



AUTISM ALBERTA
— ALLIANCE —

WORKING MEETING | NOVEMBER 3, 2017

MEETING SUMMARY REPORT

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MEETING OVERVIEW

Over 200 individuals expressed an interest in contributing to the development of an Autism Alberta Alliance, more than 120 individuals formally registered for an initial meeting on November 3, 2017. Despite, severe weather and driving conditions 56 participants were able to attend the session. There were 6 core objectives for the meeting:

- To facilitate new connections between individuals and organizations working to enhance the quality of life for persons and families living with Autism.
- To foster shared awareness of current Autism focused work in Alberta
- To create a vision for the Autism Alberta Alliance
- To determine the core objectives for the Autism Alberta Alliance
- To explore governance and structure for the Autism Alberta Alliance
- To clarify the next steps for the Autism Alberta Alliance

Participants indicated in advance of the event, that in order for the meeting to be successful it must:

network
REDUCE BARRIERS
identify priorities & next steps
understand AAA vision
SHARE IDEAS & BEST PRACTICES

DEVELOP
PARTNERSHIPS

Welcoming remarks were provided by Marie Renaud, MLA for St. Albert. The opening session of the event was geared towards sharing ideas and best practices in five thematic areas: health/medical (Lyndon Parakin), housing, employment/vocation (Sarah Taylor), school/education, and home/family/ community (Kitty Parlby). The speakers in the other areas were waylaid by the weather and the questions about key activities and how an alliance might help support work in these areas were put to the collective wisdom of the group.

COMMON AGENDA

Participants were asked to imagine that it was five years from today and that they were reflecting back on the Autism Alberta Alliance. Each participant then noted what they felt the number one success might be for the alliance. Subsequently, participants were asked to introduce themselves to one another and share their vision for the success of the Autism Alberta Alliance. A number of key themes emerged from this process (For a complete table of themes and corresponding individual participant comments see appendix A):

- Complete collaboration between all stakeholders (e.g. parents, teachers, health care and service providers, etc.) and autistic individuals to achieve a common goal across all ability levels and geographic locations.
- A central hub (go to place) for all information and resources related to Autism in Alberta.
- Common language and definition of what Autism is and what inclusion means, as well as an increased recognition and political awareness of Autism
- Informed educators/ first responders about standardized practice and clear expectations (increased awareness and appropriate accommodations)
- An active unified voice advocating for change
- An up to date database with descriptions and travel times that is accessible to the larger community (central hub) and between organizations
- Early identification of Autism and responsive intervention within the first two months of receiving the diagnosis

The Autism Alberta Alliance is... a collaboration. A knowledge hub. An advocate. An educator. It speaks with a unified voice to raise awareness of Autism, cultivate acceptance and foster accommodation across the lifespan and across all areas of Alberta in order to enhance the lives of individuals and families with Autism.

FIVE KEY THEMES

Participants engaged in a World Café to share their experience and expertise on five key thematic areas: health/medical; school/education; vocation/employment; housing; and home/family/community. The groups considered three key questions during this exercise:

- What opportunities exist in this area?
- What are the core objectives that the Alliance should focus on related to this theme?
- How should these objectives be measured?

Health/Medical

Opportunities:

- Timely access to services and diagnosis across the lifespan
- Clarity in the process for families and health professionals
- Different populations have difficulty accessing services – for example, English as a Second Language, Indigenous, rural
- Increase mental health services for parents and the children with Autism, as well as adults with Autism
- A mental health diagnosis, however, can create a barrier to receiving other services
- Lack of access to dental care
- Knowledge and understanding of complementary alternative practices

Objectives:

- Identify and translate existing best-practices (e.g. Glenrose) across the province
 - Ensure that there are a diversity of approaches to preserve a family's ability to choose the right option for them
- Enhance the coordination amongst services both within the medical space, but also cross-sectorally (e.g. healthcare and education)
- Determine how best to track Autism related data at a provincial level for monitoring/evaluating purposes but also utilize data to help efforts to foster change

Measurement:

- Decrease wait list for health-related services
- Increase the number of children with appropriate codes in the education system
- Decrease the system burden by enhancing community capacity to deal with 'routine' cases and reserving the existing specialty facilities for difficult cases
- A two-stream database is created with information for the public and also professionals (based on best available evidence)

School/Education

There was a significant interest in this area and the group sizes were very large in each round.

Opportunities:

The dialogue began to focus on defining inclusion, however, participants shared that a 6-value based definition already exists. The challenge is more around the uptake and implementation of those values related to Autism.

Some participants recommended undertaking an environmental scan to document all existing services, as well as a needs assessment in order to better understand the barriers and gaps in services. An analysis of these two documents could then provide a meaningful gap analysis to ensure that the Alliance does not create unnecessary supports or recreate existing ones.

It was reported that designing an in-service for educators, providers and families to share the findings of the aforementioned research may be a meaningful opportunity. Additionally, the group commented on a desired to be the 'go-to group' for government when seeking information on how to address questions on Autism and to provide feasible solutions.

Objectives:

The group questioned the potential mandate of the Alliance – where it was to advocate, inspire partnerships or both? Participants reached a consensus that a clear strategic advocacy agenda at a government level should be created, and should outline service solutions, current evidence, as well as family and community needs. Participants felt that local/region partnerships are an ideal mechanism to share what is going on, what is working well, and to support working together to implement or enhance services.

Measurement:

Due to the extensive and rich discussion on opportunities and objectives, participants cited only one metric for this category:

- An increase in the number of post-secondary positions for individuals with Autism
 - Participants noted that education and learning do not end at grade 12

Vocation/Employment

Opportunities:

- Create a general understanding of ASD within the business community
- Provide coaching to employers who contract or employ individuals on the spectrum about the benefits and potential challenges
- Build overall capacity for employers to actively support autistic individuals in the work place
- Create a database of existing successful employment models
- Conduct a needs assessment and compare urban vs. rural
- Conduct a pilot project to illustrate benefits and feasibility of employability of autistic individuals
 - Start with a post-secondary institution as a microcosm of society
- Partner with high schools about on the job training

Objectives:

- Advocate across ministries
- Create a means to help collaboration and decrease competition
- Support people on the spectrum through a career path and not just finding a job
- Determine qualitative and quantitative measures to assess the status of employment of people with ASD

Measurement:

- Total number of individuals with ASD who are employed /underemployed
- Length of term of employment and identification of reason for leaving or termination
- Job satisfaction of both employee and employer

Housing

Opportunities:

- Create a comprehensive map of existing housing options and better understand government supported models (in other provinces and countries)

Objectives:

- Develop partnerships with other existing alliances and communities (e.g. Habitat for Humanity, Reena, ...)
- Draw upon the skills, assets and specialities of individuals with Autism to co-build
- Research to understand existing needs, offerings and gaps
- Ensure a comprehensive deliverable that highlights urban and rural challenges and the current divide between services
- Feasibility studies on potential options
- Create a toolkit on how to start a group home

Measurement:

- Assess housing solutions and their impact on the quality of life for individuals with Autism
- Calculate the real cost of appropriate housing and the financial and social consequence of not meeting the housing needs of autistic individuals
- Decrease homelessness for autistic individuals
- Ensure individuals and families have housing options to meet the diversity of needs

Home/Family/Community

Opportunities:

A high emphasis was placed on the changing profile of Autism in Alberta (e.g. increasing prevalence, higher number of adults with an Autism diagnosis), and the need to ensure a whole lifespan approach.

Participants commented on the restrictions of depending solely on services focused on enhancing parent capacity. There was a central theme in this area to recognize the parent's critical role from birth through to the later adult years.

Recognizing the need for cross-ministerial supports was stressed. Participants also noted that a meaningful way to advocate without having to repeatedly share a personal journey would be nice to have moving forward.

Objectives:

- Participants stated that the Alliance should create a map of existing services
- Ensure that existing services meet the needs of individuals and families living with Autism, and that these services are optimally utilized
- Develop an advocacy plan to address service gaps
- Work to ensure that policy and legislation stay consistent with best available evidence
- Respecting cultural differences and ensuring that Autism-related services and supports are culturally appropriate
- Create a 'one-stop-shop'

Measurement:

Participants commented that this category was too broad and as the Alliance moves forward it should seek to meaningfully refine this area into three distinct sections. Due to the extensive and rich discussion on opportunities and objectives, participants did not cite any potential metrics for this area of focus.

CONSIDERATIONS

Based on the input of the stakeholders from the meeting on November 3rd, the following five considerations are proposed.

Governance - in order to sustain the momentum generated at the November 3rd event it will be key to outline the governance structure for the Autism Alberta Alliance. The structure should be dynamic and flexible in supporting diverse perspective, aligning with the partnership spirit of the event. Consider, for example, the collective impact framework: <http://www.collaborationforimpact.com/collective-impact/>

In general – a guidance group representing the various stakeholder categories and geographic regions should be assembled; along with a number of working groups (For example: 1. research, practice, policy OR 2. housing, education, employment, health, and home). Within each working group a 1 year action plan with specific, measurement and timely objectives can then be generated.

Research - universally throughout each of the five areas there is a recognition of limits in the understanding of the existing services, the needs, and the difference between those two. To that end, a comprehensive environmental scan, and provincial needs assessment, as well as a gap analysis could be of value. The outputs of this work could support the concurrent development of a knowledge hub and a comprehensive database.

Advocacy Plan - another core theme emerging from the group dialogue is ‘cross-ministerial action or advocacy’. An assessment of existing policy and legislation, in combination with the aforementioned research activities, could then lead to a meaningful advocacy plan and associated tools to help each member of the Alliance actively advocate for change, but with a unified voice.

Training and Educational Resources - working in partnership with key stakeholders in the education sector, support and inspire the design of targeted training resources and workshops to enhance the level of services available in school, community and healthcare.

Funding - It is imperative that funding for the Alliance be identified and secured in order to provide routine opportunities for membership to meet each year via teleconferences, webcasting, and/or in person events; as well as undertake large scale initiatives to identify service needs and explore new models; and translate the findings into an advocacy plan. Similar groups have used tools like membership fees, private philanthropy, research grants, and user pay models to fund the work.

IMMEDIATE NEXT STEPS

- 1) All registered participants, regardless of whether or not they were able to attend the event, will receive a summary report from the November 3rd event.
- 2) Offering an opportunity to broaden and strengthen the collective wisdom and future direction of the Alliance by hosting a webinar for those participants who were interested but unable to attend the November 3rd event.
- 3) Initiate a dialogue with key Government leaders to share the outcome of the stakeholder engagement event, preliminary plans for actions, and to ensure their meaningful participation in the process

MEETING EVALUATION

Participants were asked to complete a brief-post event evaluation (n = 38 unique responses). The key themes that emerged included:

- Great networking opportunity and meaningful collaboration took place
- General sense of excitement about the possibilities of the Alliance
- Surprise that there are a greater diversity of providers and potential partners than participants had previously realized
- Awareness that there are a high number of commonalities amongst ASD stakeholders
- Appreciation for the diversity of voices in the room

Appendix B contains a verbatim list of all participant comments from the evaluation forms.

APPENDIX A – VISION

KEY THEMES	INDIVIDUAL PARTICIPANT COMMENTS
<p>Complete collaboration between all stakeholders (e.g. parents, teachers, health care and service providers, etc) and autistic individuals to address common goals that relate to ASD across all ages, ability levels and geographic locations.</p>	Coordinated services.
	Complete collaboration between parents, education, healthcare, employment, human services to achieve that common goal of success across all abilities.
	Unite groups to engage in common advocacy and lobbying for change.
	Committed partnerships with community ASD supports that can link with our education staff in building capacity.
	Provincial Autism strategy (comprehensive cross ministerial)
	Coordinated network of supports for individuals (and families) that have ASD – across ministries, agencies and community supports,
	Speak with one voice towards better quality of life for those with Autism.
	To be the voice that everyone has heard of and goes to for help/advocacy and acceptance. To unite all of Alberta under one umbrella
	Community familiarity and ability to report on how the alliance has played a role to increase their understanding/knowledge of ASD.
	Accessibility to services cradle to grave for those with Autism through a collective voice
	Networking across the province to share knowledge across regions
	Collaboration between ministries are seamless providing families with coordinated wrap around services
	Reduced barriers related to quality inclusive education for people on the spectrum. Education of staff and students, quality programming for specific child skill development.
	Increased knowledge and acceptance for all people on the spectrum – regardless of their location.
	Facilitating a common approach between home and school supports.
	Government policies/services in place align with the needs of individuals and families providing support through the lifespan without gaps/cliffs providing continuity and value.
	Community response and support from the first signal of challenge
	The perspective of the family is seamless access to supports and services appropriate for them (as they choose) across the lifespan and across settings
	Every individual and family living with ASD has the support they need to be fully included in all areas of society leading full and active lives.
	Every person impacted by Autism has access to the supports they need
Collective Voice that improves outcomes for people with ASD	
Communities are understanding and accepting; support available to all anywhere; support go to families not families to supports	
Wow, that was amazing that all the parents I talked to today understand and accept their children for who they are. Not one person measured success by whether or not their child could talk verbally.	
(Funding) Political recognition of Autism	

<p>A central hub (go to place) for all information and resources related to Autism in Alberta.</p>	<p>Alliance is seen as the organization to go to for awareness, acceptance and advocacy. A central information centre. To be able to access a current update resource page on the internet of information related to awareness, advocacy, acceptance of individuals with Autism. Creation of a 'hub' that connects families to different (already identified as best practices) services in the province (and that all practitioners are consistently using it). Advocating for successful proper acceptable lifelong supports for people with ASD Parents access to supports to encourage success for their child well into adulthood Awareness: resolution of the appropriate supports across the lifespan Education, orientation to an inclusive, tolerant, accepting community building</p>
<p>Common language and definition of what Autism is and what inclusion means + Recognition and political awareness of Autism</p>	<p>All children fully included in child care (not with 1:1 aide) Consistent definition of an application of inclusion – need to have the right people in the positives of power/influence A consistent message or program used province wide to increase awareness and educate (education, health, community) Acceptance/tolerance/understanding through training/info/education</p>
<p>Educating educators/ first responders about awareness and accommodation – standardized practice and clear expectations</p>	<p>Increased capacity in providing services to individuals with Autism – teachers, EAs, community workers, family, larger community; uniformity of high quality intervention Presentations in every school at every level bringing awareness, supporting acceptance but especially their responsibility for advocacy of people with Autism at the opening staff meeting More mandatory education for EAs and teachers that focuses on special needs Awareness/standard education of educators/1st responders/health care</p>
<p>Speak up with a unified voice to advocate for change</p>	<p>Helped the government find a more strategic funding model to better meet growing/high demand for intervention and adult services Collective voice Road map/success stories of how disability serving organizations can support each other; creating a platform to advocate/influence policy</p>
<p>Up to date database with descriptions, travel times, and make accessible to larger community (central hub) and between organizations</p>	<p>Evidence-informed resources are available for: teaching/teachers, educators, families, employers, post-secondary, people on the spectrum Share and pool ideas Creative ways to share knowledge, better services in rural areas, City OT's mentoring rural OT's A database with true up-to-date services available across AB with how to be included (broken down to include travel time)</p>
<p>Early identification of Autism and responsive intervention – within the first two months of receiving the diagnosis</p>	<p>Identify of Autism and early intervention – within the first two months of receiving the diagnosis</p>

APPENDIX B – EVALUATION RESULTS

WHAT? <i>Participants were asked to share their thoughts on the experience.</i>	SO WHAT? <i>Participants were asked to expand on why that experience was important to them</i>	NOW WHAT? <i>Participants were asked what actions they might take or what they might do differently as a result of the meeting.</i>
<p>I heard people speak largely from their own experience, some with little direct experience of individuals on the spectrum some with extensive direct experience based on their work and/or a parent with their child.</p>	<p>Including autistic voices is a necessary step, as well as including those who identify another (sic) first language.</p>	<p>No comment.</p>
<p>Happy to have a variety of stakeholders in one room. Everyone is passionate and committed to making the alliance a reality.</p>	<p>Offers families more informed decisions and that there is an organization to advocate it</p>	<p>Website</p>
<p>New connections, learned about resources in different regions that not yet exist in other regions.</p>	<p>Sharing resources across the province is key to optimizing services throughout.</p>	<p>Have a conversation with Lyndon about notes I synthesized on how I can complement the contribution across the lifespan.</p>
<p>I am pleased that this has started.</p>	<p>Because we need to start working together, learning from each other and mentoring each other.</p>	<p>I have already set up a meeting to meet with education. Next meeting during better weather.</p>
<p>Pity about the weather. Good networking, good food. Nice to get together.</p>	<p>That we gain the support and backing of government.</p>	<p>Keep moving forward.</p>
<p>Well thought out productive session – many new interesting people</p>	<p>Learned of many services/resources I wasn't aware of before</p>	<p>Next session? I want to research what services/resources are in my community that I don't know about</p>
<p>A good start need to solidify lines of communication between organizations</p>	<p>To speak as one voice</p>	<p>No comment.</p>
<p>Learned about array of services and needs, and about those engaged in this work and advocacy</p>	<p>Capacity Building</p>	<p>Work towards professional development with school staff.</p>
<p>Had a good day with networking, sharing information and collaborative work.</p>	<p>From the perspective of a service provider, it is good to be connected to a larger network.</p>	<p>Share what I've learned.</p>

Well led. Very general – the focus is larger than I anticipated	You need more power brokers in the room	No comment.
That there are more resources and people throughout all of Alberta that are working hard to support people with ASD	I feel these people will all lead to positive change in society in relation to ASD.	No comment.
Great discussions. I felt that I made some great connections and learned some services I wasn't aware of. It gave me lots to think about.	I have my own child with Autism but I also support students with Autism in my career and feel this alliance can make a difference	No comment
Many people are aware of power structures separate entities if designed 'wrong' and we them designed 'right'. There are many ways to help a community, but each is only as powerful as the influence it carries	Some new ways are about to be a big part of my life 😊	I know better how to create a service, so I will be.
Excellent – informative and inspiring. Great to have a face-to-face gathering.	Opportunity to unite stakeholders around AB.	No comment.
Great networking and collaboration. Great forum to learn a variety of perspectives on important topics.	Alberta needs a collective voice and a collective knowledge 'hub' – great to see this forming.	Analyse feedback and determine priorities and how to achieve them.
Learned about resources to support individuals with ASD can access when entering the workforce.	Areas our organization can look at providing supports for individuals we already work with.	Share info with team members.
Excellent working sessions; voices represented across AB; Great Facilitator!	To know direction of Autism work/collaboration in AB	Facilitate and build on connections made today.
It was great to collaborate across services.	Ease of service navigation for parents/caregivers	Promote what the alliance is trying to achieve.
Great group of voices representing individuals with Autism, parents and families, members, professionals and service providers	That's how you get a collective voice – invite them to the table and listen with purpose.	Look forward to the next steps of the AAA!
Learned of the diversity around the province, it can make people very frustrated.	Make it hard to create cohesion.	Respond differently to families and schools.
A great group of people with a common goal. I am looking forward to seeing what comes next	I feel parent's voices are not heard.	I would like to branch out to rural areas to determine if collaboration is possible.

Nice to collaborate with others	WE need to work together, share resources so we aren't reinventing the wheel.	No comment.
Cohesion	It would be easier to share knowledge	Needs assessment compiled baselines
Great networking. Lots of common objectives. Need to maintain cohesion.	Partnerships – we are stronger together.	Have arranged a partnership meeting already when we are back home.
Great info and feeling of collaboration	To feel like my work is effective in a larger sense.	Seasonal/weather concerns.
Amazing. Lots of different opinions and I made nice connections with others.	Want to meet again asap.	Too many to mention.
Excellent facilitator who wonderfully put it all together. I learned that we are more united than I thought and I experienced a passionate knowledge and committed group of people.	It's nice to get together but there is more work to do – even more identified after today. It's important to connect and identify objectives...	But now we need to ACT. I need more specific outcomes, a governance structure, a format for how to ACT.
Great to network. Excellent facilitator. Opportunity to begin dialogue as a united front that supports individuals across spectrum.	Opportunity to grow awareness and align all aspects of services for individuals with ASD.	Attempt to build resources/community with my own practice. Contribute to the alliance as opportunities emerge.
Very inspiring to imagine a collective approach to services for this population.	No comment	No comment
Our facilitator, Lisa, was FANTASTIC! Learned about what is currently happening with different aspects of Autism services/access across the province.	Important because it gives me a better idea of gaps I may be able to address as a practitioner.	I think it is important to being pooling resources towards making a 'hub' a reality.
Good networking opportunity. Good to hear what is going on throughout the province. Still feels like the alliance lacks clarity but I am sure this will emerge over time.	Tons of fragmentation in the province on Autism supports.	I like the 5 areas of focus but feel they need more specificity, particularly home/family/community in order to inform specific actions. Do we need a Board of Directions = formal membership?
I enjoyed collaborating with everyone. Finding a lot of commonalities with others.	Being in a remote area we turn to other communities for examples on how to handle life with Autism.	Connect with others across Alberta to help bring more to my rural area. Inspiration. Thank you.

It was a good experience. That there is a need for the Alliance	I want (sic) to see us all share our resources to help strengthen all of Alberta	No comment.
Beneficial to hear experiences other cities/regions are having... Experience different views on the 5 themes discussions	In order to create a strong working alliance understanding of all stakeholders is key.	Look at those 5 domains within our region and look closer at: needs, gaps, achievements, positive aspects. All to bring back to the group.
Many gaps and a need to identify such and work towards filling gaps	Affect legislation to improve services and fill gaps	Steering group, sub-committees for core issues, add a lobbying legislation core issue.
I learned there is a more diverse group of service providers trying to reach the same goal than I anticipated.	Important to bring these people together.	Build and reach out more to other organizations.
How many different stakeholders are invested in an alliance.	Believe it will support this actually happening	Participate ongoing to see and come to fruition.
There is a networking forming AAA which will coordinate collaborate and communicate to provide a voice for the part of the ASD community	Those without voice need voice.	Bring back to my workplace the exciting possibilities of this AAA formation.