on destigmatizing disability. Project inForm's main components include research and health promotion.

Spectrum Productions (Liam O'Rourke & Dan TenVeen)

Liam and Dan presented a video on Spectrum Productions and what has materialized since last year's Summit. The idea began from an individual on the spectrum and has grown to what you have seen today. They have expanded their program largely due to CASDA and now know how to replicate it.

Closing Remarks

Debbie Irish thanked everyone for a fabulous 2 days. She expressed how these 2 days could not have happened without the help of the Planning Committee. A huge thank you to Suzanne for organizing Autism on the Hill. Safe travels to everyone. We look forward to collaborations in the near future. See you next year.