



Canadian Association for Autistic Collaboration
Association Canadienne pour Collaboration Autistique

CAAC-ACCA

What is it, and who are we?

History

- Back in 2015, the Canadian Autism Spectrum Disorder Alliance [CASDA] submitted a proposal to the Federal Government to create a Canadian Autism Partnership [CAP]
- They received funding for a two-year study of that possibility - the CAP Project - and recruited seven autistic advocates to serve on the Advisory Board in 2016
- CAP was not approved by the Federal Government

History cont'd

- ◆ Over the last four years, most of the members of the advisory group have kept in contact. An ongoing, collective dream of ours has been to create an organization to bring autistic Canadian voices to the forefront of research and policy focusing on autism.
- ◆ The Canadian Association for Autistic Collaboration/Association Canadienne pour Collaboration Autistique [CAAC-ACCA] is a result of that dream. We're just getting started, but we have hopes and plans for what we want to do.

Who Are We? Corey Walker

- ◆ Corey Walker is an autistic self-advocate and speaker from Prince George, BC. He was diagnosed with Asperger's in 2001 while in his early 20s, and since then he has made it his life's mission to empower autistics to live the best life possible, and to educate others about what makes autistics such wonderful, unique people with proper supports.
- ◆ Corey currently holds down two jobs; he is the Northern Regional Coordinator for AutismBC and he is a Project Lead for Sinneave Family Foundation on an exciting project researching evidence-based best practices for employing autistic adults.
- ◆ Corey joined the CAAC as a founding member because he was tired of the lack of supports that exist in Canada for autistic adults, especially those with Asperger's. He's hoping that the CAAC will eventually grow to represent a large segment of the Canadian autistic adult population, and can be a powerful voice in advocating for a better quality of life for its members and others like them.



Who Are We? Jackie McMillan

- ◆ Jackie McMillan is a resident of Ontario, and has been educating and advocating about autism since the 90s, speaking at local and national conferences, and helping parents, educators, and supporting professionals to understand what causes the brain inflammation at the root of autism challenges, and how to manage it.
- ◆ Trained in Environmental Health, she practiced as a Movement Therapist (Trager, Yoga, Brain Gym, etc.) and an Advanced Trauma Release Professional (Somato-Emotional Release, German New Medicine, Shamanic Training from North American and Saami Indigenous traditions, etc.) until 2011.
- ◆ At that time, seeing the rates of autism climbing so quickly, and wanting to spare others the hopelessness and debility she'd left behind through trial, error, and digging through research, she shifted to autism advocacy full time.
- ◆ Informally diagnosed by a nurse in the family in 1988, and formally diagnosed in 2008, Jackie's Thrive With Autism work can be found at <https://thrivewithautism.ca/>



Who Are We? Trudy Goold

- Trudy grew up in Toronto and graduated high school the year Asperger's was put into the DSM-IV. She moved to St. John's in 2011 at her parents' suggestion, and was finally given an official diagnosis of Asperger's in 2012 (the year before the DSM-5 came out).
- Since 2013, she has maintained an autism blog (at <https://tagaught.net/>) which talks about some of the struggles and joys of being an autistic adult, to pay forward the assistance she acquired through reading the blogs of other autistic adults.
- She dove into autism advocacy with the advent of the CAP Project, joining the Advisory Group, and hasn't stopped since, and hasn't stopped since, making appearances at CASDA Leadership Summits (2017, 2018, 2019), and INSAR Conference 2019. She was elected to the board of the Autism Society of Newfoundland and Labrador as the autistic advocate in 2017, and maintains that position at present.
- She has been interested in working on the development of an autistic-led Canadian organization working to advocate for autistics since the idea was first considered among the CAP Project Advisory Group, and is glad to be a part of its development.



Why CAAC-ACCA?

- ◆ We found ourselves disappointed by the fact that most of the organizations that are supposed to be helping us have little-to-no meaningful autistic adult involvement.
- ◆ There are non-autistics who want autistic involvement, but the fact remains that autistic Canadians do not have a strong voice in what is supposedly done on our behalf.
- ◆ We have opinions about research priorities that are not being taken into account by researchers.

Why CAAC-ACCA?

- We want to encourage researchers, policymakers, and organizations to give autistics a more prominent involvement in actual decision-making.
- We want to have a Canadian-wide organization that is led by autistics, for autistics, and responsive to the needs of autistics.
- We want to collate cross-Canada autistics' concerns, priorities, ideas, and needs, so that we can truly represent spectrum adults in Canada.

CAAC-ACCA Mission

The Canadian Association for Autistic Collaboration is a representational organization giving Autistic Canadians a voice in their future.

CAAC-ACCA Values

- ◆ Respect
- ◆ Inclusion
- ◆ Consensus
- ◆ Support
- ◆ Acceptance

CAAC-ACCA Goals

- ◆ Engaging with Autistic Canadians to ensure their voices are part of the national dialogue about autism.
- ◆ Providing a forum for the collection and dissemination of perspectives from Autistic Canadians.
- ◆ Developing a safe and reliable space for Autistic Canadians to exchange ideas and information.
- ◆ Enhancing the profile of Autistic Canadians as key partners in the development of a broader understanding and acceptance of autism.

Plans for Accomplishing Goals

- ◆ Establish connections with autism researchers to inform our membership of research projects looking for participation, and inform researchers of what our membership considers research priorities
- ◆ Set up surveys (with data protection) on numerous topics, including questions around language, research priorities, issues of concern, needs, and ideas.

Plans for Accomplishing Goals

- ◆ Open lines of communication to report survey results to policymakers and researchers
- ◆ Set up a website to act as a clearinghouse for information and communication
 - ◆ Set up a blog on the website
 - ◆ Set up a forum on the website, for communication between members
- ◆ Engage in consensus decision-making processes

Plans for Accomplishing Goals

- ◆ Encourage cross-sectoral dialogue and collaboration through our connections to researchers and policymakers

Slow and Steady

- ◆ At present, we have the following either developed or in development:
 - ◆ Interviews with researchers for our website on what research studies involve
 - ◆ The creation of our website (at <https://caac-acca.ca/>)
 - ◆ Questions concerning the development and language use in our planned surveys
 - ◆ Possible assistance regarding data protection and survey creation

What Can NLCAHR Do To Help?

- ◆ Inform us of ongoing research in autism, both provincial and federal (with permission)
- ◆ Inform other researchers involved in research regarding autism that we would appreciate being informed of any studies they are doing
- ◆ Encourage autism researchers to learn about and participate in Patient-Oriented Research

What can CAAC-ACCA Do for NLCAHR?

- ◆ Post calls for participants in research projects (mostly geared toward autistic adults and late teens) on our website as it develops
- ◆ As we grow our membership, post calls for participation in Patient-Oriented Research studies/projects
- ◆ As we gain survey information, inform researchers as to what are the specific concerns from autistics in this province



**Canadian Association for Autistic
Collaboration
Association Canadienne pour
Collaboration Autistique**

website: <https://caac-acca.ca/>

email: info@caac-acca.ca