

"We are weary and we're worn out from fighting battles, but we must persist and build trust"  
Jessica Klatt, parent

"An event like this is what we need – meeting face-to-face, teaming up and jointly being the solution  
going forward." Brooke Pinsky, parent

"We want to inspire others, to stand up, to take on the role not only for ourselves but for the thousands  
of others like us who need to be heard." Adam Glendon, Self-Advocate

Autism Alberta's Alliance, 2019

# A CALL TO ACTION

by Bill Locke, Capacity Builders December 10, 2019

December 10, 2019

Jason Scheyen  
Chairman, Board of Directors  
Autism Society Alberta  
639 26 Street NE  
Calgary, Alberta T1Y 5E1

cc: Shino Nakane, Coordinator

Dear Mr. Scheyen,

Re: Autism Alberta's Alliance

The theme of the Autism Society Alberta Alliance 2019 Conference was "A Call to Action." I am pleased to report that the conference was very successful. The event provided a well-organized opportunity for over two hundred key people from across Alberta to discuss issues of crucial importance, gain consensus on priorities, identify opportunities, build traction on strategies, agree upon specific, tangible initiatives. It has united stakeholders from across Alberta, inspiring them to take responsibility for their challenging situation.

Alberta's Autism Spectrum Disorder (ASD) community is clearly perceiving the need to take charge of its own concerns, become better organized and more vocal. With this growing confidence it will be possible to establish working groups to address the key issues that were defined at the conference, set forth action plans, and continue acting for change in the future.

The ASD community in Alberta has the right to determine and develop priorities and strategies for exercising its right to development. This event is a prime example of its proactive approach to determining and developing the programs, facilities and initiatives it needs, including complex case care, housing and independent living, and family advocacy.

The purpose of this report is not only to submit findings and recommendations regarding the event itself, but to give voice to the people involved in the event. For this reason, we are conveying the conversation; we recorded the entire event, transcribed everything that was said, and included quotes in the report from many stakeholders. We hope readers will benefit from wisdom articulated by organizers, presenters, panelists, small groups and other attendees during and after the event. This report will also help to inform future efforts to fulfill the interests of the ASD community, its partners and stakeholders across Alberta, including the formation of working groups.

As an expression of different perspectives, this report includes many quotes taken from the transcripts of the sessions. It also provides an overview and copies of key content presented during the program; findings and recommendations for the ASD community and other stakeholders.

Yours truly,



---

Bill Locke, President  
Capacity Builders



# Capacity Builders

# Contents

---

- 1 Letter from Capacity Builders
  - 3 Executive Summary
  - 4 Background
  - 5 Activities and Outputs
  - 7 Event Program
  - 10 Topics
    - Complex Case Care
    - Housing and Independent Living
    - Family Advocacy
    - Advocate's Forum
  - 14 Findings
    - Key Issues
    - Good Works
    - Opportunities for Future Development
  - 18 Recommendations
    - Short-Term Actions
    - Long-term: Funding, Community
    - Development and Capacity Building
  - 20 Next Steps and Contact
- Appendix
- Attachments
  - Marketing (Poster and program)
  - PowerPoints (Panels and presenters)



# Executive Summary

**Project Title:** Autism Alberta's Alliance, 2019: A Call to Action

**Project, Goals/Objectives, Activities, Outputs:** This event and the processes leading up to it were designed to expand communication, increase knowledge, nurture collaboration, deepen engagement, and give voice to families and persons with ASD across Alberta. It engaged key stakeholders effectively including organizers, panelists, leaders within the ASD community, registered health professionals, disability service providers, community partners and volunteers. That involvement is itself an example of uniting forces, clarifying key issues, settling priorities, setting out strategies, defining initiatives. This is resulting in action being taken to address these key issues, including the setting up of working groups and advisory panels to oversee the creation of feasible and effective projects, programs and services.

*“This alliance gives us the opportunity to bring the knowledge and strategies that we have as family members and as people with lived experiences, to connect that to the service providers who can really apply those strategies, fill service gaps and help us move forward in a way that is going to allow either ourselves or the Autistic individual in our life to lead a good quality life.” Brooke Pinsky*

**Key Findings:** This event has proven to be invaluable, having more than met written expectations. 220 people attended, including over 50 Self-Advocates and 170 other participants from all regions of Alberta. We commend the organizers for doing an excellent job of engaging stakeholders before, during, and after the event, even though the work was performed on a shoestring budget. The event succeeded extremely well as a call to action, inspiring and uniting stakeholders of many kinds from across Alberta, who were able to distill the issues of greatest importance, determine which priorities have the greatest traction, identify opportunities, and gain consensus on next steps – especially in three areas: complex case care, housing and independent living, and family advocacy. An unprecedented presence from self advocates was supported by the Advocates Forum.

**Recommendations:** The groundwork has been set in place to form working groups, which can set forth specific action plans and make these initiatives a reality, bringing clarity and much-needed changes in the future. We also recommend working closely with Sinneave Family Foundation on the planning, marketing and delivery of the 2020 ASD and Housing Symposium. In the long-term, we also encourage Autism Alberta to pursue funding to support further collaboration, community development and capacity building.

**Next Steps:** Continue to create opportunities for stakeholder engagement and forge ahead with working groups focused on specific, tangible initiatives such as complex cases, affordable housing, and family advocacy. There is also a need for capacity-building of ASD community groups, especially in rural areas, and for leadership development among self-advocates. This includes raising of funds for these efforts.

**Attachments:** The report includes a copy of all of the PowerPoints used by presenters and panelists, as well as sample promotional materials.

# Background

**About Autism Society Alberta and the Alliance:** Autism Society Alberta is a nonprofit organization dedicated to improving quality of life in the Autism Spectrum Disorder community across the province. It is also the voice of Alberta's ASD community. The Alliance is an initiative of Autism Society Alberta bringing together stakeholders from a diversity of sectors: education, employment supports, health professionals, researchers, housing, intervention specialists, sports/recreation, parents, self-advocates and others. Last fall, Autism Alberta hosted the official launch in Calgary and the vision for the Alliance came to life.

**Community Needs:** Individuals with ASD and their families are a diverse group, with a wide spectrum of broad range of impact, widely varying levels and types of abilities, and diverse backgrounds with many ethnic, cultural and linguistic differences. Individuals and their families have very different types of needs that straddle the health, education, employment, housing, and economic fronts. ASD has a lifelong impact which often affects families and individuals long after their parents have passed on. Some individuals have complex needs, with multiple medical diagnoses including mental health, which makes a variety of supports critical. Yet the jurisdictions, programs and health services in Alberta are often in separate silos, which makes identifying them and gaining their support difficult. Advocacy is essential and often requires great persistence, but it can also lead to burnout. Navigating and advocating for the right supports can be overwhelming. It is particularly difficult in rural areas where knowledge and access to services is limited.

**Mission:** As the provincial voice, Autism Alberta "addresses the common goals of the autism community by leveraging its networks and resources to gather information, mobilize awareness, promote effective collaboration among all stakeholders and taking focused action to ensure the lifespan needs of the autism community are met."

**Role:** Autism Alberta's Alliance sees itself in a multi-faceted role. It is intended to be "a collaboration. A knowledge hub. An advocate. An educator. It speaks with a unified voice to raise awareness about 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."

*"Autism isn't an option for a parent of a child with ASD. It's a passion because when you have family, when you have a child, you do everything you can to support that child."* Kim Fox



**Objectives:** The event was a strategic effort designed to bring a wide variety of stakeholders together from across Alberta to discuss and prioritize issues, find solutions, and settle on strategies for Alberta's ASD community. Ultimately, it is hoped that this event will make a difference in the lives of individuals with ASD and their families.

**Theme:** The theme and description of the day was "A Call to Action – Forming Provincial Working Groups. Participants will enjoy a day of facilitated conversations, presentations and community-building activities with stakeholders from across Alberta."

# Activities and Outputs

As with any annual conference designed to unite a wide variety of stakeholders to bring about significant impact, the majority of the activities occurred prior to the event over a span of almost one year. "Success is where preparation and opportunity meet."  
Bobby Unser

## PLANNING AND EVENT PREPARATION

Project staff, contractors and volunteers spent over 9 months and over 1,000 hours of intensive effort to settle the event theme, clarify sessions, create and support committees, develop partnerships, book speakers, prepare panelists, book hotel and contractors, manage the project, including

- Steering Committee
- 4 Panel Committees
- 3 part-time staff and 4 contractors
- 21 volunteers



## MARKETING

Thanks to a focus on marketing, the organizers more than doubled their goal for attendance, attracting 220 people. A variety of marketing strategies and tactics were used, including social media, email blasts and promotion by partnering organizations, including Autism Calgary, Autism Edmonton, Sinneave Family Foundation, Autism Canada and many other stakeholder organizations. See attached "Autism-Alberta-Alliance-Event-2019-POSTER & PROGRAM.pdf"

## EVENT DELIVERY

One-day event on Oct. 11, 2019 at the Chateau Louis Conference Centre, Edmonton:

**Numbers of attendees:** 220. This is the highest number of stakeholders from the ASD Alberta community to meet in one place

### Attendees

- Event organizers: 7
- Volunteers: 21
- Panelists and presenters: 24
- Self-advocates: 55
- Others, including ASD community leaders, builders, caregivers, educators, etc: 113

### Self-Description of Attendees\*

- Autistic Adults
- Builders
- Caregivers
- Educators
- Government Representatives
- Landlords
- Parents
- Registered Health Professionals Researchers
- Service Providers
- Students
- Others

### Locations in Alberta represented\*:

- North (Fort McMurray, Grande Prairie)
- Central North (Edmonton)
- Central (Red Deer, Alix)
- South Central (Calgary, Olds)



\*based on "Autism Alberta Alliance 2019 Conference – Attendance Statistics" (courtesy, Sinneave Family Foundation)



## FOLLOWUP

- Preparation of Autism Society Alberta's rural pilot project
- Planning and preparation of working groups (see Next Steps below)

# Event Program



Audience participation



Small group discussion



Audience participation

**Conference Program and Format** – The event united stakeholders with a variety of perspectives to present their knowledge and share their personal stories, passions and positions. They included expert presenters and resource people, persons with lived experience, government officials, sponsors, and self-advocates with ASD.

In addition, there were a variety of opportunities during the conference to dialogue, share knowledge and experience, explain positions, explore insights, and find common ground. This took the form of small group discussions and reports, Q&A, written questions, input and feedback forms, networking, and informal discussions.

The event was not limited to academic presentations. It was often very touching and human, sometimes heartbreaking, occasionally heated, and always engaging.

*“We are stakeholders, along with our allies, and have responsibility to keep ability and contribution in mind during the decision-making process and how it relates to those that need assistance.” Adam Glendon*



## Four Sessions (See Attachments, including PPT's, etc.)

**MC:** Dr. Lonnie Zwaigenbaum (Professor in the Department of Pediatrics at the University of Alberta)

**1. Complex Case Care. Panelists:** Dr. Kimberley Ward (Registered Psychologist and Executive Director of the Society for Treatment of Autism), Dr. David Nicholas (Professor in the Faculty of Social Work, University of Calgary), Dr. Katelyn Lowe (Registered Psychologist and Chief Strategy Officer for the Sinneave Family Foundation), Nadine Gall (Manager of the Integrated Brain Health Initiative & Neurodevelopmental Disorders NDD Care Coordination Program at the Alberta Children's Hospital), Clayton Kleparchuk, Program Manager, Alberta Health Services.



**2. Housing and Independent Living:** Kim Fox (REALTOR® with REMAX in Red Deer, Director, Autism Alberta and Co-Chair of the advisory committee for the Sinneave Family Foundation Housing Committee), Nicole Spring (Community Development Officer, Autism Society of the Regional Municipality of Wood Buffalo), Barbara Potter (Chief Operating Officer, The Sinneave Family Foundation) and Dr. Deborah Barrett (Director, Autism Alberta; President and owner of Anthony at Your Service.)



**3. Family Advocacy:** Lyndon Parakin (Executive Director, Autism Calgary Association, Vice President, Autism Society Alberta), Brooke Pinsky (Manager of Programs and Support Services with Autism Edmonton and Board Secretary for Autism Society Alberta), Kitty Parlby (Speaker and consultant with Autism Inspirations, Director, Autism Alberta), Jessica Klatt (Autistic parent of two boys, one with ASD)



**4. Advocates Forum:** Adam Glendon (Diagnosed with Autism in 2009, Adam works full-time as a yard freight conductor for CN Rail. He is an active volunteer in the autism community), Michael Frost (An autistic activist (art activist), Michael is currently creating art both independently and collaborating with others to explore improved access to health and dental care for persons living with invisible disabilities), Adam Kedmy (plumber and respite worker (never both together), and studies at the U of A as an autistic student, working towards a BA, double majoring in Linguistics and Sociology), Aksana Kirton (Aksana recognizes herself as an advocate, a questioner, absurdist, Buddhist, painter, writer, vocalist, neighbour, and self describes as, above all, a believer.





## Other Speakers

- Min. Rajan Sawhney, Alberta Community and Social Services
- Mike Lake, MP Edmonton-Mill Woods (and Jayden)
- Tony Flores, Advocate for Persons with Disabilities, Alberta,
- Dr. Neil Roberts – Barbara Stewart Self Advocates Fund



**Format:** As intended, the event engaged participants in a wide variety of ways, to ensure that everyone, including persons with ASD took part informally:

- Discussion Groups
  - Complex Case Care
  - Housing and Independent Living
- Whole group feedback
  - Written questions
  - Question and Answer
  - Free-form comments from the audience
- Informal discussions
  - Coffee breaks
  - Lunch
  - Networking

**Working groups:** Although the event was described as “A Call to Action – Forming Provincial Working Groups”, the working groups were not intended to be formed during the event. Instead, the sessions will inform the formation of these groups:

- Complex Case Care
- Housing and Independent Living
- Family Advocacy

*“The things that we do agree on - that common ground - we're going to work on as hard as we can, self-advocates in the lead on many of these things, bringing experts, families and organizations together, and working to try and make life better for people with Autism.” Mike Lake, MP*

# Topics

This section is not primarily designed to share findings and recommendations regarding the event itself, so much as to summarize key insights shared during the event. This includes areas of common interest, suggested strategies and specific initiatives agreed upon by organizers, presenters, panelists, small groups and other attendees.

This summary is based upon:

- Comparison of the project as proposed vs actual implementation
- Study of literature including Autism Alberta Alliance's Dec. 2018 Report
- Recording and transcripts of presenters, panelists and audience questions/comments and other speakers such as Minister Rajan Sawhney, MP Mike Lake, Advocate Tony Flores and Dr. Neil Roberts.
- A selection of key comments and points
- The author's observations
- Feedback from organizers and attendees

## COMPLEX CASE CARE

The first panel consisted of medical and associated professionals sharing questions in research, treatment, and care of persons with complex needs. What does "complex" mean? What is it we are not saying by using this term? The panelists gave different perspectives on this topic, not only to teach but to open up a conversation about mental health, address the stigma associated with it and empower stakeholders to take it on in a positive and hopeful way.

### Dr. Katelyn Lowe: "Mental Health Complexity"

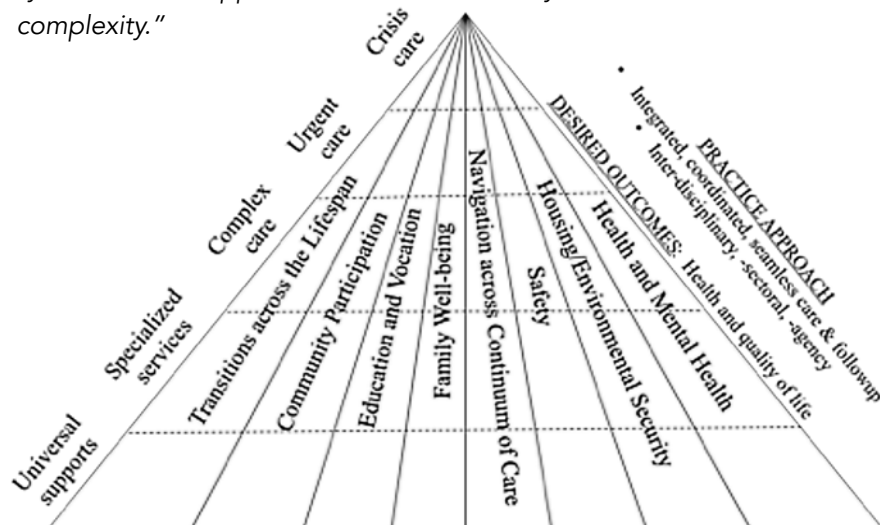
"We talk about autism being really common at one in 66, but ... 70% of autistic individuals have at least one co-occurring mental health condition, and 40% have two or more," "Suicide risk is 4-5 times higher in ASD." "The topic of mental health is complex, and it's still stigmatized. It's still very scary... a lot of people don't want to talk about it."

### Nadine Gall: "Medical Complexity"

"In the health care system, we've identified persons with ASD with complex needs as a population and as a group with really significant unmet needs where the systems in many ways are not meeting the needs of these individuals and families." "And what we're seeing amongst these families with complex needs and their caregivers and parents, we're seeing their own declining health, and their own mental health challenges. Certainly, the financial costs and burdens which you may have experienced are significant for families; the lower quality of life and even higher rates of poverty. "

### Dr. David Nicholas: "Complex Care in a Complex System"

"The question is 'How seamless is our system to respond in a meaningful way, particularly when we layer on the complexity of life and the society?' – which really speaks to living and thriving and community, and how responsive our systems are to support individuals where they're at, in terms of the need of complexity."

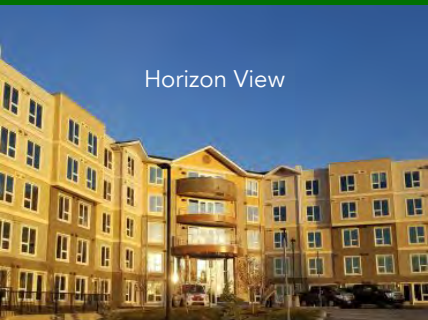


(See Attachments: 1. Complex Case Care PPT)

The panels were composed of major contributors to the ASD community, including professionals, thought leaders, family members, self-advocates coming together to share their perspectives and experiences. Summarized content also includes information shared from written notes from attendees, small group feedback, and Q&A times.

*“Horizon View Calgary has provided a stable living arrangement for my daughter, Chantal. She is around other members of the group. It's given me the opportunity to watch her grow and develop, build some self-confidence, gain some independence for herself.” Doug Morton, father of Chantal*

Horizon View



## HOUSING AND INDEPENDENT LIVING

Housing is one of the key issues faced by families with ASD. For families without adequate housing, especially those with an individual with complex needs, this need can be overwhelming. According to the speakers, it is an essential need that cannot be ignored. Fortunately, there are many excellent models and strategies to meet community-wide needs for housing, including unique supports for each individual. Panelists encouraged the audience to consider taking responsibility for this issue in their communities.

### **Dr. Deborah Barrett**

“Who will take care of our kids when we no longer can – care with all of its levels and streams, and who will make those decisions and catch the nuances that tell us we need to make some changes? Who creates a life plan and updates it with a good future in mind?”

### **Kim Fox**

“For parents,...nobody really has a life plan. They might have their will in place, they might have guardianship, ...some of the steps taken care of in their planning process. But they haven't really considered what happens for the 30 years of their child's life after they've gone.”

### **Dr. Deborah Barrett**

‘That’s where a micro-board comes in. It's composed of a small group of people, typically 5 people or less, who have a trusted relationship with the individual. It usually includes family members, guardians, or the individual and others who have a good relationship with the person with ASD. The micro-board's purpose is to listen closely to the individual (with ASD) and work with that person to create the life that individual wants. When micro-boards receive funds, they can then hire and employ support staff, who also assist the individual, often on a daily basis.”

### **Barb Potter**

Supported Independent Living involves a model that encompasses many factors, from state of readiness to a realized future. “We need a Working Group to address Supported Independent Living. The Sinneave Family Foundation is prepared to invest in facilitating, planning and hosting a two-day event in 2020 which will help us understand more clearly what's working and what's working well. We need to develop mechanisms for how we work together collaboratively across the province. And we need to start focusing on tangible outcomes. Wouldn't it be wonderful if we could measure outcomes for supported independent living in Alberta?”

The partnership formed between Sinneave Family Foundation, Aspires Housing and Horizon Housing of Calgary has opened up nine units in Horizon View, a new supported living complex for persons with ASD in the Glamorgan neighbourhood. It exemplifies a successful supported independent living model. Sinneave's video shared a testimony from Doug Morton, a satisfied father.

(See Attachments: 2. *Housing and Independent Living PPT*)

*“The secret to getting your kids the things they need is just never giving up. And as tiresome as it is, you just try and try and try. On the flip side of that is, in exchange, we need that acknowledgement from the service providers and from the decision makers that we are battle weary.”*  
Kitty Parlby

*“What I think is really so important about initiatives like this Alliance, is that it gives us the opportunity to share our knowledge and lived experience, and connect with service providers to implement those strategies, fill those service gaps and help us move forward to lead a good quality life.”*  
Brooke Pinsky

## FAMILY ADVOCACY

Families with ASD have a sometimes daunting task. Their child with ASD often needs assistance to engage in school, graduate to adulthood, live independently, work in the community, have friends, take part in recreation, find their life direction and reach their lifelong goals. Usually, it is the family that provides the bulk of assistance on this life journey. In order to care for their child, they often must prioritize their child over their marriage, jobs and other children. They sacrifice themselves and by necessity at times go without economically, socially and personally.

To find the help they need, families have to advocate, navigate and formalize supports from a wide variety of government departments, including Child and Social Services, Health Services, Mental Health, specialized educational services and Justice, to name a few. The whole process can be daunting. According to panelists, the wider ASD community, and others interested in their wellbeing, have a vital role empowering families to advocate on their behalf.

Family caregiving, advocacy and collaboration when successful has wide-sweeping benefits for the community as a whole. If the community were to provide all of the support that the families usually provide, it would cost billions of dollars of additional funding to handle the many responsibilities. Caregiving families make an enormous contribution to society, and receive great benefits themselves from playing this value-added role:

### **Lyndon Parakin**

“Being a father or mother of a child on the spectrum is like being a parent on steroids. And you don't get a break from it. You don't get to go golfing. You don't get to go on hikes. It's your whole life and there's no break from it. So it's very normal, but there is no rest.”

### **Kitty Parlby**

“I have my Autism Inspirations Facebook page and I'm telling everybody about all our lives. I share a journey. I'm demonstrating how fascinating autism can be. I show pictures of my son doing stuff, I share challenges, I share information about our Autism Society, all of those things, and I share, share, share.”

### **Brooke Pinsky**

“An important part of family advocacy is the navigation role. There's multiple systems that need to come together. The process involves multiple steps and require very specific information. And that can really be challenging for families to navigate.”

“What we're really here to talk about is how do we come together as a community and overcome those barriers – and get moving towards that path and the potential that lies ahead.”

(See Attachments: 3. Family Advocacy PPT)

## ADVOCATES FORUM

Persons with ASD often feel discriminated against. They want to be valued as they are and break down the stigma of disability; they want to be engaged meaningfully and treated seriously; they don't want to be left out or condescended. In fact, they want to be in a position of equity with others. Though there are few of them, self-advocates are taking responsibility to make change; they are advocating for themselves and others like them, seeking to bring about equity socially, economically, culturally, and politically.

### **Tony Flores – Advocate for Persons with Disabilities of Alberta**

"We aspire to break down the stigma, assumptions and erroneous beliefs about disability – and set examples for others to follow. I also believe in working together and the vital role of self-advocacy in influencing others, influencing change and removing social barriers."

### **Adam Glendon - panelist**

"Self-advocates are leaders. As a leader you need to work within the system. Show by example what can be done. If you alienate your allies, you will not only screw up your chance to make a difference, but you'll also it will also be harder for the next self-advocate to make a difference. Remind people that you are learning from them while they are learning from you. Recognize who the self-advocates around you are that you can invite. This is the first step to get others involved to help."



### **Adam Kedmy - panelist**

"There were periods in my life when I was so depressed, so unhappy with what was happening to me, when I was just barely surviving. I couldn't answer the phone, couldn't get up or go outside and deal with others. Today, I'm sitting in front of you and speaking up for others. I'm very proud of myself, but I'm still not thriving. I'm not there yet. We need you to help us to get the message out there, and to stand up for us to society across Alberta."



Tony Flores, Advocate for Persons with Disabilities

*"Remember to show them the benefits of advocating; appeal to their social justice. Encourage them to find their voice. Give encouragement and be ready to give advice when things don't go as planned. Remember, there are no stupid questions."* Adam Glendon

# Findings

This event, and the preparations leading up to it by organizers, panelists, partners and volunteers was very valuable as a means for calling ASD stakeholders in Alberta to action. It engaged key stakeholders from across the province, and gave them the vital opportunity to meet face-to-face, share their deepest convictions, discuss key issues, and agree upon specific, tangible initiatives.

The strategy supports community development through a holistic, strength based, and community-led process with the principles of cultural competence and respect for stakeholder's knowledge at its core.

## KEY ISSUES

Autism is in itself a complex and befuddling disorder, for the individual and family. The issues cross all manner of domains and portfolios, including physical, medical, emotional, educational, social, financial, legal and spiritual. It is particularly difficult for those with severe and complex disorders which impact the individual and family, causing it to fall apart, become disengaged, and erode into crisis after crisis. Fortunately, affected persons have come together to identify their common issues and define strategies to address them, as this event illustrates:

### *Lack of Respect*

Persons with disabilities including ASD often feel discriminated against. "The United Nations, with its Rights of Persons with Disabilities states we are not objects of charity, medical treatment and social protection, but rather, we are subjects with rights who are capable of claiming our rights and making decisions for our lives based on our free and informed consent as being active members of the society." Tony Flores

### *Stigma*

Stigma, lack of understanding and improper language is sometimes used regarding persons with ASD. Persons with Autism often experience condescension and feel treated as if they are second-class citizens, with their perspectives ignored. They want to be engaged in an equitable fashion. "Sometimes I take issue at being called "Autistic". If you want the current medical definition, use the 'Autism Spectrum Disorder' label, which is used for clinical study; it connotes that we are ordered differently, rather than sick." Aksana Kirton, self-advocate.

### *Lack of Engagement*

Lack of meaningful engagement of persons with Autism, including by the Autism organizations that are designed to improve their quality of life. They want to be engaged and treated seriously; they don't want to be left out or be condescended to. In fact, they want to be in a position of equity with others. Though there are few of them, they want to advocate for themselves, and to bring about equity in many respects – socially, educationally, professionally, economically, culturally, and politically.

## KEY ISSUES (cont.)

### Gaps in Programs

Gaps in programs and services to adults with ASD and their families, including

- Transitioning from children's stage to adult stage, for seniors and adults especially in rural areas – including care after parents pass on.
- Sexual/gender identity
- Safety risks and crises associated with complex needs
- Navigation through labyrinths of bureaucracies
- Transportation
- Language and cultural issues for immigrants
- Mental health
- Aging
- Financial sustainability

### Isolation

As helpful as social media and other technologies are to connect families, it is not enough to create meaningful relationships. "One of the most powerful tools that came along was Facebook. Even though I have been steered wrongly occasionally, it has connected me instantaneously to peers – to experienced and compassionate parents... But we need more than social media. An event like this is what we need – meeting face-to-face, teaming up and jointly being the solution going forward." Brooke Pinsky

### Complex & Other Needs

Gaps in understanding, medical treatment, disability services and ongoing supports for persons with complex needs, especially to address lifelong mental health issues

Gaps in preparing for and supporting independent living, including affordable housing and supports

Shortfall of support for and need for additional development of ASD community organizations especially in rural areas

Limited number of Self-advocates with ASD

Gaps in funding to meet the above needs

## GOOD WORKS

### Champions

There are many dedicated individuals, families, community leaders, government officials, businesspeople and political leaders giving voice to and listening to the above voices and engaged in developing and providing supports and redeeming this sometimes overwhelming situation. Among the many good works in Alberta are innovative strategies, homespun solutions, and well-developed programs:

- Autism navigators and self-advocates
- Primary Care Networks
- Medical education
- One-door program
- Hospitalist positions
- Cross-ministry initiatives such as the Catalyst Team and Arnika Centre
- Peer supports for individuals and families
- Family coaching
- Employment programs such as Ready Willing and Able, Worktopia, Meticulon, Spectrum Advantage, and Rotary Employment



## OPPORTUNITIES FOR FUTURE CONSIDERATION

### *Forward-Looking Perspective*

Stakeholders have a hopeful, forward-looking perspective. There are many conversations occurring about continuing and expanding these good works. Many of the current efforts are working well and should not be neglected. Yet, there are also many gaps remaining and a variety of new ideas and strategies suggested. Above all, there is the notion that a province-wide vision be developed further and voiced strongly to assist individuals, families and communities to find, advocate for and access the services and supports they need.

Another overarching suggestion is that communities develop a coordinated and flexible approach that crosses the boundaries needed to meet person-centered and family-oriented needs and possibilities, which vary widely. These opportunities are diverse as the needs they are designed to address.

Although some of the suggestions by themselves are well-thought out, together they lack a coherent plan to be effective and efficient. These opportunities would benefit from an overarching framework with clearly defined priorities, strategies, stage-by-stage process and action plan.

### *Human Rights*

Promote the fact that persons with Autism have rights that are enshrined in the United Nations Rights of Persons with Disabilities, that they are not to be treated as objects of charity but subjects with rights and decision-making authority, and often the ability to be active members of society. Whenever possible, we should be careful to listen attentively and communicate respectfully with persons with ASD

### *Personal Value*

Many participants emphasized the importance of personal value and individual ability: "I'm so fortunate to have one, maybe two beautiful autistic kids and I feel blessed to be autistic. It has really brought my perspective around to the fact that autism is awesome. I'm analytical, I'm observant, I'm out of the box. I'm a lot of wonderful things. And I don't want to change me or my son. If I could have a legacy it would be to change the world that we're living in, so that it allows my kids to be their true selves, and love themselves as their true selves – not just get through and worry about what people think, but honestly to be proud and loving of who they are. It should be a basic human right to feel like you are awesome in everything that you are, and that's all I want for my kiddos and everyone else out there who's on the spectrum or unique in any way."  
Jessica Klatt

### *Self-Advocacy*

Strive to engage persons with Autism in an equitable fashion as self-advocates, including in the workplace. They want to be engaged in a meaningful way, they don't want to be left out, and they want to be in a position of equity with others, "where everyone is treated the same... bringing all experiences (regardless of ability) to the same level. We as stakeholders, along with our allies, have responsibility to keep ability and contribution in mind during the decision-making process and how it relates to those that need assistance in a subtask." - Adam Glendon

Continue to open doors of opportunity for persons with Autism... "to have the opportunity to pursue their aspirations and live their dreams." Tony Flores

## OPPORTUNITIES FOR FUTURE CONSIDERATION (cont.)

### *Proactive Strategies*

Develop strategies to stay ahead of the increasing prevalence of ASD and take action, such as through Working Groups, in these areas:

- Complex Case Care
- Family Advocacy
- Housing and Supported Independent Living
- Self-Advocacy

### *Increased Growth*

Expand and promote self-development programs to assist personal responsibility and skill development including essential skills, employment development and for independent living.

Focus on raising awareness among employers to ensure they engage persons with Autism in a meaningful way on the team.

Additional transition planning and skill development for employment and independent living, such as the programs that Sinneave Family Foundation offers.

Remote support: Toll-free support line for people across Alberta

### *Improved Management*

Develop programs to help aging parents develop life plans for their adult child.

Create Micro-boards to manage care after parents have passed on.

'One Door' initiative to simplify and expedite access to individualized services for persons with Complex Needs

### *Increased Access*

Increased access to funding for adults with ASD, including opening up of eligibility criteria in PDD program

Increased advocacy, including recruitment and development of additional self-advocates in conjunction with advocacy programs

- Office of the Advocate for Persons with Disabilities (led by Tony Flores, who spoke at the conference)
- Office of the Advocate for Health
- Recruitment, training and support for additional self-advocates

### *Affordable Housing and Supports*

Offer by Sinneave Family Foundation to organize and fund a 2-day symposium in 2020 to enhance the ASD community's understanding of the issues especially around supported independent living; develop strategies and initiatives around this issue

Replicate and grow housing and independent living parent-peer support groups such as Aspires Housing Calgary

Development of best practices for design and construction of new builds suited to the needs of persons with ASD

Advocacy for access to existing space among affordable housing providers, such as eight units designated recently by Horizon Housing at Horizon View which partners with social service agencies to provide supports

# Recommendations

## SHORT-TERM ACTIONS

The groundwork has been done. Alberta stakeholders are ready to initiate new projects and processes. We recommend that the Alberta Alliance take action:

**Working Groups:** We recommend that Autism Alberta follow-up the event by forming Working Groups to set forth specific action plans and make these initiatives a reality, bringing clarity and much-needed changes in the future. These groups should continue to pursue the focus set out in the event and associated initiatives.

1. Complex Cases and Mental Health
2. Affordable Housing
3. Capacity Building
4. Leadership Development (e.g. self-advocacy)

**2020 Housing Symposium:** Since Sinneave Family Foundation has offered to organize and fund a 2-day symposium in 2020, we suggest that Autism Alberta work closely with Sinneave to fulfill the possibilities to:

1. Enhance the ASD community's understanding of the issues especially around supported independent living
2. Develop strategies and initiatives around this issue, such as
  1. Replication and growth of housing and independent living parent-peer support groups such as Aspires
  2. Development of best practices for design and construction of new builds
  3. Advocacy for access to existing space among affordable housing providers
3. Tie-in the symposium with the Autism Alliance goals and processes to bring about further engagement and buy-in from stakeholders

**Autism Alberta's Rural Pilot Project:** Pilot the project to collect data and increase understanding of the needs and gaps in service for individuals and families living with ASD in rural Alberta

**Working  
Groups**

**Housing  
Symposium**

**Rural  
Development  
Project**

# Recommendations

## LONG-TERM ACTIONS

We also recommend that the Alberta Alliance proceed to raise funds, develop community and build capacity.

**1: Fundraising:** Support community-driven, constituency-based planning initiatives and capacity building through:

- Multi-year funding for comprehensive community planning
- Project-based funding for capacity building, as requested by ASD communities

**2. Community Development:** Support ASD community-to-community learning by identifying:

- Funding to bring communities of practice together to share knowledge one-on-one, in small groups and in regional and provincial workshops
- Funding for the development of resources that can be shared across communities, such as toolkits, guides and websites
- Opportunities for meetings between communities, sectoral associations and government delegates from such departments and ministries as Family and Community Social Services, Alberta Council for Disability Services, Disability Services and AISH (Alberta Community and Social Services), Complex Needs (Alberta Health Services), Canada Mortgage and Housing Corporation and Alberta Seniors and Housing,
- Support the implementation of community plans and the alignment of programs and initiatives

**3. Capacity Building and Collaboration:** Develop and enhance collaboration and strategic partnerships within and between government departments to implement priorities identified by ASD communities by:

- Developing coordinated support teams with community and partner participation
- Engaging other regions, departments, governments and relevant partners
- Developing and sharing provincial and regional tools, such as a libraries and resource databases
- Aligning funding with community planning objectives and engaging governments and relevant partners to consider existing planning documents as applications for funding to invest in priorities identified by ASD communities

**Fundraising**

**Community  
Development**

**Capacity  
Building**

# Next Steps

ASD community and stakeholders should continue to meet with events and committees and forge ahead with working groups on specific, tangible initiatives such as complex cases and mental health, affordable housing, capacity building of ASD community especially in rural areas and leadership development among self-advocates.

# Contact

For further information, contact:  
Bill Locke, President, Capacity Builders  
[bill@capacitybuilders.org](mailto:bill@capacitybuilders.org)  
[www.capacitybuilders.org](http://www.capacitybuilders.org)

# Appendix

## ATTACHMENTS

### Marketing

- Poster/Program: ["Autism-Alberta-Alliance-Event-2019-POSTER & PROGRAM.pdf"](#)

### Powerpoints

- [1. Complex Case Care](#)
- [2. Housing and Independent Living](#)
- [3. Family Advocacy](#)
- [Self Advocates' Panel Notes](#)