

2019 CASDA Leadership Summit: Looking back, Looking Forward Session Highlights

At the 2019 CASDA leadership summit, Springboard Policy facilitated a workshop for all attendees to reflect on how the CASDA network's strengths, successes, and spaces for improvement, especially regarding public policy. The session included roundtable discussions and participants completed worksheets to capture their insights.

Key themes

The feedback we heard during the discussions and collected through the worksheets was varied, but some clear themes emerged.

Many participants are just learning about CASDA's public policy work for the first-time.

While a minority of participants (some of whom identified as board members) described themselves as actively involved in CASDA's public policy work, many reported that they were just learning about CASDA's policy work at the summit or in the past few months.

Participants are supportive of the Blueprint and CASDA's policy direction.

Most comments about the Blueprint emphasized that it was a helpful contribution and broadly in line with their priorities. While some highlighted areas for improvement or further development, most expressed that it is a good first step and headed in the right direction. Many participants did, however, raise questions about how CASDA could better incorporate member input, in particular for the voices of self-advocates.

Participants want more opportunities to hear about — and be involved in — CASDA's public policy work.

Participants mentioned having little awareness of what CASDA is doing between summits. Overall they want more opportunities to engage and mobilize the network. Specific ideas included regular communications with members (monthly or quarterly updates); broader communications (social media, etc.) to get the message out about CASDA's work; and supporting regional or issue-based networks within the membership. Recognizing the limits

of volunteer time, some suggested full-time staff or dedicated external supports. Some specifically raised questions of how the Blueprint was developed, with the term “transparency” used multiple times.

CASDA members see public policy as important to their mission but have gaps in their own public policy capacity.

A strong majority (73%) of respondents described public policy as “very important” to their mission, but only 19% reported having significant capacity themselves/in their organization to influence public policy. Participants see a valuable role for CASDA to keep them informed, develop research and recommendations, and represent their interests. Many felt uncomfortable personally or professionally engaging in advocacy and saw CASDA as helping to provide a voice.

The work to land a National ASD Strategy does not stop with the election.

Even if all parties were to make clear commitments to the Blueprint in their platforms, participants saw an important role for CASDA in 2020 and beyond to advise on and recommend policies, hold government to account, and convene the stakeholders and experts from across the network.

Participants want more voices to be actively included.

Many participants encouraged CASDA's leadership to embrace stronger engagement from self-advocates in the network. Some respondents highlighted the need for funding to support the participation of self-advocates, particularly those coming to the summit from Western or Northern Canada. Participants also encouraged stronger outreach to military communities, under-presented ethnic groups, LGBTQ groups, and autistic youth. Some participants highlighted the importance of bilingualism to include French Canadians.

There are a number of potential alliances for CASDA that extend beyond the ASD community.

Other disability advocates, school boards, and seniors/long-term care service networks were among those highlighted by participants as potential allies that have not been brought into the conversation. Participants also highlighted clinicians and service providers working with people with ASD including the Canadian Pediatric Society, ONTABA, and Military Family Resource Centres.

Summary of Worksheet Responses

What follows are summaries of both the ranked responses, and a representative sample of the written comments we received on the worksheets.

Where has CASDA's work on public policy been most important for you/your organization? (rank)

1. Connecting a national network (Leadership summits, CAPP)
2. Research and information about ASD to inform policy (e.g., National Needs Assessment)
3. Developing public policy recommendations
4. Building relationships with political leaders
5. Keeping the network informed about national developments

How important is public policy change to your mission? (86 respondents)

- Not important – 0%
- Somewhat important – 27%
- Very important – 73%

Note: some respondents noted that they were referring to provincial public policy

How much comfort and capacity do you have to influence public policy? (91 respondents)

- Very little – 33%
- Some – 48%
- A lot – 19%

What are your (or your organization's) greatest strengths for public policy engagement? (rank)

1. Personal or professional experience/expertise with ASD
2. Network of people to show support for public policy change
3. Special skills - communications, design, advocacy experience
4. Relationships with decision makers (politicians, public servants)
5. Time to dedicate to public policy engagement

How aware are you of the work CASDA has been doing to influence federal public policy?

- Not very aware.
- Hard to know, seems to be the same players saying the same thing year-to-year.
- Not very, not sure what steps have been made.
- Well aware.
- Apart from today's press conference – not much.
- Aware (actively involved in CASDA).
- Minimally aware. Keeping network involved = major weakness. Not seeking stakeholder input enough.
- Aware of the Blueprint but not how it was developed.
- Just learning.
- Became aware in the last two months.
- More in the past month, although admittedly not much.
- Have participated in CASDA summit every year and in CAP consultation meetings.
- Very.
- Not very – until today.
- Somewhat aware.
- Somewhat - dramatically increased today.
- Not very - short of what I learned today.
- Not well-informed about what has been accomplished to-date, I would like to be going forward.
- Very little – could briefing notes quarterly be helpful?
- I'm very new but website has great information.
- Somewhat but the process has been opaque.
- Just from this summit (my first).
- Only through the summit.

Do you feel as involved as you'd like to be in CASDA's public policy work?
What could be different?

- I'd like to do more.
- Ongoing updates about policy work.
- We would like to see a military representative in the policy work, someone from military family services.
- Lot's good but it might be necessary to engage provinces.
- This Blueprint will give easy access points.

- We could have a lobbyist to work for us each month/week.
- No. increased involvement would be ideal earlier in the process. Improved transparency.
- No, I think that researchers could be better engaged in supporting public policy work, should be involved earlier on; transparency.
- Not at all. There should be a network created.
- Transparency could be improved.
- Would like to be involved more.
- I would need to learn more, but I would like to be involved.
- Yes - current priority areas are slightly outside of our organization's focus.
- Yes.
- Would be interested in becoming more involved.
- Would like to be more involved.
- More open invitation to individuals rather than agencies.
- Not as much as I would like to be.
- I feel I have had a voice and been kept informed.
- If regular materials were sent out I could engage my local MP a bit more.
- Yes – I'm satisfied but most likely would not be if I didn't have a member of my team on the board to remain informed.
- Increased member engagement through surveys and consultations.
- More consultation with stakeholders.
- There is very little connection between leadership summits; need lead-time in communication.
- Would like to see interest/priority-focused advisory groups meeting every 2-6 weeks, feeding into and supporting public policy initiatives.
- Could see more surveys or stakeholder engagement sessions, regional engagement.
- Regional collaborations/exchanges every 2 months post CASDA.
- No. I think CASDA should improve ongoing consultation in local communities.
- More interviews like this one sent to members to gather info on important questions and get ideas.
- Maybe a monthly update e-mail would be helpful.
- I would like more frequent updates.
- First time attending the summit, would like continued involvement.
- We need more education to be advocates for our patients.
- Could benefit from military representation.

What do you think about the direction CASDA has taken in trying to influence federal public policy?

- I think it's very well thought out and most needed.
- Direction on bringing an action plan has been lacking. Statements of research and needs are good.
- Good, room for improvement.
- Full support.
- Great direction.
- Not sure what strategy they are following, what about a monthly newsletter?
- Appreciate the conciseness of the Blueprint.
- Remarkable, CASDA is making great progress in having voices and experiences heard.
- Need more members involved.
- Very supportive – practical, clear messages and plan but need to ensure appropriate resourcing.
- There have been breakthroughs that deserve highlighting – to paint a picture of the journey; perhaps more representation of self-advocates/parents whose urgency is a sense of power.
- Great starting point for a national strategy.
- Good, I like the Blueprint that was shared today.
- Good but not transparent enough.
- Blueprint is much better than previous CAPP proposal but no idea how it was developed.
- A step in the right direction.
- Blueprint is a good approach/good draft: need consultation to demonstrate broader input/support.
- Move in the right direction.
- Great job, very grateful for CASDA's hardworking volunteers.
- Very pleased!
- Seems excellent.
- I am really happy that CASDA is taking a leadership role in this as it is something I do not feel the most comfortable doing but support it.
- To be commended – there is too much of a difference across the country in services, affordability and opportunities for people with ASD and their families.
- I like the proposal described today.
- Has seemed open and direct.
- Blueprint addresses my priorities.
- Very positive!

- I think they are moving forward, making progress and being more strategic – perhaps the next step is proposing national standards.
- Very good, happy to see Blueprint.
- Overall good but missing self-advocate view.
- I think that it is moving in the right direction.
- It's a tough job and I'm glad CASDA has not only taken it on, but committed to meaningful inclusion of autistic voices.
- Needs more implementation plan development.
- I think the Blueprint is solid and well-thought out.
- I think we are headed in the right direction.
- A good start.
- I feel very positive about the approach and how its laid out for others to help with the movement.
- I admire the concerted effort to bring knowledge about how to influence policy and combine with expertise within the CASDA member organizations.
- It is time for another national needs assessment. The last was in 2014, I doubt if any member can remember the % results.
- Considerable record of successes – surveillance, research chair, needs assessment survey, CAPP, RWA, Worktopia.

What isn't CASDA doing today that you would like to see? What is working well? What's not working?

- More in the public eye so the lay-person knows about CASDA.
- Focusing on a truly Northern/territorial strategy.
- Focus on concurrent ASD & ID.
- Military representation, challenges to military families.
- I would like them to connect more rather than try to stick out. I think needs cross disabilities and can benefit different populations as well.
- Big strides in last year in growing engagement of autistic leadership.
- Another needs assessment, some practical service to relieve ASD symptoms.
- Regular communication with members – monthly newsletter.
- Need more member engagement, increased communications.
- Always need to find ways to increase communication with members and stakeholders.
- Including perspective of military & RCMP families under federal health care.
- Increased stakeholder engagement to keep community aware of activities.
- Broader consultation.

- Should be transparent with all the steps in the process of working with the federal government.
- Needs to be transparent across the process not just when the document is ready.
- Coordination/organizing summit with enough advance material and notice to adequately justify requests for travel to allow participation: more comprehensive agenda earlier and potentially greater opportunities for participation would help.
- Better bridge-building with other ASD organizations in Canada – to get back to working together and not at odds.
- More contribution from self-advocates and involvement in developing the conference.
- More representation from diverse communities.
- More representation from Quebec.
- Look to seniors care.
- It is so important to involve lived experience at every level. Challenge is the level of anger and disrespect show to parents of very vulnerable children.
- Keeping an informed registry of services available to individuals on the spectrum.
- People involved “doing” CASDA off the side of their desk – need for paid position?
- I know it has been a struggle – I would like emails from time to time on your efforts – once a year at the summit is not enough. Transparency!
- Most of the work seems to focus on the yearly conference. Great but more regular communication/advocacy materials would help.
- Increased focus on social media and communications to get the word out about your good work!
- Greater involvement in local, grassroots events.
- Improve inclusion of self-advocates.
- Focus on dissemination of research so it can reach correct end user in a timely fashion.
- Needs to be bilingual, inclusive of QC.
- Better engagement of ethnic groups that don't have enough ASD advocacy.
- Mobilize the CASDA membership.
- Find ways to bring the voice of those with higher service needs.
- I'd like CASDA to give a voice to the autistic youth and gain this perspective on their lived experience.
- More ethnic diversity at the summit, and more funding to bring self-advocates, including from the territories.
- More highlighting of self-advocate perspectives at the conference.

If all federal political parties were to commit to a National ASD Strategy in their platforms this year, what should be the role of CASDA in 2020?

- Make sure they are delivering and help create new policy.
- CASDA should be the lead and primary consultation group for delivery of the strategy.
- Hire a motivated marketing person and charge the provinces, marketing the plan to stakeholders; Keeping the momentum up; Reports on progress + stories of success; Strategic meetings with feds.
- Get the media to assist and become the national advocate.
- Tracking implementation.
- Better representation of ethnic backgrounds; inclusion of more self-advocates.
- Lead role with gov't, co-develop communications and community engagement; be part of accountability and outcomes measurements.
- Disseminate ASD Strategy to the Provincial ASD organizations.
- To continue to provide expertise and guidance and hold government and political parties accountable; to assist other jurisdictions across Canada if needed.
- Monitoring progress, co-implementation, producing report cards?
- Convene necessary expertise – bring the right people to the table. Researchers (not just the same ones) self advocates, feds + provinces.
- Ensure that there is adequate and meaningful consultation for all stakeholders across Canada.
- Reach out to the network/community, solidify the goals, make checks and create a plan to ensure the strategy is carried out properly.
- Push for a provincial Blueprint.
- A leader in providing info from stakeholders, proposing recommendations and next steps, and validation of the process.
- Continued advocacy, look at mental health and ASD.
- Keep up research (e.g. population changes, seniors, mental health, staffing challenges).
- CASDA is in touch with people on the ground and the strategy will always need input from people on the ground.
- Continue to provide data and understanding of the issues.
- Consensus of CASDA members – no small task.
- Be a resource to connect to people with ASD and professionals in the field.
- An advisory group to the Minister and ADMs, a unified national voice.
- Push for follow-through, keep parties accountable.
- Walk alongside stakeholders and hold government accountable for promised funds and services.

- Continue to take the pulse of community to identify priorities, hold government accountable.
- Help the federal government set priorities around each identified area.
- Continuing to develop public policy recommendations – the Blueprint is just the start.
- Media spokesperson for “hot” autism issues – like Ontario OAP, etc.
- Development of long-term strategy (past changes of government).
- Follow up on outcomes/actions.

Who are some potential allies for the ASD community that we have not yet brought into the conversation?

- Possibly a celebrity spokesperson.
- Indigenous leaders and families, provincial network.
- Community living/James Janeiro; David Lepofsky; Bob Rae; John Tory; Pam Damoff (ON); John Barlow (AB), Brian May (ON).
- MFRCs; seamless Canada, MFS.
- Other kids w other disabilities - competition can breed ill will.
- Mayors of large cities.
- All neurological health charities, CACL, teachers.
- Mental health field, work force leadership.
- Provincial and territorial governments; private sector.
- Education system (although provincial input is important in terms of programs classes, supports etc.); teachers, Education Ministers, school psychologists.
- Researchers.
- Journal publications.
- Teachers/teachers unions, military families.
- All other developmental groups.
- (unsure if these are already allies) More involvement from schools, medical offices, law enforcement (help them be more familiar with neuro-diverse people).
- Other people/communities who support quality of life (recreation, arts, mental health).
- Reseau National en Trouble du Spectre de L'autisme (RNETSA); Gabrielle Sabbagh.
- Connect with long-term care/aging population.
- Staff serving high-needs individuals.
- Seniors care facilities, employers.
- ONTABA.
- Shift in focus to think not only of autism-specific needs but also liaising with functional needs and supports: communication, socialization, mobility, living arrangements.

- School boards [mentioned multiple times].
- Other neurodevelopmental disability groups.
- Municipalities.
- Civil rights/human rights groups.
- Unions.
- Colleges/universities.
- Pacific Family Autism Network.
- Employers who are successful at hiring people with ASD.
- French-speaking community and new Canadians.
- Parents of older adults with ASD.
- Autistics for Autistics.
- Ontario Autism Coalition.
- Professional associations.
- Religious organizations.
- Temple Grandin.
- Geriatric specialists.
- Transport consultants.
- Potential for a more direct involvement with the Canadian Pediatric society Developmental Pediatrics Section – many of the physicians involved with diagnoses and early management are there and deal with a lot of the advocacy issues.
- Human rights/issue lens helps to unify rather than fragment based on diagnosis.
- Military Family Resource Centres.

What else do you want CASDA to know?

- Need to be informed by grassroots, have a provincial/territorial networking unit.
- Thank you, thank you for bringing the external policy think tank people to the table! This is very important, encouraging, a place from which to advocate.
- More partnerships, unique challenges of military lifestyles (transient, separation, access to healthcare, different waitlists in different provinces).
- 74% of the needs assessment responses indicated a need for more physical activities – could CASDA promote this item?
- Keep building on this momentum.
- Focus on equitable and consistent treatment programs across provinces; shared standards between provinces; national standard of treatment, make families more aware of the work and purpose.
- We want to be consulted! Please reach out in advance of publishing/launching documents/strategies.

- Focus on issues under federal jurisdiction. Develop standards for provincial jurisdiction.
- Thank you for your fierce dedication.
- “When you meet one person with autism, you’ve met one person with autism” is an important message but increasingly a barrier to action – as it makes it easy for policymakers to say there can’t be a national approach.
- Avoid duplication with AIDE hubs.
- An innovative new practices presentation would be a fabulous addition to the conference.
- Going forward there may be a need to add a keynote speaker or other PD opportunity to keep people coming back.
- Increase profile on social media – can apply for a Google ad grant.
- There could be improved communication with members to keep them informed – beyond the leadership summit, which is not enough if the public policy work picks up and consumes and (benefits from) your time and talents.
- Great to see renewed focus on public policy.
- Establish a provincial and territorial council since none of the other national autism agencies seem too interested.
- It is hard for people from Western Canada to make it to the conference – especially say a single parent without support from an organization.
- CASDA should be involved with local events in every major urban centre.
- Venues for consultation are often not autistic-friendly.
- For Blueprint: reform CPP to relieve penalty of caregiving impact for parents, financial reward for caregivers and life supports for caregivers.
- Beyond posters, organizations should have a booth to share info.
- CASDA leadership summit should have more self-advocate speakers, they need funding help for their travel.
- Think about some focus on transitions, especially of when caregivers become too old or the person with ASD becomes elderly. Topics regarding gender and sexuality/sexual health are worthwhile.
- Just a suggestion to not have long presentations during panels please.
- Issues unique to military lifestyles – transient; inter-provincial issues, waitlists.