

# Organizing Neurodivergent Self-Advocacy in Remote Communities

By Christopher Whelan

Neurodiversity YMM



# The Regional Municipality of Wood Buffalo

- Neurodiversity YMM is centred in the city of Fort McMurray in Canada, in the province of Alberta.
- We gather on the traditional territory of people who came before us: the people of the Cree, the Dene, the Dane-zaa, and the Métis
- Fort McMurray is the central hub of the Regional Municipality of Wood Buffalo
- Fort McMurray's population is approximately 66,000 people and an additional 5000 live in even smaller communities across our region
- The closest city, Edmonton, is a 5 hour drive south



A Google Maps image of Canada, with the Regional Municipality of Wood Buffalo outlined with a red border and a blue dot for where Fort McMurray is



# Fort McMurray



A photograph of Fort McMurray in the summertime

- Fort McMurray was founded as a trading fort during the days of the fur trade in Canada.
- European traders built a fort at the meeting of the Clearwater and Athabasca rivers
- Trappers from the Métis nation and the First Nations would trade animal pelts for goods like blankets, cooking supplies, clothing, guns, tools, alcohol, and anything else that their communities wanted

# Why Do People Live in Fort McMurray?

- Today, the Regional Municipality of Wood Buffalo is known as the heart of Canada's petroleum industry.
- The Athabasca tar sands is one of the most petroleum-rich regions in the world.
- The availability of high-paying work, along with Canada's reputation as a progressive and accepting society, attracts people from all over the world to come here for opportunity



Two Caterpillar mining trucks haul bitumen; tar sand filled with crude petroleum

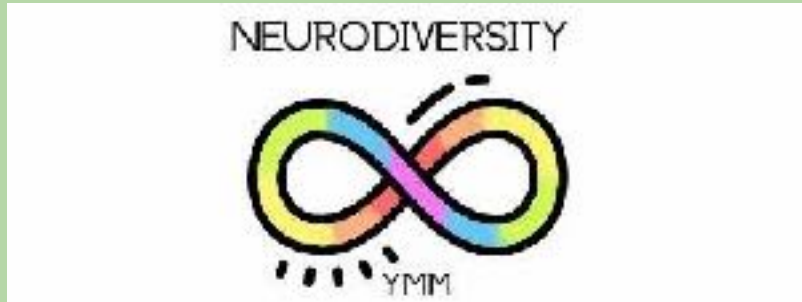
# Our Multicultural Community



Our mayor and council members attending the 2019 Multicultural Expo. Many children and parents raise flags from their home countries.

- Because there are so many opportunities here for people to make a better life, and because we are so welcoming to other cultures, Fort McMurray, while small as a community, is a very diverse and multicultural place to live.
- At the 2019 Multicultural Expo held in my community, dancers, performers, artists, and chefs represented 57 different cultures whom they belonged to.

# Neurodiversity in Fort McMurray



An infinity symbol with the colours red, yellow, orange, blue, and purple make up this symbol used by Neurodiversity YMM

- In 2006, Neuroscience Canada reported that 1 in 3 Canadians “will be affected by a brain disease, disorder, or injury”.
- Because of the population rate of the Regional Municipality, that means approximately 23,600 people in our region are neurodivergent or will become neurodivergent in their lifetime.

# Neurodivergent Human Rights in Alberta

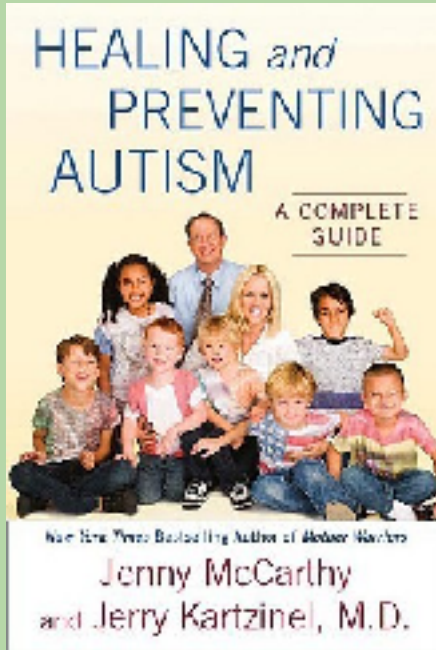
- In 2015, 49% of all cases presented to the Alberta Human Rights Commission were cases of discrimination based on mental or physical disability.
- In 2015, the Canadian Mental Health Journal reported that neurodivergent people in Western Canada were 3.5 times more likely to have suicidal ideation compared to neurotypical people in the same geographic region.
- A CBC report on the 23 people who were killed during interactions with the Edmonton Police Service since the year 2000 stated that 21 of those people “had a mental illness or disability, a substance abuse problem, or both”.
- Discrimination against neurodivergent people in our region is a community health issue that is resulting in police killings and suicidal tendencies



Police lights over an Edmonton police cruiser



# My Entry into Autistic Self-Advocacy

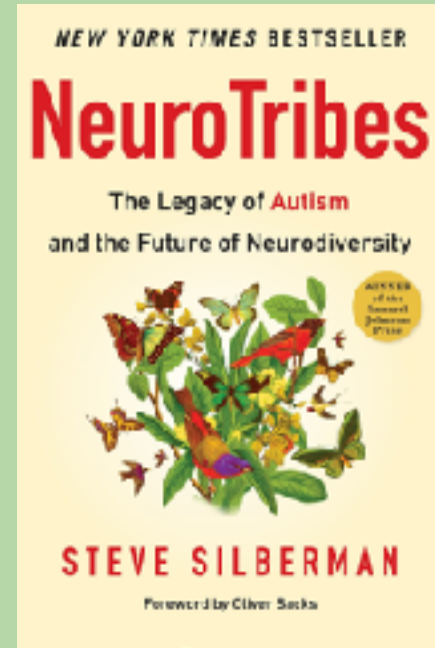


Book cover for “Healing and Preventing Autism: A Complete Guide” by Jenny McCarthy and Jerry Kartzinel, M.D.

- I became interested in the community health of neurodivergent people in 2017, when I found out that I was autistic during my own mental health episode.
- I found that literature about autism was full of language and perspectives that increased discrimination against autistic people with their focus on causes, prevention, treatments, interventions, and a search for a cure. Literature about autism is characterized by interviews with the parents of autistic children, such as Jenny McCarthy and Alison Tepper Singer that talk about what a burden their child is on their family, and how they wish autistic people did not exist.

# My Entry into Autistic Self-Advocacy

- I read Neurotribes by Steve Silberman, and learned about the world of autistic self-advocates and how we were developing an autistic culture that celebrated our lives, instead of talking about what a tragedy autism is.
- I saw that this perspective had the potential to increase the community health of autistic people by showing each other, and the world, what valuable and important people we are.



Book cover for “Neurotribes: The Legacy of Autism and the Future of Neurodiversity” by Steve Silberman

# Autistic Self-Advocacy



Christa Holmans, with pink sunglasses and red chewing necklace

- Self-advocates that I found on Twitter like Sara Jane Harvey and Christa Holmans taught me about how beautiful autism can be, and how beautiful your life becomes when you learn to accept who you are and celebrate who you are.
- From learning to accept myself, I wanted to help other autistic people learn how to accept themselves, and start a revolution of love and positivity this way, here in my hometown.



Sara Jane Harvey, posing with her cane against a handrail

# How Do You Start an Autistic Community in a Remote Region?



A view of Fort McMurray from the sky

- The issues with applying the existing models of building a neurodivergent community in the Regional Municipality of Wood Buffalo are rooted in how far we are from a city (Edmonton), and how underpopulated our town is
- Neurodivergent communities such as the Autistic Network International, the Autistic Self-Advocacy Network, A4A Ontario, and Autistic UK, developed organically from how populated their regions of the world are. Many autistic people could meet together because many *people* could meet together, due to how packed together millions of people are in the regions where they developed.

# Using Social Media

- I contacted the administrator of the local “Buy and Sell” page on Facebook for Fort McMurray, to get permission to advertise that we were building a community organization for autistic people.
- After two months of advertising, I had found 4 other people in my community who wanted to start this organization with me.



“Facebook Marketplace”; Facebook’s classified buy and sell service

# Our First Meeting - July 9th, 2019



An office closet with chairs arranged in a circle

- Our first meeting was held in the office supplies closet of my workplace.
- At our first meeting, we said that because it was so difficult to find and contact out-and-proud autistic people, we should instead open our group to all people of all neurodivergences.
- We named our group Neurodiversity YMM and included all people of all divergent minds

# Monthly Meetings

- Initially, our only program was a once-per-month circle meeting - we avoided the term “support group” because it sounds like we are in a grief process or trying to overcome something together like alcoholism or the loss of a family member. We simply said “Neurodiversity YMM meeting”, a meeting of our members.
- For the first 45 minutes, we go in a circle talking about as much or as little about ourselves as we like. Once we are finished speaking, the person to our left is given space to say what they want to say about themselves. This model is important because I have previously been in autistic self-advocate groups where discussions were not facilitated. Some people soaked up all of the oxygen in the conversation, talking on and on, while other people did not get a chance to speak at all. When we facilitate our conversations, everybody gets to be seen and heard.

# Facilitation Tool: Talking Stick

- We used a “talking stick” at our meeting. This talking stick was placed in the middle of the room, and anybody who wanted to speak could pick up the stick. Once the person who was speaking was finished their thought, then the person with the stick got to speak.
- This was implemented because people, particularly autistic people, tend to have difficulty in knowing how to interrupt a conversation to say something important. If you had something to add to what a speaker was saying, or you wanted to offer support to them, you could pick up the talking stick and have your chance to say what is in your heart.



A stick painted green and wrapped with gold-coloured string



# Facilitation Tool: Web Chat Channel



The logo for the web chat service Zoom

- Another facilitation tool we used was a video chat channel, before COVID-19 happened and the whole world had to communicate on video chat channels.
- We implemented this starting last summer because we were meeting in the evening, and after a day of work many neurodivergent people did not have the social energy to go to a meeting; they just wanted to stay home and relax.
- A video chat channel made it possible for people to attend a meeting from a more familiar place that they were comfortable with, if they were uncomfortable meeting in an unfamiliar place. They could still talk to the group and engage with us.

# Facilitation Tool: Web Chat Channel

- A happy side effect of having the video chat channel was that people from the outlying smaller communities and First Nations could now call in to our meeting and participate this way. Now we could include neurodivergent people who could not physically access our community.
- We also had more engagement from multiply disabled people who could not get to our location due to physical limitations. The video chat channel helped us engage even more of our community this way.

# Partnerships with other Autistic Advocacy Groups

- After creating our Facebook page and advertising our new organization on social media pages for neurodivergent Albertans and Canadians, we received messages of support and solidarity from other neurodiversity rights groups like Autistics United Canada and the Alberta Hummingbird Project. We would collaborate on projects with each group
- the Alberta Hummingbird Project helped us to organize a demonstration against Autism Speaks Canada's discriminatory mission of cause, prevention, treatment, and cure for autism, at their annual fundraiser in Edmonton in September 2019.
- Autistics United Canada helped direct us to a toolkit for organizing an event for the Disability Day of Mourning on March 1st, 2020, where we named and honoured disabled people who were murdered by their caregivers.



The logo for Autistics United Canada; eight infinity symbols linked together, each a different colour

# Partnerships With Other Local Disability Orgs



The logo of the municipality's RACIDE committee; the committee on diversity and inclusion. The logo is four ramps made of multi-coloured triangles

- We have partnered with our local Autism Society of Alberta branch to help develop social programming for autistic adults, and training on autism inclusion for our community.
- We have partnered with the Regional Inclusive Committee to organize the 2020 Disability Day of Mourning and present our efforts to prevent discrimination against disabled, neurodivergent, aging, and chronically ill people.
- We have partnered with our municipality's Regional Advisory Committee on Inclusion, Diversity, and Equality to help build networks to address hate-based incidences against people from minority groups in our region.

# Challenge: Membership

- One challenge faced by our budding organization is membership.
- Neurodivergence is highly stigmatized in our world, and we quickly ran out of people in our region who openly identify as neurodivergent.
- We have however made incredible progress in improving our membership. At our first meeting in July 2019 we made the goal of increasing our membership to 15 people in the next 12 months. In July 2020 we now have 41 members.
- We were able to accomplish this through extensive outreach with other nonprofit organizations who helped us market our resources to their members, and also by working with other organizations to make our region safer to be neurodivergent in.
- Our best tool for this is education, and I have had many meetings with organizations and the community to teach the principles of neurodiversity and neurodivergent pride.

# Program: Neurodiversity Storytime

- In June 2020, we started Neurodiversity Storytime, where, with permission from the authors, we read poems, articles, infographics, and books written by neurodivergent people on the topics of acceptance, pride, and health.
- This is a guerilla radio, punk rock way of getting these messages out into our community.



Book Cover for Loud Hands: Autistic People, Speaking, edited by Julia Bascom

# Program: Neurodiversity Storytime

- Since we were formed, we have had neurodivergent people and parents of neurodivergent people come to us and ask for help in finding acceptance and pride, and we have directed them to books written by neurodivergent people, speakers, and disability justice academics, but this is not the most efficient way to make the community more accepting.
  - 1) People are coming to us for help, which requires courage and social energy, so not everyone is getting the resources they want.
  - 2) Telling somebody to go read a book means that we are asking them to take on a great big project to help themselves.
  - 3) Only the people who have heard of us and who want to learn more about neurodiversity are being exposed to neurodiversity ideas.

# Program: Neurodiversity YMM

- Neurodiversity Storytime is a way for us to get neurodiversity ideas out into the community, a little bit at a time.
- When I go on live stream, people will sit and listen for a few minutes, or maybe they are scrolling through Facebook on their phone and they see my livestream, and just for a minute or two I have their attention and I can get some neurodiversity ideas out into their mind. This is a much more efficient way to make the community more accepting of neurodivergent people, because it addresses those 3 problems I talked about.
  - 1) We are the ones sending messages out into the community; it's us making that effort.
  - 2) Listening to somebody for a minute or two is much easier than reading a whole book.
  - 3) We are educating people who may have never heard of neurodiversity before; I share my livestream on community pages so people who are in all levels of knowledge about neurodiversity are listening to the stream.



# Program: Art Therapy



Someone uses colouring pencils to make art

- Another program that we have developed is Art Therapy.
- On sundays, one of our other directors at Neurodiversity YMM helps us to communicate feelings that are stuck inside of us into art.
- Verbal communication and written communication is not always possible for us, and when it is possible, it can be difficult to communicate complicated feelings. We can trip over our words, or not find the words we want, or use the wrong words.
- Art helps us to communicate things when words fail. So by working together in making art, we can communicate those complicated feelings.

# What We Have Learned in One Year

- **Collaborate!** The most important thing to remember when building a social justice organization is that you need to find allies in your community. We broadened our scope and we began to build partnerships with other disability organizations in the municipality and outside of it; organizations that covered all of Alberta and even all of Canada. Other organizations helped us secure the resources we needed to put our programs on, and to increase our membership by spreading the word about our organization. This took many meetings with other organizations but the network that we have built has made Neurodiversity YMM strong.
- **Always think of accessibility.** Think about how you can change the environment to include more people in your meetings. For us, the video chat channel, the talking stick, and the facilitated conversations allowed more and more people to access our meetings that they would not normally be able to. When you are in a small community, every member counts. Every member that does not show up is missed. Make sure that everyone understands this and how much it means to you when somebody is unable to make it to a meeting

# What We Have Learned in One Year

- **Be patient and set realistic goals.** 15 members in one year was a realistic goal for our region of 71,000 people. Start there, and keep pushing every month to advertise your group and build more partnerships in your community. Many of your partnerships will not immediately give you the results you want to see in memberships and resources, but often they open doors for you that you would not be able to access otherwise. Attend all of the meetings with other groups that you can, and don't expect immediate results. Everything will add up if you keep at it.
- **Respect every member.** Social justice groups tend to have lots of different people with lots of different ideas, and everybody is on a different level of their journey of pride and acceptance. Keep the space safe for people to say what they want to say, as long as it is something constructive, and mediate between members who have different perspectives. Make sure that everybody knows how important they are, as long as they respect the group and all of the people who call it home.

# What We Have Learned in One Year

- **Share the responsibilities.** Don't let yourself take all of the work. This can be hard for autistic people because we have a vision in our head about what something should be, and we sometimes feel upset when something isn't what we imagined. But it's not as bad as burning yourself out because you needed to handle too much. Some people in your organization will have talents and strengths that you do not have. What better way to show the world the strengths of all autistic people than by sharing the responsibilities? The end result may not be what you had planned, but it is what the autistic people built together, and that to me is beautiful. Protect your magic, show patience and kindness to the people helping you in your projects, accept that it will not be what you had envisioned, but that what will be made is even better.
- **Balance the happy and sad.** Losing even one member is a hard hit against a small organization, and a really easy way to do that is to keep everything depressing. Fighting for disability rights can feel exhausting, and you need to balance that out with some fun times with your members. Have a pizza party, go swimming together, play some online games. Building your community and feeding your team is just as important as fighting for your rights.

# What We Have Learned in One Year

- **Be kind to yourself.** You will mess up, lose partnerships, and lose members. You have to believe that it's just a setback, it's not the end of your advocacy or your organization. Be kind to yourself and let yourself make mistakes. Take breaks from activism when it is too much for you right now, but promise to come back to it once your health is taken care of. Showing kindness to disabled people is a revolutionary thing; you are changing the world just by being kind to disabled people. That's even more impactful when that disabled person you are kind to is yourself.