



# The Future of Autism Supports and Services in Alberta

## A Wake-Up Call

By Bill Locke and Ken Fast  
Capacity Builders  
December 7, 2020

Results of Virtual Town  
Halls and Survey

# Lived Experience

On November 10 and 12, 2020 eighty-four people from around Alberta participated in virtual town halls, and sixty-five responded to an online survey.

What do these participants have in common? They each have a lived experience of life on the Autism spectrum, facing extraordinary challenges every day and taking every step possible towards a meaningful life. They are individuals on the spectrum; parents, spouses and family members; professionals and frontline workers in the community.

Every one of the participants are affected by powerful forces influencing systemic change to services and supports: low oil prices, a depressed economy, a deepening provincial deficit and the COVID-19 pandemic, with its unpredictable health risks, shutdowns and daunting mental health pressures. They were honest and open about their situations.

## A Taste of What They Said

*I think meetings like this allow us to come together and encourage growth in whatever direction is needed so that our full potential can really be reached, rather than the system pruning or forcing us to be shaped into a precast mold. That applies to any autistic child, any person or individual and our society as a whole.*

*Society with its structures demands certain skills of its populace. What people forget is that these skills are just hard to develop for autistic folks. They need specialized skill-training. That's what we have to stand up and say to officials.*

*I have to be able to tell my son or daughter what the problem is, and they have to be able to communicate these lessons to their contemporaries if they are all going to survive.*

*All that most kids want to feel is a sense of belonging, a sense of purpose to give themselves value. Employment gives a person a sense of purpose, a sense of value, a sense of something to be proud of. And if we don't have the ability to include them, how will they understand their worth and their value in the community?*



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- Marketing (Poster and program)
- Key Documents
- Video



NOTE: Capacity Builders acknowledges that language is important and preferences vary, so a mix of Person-First and Identity-First language is used to represent all perspectives.

December 7, 2020

Jason Scheyen  
Chairman, Board of Directors  
Autism Society Alberta  
3639 26 Street NE  
Calgary, Alberta T1Y 5E1

cc: Shino Nakane, Coordinator



Dear Mr. Scheyen,

Re: Autism Alberta's 2020 Town Halls and Online Survey

The focus of Autism Society Alberta's 2020 Town Halls and Online Survey is *"The Future of Autism Supports and Services in Alberta - A Wake-Up Call"*. Autism Alberta asked its constituency to identify common concerns, especially ongoing *"access to programs, quality of service delivery, critical gaps in policy, programs and services, barriers to those services, and possible gaps in funding."* Autism Alberta also gathered its constituency in an effort to develop practical solutions.

It is our opinion that the town halls and online survey effectively created an open and honest forum for discussion among stakeholders across Alberta. These measures have given the Autism community an opportunity to speak and be heard, by each other, the wider population and decision-makers responsible for policies and programs.

I am pleased to report that these efforts have been successful so far. These measures engaged a total of 148 stakeholders from across Alberta to discuss issues of crucial importance, gain consensus on priorities, identify opportunities, and build traction on strategies. Now the effort must go to the next step if it is to realize the change that your group has identified. Your constituency will need to advocate and take action collectively to take responsibility for making these specific, tangible and feasible initiatives a reality.

Ironically, the isolation, tension and sense of desperation that has arisen among individuals and their families on the autism spectrum during the pandemic has also forced many in this community to reach out for help, forged a committed effort among organizers to respond to their community's needs and created a new and stronger voice than perhaps ever before.

This report is designed to assess the effectiveness of the events, aggregate findings, delineate stated priorities, and submit recommendations not only for the events themselves, but for future plans for services and supports in Alberta. Above all, it gives voice to participants. For this reason, we recorded the online events. They resulted in 36 hours of conversations with 289 pages of transcripts of breakout discussions and 17 pages of comments from the survey. Quotes in this report (and an accompanying video) are taken directly from participants.

We hope readers will not only benefit from the collective wisdom articulated by stakeholders, but grow in empathy for each others' needs, goals and interests. If successful, this report will spur on the Autism community to take ownership of its place in Alberta and stand up for the supports and services it deserves with the relevant authorities, together improving the lives of the tens of thousands of persons on the autism spectrum and their families across our province.

Yours truly,

A handwritten signature in blue ink that reads "Bill Locke". The signature is written in a cursive style and is positioned above the printed name and title.

Bill Locke, President  
Capacity Builders

# Executive Summary

**Project Title:** *The Future of Autism Supports and Services in Alberta - A Call to Action.* Autism Society Alberta's 2020 Town Halls and Online Survey.

**Project, Goals/Objectives, Activities, Outputs:** Organizers from Autism Alberta and its affiliate Autism community organizations from across Alberta set out to engage the Autism community and its stakeholders to identify common concerns, especially ongoing "access to programs, quality of service delivery, critical gaps in policy, programs and services, barriers to those services, and possible gaps in funding." Autism Alberta also gathered its constituency in an effort to develop practical solutions.

It held two virtual town halls, on Nov. 10 and 12, 2020 and posted an online survey. The town halls involved breakouts based on demographics and asked three guiding sets of questions: 1. Concerns and Issues, 2. Critical Programs and Services, 3. Recommendations for the Future.

**Key Findings:** These events and measures proved to be very successful. They engaged 84 participants in the Town Halls and 65 respondents from across Alberta, including individuals with Autism, family members young and old, Autism community organization staff, and associated professionals. We commend the organizers for doing an excellent job of engaging stakeholders before, during, and after the events. We found that the Autism community is struggling greatly during the pandemic, as everyone is, but with the added pressure of uncertainty related to provincial programs that they feel are critical, and are now on the budget chopping block. There continue to be serious gaps in service for individuals on the autism spectrum, especially those with complex needs. As well, affordable housing is missing for many.

**Recommendations:** The Autism community is adamant that PUF, AISH, FSCD, PDD and Income Supports be maintained, indexed, and improved. Above all, PDD needs to be updated to accommodate persons on the autism spectrum with IQs above 70. Family Managed Services should also be opened up so families can use the funds needed to meet person-centred needs tailored for persons on the autism spectrum. The Autism community also seeks support to build capacity of its organizations to assist in navigation, advocacy and

increased access to supports, especially for families in rural areas.

**Next Steps:** We suggest that the organizers study, evaluate and promote this report, and follow-through on suggestions for improvements in provincial programs.

**Attachments:** In addition to the attachments that go with this report, we have produced a short video with segments from the Town Hall events.

*"So-called 'best practices' or 'evidence-based' programs are actually cookie-cutter approaches which are based on antiquated myths about how to or not to support autistics which are not only inappropriate but can be damaging to complex needs autistics."*

# Background

**ABOUT AUTISM SOCIETY ALBERTA AND THE AUTISM ALLIANCE:** Autism Society Alberta is a nonprofit organization dedicated to improving the quality of life of the Autism community across Alberta. The Alliance is an initiative of Autism Society Alberta. It brings together stakeholders from the worlds of education, supported employment, health, research, housing, sports/recreation, family, and (perhaps most importantly) self-advocates.

**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 and the Alliance is designed 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.”

## **NEEDS AMONG THE AUTISM COMMUNITY DURING COVID-19:**

Though they share the diagnosis of Autism Spectrum Disorder, individuals on the autism spectrum and their families have a wide range of health, education, employment, housing, and economic needs. As this report indicates, these needs have been greatly exacerbated during the pandemic. Those suffering from anxiety and fears due to the usual concerns have often become more anxious and fearful - and for good reason. They have struggled more than ever to access programs and services; wait lists have also increased these past eight months. Many have lost their jobs; incomes have plummeted; some are facing homelessness for the first time in their lives. As a result, there is a dramatic increase in mental health issues, sometimes leading to suicidal ideation and hospitalization.

**ECONOMIC PRESSURES:** At the same time, Alberta’s economy is troubled; unemployment has been on the rise. To make matters worse, the provincial government is facing a large deficit. The Treasury is under pressure to reduce budgets across the board. No ministry is immune from cuts, including Community and Social Services, home of many provincial disability and income support programs. The Autism community, which depends on such programs as AISH, FSCD and PDD, feels that it is on shaky ground.

**OBJECTIVES:** The town halls and online survey provide the Autism community an opportunity to “discuss the future of Autism supports and services in Alberta for all ages (across the lifespan) in the post-pandemic climate...to identify common concerns...to work together to find practical solutions for a brighter future.” Above all, Autism Alberta has united the Autism community to “share our lived experiences to address our own needs, guide our work as a collective community and help build a call for action.” This report sets out to see if these lofty goals were realized, summarize the discussion, highlight priorities set by the Autism community, and bring voice to its recommendations. This report will be used to inform government authorities, community partners and internal program development and strategic direction for Autism societies across Alberta.

“My son has Autism. He qualifies for programs but they don't come out to the Oyen area and I cannot afford to drive back and forth to the city every two days. “

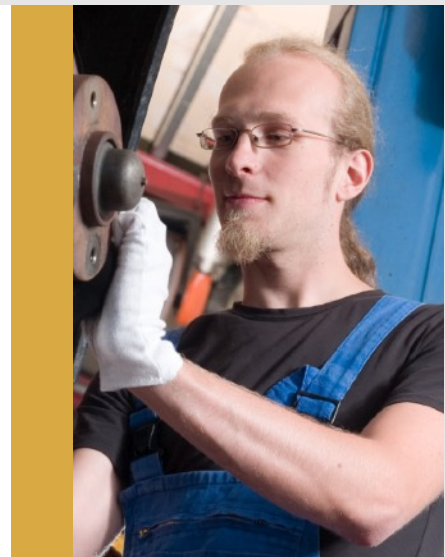


# Background (cont'd)

**FOCUS:** Autism Alberta turned to its constituency to identify common concerns, in particular access to programs, quality of service delivery, critical gaps in policy, programs and services, barriers to those services, and gaps in funding. It also looked to its constituency to identify critical services and supports, and to discover practical solutions which the Autism community could help bring about.

## PLANNING AND EVENT PREPARATION

Under the direction of a Steering Committee, Autism Alberta developed a plan to hold virtual town hall events and an online survey open to all Albertans. The events and survey contained a series of key questions related to concerns, critical programs and proposed solutions. The questions are shown in Key Questions below. Also see Attachments *"Autism Town Halls - 1 & 2 GUIDING QUESTIONS.pdf"* and *"Survey Responses - Future Autism Services Nov 24 2020.pdf"*



**WHAT:**  
We are inviting individuals and families from the autism community to join one of our upcoming Town Halls to discuss the future of autism supports and services in Alberta for all ages (across the lifespan) in the post-pandemic climate.

This is an opportunity to identify common concerns (access to programs, quality of service delivery, critical gaps, barriers, funding...) and work together to find practical solutions for a brighter future.

**WHY:**  
Sharing our lived experiences will help each of us to address our own needs (families and autistics,) guide our work as a collective community, and help build a call for action.

Let's work together to preserve Alberta's established culture of supporting our most vulnerable citizens.

Please register in advance for one of the events using the links below.

Tuesday November 10 12:00-2:00 pm  
[AutismFuture1.eventbrite.ca](https://www.eventbrite.ca/e/autism-future-1)

Thursday November 12 7:00-9:00 pm  
[AutismFuture2.eventbrite.ca](https://www.eventbrite.ca/e/autism-future-2)

## COMMUNITY ENGAGEMENT

This initiative was jointly performed by Autism Society Alberta, Autism Calgary Association, Autism Society of Edmonton Area, Autism Society of the Regional Municipality of Wood Buffalo, Peace Autism Society, and Chinook Autism Society. The collaboration recruited facilitators and note-takers from its staff and volunteers, and provided them with training. (See Attachments *"Autism Town Hall - 1 & 2 FINAL MESSAGING Session plan.pdf"* and *"Autism Town Hall - 1 & 2 Facilitation TIP SHEET.pdf"*) Using social media, email blasts and promotion by partnering organizations, the town halls attracted a total of 148 participants, including 84 in the town halls and 64 in the online survey. (See Attachments *"Autism Town Halls 2020 POSTER.pdf"*)

# Town Hall Events and Online Survey

## VIRTUAL TOWN HALLS

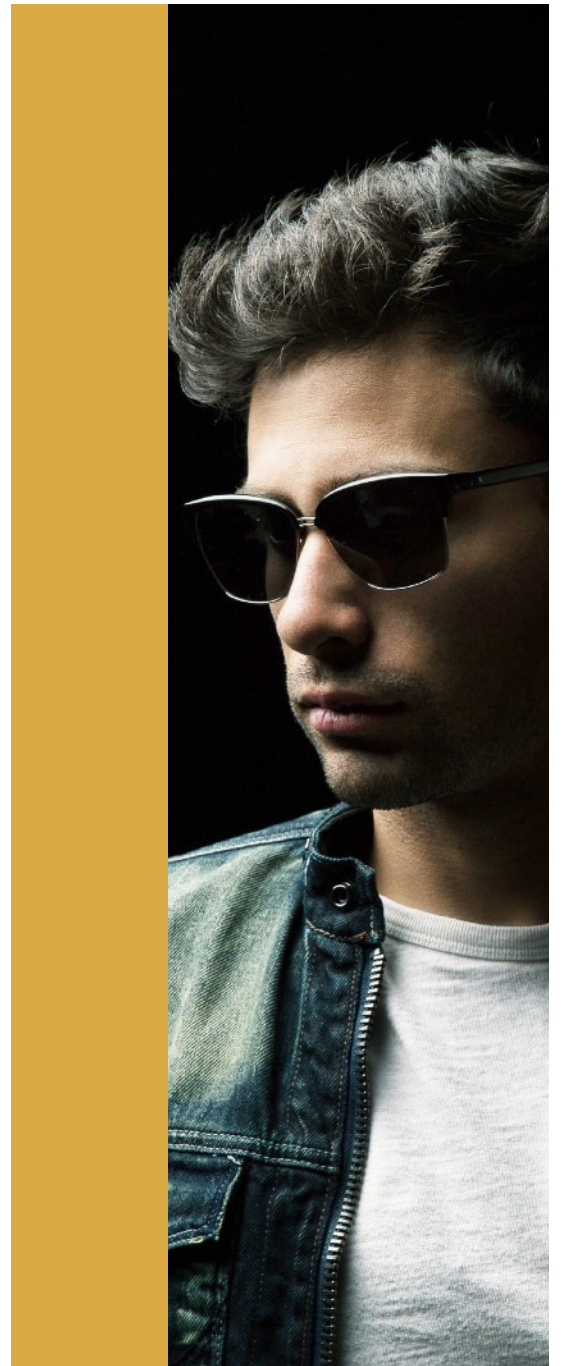
- Virtual town halls were held on ZOOM on Nov. 10 and 12, 2020. Each event was approximately two hours in length, with a short opening and closing statements from Executive Directors from Autism Calgary and Edmonton.
- Each town hall involved simultaneous breakout groups, each with a facilitator and note-taker from across Alberta. Event organizers also floated between breakouts to monitor and support the discussions. All of the statements, breakouts, chat and text were recorded and transcribed. A total of 36 hours of video was compiled.

### Numbers of Participants:

- Town Hall participants: 84

### Breakout Groups: 18 groups, including:

- Toddlers/Early Intervention (Ages 0 - 6) - 3 groups
- Children & Tweens (Ages 6 - 15) - 4 groups
- Youth and Transition (Ages 15 - 19) - 2 groups
- Adult PDD / AISH (Ages 18+) - 4 groups
- Adult Non PDD (Ages 18+) Service - 2 groups
- Autistic Voices (Autistic Individuals) - 3 groups



## ONLINE SURVEY

- The survey was collaboratively developed and administered by The Sinneave Family Foundation.
- Participants: 65
- See Attachments: *"The Future Autism Supports and Service Survey.pdf"*



# Guiding Questions

## VIRTUAL TOWN HALLS

### 1. CONCERNS

- What are your current concerns since the pandemic and/or recent changes to programs?
- What are your challenges related to longer term problems with systems of support? (eg., gaps, access, barriers)
- What are the impacts these challenges are having on your quality of life? (eg., basic needs like food, restricting growth towards more independence, mental health)

### 2. CRITICAL PROGRAMS

- What program do you feel is critical and should not be changed? (Share a success) i.e. AISH, FSCD, PDD, Income Supports

### 3. RECOMMENDATIONS

- What recommendations do you have for addressing your biggest challenges?
- What programs or program changes are needed to address gaps? (helping autistic individuals to be able to contribute meaningfully and/or become more functionally independent)
- Where are some areas for efficiency to allow limited funding to offer greater support for more people (how can we find ways to increase efficiency in Alberta's needs-based system)?

## ONLINE SURVEY

### 1. CONCERNS

- Are you currently on a wait list for services?
- How would you rate your ability to access current programs and services?
- How much difficulty do you or your child/adult have with completing their daily activities?
- Use of disability-related provincial program funding, including
  - Education: PUF (Program Unit Funding)
  - Community and Social Services programs:
    - FSCD (Family Support for Children with Disabilities)
    - AISH (Assured Income for the Severely Handicapped)
    - PDD (Persons with Developmental Disabilities Program)
- What are your current concerns since the pandemic and/or recent changes to programs?
- Describe your challenges related to longer term problems with systems of support (e.g., gaps, access, barriers)
- What are the impacts these challenges are having on your quality of life? (e.g., basic needs like food, restricting growth towards more independence, mental health)

### 2. CRITICAL PROGRAMS

- What program do you feel is critical and should not be changed?

### 3. RECOMMENDATIONS

- What recommendations do you have for addressing your biggest challenges?
- What programs or program changes are needed to address gaps? (helping autistic individuals to be able to contribute meaningfully and/or become more functionally independent)
- Where are some areas for efficiency to allow limited funding to offer greater support for more people? (How can we find ways to increase efficiency in Alberta's needs-based system?)

# Responses

## VIRTUAL TOWN HALLS AND ONLINE SURVEY

For the sake of brevity, we have combined the responses from the Town Halls and Online Survey into this short summary:

### 1. CONCERNS

- **WAIT LISTS:** 42% of respondents are on wait lists for services
- **ACCESS AND NAVIGATION:** 66% found it difficult or very difficult to access current programs and services
- **DAILY LIVING:** 95% of persons on the autism spectrum who responded have some level of difficulty completing their daily activities
- **PUF:** 47% are ineligible for PUF funding
- **FSCD:** 53% are eligible for FSCD funding
- **AISH:** 53% applied for and were rejected or are ineligible for AISH
- **PDD:** 47% were ineligible for PDD. 13% were unaware it existed.
- **FINDING EFFICIENCIES:** Many are very concerned about cuts to critical programs. There may be better use of funds, but do not cut.
- **FAMILIES:** Families providing care are burning out; many struggle to handle their FMS administrative and management duties which are time-consuming - this prevents them from working and getting paid; aging caregivers cannot sustain their efforts. Current approach for use of FSCD and FMS program dollars prevents families from using funds to support admin/management duties, address person-centred needs, customize strategies or access relevant programs and services
- **SERVICE PROVISION:** Many individuals on the autism spectrum and their families were dissatisfied with quality of services and lack of transparency at agencies. Sometimes, service is unavailable due to lack of staff.
- **HOUSING:** Few individuals on AISH can find affordable housing: many feel they are at risk of homelessness
- **MENTAL HEALTH:** increased anxiety and depression during the pandemic. This stems in part from uncertainty of critical program funding especially AISH.
- **RURAL AREAS:** Lack of access to programs and services in rural areas
- **PROGRAMS OUT-OF-DATE:** PDD eligibility based on IQ neglects the vast majority of persons on the autism spectrum who feel they should qualify.
- **COMPLEX NEEDS:** Individuals on the autism spectrum often have mental health issues. Though complex needs cases receive 70% of PDD funding, often the Autism individuals among them lack customized services, have difficulty accessing the specialized services they need.
- **STAFF TRAINING:** Special training is needed by all frontline staff dealing with complex needs individuals
- **EMPLOYMENT:** 85% of individuals on the autism spectrum are unemployed. Though they may be receiving Income Supports, AISH and PDD, they feel their employment potential is overlooked. Many want to work, at least part-time, and need the additional income.
- **LIMITED INCOME:** Many individuals on the autism spectrum and families struggle to pay their bills.
- **ABLEISM:** Many individuals expressed concern that they are systemically discriminated against, not only in provincial programs, but by society at-large.

*"When I hear that the provincial government wants to "find efficiencies" it makes me afraid."*

*"We are very concerned about reduction in support for PUF and FSCD."*

*"If program funding is decreased, it will result in fewer supports, which we direly need."*

*"The lockdown has been very stressful. We are exhausted from the pandemic."*

# Responses (cont'd)

## 2. CRITICAL PROGRAMS

- PUF
- FSCD
- PDD
- AISH
- Income Supports

## 3. RECOMMENDATIONS

- CRITICAL PROGRAMS: Do not cut any of the above programs.
- FINDING EFFICIENCIES: Maintain and index these programs but make better use of the funds within the totals. For example, move funds allocated to individual clients (especially complex needs) out of Agency Managed Contracts to FMS agreements and give control to families to make better use of funds at a lower cost.
- FAMILIES: Increase funding to families to assist in administration and management efforts
  - Provide simple enterprise management software and training to use the software to all FMS families
  - Open up FMS to allow families to contract out direct services to nonprofit, service providers and companies
  - Give discretionary control of funds to families so that they can use program funds, including PUF, FSCD and PDD as needed
- WAIT LISTS: Decrease wait lists by simplifying the approval and intake process and by speeding up access to programs. Decrease overall spends as described above to make room for those on waiting lists.
- ACCESS AND NAVIGATION: Build capacity of Autism community organizations across Alberta so they can assist in visioning, planning, navigation, linking and advocacy for Autism individuals and families to obtain needed services
  - Provide core funding to these organizations to play this critical role
- SERVICE PROVISION: Approve and accept more qualified service providers. Create a free-market approach to services so families can shop for and find bespoke services. Increase transparency in service provision by agencies.
- PROGRAMS OUT-OF-DATE: Open up eligibility for PDD so that persons on the autism spectrum whose IQ is over 70 can qualify.
- COMPLEX NEEDS: Support innovative and specialized services tailored to the needs of individuals with mental health issues.
- MENTAL HEALTH: increase funding for respite for families
- STAFF TRAINING: Increase training for frontline workers, including FMS and Service Provider employees
  - Require specialized training for frontline workers with complex needs individuals
- ABLEISM: Address the systemic issues which trample on individual rights to meet basic needs such as health, education, shelter and inclusion. Train and pay advocates in all regions of Alberta.

*“Families need discretion over use of their funds in PUF, FSCD and PDD.”*

*“I am a family support worker with one of the Autism organizations. We have been working on some wellness calls and hearing a lot of concerns from some of the families.”*

*“I work at Autism Calgary. We are currently involved in a project with Scouts Canada where we are working together to help set up templates to launch Autism friendly scouting troops across the country.”*

# Findings

## OVERARCHING SIDE-EFFECTS OF THE PANDEMIC

There are a number of concerns that surfaced again and again in the Town Halls and Online Survey. The single biggest issue facing all participants in the past year is the pandemic. It has had an overarching effect and accelerated long-standing pressures on people on the autism spectrum and the wider community. As Maayan Ziv, CEO of AccessNow, and a self-advocate for the disabled puts it, almost everyone is struggling during the pandemic:

*“It’s hard on everyone. People with disabilities and their families are hit even harder and that story is not widely known. People who have had to isolate from loved ones in order to limit the risk of exposure, or those unable to get basic needs met due to new financial constraints or gaps in care are in a real bind.”<sup>1</sup>*

*“The pandemic shut down most of the social supports that I had access to.”*

*“I think the community is struggling to be able to navigate through the system, get somebody to answer the phone and to be able to move forward.”*

## BARRIERS TO ACCESSING SUPPORTS AND SERVICES

COVID-19 has created additional barriers, hindering access to supports and services not only in the social services sector, but also in health care, education, employment and the economy. That includes something as fundamental as being able to access the crucial information people on the autism spectrum need to obtain food, shelter, medical care and transportation.

## THE ROLE OF FAMILIES

Disability places a set of extra demands and pressures on families, including a financial burden to cover additional costs for health, education, psychological and social services; buying or renting equipment and devices; making accommodations to the home; transportation; medications; and special food. Families in Alberta that qualify for financial support from such programs as PUF, FSCD and PDD are very fortunate. But financial burdens are the tip of the iceberg. In the current system, FMS agreements pay little or nothing to families to administer and manage the operation. It is vital that families be supported financially to cover this ongoing effort, but beyond that, they need social, emotional and physical supports to maintain a healthy lifestyle and partnership.

Families that play this significant management role would benefit from FMS training, especially to recruit, train, manage and retain staff. Enterprise management software and training in the use of this type of technology would also help.

*I have a son who is 27 years old. He receives PDD supports. He shares an apartment with another young man with staffing supports around the clock provided by an agency and when COVID started, families were asked if they were able to bring their family members home so he came back home...*

# Findings (cont'd)

## SENSE OF ISOLATION - AND REJECTION

Isolation has also increased. Caregiving staff and their supervisors have had to limit contact, sometimes for longer terms. Persons on the autism spectrum and their families are in more of a bubble than before. Transportation, especially for individuals and families in rural areas, continues to be an issue.

Together, these problems make many people on the autism spectrum and their families feel as if they've been forgotten. As Ziv says,

*"It reinforces this feeling of being kind of left behind, excluded and rejected by society. We live in a world that's filled with ableism and biases against the disability community. Disabled people's lives matter."<sup>1</sup>*

*"I've been spending too much time at home right now, and that's increasing the conflict that I have, between trying to care for myself, but not succeeding very well, and trying to be a care partner for my mom."*

## DIVERGENT NEEDS AND CONCERNS

Some persons on the autism spectrum live more or less independently with little or no outside support, and can get by quite easily. Others need in-home and out-of-home support frequently. Income may be the single most effective and adaptable tool for providing services. It pays for access, security, and a decent place to live. It doesn't buy inclusion or friendships or self-acceptance, but it deters the practical effects and some of the barbs of ableism. In difficult times as these, funds can prevent inconvenience from becoming a life-threatening crisis.

Funding can buy and deliver groceries, pay to play online games, provide some companionship and keep a person sane during extended lockdowns.

We cannot forget that a great many persons on the autism spectrum have limited to no income, with little to no flexibility. Very few have savings for emergencies. Most programs that provide a secure income for disabled people, like AISH, CPP-D, Income Supports, don't allow them to save, even for emergencies. But these programs are critical for day-to-day needs, be they food, rent, social engagements and peace of mind. The risk of losing these sources of ongoing support creates untold fear and trembling.

*"COVID isolation caused many regressions in our son with autism."*

# Findings (cont'd)

## COMPLEX NEEDS

This is, as would be expected, a very complicated subject. There are many gaps in understanding, medical treatment, disability services and ongoing supports for persons with complex needs, especially to address lifelong mental health issues. But it is a growing population, and the current funding approaches cannot be sustained. This population's needs must be addressed.

## IMPORTANCE OF EMPLOYMENT

It may seem counterintuitive, but the most obvious way for persons on the autism spectrum to obtain income and build wealth is to work. This is a possibility in spite of the fact that 85% of adults on the autism spectrum are unemployed. We too often forget that people are not defined by their disability; they are people with a disability. Often, they have valuable abilities - and training, skills, credentials, dispositions, and unique talents - that make them as or more valuable to employers and society than "neurotypicals."

No disabled person is entirely powerless or without advantages - in this pandemic and afterwards. It's true that some face more barriers than others, and not just medical, but there are nevertheless proven ways to empower, equip and employ a significant number of the Autism community.

## ABLEISM

As we stated in the 2020 Autism Alliance report, "persons on the autism spectrum 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 to. In fact, they want to be in a position of equity with others."<sup>3</sup>

As Autism pioneer Dr. Temple Grandin puts it, persons with Autism are "different, not less." Some adults on the autism spectrum have led a neurodiversity movement that celebrates autism as a natural variation of the human condition and opposes efforts to cure it. These advocates prefer supports and accommodations for people on the autism spectrum, rather than treatments that would erase harmless autistic behaviors.

Though self-advocates are few in number, as this report found, they are growing in number and strength. Self-advocates are taking responsibility and are assertively making change; they are advocating for themselves and others like them, seeking to bring fairness and real inclusion.

*"We have been waiting several months for FSCD to give us a case worker so that we may get funds for our child. Our 19-month old child needs services now. As of yet, we are told there is no estimated time in which we may be responded to."*

*"I am having major difficulties finding programs that are still running due to COVID-19."*

# Findings (cont'd)

## PLACE OF EMPATHY

Somehow, in the past year we have all found ourselves in the same boat. COVID-19 has hampered access to supports and services and increased isolation for everyone. Fortunately, there is a positive spinoff: it also seems to be shifting the population toward a strange new kind of empathy. Hopefully, the pandemic will forge a new source of kindness, compassion and understanding. Previously, when persons with disabilities sought special accommodations it was considered too much to ask for. Today many of these requests may be taken seriously.

Members of the Autism community have the opportunity to use this time of widespread frustration to fuel the changes that have been long sought for.

*“The Autism community needs its own voice at the table with the provincial government.”*

## INCREASED DETERMINATION AND SELF-ADVOCACY

Persons on the autism spectrum, especially self-advocates, seem to be increasingly aware of the opportunity for change in Alberta and are becoming more assertive on behalf of themselves and others on the autism spectrum. This includes something as simple as knowing their rights, objecting to something that makes them uncomfortable, expecting fair treatment, having their opinions heard, and seeking explanations for policies, programs, services and use of funds that do not seem to make sense. This is particularly true for provincial programs and services designed to assist persons with disabilities.

People with disabilities are often overlooked, especially when it comes to policymaking during difficult times as we are experiencing in Alberta. Members of the Autism community, especially self-advocates, want policymakers to deepen their understanding about the world of Autism and include people in that world to deter discrimination, and ultimately to overcome ableism, especially during the pandemic.

*“Where I think this is going is developing skills, taking a proactive stance and developing self advocacy, and strengthening the advocacy effort of the Autism community.”*

“It is very important for people to support their disabled family members, friends, clients, and colleagues during this time. In addition to the ubiquitous stress of the pandemic, people with disabilities face additional stress and trauma due to the devaluation and discrimination against people with disabilities that occur during times of crisis.”<sup>2</sup>

# Recommendations

## ACTIONS

**COMMUNITY ENGAGEMENT:** First of all, we recommend that the Autism Society Alberta and the Alberta Alliance continue to engage the Autism community and stakeholders across the province to share their concerns, identify priorities, and propose actionable strategies that can be applied.

**PUBLIC AWARENESS:** Secondly, step up public awareness about the autism spectrum, not only its issues, but also its solutions as described here. This includes a realistic and up-to-date portrayal of life on the autism spectrum, and its challenges, exposing myths and promoting opportunities and role models. It also includes the rights and responsibilities of citizens to health, education, employment and social services. Finally, the public needs to know the critical issues facing the Autism community.

**ADVOCACY:** Thirdly, we recommend a targeted advocacy campaign to reinforce the importance of maintaining, updating and improving critical programs, especially PUF, AISH, FSCD, PDD and Income Supports.

**CAPACITY BUILDING:** Finally, we recommend that Autism Alberta, Alberta Alliance and the regional community associations such as Autism Calgary and Autism Edmonton continue to grow and fulfill their role as the voice, support, and champion of individuals with Autism and their families.

This includes increased collaboration and creation of strategic partnerships within and between government departments to implement priorities identified by Autism communities for the purpose of:

- Expanding programs and services to every region, especially rural areas
- Enhancing navigation and access to those services
- Maintaining, updating and improving PUF, AISH, FSCD, PDD and Income Supports.,
- Developing advocacy efforts such as leadership training of self-advocates
- Establishing permanent funding to support the intermediary role that Autism Alberta and its affiliate community organizations play for individuals and families on the autism spectrum

The future of Autism supports and services depends upon it.

**Community  
Engagement**

**Public  
Awareness**

**Advocacy**

**Capacity  
Building**



# Next Steps

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We propose that Autism Alberta and the organizers of the Town Halls and Online Survey set up an Action Plan to study, evaluate and promote this report. We also suggest that the Action Plan take steps to implement the recommendations.

# Acknowledgements

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- Lyndon Parakin and the staff and volunteers at Autism Calgary Association
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- Ken Fast, Northern Rain Studio
- Other Town Hall contributors

# References

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1 *Accessibility: What we can learn from the disabled community during COVID-19. Podcast Interview with Maayan Ziv, CEO AccessNow on This Matters, with Irene Gentle, Editor, The Star, November 27, 2020*

2 *Fighting for the Disability Community During COVID-19: An interview with Drs. Emily Lund and Kara Ayers on ableism and coronavirus by Jamie D. Aten, Psychology Today, July 21, 2020*

3 *Autism Alberta's Alliance 2019, A Call to Action by Bill Locke, December 10, 2019*

# Contact

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# Attachments

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## Marketing

- Poster/Program: "Autism-Alberta-Alliance-Event-2019-POSTER & PROGRAM.pdf"

## Key Documents

- "Autism Town Halls - 1 & 2 GUIDING QUESTIONS.pdf"
- "Autism Town Halls - 1 & 2 FINAL MESSAGING Session plan.pdf"
- "Autism Town Halls - 1 & 2 Facilitation TIP SHEET.pdf"
- "The Future Autism Supports and Service Survey.pdf"
- "Survey Responses - Future Autism Services Nov 24 2020.pdf"
- [Town Hall SURVEY Future of Autism Supports & Services in AB Nov 2020](#)

## Video

- "The Future of Autism Supports and Services in Alberta - A Wake-Up Call" - 4 min