

OCT.06.2021

**CANADIAN
AUTISM
LEADERSHIP
SUMMIT**

**EVALUATION
REPORT
2021**



CASDA ACTSA



Dear CALS2021 attendee,

Thank you for joining us at the 7th Annual Canadian Autism Leadership Summit (CALS2021) on October 6, 2021, an initiative of the Canadian Autism Spectrum Disorder Alliance (CASDA).

Over the course of this conference, dynamic and through-provoking conversations took place. There were countless stories of meeting new people, engaging with different perspectives and learning new ideas. This illustrates the strength of our community.

This year, we heard presentations on: Visioning a National Autism Strategy, The Need for an Autistic-led Equity Journal, Navigating Language Use in Autism, and Moving from Strategy to Policy. We focused on themes that would support the federal government's development of a National Autism Strategy.

In this report, you will learn about who attended, what people thought of the content of this year's Summit, opinions on each session, and highlights from social media. We summarized the responses in the report but also appended the full results at the back of the report.

At CASDA, we love to hear from you, the community, as we move your ideas, concerns, and suggestions forward to support the government's development of a National Autism Strategy.

If you want to view talks that you missed, please reach out to us at summit@casda.ca. CALS2021 presentations that we have consent to host and share will be available to Summit attendees, and may be accessed by others for a small fee.

Best wishes,

The CALS2021 Planning Committee

CALS2021 RECAP

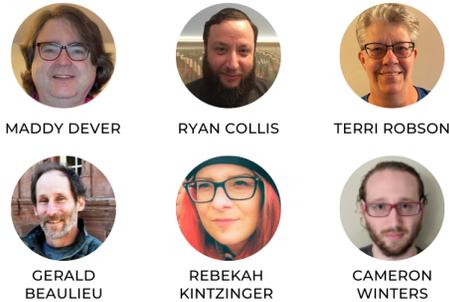
THE NEED FOR AN AUTISTIC-LED EQUITY JOURNAL

PANEL

MODERATORS

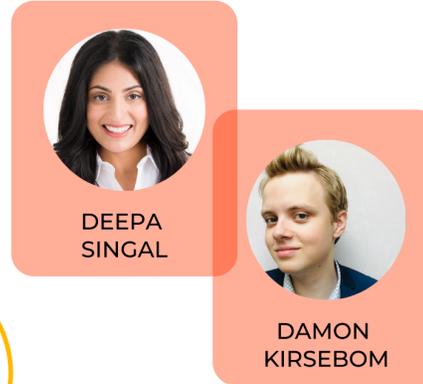


PANELISTS



KEYNOTE

VISIONING A NATIONAL AUTISM STRATEGY



NAVIGATING LANGUAGE USE IN AUTISM: RESPECT, RIGHTS & CULTURAL VALUES

PANEL

MODERATORS



PANELISTS



MOVING FROM STRATEGY TO POLICY: COMMUNITY ENGAGEMENT ON A NATIONAL AUTISM STRATEGY

PANEL

MODERATORS



PANELISTS



OPENING REMARKS



CLOSING REMARKS



TABLE OF CONTENTS

01

ABOUT ATTENDEES PG. 4

02

EVENT FEEDBACK PG. 7

03

NATIONAL AUTISM STRATEGY: JAMBOARD RESPONSES PG. 14

- How do current federal government-funded initiatives fit within the upcoming National Autism Strategy?
 - How should these current funding initiatives be organized in a National Autism Strategy?
 - What other types of initiatives are missing?
 - Do you have any other comments about initiative/programs for autism at the federal level?
- What are some things to work on moving forwards with a National Autism Strategy?

04

SOCIAL ANALYTICS PG. 17

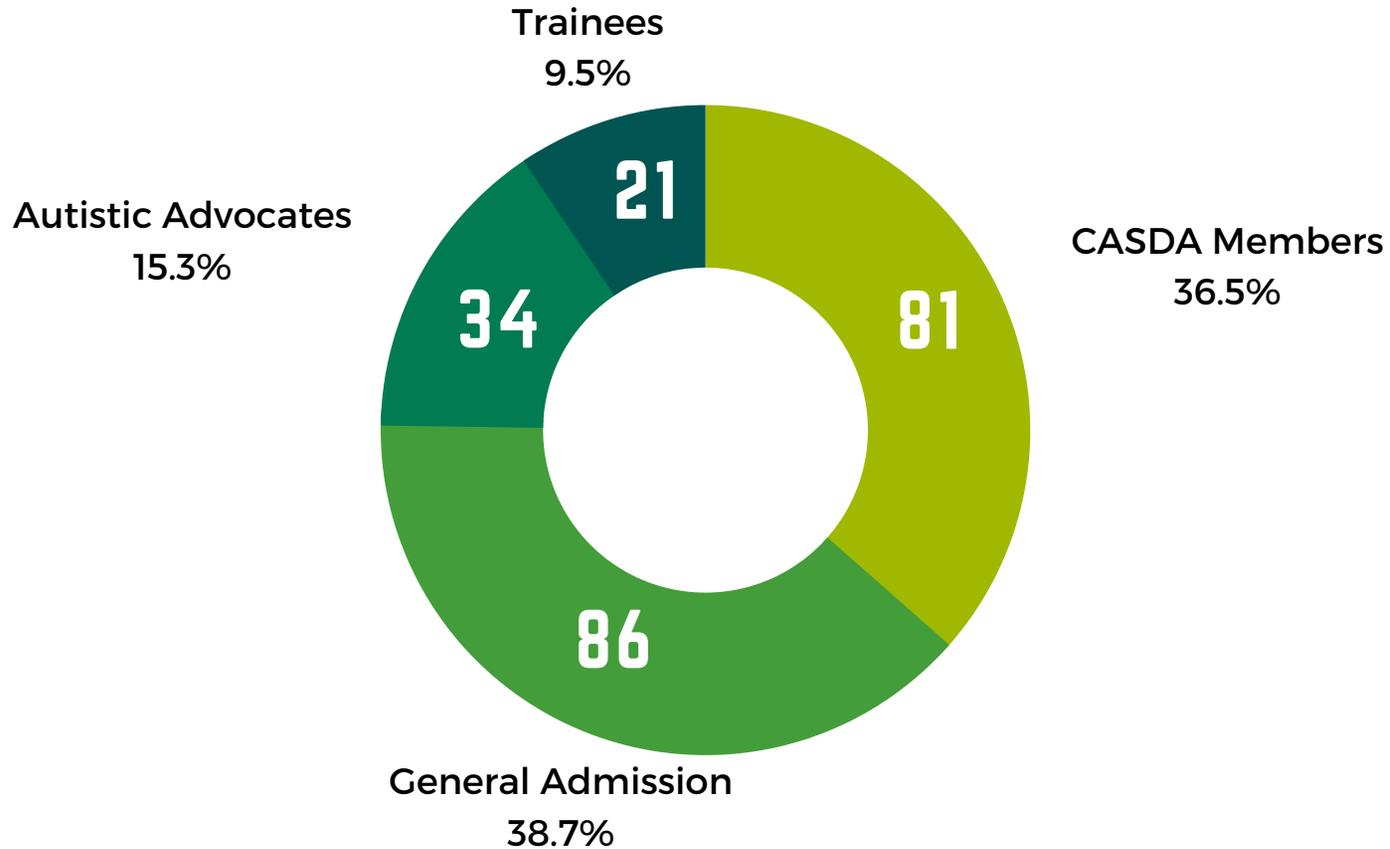
05

APPENDIX: FULL RESPONSES PG. 22

01

ABOUT ATTENDEES

TOTAL REGISTRANTS: 222



01

ABOUT ATTENDEES

REGISTRANTS PER PROVINCE

ONTARIO: 42.6%

BRITISH COLUMBIA: 16.7%

ALBERTA: 14.7%

QUEBEC: 8.8%

REST OF CANADA: 14.2%

INTERNATIONAL: 3.0%



NOTE:

91.9% of registrants indicated their province location on Eventbrite.

**GOOD
AFTERNOON
FROM PEI.**

**GOOD
MORNING FROM
EDMONTON AB**

**Good Morning
from Thunder
Bay, Ontario.**

**Greetings from
Calgary!**

**Good morning
from Regina,
Saskatchewan.**

**Good
Morning from
Ottawa!**

**Good morning from
Montreal! 😊**

**Good morning
from Burnaby,
B.C.! :))**

**Good afternoon
from
Newfoundland :))**

**GOOD
MORNING
FROM
TORONTO!**

**Good
morning
from
Winnipeg.**

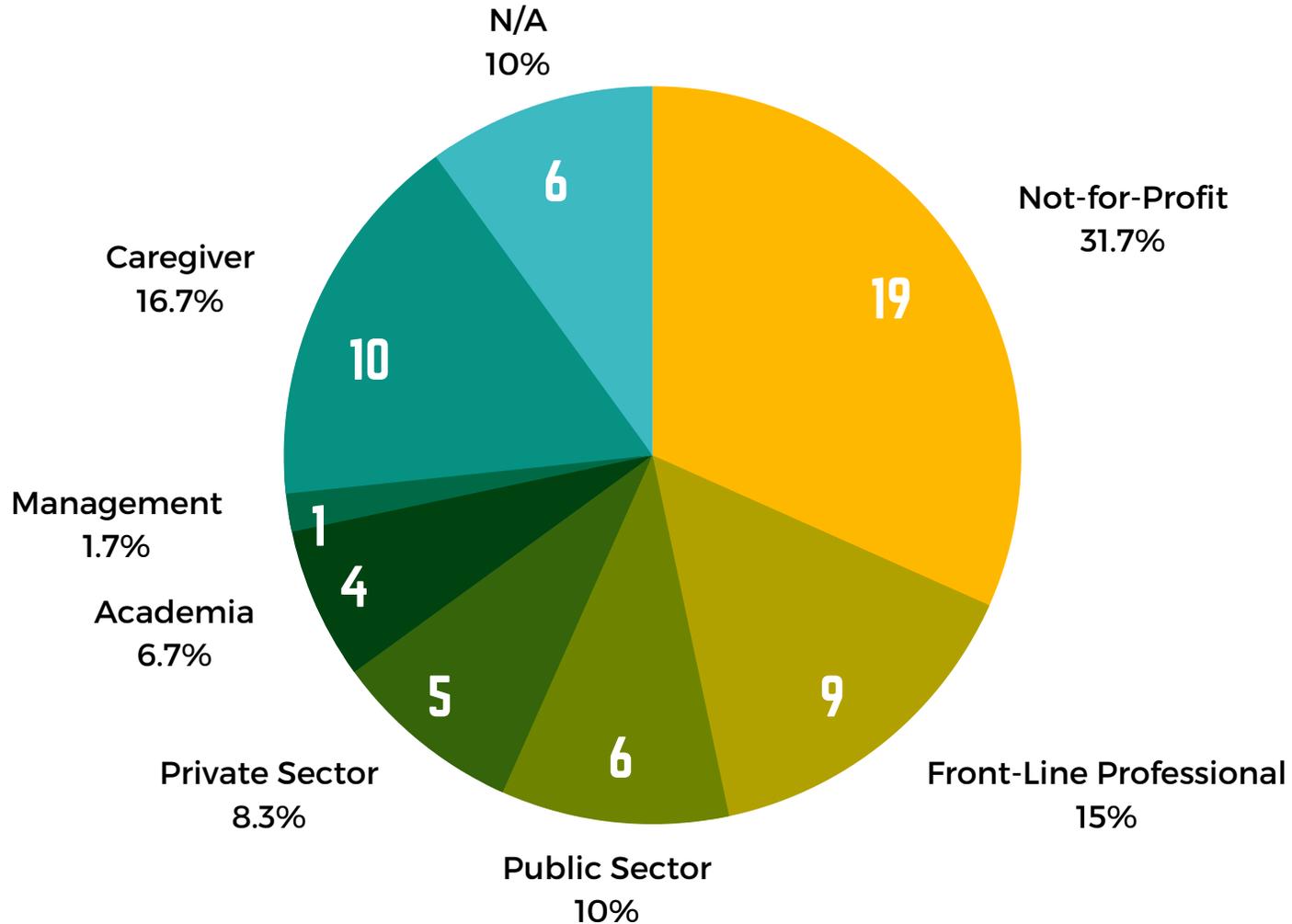
**Good morning
from Vancouver!**

NOTE:

Comments on this slide were taken from the Airmet chat from the day of the Summit.

EVENT FEEDBACK

PLEASE TELL US ABOUT THE **SECTOR** YOU WORK IN:



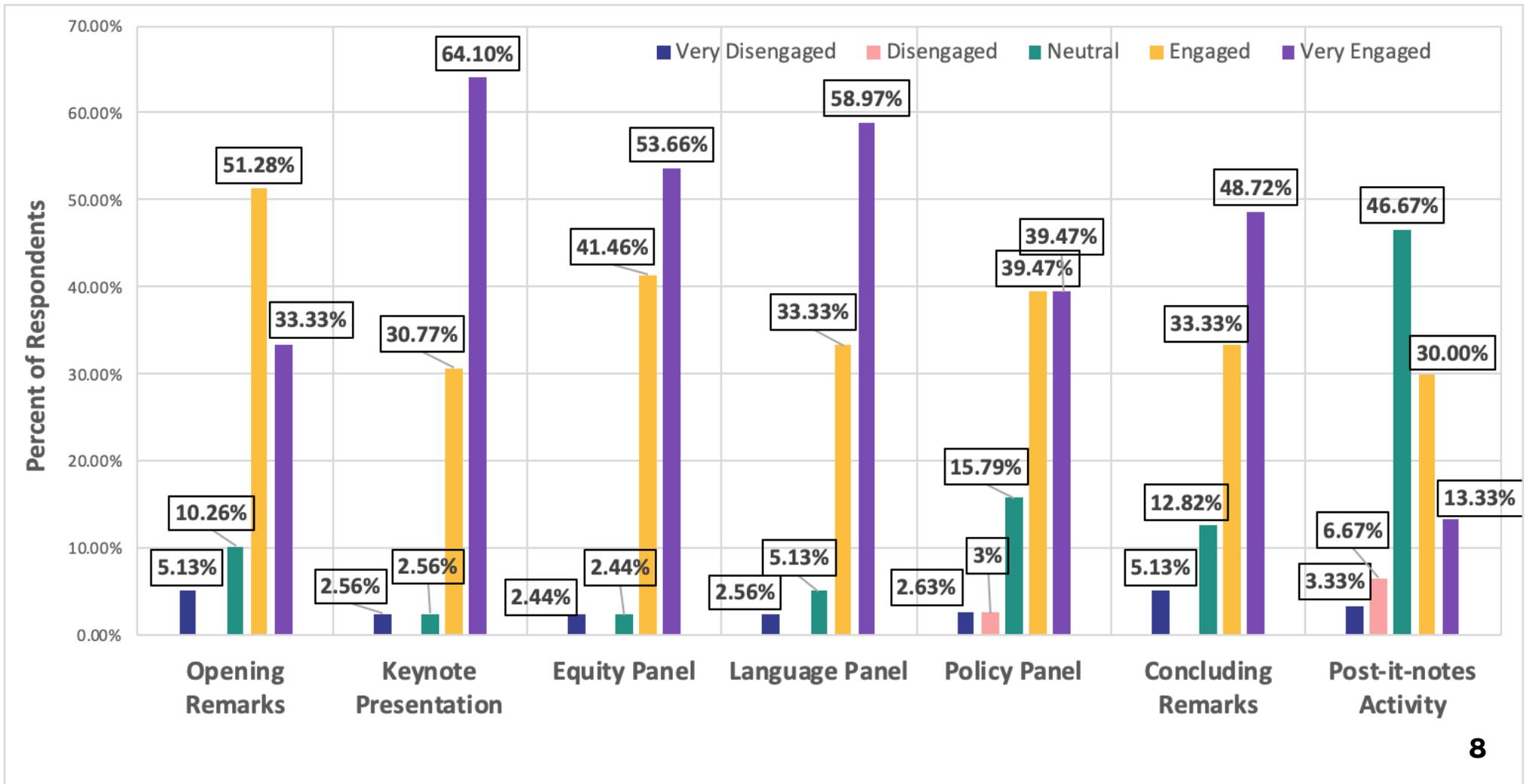
NOTE:

The data presented in this section, "Event feedback" was collected from the 21 registrants that completed the Post-Summit survey. Registrants could select multiple responses. Full responses can be viewed in the Appendix.

02

EVENT FEEDBACK

PLEASE INDICATE THE EXTENT TO WHICH YOU FELT **ENGAGED** DURING THE FOLLOWING ACTIVITIES:



02

EVENT FEEDBACK

PLEASE TELL US WHAT YOU **THOUGHT** ABOUT THE SUMMIT.

The information presented will be useful in my work.

97.4%

Attending the Summit has increased my knowledge of the work related to a NAS.

92.3%

My expectations of the Summit were met.

94.7%

The Summit met its aims and objectives.

94.4%

I would attend future Summits.

100%

I would invite another person to attend future Summits.

94.4%

02

EVENT FEEDBACK

HOW LIKELY ARE YOU TO **RECOMMEND** THE NEXT SUMMIT TO A FRIEND/COLLEAGUE?



8.90
AVG. RESPONSE

40
RESPONSES

NOTE:

- Net Promoter Score (NPS) = +70
- Detractors = 8%%
- Passives = 14%
- Promoters = 78%

The NPS is the leading metric for calculating client satisfaction.

DID YOU GET WHAT YOU INTENDED TO?

Overall, the majority of respondents stated that they got what they intended to at the Summit. A number of responses centered around their appreciation for the keynote presentation and the opportunity to hear from self-advocates. Other respondents referenced having few expectations at the beginning of this year's Summit and ultimately being pleased with the content and presenters. The ability to network was another common reason for attendee's level of satisfaction.

DID YOU FEEL THAT YOU WERE MEANINGFULLY INCLUDED?

Respondents stated that they felt they were meaningfully included throughout the Summit. Respondents indicated how the introduction of multiple methods of submitting feedback was helpful, as was the number of support methods to aid in their contribution.

HOW MANY NEW CONNECTIONS DID YOU MAKE?

On average, respondents indicated that they made 2 new connections. Some made even more, at about 6 connections. Other respondents noted that they made less, which was, for the most part, explained as being due to not fully participating and connecting with old connections.

WHAT PARTS OF THE SUMMIT INFORMED YOU ABOUT A NATIONAL AUTISM STRATEGY (NAS)?

In the survey, many respondents indicated that CALS 2021 was overall instructive and informative about a NAS. For some respondents, the content of the Summit was a review of information they were previously familiar with. The background and history of CASDA's goals were highlighted as informative about a NAS.

WHAT HELPED YOU IN YOUR **ADVOCACY** RELATED TO A NAS?

The majority of respondents indicated that there were quite a lot of aspects at the Summit that aided their advocacy in relation to a NAS. Respondents referenced the Panel entitled: "Navigating Language Use in Autism: Respect, Rights & Cultural Values." Others stated that the emphasis on the need for action and the opportunity for networking was helpful. There were respondents that indicated that there was little to none that helped in relation to their advocacy, though they did not provide background for their responses.

WHAT WAS THE **MOST VALUABLE** ASPECT OF THE SUMMIT?

Predominantly, respondents wrote that the varying perspectives from Autistic presenters and the overall content presented at the Summit were the most valuable aspect of CALS2021. Others noted that the networking, the panel entitled, "Navigating Language Use in Autism" and the keynote presentation, "Visioning a National Autism Strategy," were the most valuable/beneficial aspects of the Summit.

WHAT WAS THE **LEAST VALUABLE** ASPECT OF THE SUMMIT?

Respondents noted that at times, the amount of content being presented could be overwhelming, primarily because of the chat functionality during the panels which required multi-tasking. Others found navigating the virtual networking tables on the platform difficult, and found the panels to be presenting more information than there was time for, making them feel rushed. For some respondents, the content of the closing remarks was the least valuable, while other respondents stated that there wasn't any aspect that was the least valuable/beneficial. **12**

WHAT WERE YOUR THOUGHTS ON THE PANEL: "THE NEED FOR AN AUTISTIC-LED EQUITY JOURNAL"?

Respondents overwhelmingly noted the value of information that came from this panel. The Canadian Journal of Autism Equity (CJAE) was referenced as an important resource for Autistic individuals as a peer-led and reviewed journal that can be used in research, academics, and policymaking. Respondents found the panelists to be well informed and appreciated the panel addressing the need for all Autistic voices.

WHAT WERE YOUR THOUGHTS ON THE PANEL: "NAVIGATING LANGUAGE USE IN AUTISM: RESPECT RIGHTS & CULTURAL VALUES" ?

This panel was described as informative, relevant and eye-opening. Respondents voiced their appreciation for the variety of perspectives provided throughout the panel; however, there were suggestions to include more diversity among the speakers. Respondents felt that this panel led them to reevaluate their language use and further investigate cultural differences involving language surrounding autism.

WHAT WERE YOUR THOUGHTS ON PANEL "MOVING FROM STRATEGY TO POLICY: COMMUNITY ENGAGEMENT ON A NATIONAL AUTISM STRATEGY"?

Respondents noted how the presenters were well informed and how the content and the important message of the panel was powerfully captured. Many responses valued the need for diverse Autistic voices and collaboration in developing policy. Some respondents indicated their preference between a National Disability Strategy and a National Autism Strategy.

NAS: JAMBOARD HIGHLIGHTS

We need more resources for supportive housing, and person directed, individualized supports for life and social skills--which vary by jurisdiction quite dramatically.

We need more affordable transportation options for people in both urban and rural areas, including public transit, inter-city buses, passenger trains (especially passenger trains), marine and air travel.

Autism services vary from province to province across Canada. Provincially some provinces have access to many resources and funding. While others have programs that are age based and a child ages out of them. How does this contribute to inclusion?

Actual inclusion enforcement. Require businesses and organizations to be accommodating in a proactive manner, rather than a reactive manner.

Empowering organizations and local advocates to understand the research and recommendations so that they can move things forward. These are powerful ideas...they need to be understood and shared.

NOTE:

The data presented in this section, "NAS: Jamboard Sessions" was collected from attendees who submitted their responses on the jamboard.google.com platform during the event. Full responses can be viewed in the Appendix.



NAS: JAMBOARD RESPONSES

HOW DO CURRENT FEDERAL GOVERNMENT-FUNDED INITIATIVES FIT WITHIN THE UPCOMING NATIONAL AUTISM STRATEGY?

How should these current funding initiatives be **organized** in a National Autism Strategy?

In the polling regarding initiative organization in a NAS, responses were focused primarily on accessibility, and providing a variety of resources and services to Autistics. Respondents indicated the desire to devise a **universal access point** for support and resources across Canada, as well as a **standardized system for diagnosis**. The need for service options for individuals and families across jurisdictions was also presented, including housing, mental health services, education, legal services and more. Some responses also noted the need to recognize the intersectionality of disabilities.

What other types of initiatives are **missing**?

Respondents indicated that important initiatives are missing related to housing, employment and income, education, and diversity. The importance of supportive and accessible programs for housing, employment and education was noted, allowing for **easier navigation** through processes and availability in all communities. It was also indicated that initiatives tailored towards Indigenous individuals with autism are missing and should be included. Further measures regarding **accessibility for education** included access to Augmentative and Alternative Communication (AAC) and free post-secondary education at all levels. Responses focusing on income note **eliminating income-tested benefits** and making supportive programs available in rural and northern areas.



NAS: JAMBOARD RESPONSES

Do you have **any other comments** about initiatives/programs for autism at the federal level?

Respondents commented on the inclusion and accessibility of programs throughout Canada, the amount of **public awareness and education** about neurodiversity, and the inclusion and recognition of comorbidities within a NAS. Accessibility was a common theme in the polling, regarding assessments and services for autism. Many responses were regarding the creation of a national database of supports for individuals, families, and organizations, as well as **making services more accessible and universalized** across Canada. Participants presented the importance of awareness and educating the public on autism.

WHAT ARE SOME THINGS TO WORK ON MOVING FORWARDS WITH A **NATIONAL AUTISM STRATEGY**?

The primary response themes were regarding actionable steps and including various perspectives in a NAS. Respondents are looking for a NAS that includes strategies and **action plans** for the fast implementation of supports and services. Respondents noted the need to **reframe autism** to the public and **re-evaluate the language** used in policy making. They also indicated the need for the inclusion of all Autistic voices in creating a NAS to ensure representation throughout all communities.

04

SOCIAL ANALYTICS

HERE'S WHAT PEOPLE HAD TO SAY ABOUT #CAL2021

CALS2021 IS TRULY INSIGHTFUL; I HAVE BEEN FOLLOWING THE PANEL DISCUSSIONS; LET ME TELL YOU: THESE HAVE BEEN VERY INSIGHTFUL.

AS A CAREGIVER, RESEARCHER AND ADVOCATE, SOOOO LOOKING FORWARD TO CANADAS NATIONAL AUTISM STRATEGY IN 2022 THANKS TO THE GREAT WORK OF @ASDALLIANCE

TRANSFORMATIVE CONVERSATIONS ABOUT #INCLUSION #IDENTITY AND #LANGUAGE AT #CAL2021

CE FÛT UNE JOURNÉE RICHE EN INFORMATIONS NOTAMMENT SUR L'UTILISATION DU LANGAGE. CELA NOUS FORCE À RÉFLÉCHIR AUX TERMES QUE NOUS UTILISONS AU QUOTIDIEN EN AUTISME.

CAPABLE ABLE POWERFUL #CAL2021 EVERY #AUTISTIC COUNTS.

THIS WAS A FANTASTIC SUMMIT WE HAD THE PRIVILEGE OF ATTENDING YESTERDAY!

THIS IS WHAT COLLABORATION LOOKS LIKE. CASDA HAS CLIMBED TO A NEW LEVEL AT THIS SUMMIT. A NEW GENERATION OF IDEAS IS TAKING THIS ORGANIZATION TO NEW HEIGHTS.

AN IMPORTANT PLATFORM TO BRING FORWARD A WIDE RANGE OF AUTHENTIC EXPERIENCE THAT REPRESENTS ALL AUTISTICS #CANADIANJOURNALOFAUTISMEQUITY

04

SOCIAL ANALYTICS

HERE'S WHAT PEOPLE HAD TO SAY ABOUT #CAL2021



Spero Careers Canada @SperoCareers · Oct 6 ...
 What an amazing panel on language use in the autism community! A really diverse panel and discussion on how language affects biases and direction of conversations. #CAL2021



Shantu Ellis @ShantuEllis · Oct 6 ...
 I had an amazingly eye-opening day at #CAL2021 Thanks so much to @ASDalliance and all of the sponsors for putting on such an important event. #AutismAwareness #NeurodevelopmentalDisabilities #MentalHealth #ChildHealth @KidsBrainHealth



Peter M Boehm @SenBoehm · Oct 6 ...
 Thanks! Associations, entrepreneurs, individuals, self-advocates, families, governments and yes, parliamentarians: we all need to work together towards developing an effective #NationalAutismStrategy @ASDalliance



Spero Careers Canada @SperoCareers · Oct 6
 @SenBoehm thank you for the lovely chat this morning to kick off #CAL2021 with @ASDalliance :)



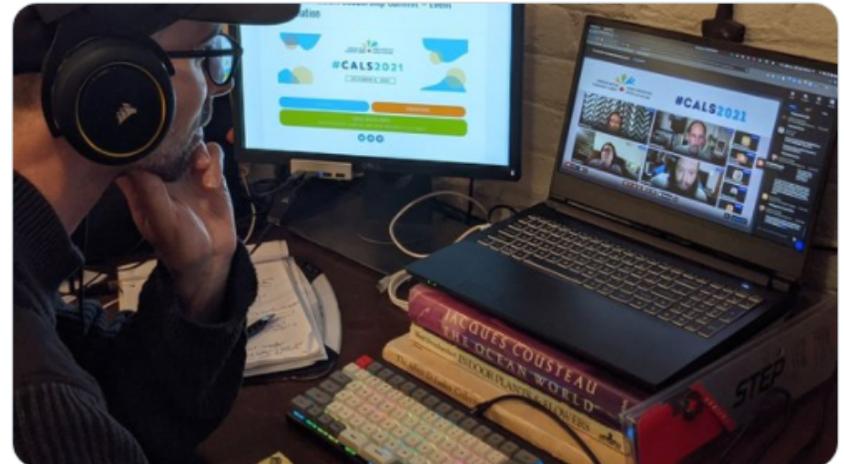
Hilda S. W. Ho, PhD, MPH @HildaSWHo · Oct 4 ...
 Excited to be invited as a panelist at the Canadian #Autism Leadership Summit! Looking forward to discussing issues related to culture and language, as well as the use of diagnostic labels to access services. See you all on October 6th #CAL2021!



Horizon Educational Consulting @HorizonEConsult · Oct 6 ...
 Attending the Canadian Autism Leadership Summit today to learn, support and share #students #cals2021 #equity #AUTISM



Kenneth S Dyson, PhD @dysonsphere · Oct 6 ...
 Pleased to be attending #CAL2021 @ASDalliance towards building a Canadian National Autism Strategy. Important to amplify underrepresented voices in this endeavor.



Réseau national d'expertise en TSA @ReseauTsa · Oct 6 ...
 Le RNETSA participe aujourd'hui au 7ème congrès de l'Alliance canadienne du trouble du spectre de l'autisme @ASDalliance #autisme #CAL2021 #réseautage

04

SOCIAL ANALYTICS

TOP MENTIONS & BEST PERFORMING CONTENT



CASDA @ASDalliance · Oct 5

Last chance to grab your ticket to #CAL2021!

Tomorrow at 9:30AM (PST) / 12:30PM (EST), at the 2021 Canadian #Autism Leadership Summit, editors of @TheCJAE will share their journey on building an Autistic-led platform that brings #equity issues to light.

cals2021.eventbrite.com



Jim Munson ✓
@SenatorMunson



Just listened to Damon. His message must go beyond the borders of the autistic world .As Dr. Deepa Singal said ,”are we really listening” In my view ,the voice of non verbal autistics must be be front and centre in any National Autism Strategy.#CAL2021

THE NEED FOR AN AUTISTIC-LED EQUITY JOURNAL PANEL

MODERATORS

MACKENZIE SALT

TANYA MCLEOD

PANELISTS

MADDY DEVER

RYAN COLLIS

TERRI ROBSON

GERALD BEAULIEU

REBEKAH KINTZINGER

CAMERON WINTERS

CANADIAN AUTISM LEADERSHIP SUMMIT

FORUM CANADIEN DES EXPERTS EN AUTISME

3
 6

CASDA @ASDalliance · Oct 6

#CAL2021 is in full swing! We are now welcoming Damon Kirsebom & @DeepaSingal to the virtual stage starting for their keynote presentation: “Visioning a #NationalAutismStrategy.” twitter.com/ASDalliance/st...

12:27 PM · Oct 6, 2021 · Twitter for iPhone

8 Retweets 1 Quote Tweet 17 Likes

Impressions	2,730
Total engagements	51
Media engagements	29
Detail expands	9
Likes	6
Retweets	3
Link clicks	2
Profile clicks	2

Summit posts received 7453 impressions that day

THANK YOU

7TH ANNUAL
CANADIAN AUTISM
LEADERSHIP SUMMIT
CALS2021



THANKS TO THE SUPPORTERS OF #CAL2021



WE ASKED ATTENDEES THE FOLLOWING QUESTIONS AFTER THE COMPLETION OF THE SUMMIT, HERE'S WHAT THEY HAD TO SAY.

Why did you attend the Summit?

- I facilitate programs for people on the Spectrum as well being a parent of two adult autistic children. Our kids have had so many struggles but have over come so many obstacles and opposition and made it to the other side of earning their degrees and having sustainable employment - I want all people on the Spectrum to reach their full potential, whatever that may be. So my point for attending the Summit was to get a pulse on current events, policies and movements to further support our children and my clients.
- Personal growth
- I attended it for networking and to hear about the latest updates relating to a NAS in Canada.
- To hear my neurosiblings present
- I work and live in the autism space and enjoyed being part of the organizing committee.
- I was hoping to have the boy that I support at work listen in to the summit (he is non-speaking) and is learning to spell to communicate. Unfortunately I was not able to attend work today for medical reasons. I learnt a lot and would like to get more involved in helping autistic people to have their voices heard and have a seat at the table.
- I am also embarking on some research/policy making as a part of my job role.
- Interested in changing climate around neurodiversity and inclusion.
- I want to make the world more accessible for autistic people.
- To learn more about the NAS.



APPENDIX: FULL RESPONSES

WE ASKED ATTENDEES THE FOLLOWING QUESTIONS AFTER THE COMPLETION OF THE SUMMIT, HERE'S WHAT THEY HAD TO SAY.

Why did you attend the Summit?

- Personal growth and enjoy the speakers look forward to in person networking but enjoyed the virtual aspect as well. Watched on projector with husbands link but wanted to let you know I did attend. Had to leave briefly for doctor appointment and missed a bit.
- for self awareness and growth
- Networked Creating a smaller local autism strategy so learning about data and contents of national strategy is helpful
- Gain better understanding of the needs, priorities and perspectives of autistics
- Professional and personal interest.
- Personal growth. Networking. The need to be a part of what is happening in my autistic community.
- Personal growth
- To gain knowledge and educate myself to advocate in the non profit sector. To advocate for future change and growth of Autism acceptance.
- I recently joined an organization that supports people with autism so it was a combination of education, networking and personal growth. It was very informative - even the quick break out rooms - and I was grateful to have had the opportunity to participate.
- Networking, professional growth and keeping on top of latest in ASD
- networking, learning from speakers, learning from attendees



APPENDIX: FULL RESPONSES

Did you get what you intended to? Why or why not?

- Yes x5
- Yes, but I need to network to others from this now! You guys created more work for me!
- Yes, I did because of the connections I made, the familiar faces I got to see and the information I was able to hear about.
- I didn't have a lot of expectations. I came in open-minded. I was very happy with how many Autistic speakers you had and that you provided space and a platform for non-speaking/non-verbal Autistics. I guess as someone who did come to previous Summits, I see movement and I see a lot of the same old, same old. I applauded the movement. I am an action type of person. All in all, I enjoyed the Summit. Being able to step back into it online gave me a lot more control over my experience. I am considering coming back in person.
- Yes, I wanted to hear Damon's story and hope to be able to share it with the student that I work with. It was great to hear the perspectives of the other speakers as well.
- I did - relevant, thought provoking, hearing from autistic people, being able to ask questions, being able to network.
- Yes am better informed on the changing environment in terms of the need for meaningful participation of autistics in decisions that affect their quality of life. Also am better informed re rational for sensitivity of deficit based language and its relationship to mental health.
- I really appreciated Damon's keynote speech. This made the day worthwhile to me.
- Yes, did not really have expectations
- Absolutely.
- I was not sure what to expect this year. I found it it very interesting

Did you get what you intended to? Why or why not?

- It was refreshing to hear from a non-speaking Autistic. However, families of children/adults with level 3/high support needs autism - the type of autism that requires 24/7 care, accompanied by intellectual disabilities and severe impairments across all domains of life - appear to be left out of CASDA. There needs to be a recognition that some Autistic people, whether children or adults, do not and may never have, the ability to communicate, and their parents/caregivers/therapists, deserve to have a space to voice their experiences and concerns alongside equally important articulate adult Autistic voices. It's nice to hear about issues like acceptable language, journals that highlight Autistic voices, etc., for those who are able to participate in and benefit from these discussions, but the issues concerning the "high needs end of the spectrum", and the complex, continual challenges they present for caregivers, seem to have been forgotten. Why is this? Issues such as crisis supports, increased funding for respite and therapy, supportive housing, mental health and wellbeing of caregivers, etc., also merit focused discussion and attention. Many such families are silently living in crisis, some of whom are unable to work or retire due to the intense and never-ending caregiving and economic demands of supporting a dependent child throughout life. The issues presented sadly do not reflect or include their experiences. The experiences of families raising children who cannot articulate basic thoughts, whether through vocalizations, AAC or any other method, simply do not feel well represented at CASDA. For this reason I felt disappointed and excluded much of the day and many others in these situations have expressed feeling alienated from attending to begin with due to this being a continual problem.

Did you get what you intended to? Why or why not?

- Always refreshing to attend, educational, information and networking.
- yes, And more
- Yes - full participation Networked Listened
- As usual progressing to slowly
- I think that some of the panels' topics were not described accurately enough in the materials. I would have benefitted from more conversation about what I/others could do to move these ideas forward.
- I did. Mostly. I met some interesting and insightful people. I was inspired and humbled by the words I heard. I left early due to overload...but enjoyed my experience
- Yes. I wasn't sure what to expect but came away with greater knowledge, understanding and respect for those who have been working on a NAS, and those who working so hard to break down barriers.
- Yes, I intended to make new connections in the NFP and Autism Community and accomplished this.
- Yes, learned from speakers and attendees and connected with some speakers and attendees
- This was far more than I expected. This summit really moved CASDA to another level.
- Yes! and more than I expected. First person/lived experiences, knowledge is so key to the ASD field and we need to do more so in having these voices heard and their input actioned. The onus can no longer be on Autistic individuals and their family/support networks alone, it must be shared with communities and society as a whole. It is their right as fellow human beings and it is the neurotypical ethical and moral obligation to remove systematic barriers and increase accessibility for all.



APPENDIX: FULL RESPONSES

Did you feel that you were meaningfully included? Why or why not?

- Yes x9
- I felt that I was meaningfully included since there were multiple methods of submitting feedback in the polling (Google Docs and Jamboard) and multiple ways of getting help in filling them out if needed.
- I'm not sure how to answer this question.
- Yes though I may have missed some activities.
- Yes with chat boxes and group networking
- I was limited only because of the juggling I had to do on my end.
- However, WiFi was the nemesis of the day and some polling was not able to submit and as watched from one device instead of two due to rural WiFi challenges missed the day of survey.
- Yes - opportunities to engage
- I feel that I was as included as much as possible within the timeframe we had.
- I wish the break out rooms would have been a little longer - 10 minutes is not very helpful beyond introducing yourselves. It was obvious that people were happy to see each other again and wanted to really have a chance to talk.

What part(s) of the Summit informed you about a National Autism Strategy (NAS)?

- The opening and concluding remarks
- I found all the information informative.
- It was mainly a refresher to me given that I have previously participated in and/or submitted my feedback at previous CAHS sessions during the summer.
- None. I came into it informed.
- Hearing about the work of sub committees, history of CASDA.
- All/All parts x2
- I honestly did not know that a national autism strategy was in the works, good to know
- NAS focused discussions.
- Combination of areas
- The need for ongoing involvement of self advocates/panel. The panels addressed findings
- All I am allowed to say is currently you are on the wrong track
- understanding autistic perspective, choice of language
- The personal reading that I did about the NAS in advance of the summit.
- I do not think I understand this question
- Speakers open discussions
- Certainly the last session with the 3 lead researchers (PhD candidates?). Their work is very interesting and I would like to have heard more about who they are engaging with in the community, what parts of Canada, how they are engaging, what has been the response, etc. This information was included in their presentations but it was done very quickly.
- I would say all parts as the discussions are directly and indirectly related to a uniformed strategy that includes the full life span on the spectrum.

What part(s) of the Summit informed you about a National Autism Strategy (NAS)?

- Finding out more about CASDA from its roots to its strategies and the information I can share with my family and clients, so they can self advocate further.
- Again, it was mainly a refresher to me given that I have previously participated in and/or submitted my feedback at previous CAHS sessions during the summer.
- None.
- The stress of the need for action not just admiring problems or gathering data (though there is a role for the data of course). Considering how one action will impact others. Ongoing involvement of autistic people and their caregivers, not just consultation.
- Not sure
- Being able to connect with people working on the policy recommendations. A clearer way to do this next time would be great.
- All
- Language session
- Links to the research.
- Review of strategy
- the true stories of the panel speakers, help me to have hope for my daughter
- Hearing from self advocates was the most impactful part for me
- That you are not the best voice for autistic people
- understanding autistic perspective, choice of language
- Hearing from autistics about autistics is critical in how we move forward with the NAS.
-



APPENDIX: FULL RESPONSES

What part(s) of the Summit informed you about a National Autism Strategy (NAS)?

- Gained knowledge in specific areas of interest.
- I am not involved in this aspect at the moment.
- Navigating Language...

How many new connections did you make at the Summit that you will follow-up with?

- Only the ability to connect later on with people that presented. So knowledge on where to turn next which in itself is quite useful. Not sure if the Summit provides an attendees contact list or not?
- Two connections. However, that is partly because I could not stick around after 5:10pm and I attended the Summit in the afternoon due to work in the morning.
- None. I didn't exchange info with anyone nor did anyone approach me for my info.
- Several (3-4).
- 6 and saw some old colleagues and reunited communications with them. I will also look at articles, websites and books that people shared with me today and join CASDA as an associate member.
- Not my focus but did save all speakers and sponsors contact info
- 2-4
- Just casual conversations, would not be connecting personally but will look into the Sinneave Foundation



APPENDIX: FULL RESPONSES

How many new connections did you make at the Summit that you will follow-up with?

- Husband will be reaching out to others as previous speaker/attendees
- none :< wish I could have made more I had trouble understanding the networking rooms (Im new to this)
- 5
- None
- 1/one x3
- 4-5
- The open discussion in the smaller private rooms allowed for networking.
- There are 3 connections that I am following up with.
- a few

What was the most valuable/beneficial aspect of the Summit?

- The wealth of information!!
- The wealth of knowledge on the various topics that were presented at the Summit from language to the CJAE
- Being able to listen to my neurosiblings.
- Damon's story and hearing his perspectives as well as all the other autistic speakers.
- Knowledge and perspective sharing.
- Networking, varied information.
- Hearing from lived experience
- Excellent speakers! It is clear CASDA is trying to do good things for autistic people - but you can always do better!
- Damon's presentation. Had a good and motivating energy. Great autistic perspectives shared.
- all
- discussion on language Keynote so insightful and meaningful
- It was informative and inspiring. The most valuable aspect was the first-person experiences.
- non traditional voices
- Hearing from BIPOC and non-speaking panelists.
- Energy and information
- Networking Hearing personal stories from self advocates Thinking about data
- language panel was very powerful, will influence my practice
- Conversation about strategies to improve services and supports for autistics.
- Being in the presence of so many amazing autistics at the same time



APPENDIX: FULL RESPONSES

What was the most valuable/beneficial aspect of the Summit?

- The format of the Summit. and speakers make the Summit. Exciting, engaging and knowledgeable.
- The keynote speaker - Brendan I think his name is - was extraordinary. I can't find the words to express how impactful his story was to me beyond the tears in my eyes. For me, he set the stage for the day.
- The Keynote Speaker Damon Kirsebom
- Opening keynote

What was the least valuable/beneficial aspect of the Summit?

- No high speed WiFi as yet. Look forward to the next summit!
- activities
- Questions such as, "what motivated you to ...?"
- I felt lost when I first logged on.
- The discussion of the journal was a bit lengthy and I was uncertain as to how it fits into the development of a NAS. Again, the summit really appeared to address independent advocates and I didn't see where anyone else on the spectrum fit in. It certainly strengthens my resolve that this group needs a tremendous amount of support.
- I loved the platform however, the inability to spotlight the presentations to screen size wasn't helpful. the side panels could be distracting with questions etc. other than that i thought it was great!



APPENDIX: FULL RESPONSES

What was the least valuable/beneficial aspect of the Summit?

- Everything was valuable. Keep it up!
- Jim Munson and Autism Speaks. Both should step away now. It was distasteful to make it all about Jim in the end.
- I had a hard time focussing on the speakers because I wanted to also see the chat and the discussions going on. I said I was very engaged because of the topics being discussed but I have a hard time multi tasking
- It was all great.
- Seemed there wasn't adequate time to really delve into last couple of panels
- Not enough representation from BIPOC autistic people.
- I liked the table networking visual, this was great, but it would have been better to forgo the sponsorship titles on the tables and have the tables named by subject matter. Navigating the tables to find the right discussion/person was hard.
- none/not applicable x4
- Feeling as though families of those with high needs children were left out.



APPENDIX: FULL RESPONSES

What was the least valuable/beneficial aspect of the Summit?

- I think all the information was valuable. I don't see a question on the survey for "suggestions on how we could have improved the Summit" So I will just add it in here, I hope that's ok. I felt there was a lot of information coming in, which was great but at times overwhelming to digest in such a compacted amount of time. I understand the limitations of the time zones and including everyone from across the country; so please this is constructive criticism b/c I understand the HUGE amount of work that went into the organization and was amazed at how flawlessly it all came together) Just one other suggestion from those that were presenting their research and studies. I found they were reading alot of information of their prepared sheets very quickly - maybe bullet points or a shared screen with bullet points would have been more effective. I think the other factor was 5 1/2 hours of packed screen time with no opportunity for breaks seemed alot. Which is why I missed round table discussions and a chance to interact. One thing I guess we've all found over Covid that screen meetings vs in person are definitely different. But I do think you did an amazing job with the overall Summit juggling time zones, audiovisual and content. Kudos.

What were your thoughts on the "Need for an Autistic-led Equity Journal" panel?

- I think the Journal is a brilliant idea. I work and do programs with people on the Spectrum as well as being a mother of two adult children that are on the Spectrum. I am going to circulate this information to my data base for sure. I find the general patronizing attitude towards those on the Spectrum not only disheartening, disrespectful, and dismissive - but more importantly Totally Untrue. Working with this population has led me to meet some of the most brilliant minds in our society.
- I think this is a very valuable resource that will be viewed as a must review journal for research and academics, policy makers, etc.
- Everyone was so well informed, well spoken and addressed very real needs felt in the autism community.
- I felt this was a very good panel. Very much enjoyed the speakers. I learned more about the Journal than I knew before.
- I was impressed by what the journal has achieved and what it's working towards. To know that there is a peer lead, peer reviewed journal for autistic voices is amazing.
- I think there needs to be more diversity in the autistics, we need to hear more from non-speaking, minimally speaking or unreliably speaking autistics. It was great that there were many self advocates on the panels, we just need more.

What were your thoughts on the "Need for an Autistic-led Equity Journal" panel?

- Accessibility/viewership aims that are targeted towards *both* academia/government and the community (both autistic and otherwise). We need autistic-led sources of information that are informed and reliable and that are consumed by diverse individuals, professions, and industries. Otherwise, valuable information that could inform policy and practice is sectioned off from those who need those perspectives.
- Articulate and helped me see the need for autistic voices and autistic people supporting each other to raise voices. Thought provoking.
- This will be a tremendous resource for sharing the voice of neurodiversity
- Great speakers who say they want more diversity represented on the journal in regards to submissions. I agree- there also needs to be more diversity represented on the editing board - racial/cultural diversity - non-speakers, etc.
- This session helped me to better understand this and see its value. For many, research is inaccessible, confusing or boring. But, reviewing this journal, I see that it is about stories and creativity. This wasn't evident to me at first.
- excellent
- very academic discussion sometimes lost but still important for autistic academia
- I am interested to see where the editors will take it. For now, I think the vision/mission is a bit too broad, but it will be shaped by the response of the Canadian community
- Great to hear about this important initiative, however, I wish the Autistic-led Equity Journal also contained an open, welcoming space for families whose Autistic children could not independently, or even collaboratively, participate in such an initiative. How can their experiences be represented?

What were your thoughts on the "Need for an Autistic-led Equity Journal" panel?

- Great to hear about this important initiative, however, I wish the Autistic-led Equity Journal also contained an open, welcoming space for families whose Autistic children could not independently, or even collaboratively, participate in such an initiative. How can their experiences be represented?
- Fantastic look forward to reading the next journal!
- Everything was amazing, perhaps though it would be nice to give listeners external resources to go to since some of the material could be very triggering and make people feel lost or isolated.
- Helped me hear and understand autistic viewpoints
- Enjoyed the different perspectives of the speakers
- The speakers were great. I think the question selection was underwhelming. Asking them why they joined did not contribute to elevating the conversation. Rather questions like those posted by the audience (e.g., how do you make decisions about themes, or explain the submission process) were much more practical and helpful. I think that the editors of the journal should also consider how they will work with stakeholders to ensure the journal stays relevant and respected by the non-autistic community. I think the journal has the opportunity to change what and how we do what we do. However, I fear that moving away from data and focusing on giving a voice to the voiceless has the potential to shift the publication from a journal to a magazine (thereby losing some of the non-autistic audience).
- I'm fully comfortable with what I heard.
- Interesting
- Great all around.



APPENDIX: FULL RESPONSES

What were your thoughts on the "Need for an Autistic-led Equity Journal" panel?

- I thought this was very interesting to hear the breadth of knowledge and expertise being brought to the table. The speakers did not often repeat what others had said so the conversation continued to build over the presentation. I always find the most impactful stories are those that speak to lived experience even if wrapped around an issue that is being presented.
- I really enjoyed this panel. I have since read the journal and referred many people to read it and submit to it.
- Speakers were very good, knowledgeable and passionate! I think they highlighted the key pressing points and the need to continue this work

What were your thoughts on the "Navigating Language Use in Autism: Respect Rights & Cultural Values" panel?

- This was informative for me. It was good to hear from Autistic individuals and hear how they see language and how they would like to be addressed. How we communicate no matter who we are is so important. It was also encouraging to hear from health care professionals that are aware and are trying to change the 'negative' language around Autism. I think people with Autism are probably more intelligent than many of their peers.
- I thought this was right on point and very timely.
- Everyone was so well informed, well spoken and addressed very real needs felt in the autism/autistic community.
- I enjoyed this panel a lot. It's one of the reasons I signed up for the Summit.
- My absolutely favorite panel discussion. Brought me to tear and has made me re-evaluate my language choices. This is one of the sessions I can't wait to see again.
- The speakers were great, it is good to hear from different cultures and the language. I feel that presuming competence and the Least Dangerous Assumption, is a priority. What we see on the outside of an individual is not a true representation of what is going on in the inside.
- This is relevant and responsive. The cultural attitudes toward ASD diagnosis were helpful in my own understanding. I look forward to investigating more about the cultures of my students, intersectionality, and thoughts about ASD in various cultures.

What were your thoughts on the "Navigating Language Use in Autism: Respect Rights & Cultural Values" panel?

- I appreciated learning about the interrelationship between deficit based language and mental health.
- Excellent speakers. Disappointed there was only one Black speaker - she was excellent. I hope her words will be taken seriously - along with the Indigenous speaker and Elsbeth Dodsman. Their voices matter so I hope the CASDA and the government actually listen to what they had to say and implement those recommendations meaningfully. I am skeptical that that will be possible if CASDA keeps the 'D' in their name (for disorder) and continue to partner with Autism Speaks.
- Great conversation. I think it's great to have calls to action and a few strong messages for people to take away. It helps us organize our thoughts and have a sense of direction.
- I still don't hear my son's voice reflected, an autistic adult who speaks but is extremely limited in his understanding of the world or issues related to his personal care and daily life. His caregivers are his advocates. It would be nice to see that role recognized in a positive way instead of presented as insensitive, controlling, disempowering to the son or daughter or sibling we love and support.
- Mind blowing
- Important as language is ever changing
- Various perspectives; clinician experience not well represented but I applaud the effort
- I appreciated diverse (BIPOC) perspectives being included.
- Very engaging.
- Very insightful

What were your thoughts on the "Navigating Language Use in Autism: Respect Rights & Cultural Values" panel?

- I love how the panel on the journal agree that story submission should NOT just be written from, my daughter communicates thru art and painting, if she were to be given a voice in this regard it would have to be accept thru her art which is very abstract but is still non the less, a voice thank you for saying what you did
- Priority for language use - defining/clarifying the evolution of supports (aka the ABA issue)
- Good discussion. However the discussion was not what I was expecting given the description of the panel. I think there needs to be discussion afterward about practical strategies that people can do tomorrow to help push these critical ideas forward.
- I was deeply touched by what I heard. There is a lost generation of autistics 45-60 that slipped through most cracks in the systems and struggle financially and emotionally still.
- Super !
- Informative and refreshing.
- I am new to this sector and am only starting my journey to understanding autism. The discussion was very interesting but, as I found in all presentations, the discussion seems to be focused on independent advocates. There appeared to be no discussion on those who are most profoundly affected. It was never conveyed how that sector fits into the NAS.
- It was great representation from different professional perspectives regarding the usage of terminology for the how, when and why certain terms are used across different setting/situations and the conflict that comes from shifting from certain usage as relates to needs based supports and representation of individuals.

What were your thoughts on the "Moving from Strategy to Policy: Community Engagement on a National Autism Strategy" panel?

- This was good too. If communities are involved it will educate the "average person on the street" and hopefully lead to better outcomes for those on the Spectrum. And in so improving the lives of those on the Spectrum society at large will reap the benefits of the perspective and intelligence that this population can share but up until now has been blocked for the most part. We need to comprehend - "we are more alike than we are different" then progress can happen for all of us.
- I think that the message was loud and clear. Policy makers should not be creating policy without the inclusion of Autistic people which include that they are on actual teams not just as advisors.
- Everyone was so well informed, well spoken and addressed very real needs felt in the autism community.
- Personally, I have not bought into a NAS over an NDS. So I am not on board with moving this to policy. Not with so many Autistic people not buying into it. If a NAS were to come into policy I can't see how it could ever represent especially BIPOC Autistics. You have barely begun to hear from us, so moving forward into policy is at the detriment of Autistic people.
- I think that the speakers were good, and as they said policies should not be written unless the people that they are writing the policies for have a say.
- This is the key piece. Thinking how policies, organizations and levels of government will intersect is really key.
- Great speakers. "What happens when making policy when we don't all agree? For example, decision making capacity, the definition of "capacity". Do you move on for the sake of the group and overall goal? School education and acceptance. Day care professionals and teachers mandatory training. Making change from the ground up.



APPENDIX: FULL RESPONSES

What were your thoughts on the "Moving from Strategy to Policy: Community Engagement on a National Autism Strategy" panel?

- Priority areas - policies and practices that support social inclusion - inclusive housing, transportation - accessible and equitable lifespan resources and funding services based on best practices and evidence informed practice across all communities including rural and remote
- There needs to be a National Disability Strategy, not a National Autism Strategy. Elsbeth was the only one who discussed this issue and the opposition to the NAS from the autistic community, that was disappointing.
- I would really love the opportunity to participate in knowledge translation in relation to the strategy/policy. This session was a bit overwhelming given that so many topics were briefly introduced, but I was able to identify someone to speak with and ask questions afterwards, so that was helpful.
- Motivating
- Also very academic but still brought important points forward that would be applicable at the grassroots level
- Yes - my thoughts exactly - what will be done with the info we gather?
- We need experienced people in policy.
- Ensuring the needs of people at all parts of the spectrum are well represented, including those who cannot articulate their own needs.
- Look forward to seeing the strategy be a reality.
- priority must be given voices to the voice less and support to caregivers
- Need to be Autistic lead and designed. Stop the ableist language
- I feel that this was the "least favourite" because I felt it vague in solutions. More of what is out there...is not the full solution

APPENDIX: FULL RESPONSES

JAMBOARD RESPONSES

How should these current funding initiatives be organized in a National Autism Strategy?

What other types of initiatives are missing? E.g. a basic income program, etc.

Should be flex funding

Some sort of universal access for support and resources, as well as diagnosis. Working with military families. It can be very frustrating having to prove to so many different people a diagnosis. They can receive a certain amount.

What are autistic persons saying would be most helpful?

The Disability Tax Credit criteria needs to be revised, so that it is easier for all disabled Canadians to access the credits, and more importantly, be able to open an IGDP. The criteria focuses too much on physical challenges.

I feel the push for the NAS needs to take a pause to take into consideration the many autistic voices opposed to the NAS.

Universal access point for autism support and resources. A National Autism access platform.

I feel a wider conversation on the need for a National Disability Strategy is needed. Disabilities are often intersectional - a disability strategy can take into account all forms of intersectional disabilities.

It should also address the other resource areas mentioned here such as sustainable housing.

For indigenous populations need a distinction based approach that recognizes the unique needs of First Nations, Metis, and Inuit.

A single point of diagnosis and eligibility for access of all programs. Its degrading to try to keep convincing so many different parties of diagnosis and needs.

Fewer mandates and less emphasis on Applied Behavioural Analysis (ABA) for autism. ABA is outdated, we need to move on to better ways that respect mental health needs.

More initiatives that see autism as a neurotypical, albeit with many challenges, but not a disorder or a deficit.

Ensure supportive employment programs are available in rural and northern communities not just cities - think outside the box and offer virtual support.

First Nation reserve autism supports. Develop a National Indigenous Autism Centre.

Truly affordable housing

We need a basic income for all Canadians. This program should ensure everybody in Canada can afford to meet their basic needs. This program should not be income tested, except maybe for those who are.

A basic income program that does not penalize us working

A place where researchers share their findings in a consolidated location so that organizations have a solid information source when choosing resources of interventions they will use and support.

We need more affordable transportation options for people in both urban and rural areas. Including public transit, inter-city buses, passenger trains (especially passenger trains, marine and air travel).

Ensure the DTCC allows for inclusion of ASD - it's immoral to have to re-apply every 4-5 years to prove ASD diagnosis and required supports.

Lifespan approach to service access

Five post-secondary education at all levels, so that those living financial hardships due to their disabilities can still receive post-secondary education in order to further their personal and career growth.

Transition to community supports beginning in junior high grades/upper elementary.

I feel what's missing are community supports when your child ages out of programs from an autism organization. Then the referral to a child development centre is given and a child.

Trauma-informed approaches.

Accessible housing. If I can't navigate it, being affordable won't accommodate me.

Ctrl + Shift + P and write your answers here in sticky notes!

The speaker Damon mentioned Maria Datohoke - she is fantastic. So I level up autism, SCERTS model, etc. From these more updated reconceptualization approaches for autism.

1. Autistics experience higher rates of abuse and victimization which is further compounded by intersecting identities. More social services and supports for autistics to alleviate...

2. The impacts of this victimization: self-harm, mental health services, trauma-informed care, neurodivergent affirmative therapies, legal services, funding for education.

I often worry that children without an ID cannot access funds that are still needed for safety and social programming for their children.

We need more resources for supportive housing, and person directed, individualized supports for life and social skills - which vary by jurisdiction quite dramatically.

Allowing for options or choices for individuals and families based on individualized identified need... some people may want to use a consultant, others certain types of therapists or AT.

Less emphasis on behaviourist approaches, such as ABA.

I think whatever language the NAS uses, it should include the reasons why it was chosen and also acknowledging that there's no one language to describe autism.

Actual inclusion enforcement. Require businesses and organizations to be accommodating in a proactive manner, rather than a reactive manner. Eg. childcare requiring a specialized teacher per room, regardless.

Do families have choice in the types of services and supports that they will undertake?

AAC access and presuming competence trainings in schools. I agree with this completely. I work in public schools in BC and AAC is taught but it is very narrow and only Touch Chat is recognized because of

AAC access and presuming competence trainings in schools. I agree with this completely. I work in public schools in BC and AAC is taught but it is very narrow and only Touch Chat is recognized because of

Do you have any other comments about initiative/ programs for autism at the federal level?

Summit 2021 Survey Question 2: What are some things to work on moving forward with a National Autism Strategy?

NAS must have F/I/T indicators tied with funding targets across all pillars.

I provided feedback during the summer CANS sessions or I had my feedback sent to individuals who were attending the sessions when I couldn't myself.

Federal government can review provincial laws that limit or create barriers to disability inclusion.

Continuous working on NAS - without it there will be continued choppy road of funding for all support we need. Strategies eventually turn into Action Plans with funding if there is political will. Outside policy works will pull.

The National Autism Strategy shouldn't focus just on autism, but all the co-occurring disabilities also impact autistics. That's not the right word, but I'm not sure what other words I can use to describe it.

How are autistic persons treated within the criminal justice system - when they are victimized by crime? when they are criminalized?

Empowering organizations and local communities to understand the research and recommendations so that they can move things forward. These are powerful ideas...they need to be understood and

Community understanding, common definitions of neurodivergence, autism (and resources to help community understanding).

As well as listening to the voices that oppose it, listen to the balance it out.

Choices for individuals and families, organizations

Inclusion of neurodivergent voices in decision making/consultation/consultation.

Allow Indigenous people to lead, plan, and develop their own autism initiatives.

We need action, not a strategy.

... THESE we need real-life real-time solutions/policies that can be implemented today

Get real about the microaggressions autistics face in our daily lives. How we interact as a society is founded in neurological norms.

The benchmark for a "fairly" is defined by stereotypical standards. We must deconstruct our approaches. Productivity is not the only measurement of a successful life.

Knowledge translation of policy compendium reports.

Actionable steps.

Ctrl + Shift + P and write your answers here in sticky notes!

One report/data base that consolidates best practices and supports from which families, organizations may choose would be helpful - it needs to be vetted/strategies and supports need to be recommended by autistic persons.

Create a National Disability Strategy instead of the NAS. Look at radical disability access initiatives such as mandates for Universal access strategies in schools, businesses, etc.

Autism services vary from province to province across Canada. Provincially some provinces have access to many resources and funding. While others have programs that are a

School resources for teaching about neurodiversity; professional development for staff around how to understand and teach neurodiversity (and intersectionality).

needs to be a federal policy support all autistic people living autism.

By othering Autism as separate from disability and by the radical exclusion of Autistic led voices, there's no reason for the Fed's to listen.

If we are listening to all autistic voices should we not include those who feel they were helped through "good" ABA practices that include looking at sensory issues etc?

on this doesn't feel like a de-funding of outdated and misguided autism supports such as Applied Behavioral Analysis and Intensive Behavioural Analysis.

on this thinking this

<<< Second this.

More public awareness campaigns (television, web) that helps reframe autism for the public.

1. In my province (N.S.), ABA is the only government funded therapy for autistics and many professionals who denounce ABA have to call themselves ABA to get funded...

2. Alternative psychological and social support systems and therapies that reject ABA practices and conversion therapies.

All of the programs are reactive rather than proactive. While in theory they provide support, it is only if those persons have the income available to utilize while they wait for reimbursement. This creates barriers and

<<< Yes please!

NOTE:

The data in presented in the following pages was collected from the above images. This year's survey was conducted on jamboard.google.com where individuals could collaborate with and see other attendees thoughts.



APPENDIX: FULL RESPONSES

WE ASKED ATTENDEES THE FOLLOWING QUESTIONS AFTER THE COMPLETION OF THE SUMMIT, HERE'S WHAT THEY HAD TO SAY.

How do current federal government-funded initiatives fit within the upcoming National Autism Strategy?

Current government and government-funded national initiatives and programs include:

- Enabling Accessibility Fund
- Ready, Willing, and Able
- Autism and Intellectual Disabilities Knowledge Exchange Network (AIDE)
- Social Development Partnerships program
- The Autism Spectrum Disorder Strategic Fund
- National Autism Surveillance System (NASS)
- Entrepreneurs with Disabilities Program
- Canada Disability Benefit
- Disability Tax Credit
- Canada Pension Plan disability benefits
- Canada Disability Savings Grants and Bonds
- Disability Inclusion Action Plan

NOTE: This year's survey was conducted on jamboard.google.com where individuals could collaborate with and see other attendees thoughts.

How should these current funding initiatives be organized in a NAS?

- Some sort of universal access for support and resources, as well as diagnosis. Working with military families, it can be very frustrating having to prove to so many different people a diagnosis. They can receive a certain support in one province and have to completely reapply and and such to access almost the same thing in a new province.
- Should be flex funding
- What are autistic persons saying would be most helpful?
- The Disability Tax Credit criteria needs to be revised, so that it's easier for all disabled Canadians to access the credit, and more importantly, be able to open an RDSP. The criteria focuses too much on physical challenges.
- Universal access point for autism support and resources- A National Autism access platform
- I feel the push for the NAS needs to take a pause to take into consideration the many autistic voices opposed to the NAS.
- I feel a wider conversation on the need for a National Disability Strategy is needed. Disabilities are often intersectional- a disability strategy can take into account all forms of intersectional disabilities.
- I think whatever language the NAS uses, it should include the reasons why it was picked while also acknowledging that there's no one language to describe autism.
- For Indigenous populations need a distinction based approach that recognizes the unique needs of First Nations, Metis, and Inuit

How should these current funding initiatives be organized in a NAS?

- Less emphasis on behaviourist approaches, such as ABA
- We need more resources for supportive housing, and person directed, individualized supports for life and social skills--which vary by jurisdiction quite dramatically.
- Allowing for options or choices by individuals and families based on individualized identified need - some people may want to invest in counselling, others certain types of therapies or AT devices, respite.
- It should also address the other resource areas mentioned here such as sustainable housing.
- A single point of diagnosis and eligibility for access of all programs. Its degrading to try to keep convincing so many different parties of diagnosis and needs.
- Fewer mandates and less emphasis on Applied Behavioural Analysis (ABA) for autism. ABA is outdated; we need to move on to better ways that respect mental health needs.
- The speaker Damon mentioned Mona Delahooke- she is fantastic. So is Level Up Autism, SCERTS model, etc. Push for these more updated neuroscience/relational approaches for autism
- I often worry that families of children without an ID cannot access funds that are still needed for safety and social programming for their children.
- Autistics experience higher rates of abuse and victimization which is further compounded by intersecting identities. More social services and supports for autistics to alleviate the impacts of this victimization. Re: housing, mental health services, trauma-informed care, neurodivergent affirmative therapies, legal services, funding for education.

What other types of initiatives are missing?

- Lifespan approach to service access
- Truly affordable housing
- First Nation reserve autism supports. Develop a National Indigenous Autism Centre.
- Ensure supportive employment programs are available in rural and northern communities not just cities - think outside the box and offer virtual support!
- We need more affordable transportation options for people in both urban and rural areas, including public transit, inter-city buses, passenger trains (especially passenger trains), marine and air travel.
- We need more resources for affordable supportive housing, and person directed, individualized supports for life and social skills.
- Ensure the DTCC allows for inclusion of ASD - it's immoral to have to re-apply every 4-5 years to prove ASD diagnosis and required supports
- I feel what's missing are community supports when your child ages out of programs from an autism organization. Then the referral to a child development centre is given and a child ages out of that as well. What's next when a parent has no choice for alternative therapies including school? This has been the case with my child in our province of Saskatchewan.
- We need a basic income for all Canadians. This program should ensure everybody in Canada can afford to meet their basic needs. This program should not be income tested, except maybe for those who are making six figure salaries and above.
- Free post-secondary education at all levels, so that those facing financial hardships due to their disabilities can still access inclusive post-secondary education, in order to further their personal and career growth.
- Caregiver CPP benefit

What other types of initiatives are missing?

- Neuroscience approaches to support mental health and emotional needs that lie beyond external behaviours. Approaches that respect autistic people's unique nervous systems
- More supports that do not measure autistic children to a presupposed ideal 'norm'. More relational approaches and fewer compliance-based approaches.
- AAC access and presuming competence trainings in schools
- Trauma-informed approaches.
- More initiatives that see autism as a neurotype, albeit with many challenges, but not a disorder or a deficit.
- Transition to community supports beginning in junior high grades/upper elementary
- Do families have choice in the types of services and supports that they will undertake?
- Accessible housing. If I can't navigate it, being affordable won't accommodate me.
- A basic income program that does not penalize us working
- A place where researchers share their findings in a consolidated location so that organizations have a solid information source when choosing resources or interventions they will use and support (hopefully approaches are vetted by/recommended by/endorsed by autistic people).
- Actual inclusion enforcement. Require businesses and organizations to be accommodating in a proactive manner, rather than a reactive manner. Eg. childcare requiring a specialized teacher per room, regardless
- An initiative for families that are impacted by systemic discrimination for having an autistic family member
- AAC access and presuming competence trainings in schools. I agree with this completely. I work in public schools in BC and AAC is taught but it is very narrow and only Touch Chat is recognized because of the cost of training but there are so many other methods....It should be what works for the student not what fits best into the budget.

Do you have any other comments about initiative/programs for autism at the federal level?

- Create a National Disability Strategy instead of the NAS! Look at radical disability access initiatives such as mandates for Universal access strategies in schools, businesses, etc.
 - Yes please!
- One report/data base that consolidates best practices and supports from which families, organizations may choose would be helpful - it needs to be vetted/the strategies and supports need to be recommended by autistic persons.
- School resources for teaching about neurodiversity; professional development for staff around how to understand and teach neurodiversity (and intersectionality).
- More public awareness campaigns (television, web) that helps reframe autism for the public.
- We need free adult assessments for all disabilities across Canada, with minimal wait times to access these services.
- If we are listening to all autistic voices, should we not include those who feel they were helped through "good" ABA practices that include looking at sensory issues etc?
 - Second this.
 - I'm thirding this
- Autism services vary from province to province across Canada. Provincially some provinces have access to many resources and funding. While others have programs that are age based and a child ages out of them. How does this contribute to inclusion?



APPENDIX: FULL RESPONSES

Do you have any other comments about initiative/programs for autism at the federal level?

- NAS must have F/P/T indicators tied with funding targets across all pillars.
- I provided feedback during the summer CAHS sessions or I had my feedback sent to individuals who were attending the sessions when I couldn't myself.
- In my province (NL), ABA is the only government funded therapy for autistics and many professionals who denounce ABA have to call themselves ABA to get funded...2. Alternative psychological and social support systems and therapies that reject ABA practices and conversion therapies.
- All of the programs are reactive rather than proactive. While in theory they provide support, it is only if those persons have the income available to utilize while they wait for reimbursement. This creates barriers and perpetuates poverty.
- Federal government can review provincial laws that limit or create barriers to disability inclusion
- There needs to be better federal policy to support all disabilities, including autism
- Listen to autistic voices who call for a defunding of outdated and misguided autism supports such as Applied Behavioral Analysis and Intensive Behavioural Analysis (ABA and EIBI)
 - This doesn't feel in good faith. Autistic people aren't about silencing other Autistics

What are some things to work on moving forwards with a National Autism Strategy?

- Continue working on NAS - without it there will be continued crappy lack of funding for all support we need. Strategies eventually turn into Action Plans with funding if there is political will. Outside policy wonks will pull the plug if there is outward fractioning of the autism and autistic communities.
- Empowering organizations and local advocates to understand the research and recommendations so that they can move things forward. These are powerful ideas...they need to be understood and shared.
- The National Autism Strategy shouldn't focus just on autism, but all the co-existing disabilities that also impact autistics. (Not sure that impacts is the right word, but I'm not sure what other word to use.) Make sure it includes actionable steps that can be implemented right away.
- As well as listening to the voices that oppose it, listen to the voices supporting it to balance it out.
- Community understanding, common definitions of neurodivergence, autism (and resources to help community understanding).
- Knowledge translation of policy compendium reports.
- Allow Indigenous people to lead, plan, and develop their own autism initiatives
- How are autistic persons treated within the criminal justice system? - when they are victimized by crime? when they are criminalized?
- We need action, not a strategy.
 - THIS! we need real-life real-time solutions/policies that can be implemented today
- Take a pause on the NAS and listen to autistic voices who oppose it.



APPENDIX: FULL RESPONSES

What are some things to work on moving forwards with a National Autism Strategy?

- Choices for individuals and families, organizations
- Inclusion of neurodivergent voices in decision making/recommendation making.
- Getting real about the microaggressions autistics face in our daily lives. How we interact as a society is founded in neurotypical norms.
- The benchmark for a "deficit" is defined by neurotypical standards. We must decolonize our approaches. Productivity is not the only measurement of a successful life.
- Actionable steps.