

Autism Alberta's Alliance Launch Event

On October 15th, Autism Society Alberta launched Autism Alberta's Alliance. More than 220 stakeholders including parents, professionals and self-advocates from across Alberta gathered to hear and discuss panel presentations on four themes:

- Diagnostic assessment in Alberta
- Improving mental health across the lifespan
- Navigation & transition planning
- Challenges facing adults with autism spectrum disorder and their aging parents

The following summary discusses the six primary opportunities that stakeholders identified for Autism Alberta's Alliance as well the key paths forward.

OPPORTUNITY

Autism support has been too narrowly and traditionally focused. This creates gaps in service and missed opportunities for support.

Directions:

Move focus beyond children. Large gaps exist in **adult** services, support, diagnosis/assessment, treatment, and awareness. Broaden support and services across the entire lifespan of the individual with ASD (and their family).

- “Gaps exist in adult services for newly diagnosed adults (most services are geared towards therapies for children). It's difficult to find adult OTs, psychologists, etc. that are funded.”
- “Seek partnership/grant to partner with AHS to launch adult autism clinic in Calgary.”
- “Would an outreach model work to extend the Glenrose Hospital Adult Autism Diagnostic Clinic's services into other cities and even as a mobile model regionally (versus recreating the service)?”
- “A study needs to be undertaken of undiagnosed/new-diagnosed adults and identify gaps in services. This may help to make a case for AHS allocation of resources to address this issue.”

Move beyond single diagnosis. **Dual diagnosis** is an issue that isn't being addressed enough. Co-morbid conditions, and those with additional complex needs, should be seen as an equal priority for physical and mental health services.

Move beyond traditional definitions of medicine and wellness. Incorporate mental health services and access to alternative medicine and wellness services. Move to a more **holistic approach** to treatment of those with ASD.

- “If families had access to mental health, sooner, might not escalate to crisis which is more expensive to the system.”
- “Build strategies to create a better wholistic life approach. Mental health, physical health, social environment.”
- “We need increased mental health access for children, adults, and families with ASD, and financial support for the cost.”

Move beyond traditional players (“gatekeepers”). Educate and involve more than the traditional partners, such as schools, teachers, police and emergency services, day care centers, etc. Educate, advocate, and involve everyone who is involved in the lives of those with ASD.

- There is a hierarchy around diagnosis, assessment, and treatment, and many specialists are being under-utilized to diagnose. There is a lack of trained professionals. **The diagnostic team needs to be widened.**
 - “The medical model needs to be more inclusive of other professional groups, not just doctors and therapists. Where are the teachers?”
 - Opportunities: Educate GPs to screen and diagnose, more registered psychologists certified to diagnose and also provide support, educate daycare center providers for early detection in preschool children, educate pediatricians for early diagnosis.
 - “by following the clinical/medical model for assessment and treatment you are excluding the education system, a key component in identifying children in need.”
 - “Educate GPs to screen and diagnose. Enables access to everyone in every area of the province.”
 - “Lobby for streamlining of assessment services to utilize services of psychologists as a publicly-funded way to reduce burden on families and improve access to diagnosis in a timely manner.”
 - “Build capacity through education of those who support/interact with people with ASD but are outside of the ‘autism community.’ I.e. family doctors and other medical professionals, teachers, caseworkers, psychologists, social workers, community organizations (sports, recreation). Broaden who knows how to support and deal with people with autism.”
 - “Develop an autism handbook for frontline workers, such as teachers, social workers, doctors.”

Move focus beyond city centers and into **rural and remote areas** of the province where they are being under serviced and under supported.

- Utilize technology, training/educating, mobile teams, telehealth support
- “Training and support of clinicians in rural communities to be able to assess and treat ASD and mental health issues.”
- “Create more equal opportunities and access for families across the province, both with respect to treatment and assessment. Train more clinicians in rural communities.”
- “Create working group on rural cooperation. Involve rural family doctors?”

OPPORTUNITY

Improve cooperation, communication, collaboration, and information sharing between important stakeholder groups

Directions:

Develop a working group to:

- “Connect and bring together service/program providers (agencies, societies). Help them collaborate and share.”
- “Facilitate communities of practice to focus attention on specific issues (i.e. adult diagnosis, mental health, capacity building). Have these communities report back to the larger group.”
- “Doctors and diagnostic teams working with service providers to develop recommendations for needs-based, functional assessment to get children into services faster.”
- “Working committee to identify opportunity for cross-ministerial cooperation (i.e. dentistry for special needs, mental health.”
- “Could the role of the Alliance be to compile what others are doing and bringing these providers together to ‘program share.’ If we really want what’s best for Albertan’s with ASD then we should share and duplicate the programs that work well in other areas.”

OPPORTUNITY

Information is difficult to obtain, access, and find.

Directions:

Referral lists for medical doctors and professionals

- “Assemble of list of psychologists working in the area/expertise to pool resources and to assist families to navigate range of services with ‘pre-approved’ service providers.”

Create a web-portal or online directory

- “Information hub/hotline/website providing individualized information directory for need and for short-term/long-term support regarding education, financial planning, friendship and employment opportunities, housing, direct services, etc. Connect ASD individuals and their families with services they’ll need through the life span.”
- “Create a web portal that lists service providers in all parts of the province.”

OPPORTUNITY

Advocate for life stage support and transitional preparation for the individual with ASD.

Highschool → post-secondary → workforce & living on own → retirement

Directions:

There is a need for more experts available after diagnosis and throughout the individual’s life span.

- “When PUF ends, how do parents get their kids support throughout school years?”
- “Build consistency across the province for access to assessment and diagnosis services and set standards for process requirements. Make sure all people in the province have access to the same level and quality of services, at all ages”
- “How can we support individuals in retirement or newly entering school system? We need to build a continuum of services across the life cycle.”
- Long-term housing or intentional communities

- “Advocate to GOA to create publicly-supported homes for those with autism. Long-term housing with wrap around care.”

OPPORTUNITY

Strengthen communication between Autism Alberta and the ASD community/members

Directions:

There needs to be ongoing communication back to the community of steps the Alliance is taking, the work being done, and the results seen. This community wants to always be informed.

OPPORTUNITY

Normalizing behavior in the community and educating the public to break the stigma and stereotypes of autism. There is a lack of awareness of ASD within the broader community.

Directions:

Educate gatekeepers.

- “Educate gatekeepers (medical professionals, teachers, families, daycare personnel, etc.) that autistic traits are an exaggerated form of normal traits and separate from the disease model.”
- “Currently, diagnosis=failure (for the ASD individual). Diagnosis should come with a sense of identity and a welcoming into the community.”
- “De-stigmatization of the autistic conditions is a campaign led by how those at the influential positions can start and enforce.”

Community ambassadors

- “Continue to build awareness and educate the public. Teach acceptance and what inclusion looks like. Share what’s happening across the province.”

NEXT STEPS

This event successfully brought together stakeholders from across Alberta to have meaningful dialogue and to identify significant needs in the autism community that we can address collectively.

This report will be reviewed by the planning committee to identify actionable next steps, including significant areas of interest, stakeholder engagement, clinical advisory groups, greater involvement and leadership of self-advocates and collaborative partnerships.

A big thank you to our planning committee members for their hard work and the Sinneave Family Foundation for their support as title sponsor.

We look forward to our next gathering.

THE PRESENTERS

Special Mention

Honourable Mike Lake, Member of the House of Commons of Canada for his heartfelt letter welcoming our stakeholders.

Honourable Irfan Sabir, Minister of Community and Social Services, Government of Alberta for providing opening remarks to launch our alliance.

Presenters

ASD Diagnostic Assessment in Alberta: Innovations, Opportunities and Needs

Dr. Lonnie Zwaigenbaum, MD, Stollery Children's Hospital Foundation Chair in Autism, Director Autism Research Centre and Site Lead for Child Health, Glenrose Rehabilitation Hospital, Professor, Department of Pediatrics, University of Alberta. Health Services

Dr. David Nicholas, Ph.D., Professor, Faculty of Social Work, University of Calgary

Dr. Ade Orimalade, FRCPC MRC Psych CCT (Developmental Disability Psychiatry) PgDip (Mental Health Law), Assistant Clinical Professor, Dept. of Psychiatry, University of Alberta, Consultant Psychiatrist, Alberta Health Services

Dr. Yogesh Thakker, MBBS, MD (Psychiatry), MRCPsych (UK), CCT (Psychiatry of Developmental Disability -UK), Consultant Psychiatrist, Alberta Health Services, Edmonton and Stony Plain, Clinical Lecturer, Department of Psychiatry, University of Alberta, Lead Psychiatrist for the Community Outreach Assessment and Support Team (COAST Edmonton)

Dr. Greg Skinner. MD, CCFP, LMCC, Bsc, Physician, Gregory J. Skinner Professional Corporation

Improving Mental Health Across the Lifespan: Art or Science?

Dr. Katelyn Lowe, Ph.D., R. Psych, Chief Strategy Officer, Sinneave Family Foundation

Dr. Shane Lynch, Ph.D., R. Psych, Director of Professional Practice and Evaluation, Sinneave Family Foundation

Julie McLennan, MA, Mental Health Clinician, Shared Care Mental Health Program, CUPS

Julie Eggers, R. Pysch, Educational Counsellor, Southern Alberta Institute of Technology, Student Development and Counselling, Learner and Academic Services

Navigation/Transition Planning - A Provincial Perspective

Carole Anne Patenaude, Executive Director, Autism Edmonton, Board Director, Autism Society Alberta

Lyndon Parakin, Executive Director, Autism Calgary, Vice President, Autism Society Alberta

Allison Pike, Board Member, Chinook Autism Society, Lethbridge, Member of Provincial Parent Advisory Committee, Alberta Human Services

Nicole Spring, Community Ambassador, Autism Society of the Regional Municipality of Wood Buffalo

Kitty Parlby, Board Director, rural representative, Autism Society Alberta

Who Will Take Care of Our Kids?

Carolyn Dudley, MSc N., Board Director Autism Society Alberta