

Canadian Autism Spectrum Disorder Alliance Annual General Meeting (AGM) MINUTES Fiscal Year 2021

Tuesday April 26th, 2022 12 PM EST Virtual Pan-Canadian Zoom Meeting

Present:

CASDA Board of Directors:

Debbie Irish (Chair), Karen Bopp, Pascale Castonguay, Maddy Dever, Jill Farber, Brian Foster, Nathalie Garcin, Rebekah Kintzinger, Anne Kresta, Tanya McLeod, Shino Nakane, Susan VanDeVelde-Coke, Kim Ward, Margaret Whelan, Arshad Zaver

CASDA Staff:

Franziska Morin (Executive Coordinator), Stephanie Cote (Manager, Policy Initiatives)

Members: Names of attendees of the AGM are listed below. Quorum was met.

Grant Bruno

Rosemarie Carreiro

Nicole Eddv

Stephanie Ehret

Nathalie Garcin

Jennifer Houselander

Stephanie James

Lori James

Tim Konditi

Julie Lavigne

Dave Mikkelsen

Melinda Noyes

Kitty Parlby

Janice Pounder

Amy Quintal

Ben Reiman

Brandon Rudics

Lance Scout

Rebecca Stevens

Stephanie Williams

Pearl Yellow Old Woman-Healy



1. Welcome and Call to Order

Debbie Irish, Chair of the CASDA, called the Annual General Meeting for the Fiscal Year 2021 to order at 12 PM EST.

Lance Scout provided the land acknowledgement and opening prayer

2. Approval of Agenda

Materials: 2022 Annual General Meeting Agenda

All members who are in good standing 45 days in advance of the AGM are eligible to vote and have received an AGM package with the agenda, last year's minutes and audited financial statements by email. Please note that there will only be one vote per organization.

BE IT RESOLVED THAT THE 2022 Annual General Meeting Agenda is approved.

Motion to approve: Shino Nakane, seconded Tanya McLeod. Motion passed.

3. Review and Approval of Minutes for AGM May 14, 2020

Materials: 2021 Annual General Meeting Minutes

The minutes of the 2021 Annual General Meeting were circulated to our members for review prior to the meeting. Any questions, comments or corrections were added to the chat.

BE IT RESOLVED THAT THE 2021 Annual General Meeting Minutes are reviewed and approved.

Motion to approve: Maddy Dever, seconded Kim Ward. Motion passed.

4. Chair Report

Next on the agenda is remarks by the chair. An AGM is a meeting to take care of business and celebrate accomplishments. I have been on the CASDA board for eight years and the board chair for the past three. We have accomplished a lot, including receiving funding from the Canadian government and hiring a strategy and operations director. We also advocated for a National Autism Strategy and received a commitment from the Minister of Health and the Minister of Employment Workforce Development and Disability Inclusion. Our staff and board have worked hard and our brand recognition has increased. I am proud to have been a part of this organization and am leaving the board in great hands. Margaret Whelan will now walk you through CASDA's year-end review.



5. Annual Election of Directors

Kim Ward introduced the slate of Directors for membership.

BE IT RESOLVED THAT the following persons are hereby appointed to terms of two years on the CASDA Board of Directors:

New Directors:

Gail Francis Priscilla Burnham Riosa Pascale Castonguay Anne Kresta

Motion to approve: Rebekah Kintzinger, seconded Jill Farber. Motion approved.

6. Year in Review

Let's start with April of last year where we launched the Canadian Journal for Autism Equity. The thing that was most exciting about it is that it is Autistic authors, artists, and editors driving this journal. It has been a very exciting development in the field, offering a platform that amplifies voices of marginalized individuals, and shares their perspectives directly with decision makers, and with our members.

Also in April, we partnered with Inclusion Canada to develop this resource on employment, providing a platform that helps individuals on the autism spectrum, and those with intellectual disabilities, find jobs and work during COVID and beyond. It was meant for companies so that they can effectively hire workers and build inclusive workplaces. It's clear that this will have legs going forward because it provides the foundation for building ongoing acceptance and understanding of the need for inclusive workplace environments that include Autistic Canadians.

For a second year we're partnering with Kid's Brain Health Network to develop policy working groups. We have been aligning that in two ways. One with our own perspective on a National Autism Strategy, but also the work that the government is doing, and leading the development of the strategy so the fellows that we are working with will continue to work on producing policy briefs. The three main areas were the ones that were also identified for the work that was being done on the survey by the academies last year. Again, we were seeking alignment so that we can strengthen and amplify the voice that we have in advocating on behalf of a strong and stable National Autism Strategy.

We worked with Ready, Willing & Able, one of our partners as you know, in the building employment opportunities area, to complete an environmental scan of provincial and



territorial employment programs. It is assuring that we look at supports that are available to Autistic job seekers and employees, and their employers, and the service providers. All these key players ensure that we have successful employment opportunities for Autistic Canadians, and successful workplace environments for those employers who wish to engage with our broad community including Autistic individuals.

Next, take us to June. And this was a very exciting development where three of our board members Maddy, Rebekah, and Corey were able to represent CASDA at the convention on the Rights of Persons with Disabilities through the UN. Their conversation was about providing insights about institutionalization, and deinstitutionalization, and how to make that successful. I may be skipping ahead, but I know that one of the things that was in the successful outcomes, was the introduction of, and impressing upon those who were there, of the importance of the right kind of language of inclusion. Special thanks to Rebekah for making that happen.

Next was a partnership that we had with CCRW, that was related to a research project seeking to understand how community agencies support and connect with job seekers that have disabilities, and who might be in the financial sector. We identified some relevant resources to inform the Disability Confidence in Finance Toolkit through an autism lens. Again, I think this reflects a direction that CASDA is going in, that it's not just our own sector, but engaging with other sectors, and bringing to that conversation the Autism lens. Next, a Pediatric Autism Research Cohort where we supported McMaster's Autism research team in generating knowledge about diverse pathways and outcomes for children on the spectrum, during the preschool enterally school years. The research that was generated is intended to help enhance communication between clinicians and families as they work to develop more personalized support.

We had a very busy month in June, we also connected with the Canadian Institutes of Health research looking at ways that we can generate knowledge on the factors that contribute to the diverse pathways and outcomes. This has become a catalyst for some future work that CASDA is currently doing.

We're into the summer months already, and you can see that the levels of partnership that CASDA has engaged in have begun to grow in an exponential way, and I think that's a great tribute to the work of the CASDA team. In parting with the Institute for Research on Public Policy we were able to highlight the need for engaging with Autistic and Autism communities to develop a sustainable Autism strategy. With the new funding that went to the research that just got finished by the academies and the position that PHAC is taking around more leadership with respect to pursuing the National Autism Strategy, it's important for us to make sure that our voice keeps focusing on the fact that we need stability and good governance if we're going to have a successful and sustainable National Autism Strategy. This is how we were able to articulate that, through publication in this particular journal.



Again, partnering with McMaster, we were able to get funding through the Health Systems Impact Fellowship for two fellows Mackenzie Salt and Sara Lacarte. It's going to be an interesting 18 months ahead as we work on this, as we have the fellows in place, now we are starting to define what mechanisms and tools we are going to use for the advancement of evidence-informed systems change. I'm quite delighted to see that some of the work of Mackenzie is going to build on the original work that was done by Jonathan Wise back in 2014, around these assessment surveys and new set, as a launchpad for some of the subsequent work that this group is doing.

For those of you that feel that we are in a never-ending election cycle, CASDA, our team, and our members were very active during August, around the last federal election to make sure that Autism and a National Autism Strategy remained on the front and centre of the platform. We need to be vigilant that were not giving any wiggle room to have this backslide, so we're quite happy with the outcome of that, the level of engagement of our members, and the political penetration that we had in making sure that people were talking about this, in the United clear voice on why this was necessary and clearly getting the message out there that we are not backing down this needs to happen.

Now as we launch into the fall. We see the movement in working with the Pan-Canadian Disability Coalition. Again, advocating with all the major political parties that we must stay focused on disability issues. That debate that we were part of facilitating, or nudging along had more than 1300 registered participants, 700 of whom also attended the debate which was streamed.

Next, we brought together 75 stakeholders from across the country to engage in a conversation about an Autism Data Collaborative. It is in response to recognizing there's a lot of research going on, but we don't have a good mechanism yet for coordinating all of it or leveraging the relationships and partnerships that are out there. What came out of that was an articulation by a large number of the Autism researchers and related interested parties across Canada in forming a Pan-Canadian Autism Data Collaborative. Subsequent to that there are three working groups looking at specific areas of Autism data where we can build true collaboratives.

Next, we have our Autism Leadership Summit in October. which is always an exciting time for people who are involved with CASDA. 200 participants, panelists, moderators, coming together, where we learn about a weigh in on autism policies, and it's what keeps us focused on the issues related to advancing National Autism Strategy.

With the changes that were happening in Public Health Agency of Canada we felt it was necessary to submit to them a policy brief that outlines our position. Meaning, who we are, why we are credible, the work we do, providing an update on the National Autism strategy since 2019, discussion of current projects and activities. The driving force behind that is to



ensure that the faces may change at the Public Health Agency Canada, but the credibility and focus of CASDA does not change.

We also prepared a brief for Employment and Social Development Canada that looked at, again goes back to some of the work that Rebekah was doing, ensuring that we can influence the use of language as it relates to autism in government activities. That way they're developing policy, writing documents, that they are using language that is accessible to the Autistic community.

January was when the Senate committee announced that they were going to be issuing a draft legislation that would require a National Autism Strategy and attached to it a time frame. CASDA mobilized around this very quickly, we analyzed the bill, submitted some feedback on it, and then invited us to the list of witnesses to address it. We had some excellent questions from the floor, some interesting dialogue and so on, and we were able to follow up with a document submitted to them that answered the questions of the senators. And we also proposed some language that would strengthen the bill.

We testified that, was a very interesting experience, and I feel confident that as a result of the testifying, that quite a number of our members made, it was very impactful on the senators. We heard back from them about how we had broadened their understanding and perspective on the importance of this bill, particularly as we made it real for them. About what this bill actually means, what a strategy really means for the lives of Autistic individuals and their families, that people care for them and their communities.

This is where we have been able to secure an ongoing, very visible role for Debbie Irish, even as she tries to step down from her leadership role at CASDA. That is that, in collaboration with five other organizations, we have been awarded the Secretariat for the Pan-Disability Coalition grant. Debbie will be leading that on behalf of CASDA, focusing on the collective impact and building capacity within the sector.

I hope you can begin to see that there are a number of emerging themes here. One is that we have been very effective in engaging with other disabilities and the disability sector broadly and continuing to add an autism lens. I think that's breaking down the barrier of people thinking that Autism was just over there, that we were only little pieces on her own, and it's absolutely not the case.

Our next slide is inclusion at work, a series of webinars that included Inclusion Canada, Ready, Willing & Able, and The Inclusive Workplace, in providing practical and applied strategies that support inclusive hiring, and showing examples about how businesses can build accessibility, and how inclusive workplaces benefit from everyone, for everyone. I'm hoping that you've been seeing some of the things that have been written in the newspaper recently. A number of articles articulating how employers and workplaces are being quite vocal about how the inclusion of people with disabilities, and Autistic individuals are adding value to their workplace environment.



If I keep going on this, I have just two more things that talk about what happened in April, which is not technically a year in review, because it is in this year. But we did have our most recent summit, with about 300 attendees, and it was the first time that we were able to award the Jim and Ginette Munson Autism Leadership Award to Whitney Hodgins. I have to say, that was an unbelievable experience, receiving those nominations, and then coming across a nomination for a person who made such an incredible but quiet contribution in leadership to the field of Autism. I certainly hope that we find a way to Whitney Hodgins close to our hearts and be involved with us at CASDA.

The last piece before I pass this over is to announce that Ready, Willing & Able was able to secure continued funding of \$20 million, and that the project that is jointly sponsored by Inclusion Canada and CASDA will continue to move forward with this three-year investment.

7. Annual Approval of Financial Statements

Materials: Financial Statements December 31, 2021

Arshad Zaver presented highlights from CASDA's 2021 audit. The audited financial statements present fairly in in all material respects that affect the financial position of the Canadian Autism Spectrum Disorder Alliance as of December 31st of 2021, in addition to the results of operations and cash flows of the year in accordance with Canadian accounting standards for non-profit organizations. It is a clean audit, the most desired audit opinion. Overall assets experienced an increase of 95% compared to the year prior, due to the influx of cash related to deferred contributions. Cash comprises 82% of assets, the internal affairs committee will have to consider whether an investment portfolio is worthwhile to hold onto cash that is not required. The 2021 year finished with \$609,115 in total revenue, compared to the \$375,327 the year before, which was a positive change of 70%. Operations comprised 46% of total revenue. Total expenses increased by 70%, mainly driven by increase in staff wages. In 2020 we only had 4 staff on payroll, in 2021 we have 8 staff on payroll and 9 summer students.

BE IT RESOLVED THAT the Members accept the 2020 financial statements.

Motion to approve: Debbie Irish, seconded Kimberly Ward. Motion approved.

8. Appointment of Auditors

BE IT FURTHER APPROVED THAT Casey Levy Carter Maclean is hereby reappointed the public accountant of the Corporation to hold office until the close of the next annual member's meeting or until a successor is appointed, at such remuneration as may be fixed by the directors, and the directors are hereby authorized to fix such remuneration.



Motion to approve: Debby Irish, seconded Shino Nakane. Motion approved.

BE IT FURTHER APPROVED THAT Casey Levy Carter Maclean is hereby reappointed the public accountant of the Corporation to hold office until the close of the next annual meeting.

9. Organization Rebranding

I'd like to call upon our new board member Pascale who will introduce a special resolution to change CASDA's name. This name change was introduced at this year's summit. This name change was suggested by the autistic community to reflect updated and respectful language.

Here is a special resolution to approve the corporate name change. Be it approved that the name of the organization be changed from "Canadian Autism Spectrum Disorder Alliance" to "Autism Alliance of Canada", as well as "L'Alliance canadienne des troubles du spectre de l'autisme" to "Alliance canadienne de l'autisme".

Motion to approve: Susan VanDeVelde-Coke, seconded Brian Foster. Motion passed.

10. Remarks of Outgoing Directors

Before we finish our proceedings, we would be remiss if we didn't recognize the contributions made by Debbie Irish. At the end of the month, she will be finishing her term as chair of the board, well actually two terms, as she was doing such a great job, we couldn't let her go, after just getting us started on her new direction. The last four years under Debbie's guidance have been transformative for CASDA. To list just a few of the growth areas she has led us through building the capacity for and securing the funding for summer students, followed by research fellows, Ph.D. students, and the list goes on. She and Jonathan have been a powerhouse duo in this regard. Securing the funding for, and then hiring core staff to enable CASDA to fulfill its aspirations as a driving force to advance the National Autism Strategy. She empowered this new staff group to envision a new era for CASDA, beyond finally getting a National Autism Strategy a reality. Debbie has led us through not just one, but two strategic planning processes. She showed the leadership necessary to support a name change and a shift in organizational objectives. Not least of all, steering CASDA forward with the true engagement of Autistics, ensuring their voices and in fact their hard work, could be integrated into all CASDA activities. There are more than can be added to this list, but I'm sure she is already ready to be out of the spotlight. As it is so I will leave it as this incomplete list of her contributions to CASDA. One last thing, Debbie was the brains behind developing the leadership summit and creating the Jim and Ginette Munson Autism Leadership Award. Now there were some who dared to wonder those four years ago, whether it was the right thing for CASDA to have a chair that did not work in an Autism-specific organization. Through Debbie's tenure, CASDA has been able to show that it embraces a wide range of committed Canadians who want to work together to secure a



National Autism Strategy. She ensured we have a bigger tent and one that is both inclusive and diverse. She led CASDA to a heightened profile at the federal level, and among our members. Debbie has spent her entire professional career committed to a better life for Canadians facing the challenges, discrimination, and lack of inclusion that comes with having a disability. She honed her focus on Autism while at the Geneva Centre for Autism and brought the skills she acquired while at Toronto Community Living in Geneva Centre to a leadership role at CCRW, bringing her brand of awareness, advocacy, and human rights into the discussion of workplace opportunities. Yes, Debbie has absolutely been the right chair for CASDA. The right person, at the right time, bringing the right leadership to our organization. Thank you, Debbie

11. Motion to End meeting

Debbie Irish thanked the members of CASDA for their attendance and support of CASDA and invited Shino Nakane to introduce the members of the panel.

Motion to approve: Susan VanDeVelde-Coke, seconded Kimberly ward.