

HONEST CONVERSATIONS

Episode 5 - Tools & Resources

HOST: Ally Garber

SPEAKERS: Stacey Herperger, Cyndi Gerlach

You are listening to the fifth episode of “Honest Conversations”, a podcast about Canada’s Autism Strategy. After the Federal Government’s Commitment in 2019 to produce a national plan to improve the lives of people with autism, the Autism Strategy was announced on Sept 26th. The objective of this series is to share the Autism Alliance of Canada’s expertise and reflections, with our members, as key leaders at the national level, now that the Strategy has been released.

Ally Garber 00:00

Hello and welcome. You’re listening to *Honest Conversations*: a podcast about Canada’s National Autism Strategy. I’ll be your host. Ally Garber. Hello to everybody listening, and of course, to our two guests. Today, we have Stacey Herperger and Cyndi Gerlach joining us, and we’re going to dig in on the fifth priority within Canada’s first Autism Strategy. Priority area five is tools and resources, and its vision is a Canada where accessible and evidenced-informed tools and resources are available to support Autistic people, their families, advocates and caregivers across the life course. So within the National Autism Strategy, a number of different tactics have been identified within this priority, and we’re going to have Stacey and Cyndi speak to these today. A few of them, I’m not going to list all of them include providing access to updated information on the Government of Canada’s web page with sustained, accessible and culturally relevant resources with a focus on providing information for Autistic people and caregivers. Also work with provinces and territories to strengthen the provision of evidence-based information on autism, including effective treatments and ineffective or harmful treatments to ensure consistency of information across Canada, certainly something that has been flagged by many over the years, and supporting online platforms with evidence-based information regarding autism to support Autistic people, their families and caregivers. So I’ll turn it over to Stacey and Cyndi.

Thank you both for being here today. Really appreciate your expertise. Stacey is Director of Development Advocacy and support of living programs with the Autism Resource Center. Cyndi is an Autistic self-advocate and mother of two Autistic kids, well, in their 20s now, I guess, and both are members of the Board of Directors for the Autism Alliance of Canada. They are well respected, well regarded advocates and spokespeople. So we’re really excited to have you both here, and I’m wondering if I could start with Cyndi. Do you mind just introducing yourself, maybe sharing your experience and background with Autism Alliance of Canada?

Cyndi Gerlach 02:29

I’m Cyndi Gerlach. I come to you from the unceded territories of the Coast Salish people, in particular the Squamish and the Tsleil-Waututh nations, also known as North Vancouver, British Columbia. I started my journey when my middle son was diagnosed with autism back in 2001, where the prevalence rate was one in 350 and today in British Columbia, the prevalence, this last

go around from last year is one in 30. My journey started with trying to break down barriers, trying to break the stigma of autism, to be quite honest with you. I mean, the stigma still is there. I became involved with the Alliance when I attended a conference to support a friend of mine who is a non-speaker. He was presenting, and I was excited to see an organization that was nationally recognized, but was trying to lead and change the way we perceive autism in this country. And so I got involved by joining and helping out with developing the next several conferences, and then decided I wanted to join the board and be a part of an organization that was truly reflective of how Autistic people are feeling.

Ally Garber 03:57

Amazing. Thank you so much. And Stacey, over to you.

Stacey Herperger 04:00

So I've been working with the Autism Resource Center for, coming on, 11 years. When I first started working here, I was running our camp programs with kids. I've had multiple different roles over the last 11 years, working in our adult programs, life skill building programs and running our employment division as well. My current position was just created to help our organization kind of get our name out there, but also advocate for the Autistic community in Regina and create more opportunities for connection and explore different avenues to provide housing for Autistic people in Regina who need a little bit more support to live independently but don't need like a full time group home.

Ally Garber

Right.

Stacey

In my new position, I also explored other connections that we could make, not only in Regina, but across the country, and the Alliance had an opportunity to join the board, so I'm just brand new to the board just a couple months ago. I'm really appreciating the insight and information from across the country, and different perspectives of how things are going in other provinces.

Ally Garber 05:29

The Alliance is an exceptional organization. And Cyndi, I echo a lot of your take on what you thought when you first came in touch with with the organization, and certainly the leadership that they've shown over the last decade and more in advocating for a National Autism Strategy I think is in large part why we're here today talking about a National Autism Strategy. So of course, on this podcast, we're exploring all of the different priority areas. So while you're both here to talk about tools and resources, I fully expect us to branch off into other topics, because we can't just kind of filter our experience into one little section. But you know, one of the things that did stand out for me when I saw the list of tactics is that repeated notion of evidence-based treatments. And I think that's something that certainly from my experience as a parent, when you first learn about autism, if you do not have a vast understanding of what it is, you're going online and you're searching for you know, supports and resources. And it's very, very easy for families to be given information that isn't accurate, does it, is it not evidence-based? And there's a lot of people that take advantage. I know, certainly some families who have spent 1000s of dollars, you know, seeking quote-on-quote therapy that was not, you know, evidence based or any research behind it. So I'm wondering, you know, maybe I'll start with you, Cyndi, if that's okay, in terms of what you

think about the federal government within the National Autism Strategy, identifying that as an issue to solve.

Cyndi Gerlach 07:20

As an Autistic person, I'd like to try and reframe it a little bit by commenting that evidence base is absolutely important, but I think what we also need to be doing is looking at the person first and foremost, right? When my children were diagnosed, autism was meant to be cured, and that, I still think, is a fundamental challenge, because, you know, there's still this perception that we need to make them indistinguishable. So for me, evidence-based is about making sure that the approaches that families are taking, or even myself, like, you know, if I need a counselor, I need to find somebody who understands autism. And I think that's really, really important, right? There are a number of areas that we still don't understand, and I think it's really, really important that when researchers are looking at it, they're looking at it through the lens of an Autistic person, and not as a "we need to fix you", because I don't feel like I need to be fixed.

My children, who have higher needs than I do, much higher needs than I do, they also don't need to be fixed. But what they do need is, where I would like to see this evidence base going, is if you present in a particular way, what kind of resources, what kind of supports do you need? Because I'm quite different than my children, and I think if I was diagnosed at a much younger age, I would have needed different types of resources. So I would like to see those resources based on if you're a non-speaker, if you have other co-occurring conditions, like there are tons of kids with significant gut issues, with significant medical issues, and unfortunately, we are still in a place where if you have a diagnosis of autism, the autism overshadowing, doctors will not look at the co-occurring conditions that are making up, like, if you're in a lot of pain and you can't speak, of course, you're going to have behavioral issues, and no amount of behavior support is going to make that go away. So we really need evidence-based to find out why is an individual, like we need to know the why, and we're not doing the why.

Ally Garber 09:43

Thank you for that clarifier regarding, you know, the term evidence-based, because you're right. You know, again, and I'm speaking purely from a parent perspective, when you are given that diagnosis by medical professionals, oftentimes the way it is framed as "here's what you can do to get your child closer to the quote-on-quote norm". And it wasn't until I started to very thankfully, shortly after my son was diagnosed, speak with Autistic teenagers and adults, my perspective completely shifted, and I quickly learned that a lot of the, you're right, evidence-based and science backed, therapies and interventions, which is a word that still bothers me a little bit, were focused on that objective of, you know, it works for a specific type of individual who has very specific needs, whereas completely this is the spectrum is very vast, and the challenges and supports, you know, are also very diverse and vast. So thank you.

You just, you were so articulate on that, I really appreciate it. Stacey, what's your take on, you know that that notion of, you know, making sure that provinces have consistent information, evidence-based, you know, focusing on the consistency across the province. I know you mentioned in your introduction that it's been interesting to you to kind of see what the other provinces are doing. So, you know, have you noticed a gap in what one province is offering is very distinct from what another is?

Stacey Herperger 11:17

Yeah, there are a lot of differences in access to programs and services and availability of information, or sort of in-person support, instead of trying to navigate all the information online

and figure it out on your own, I think, across more populated areas versus people who live in more remote areas. But just to piggyback off what Cyndi said when I was reading the strategy a couple of times, they used the word treatment, and I feel like that also just didn't sit well with me, because it's not, to me, treatment is similar to what she described as like trying to get rid of the Autistic traits or tendencies, and that's not at all what I think the evidence would lead people to believe if they were looking at the right evidence, I suppose, more of like a social based model of evidence, like including the Autistic community, and instead of the medical based model of looking at deficits in order for assessment and stuff like that. So I think there is a way to use research and evidence to get the valuable information, and there's also ways to make it less valuable if you're speaking with the right or wrong people

Ally Garber 12:53

Right. I maybe got ahead of myself with that first question, but because I do want to know, once you were able to dig in and have a look at the strategy broadly, not just the pillar we're speaking about today. What was your first, your first takeaway after, after reading through the strategy in terms of, you know, is this what you hope to see?

Cyndi Gerlach 13:14

You know, I think I was super excited before it was coming out, that we as a nation were actually talking about this, right, and that it was going to happen, and when it finally came out, like I had really high expectations. I had high expectations because Autistic people have been telling the nation, their province, their communities what's missing, and I felt deflated when I saw it. When I first read it, it was like, this doesn't say anything. There's no teeth to this. There's no action. There's no 'we're gonna have this done by this date'. Where my passion lies right now is around medical services and psychiatric care and housing and employment. And I was expecting to see, you know, by 2020-30, we're going to have X amount of doctors who are going to be trained, and we're going to have housing. You know, there wasn't that. It's a good start, but there's nothing to it. And my fear is it is just going to get shelved, and it's not going to really change anything in my community and in my province. Because before it came out, I was like saying, if you know, we're going to have this, this is going to be, you know, like, get ready. We're going to have a strategy that's going to really take us out of and to help break down that stigma. It's not there, but it's a start, like it's a starter. We can say we have one, but we need to have teeth to it.

Ally 14:49

I know in the official response provided by the Autism Alliance of Canada, the strategy was positioned as aspirational. But the organization, you know, also, you know, echoing your your comments, Cyndi noted, there were no clear targets, and I think it's been very demoralizing for the community, and using the term community broadly in terms of Autistic Canadians and families and caregivers, is that, you know, it does seem that whenever there's an election about to take place, you know, we hear the promises, and then the other parties' promise as well. And then, you know, when push comes to shove, they're like, Okay, you know, whatever government has the mandate, they put something out to say they did. But I think, you know, what is lacking here is real leadership and guts, you know, because, and that goes for any sort of strategy that comes forward from any level of government, is who's willing to kind of, really, instead of focusing on getting re-elected, actually just focusing on doing the job that needs to be done. And sometimes that is going to, you know, silo some groups, or, you know, disappoint some

people. But I think your perception of the strategy is shared, shared by others. Stacey, what about you? What was your take when you first looked through the strategy?

Stacey Herperger 16:19

I think it was fairly similar, to be honest. There is a lot of good points, and it's sort of a good starting off discussion piece, maybe, but I think it really lacked a lot of the action points still seem like they're just describing thoughts that they might do in the future instead of actual action of what will take place, especially for this section, a lot of the action points were just making sure that information can be shared easily when the main topic was supposed to be tools and resources, and information can be a good resource, but what about all the tools and something like tangible that people can actually use?

Here we do our program more individually, so it's based on the person that we're working with. But I feel like there could be funding for organizations to create programs that help people with navigating executive function in the workplace or supporting your daily routine, so that you can not be overwhelmed at work and still take care of yourself, have a work-life balance like things that could be used practically, instead of just reading information and trying to figure out how to apply that to yourself.

Ally Garber 17:55

Well, I think, as Cyndi said, and I'll ask, you know, for her to expand on the same question is that, you know they do note in the list of different objectives within this priority area is, you know, develop new tools and resources and gap areas. But you know what tools, what resources? You know, obviously, within each province, there are things that are working, you know?

What about providing, as you said Stacey, funding to be able to amplify what's working and then identify what's missing. So Cyndi, you talked about the number of doctors who are specifically trained in a certain area, and you also identified a really, really big issue of the co-occurrence of mental illness for Autistic individuals, and I think that's a massive gap. And you're right, that that target, I think, would have been, would have allowed for more accountability. Can you expand on that a little bit more?

Cyndi Gerlach 18:51

Currently, right now, in the province of BC, if you're under, if you're a child, if you're a youth, up until the age of 18, you can access psychiatric care. You can access appropriate types of care. Once you become an adult, you could wait for years to get an assessment. Psychiatrists don't have the training to work with non-speakers, minimal speakers. We don't have specially specialized doctors, as they do in the United States where, you know, I could go see a family practitioner who specializes also in autism, so that they can look at testing and understanding right, the co-occurring conditions, like I know a family here who's desperately trying to get help for their child because nobody knows what to do. And so I had hoped, really had hoped, that the federal government would have said, like, we need medical doctors. We need psychiatrists. We need the fundamental, I can't, my son, one of my sons, will never be able to get a job until we can get psychiatric help for him.

And so at 26 years old, we've been looking for a psychiatrist for six years, and yet he wants to work. And so how can he work and be a functional member of society if he can't get the medical help that he needs. Housing is great, but who's going to support him if he still doesn't have that? We seem to think that autism stops at 18 or 19, depending on what province you're in, and then we are going to have one in 30 adults, and a third of them are gonna need so much more support. What the heck are we doing? I said this to a politician 20 years ago, if we don't get in front of

understanding the co-occurring conditions of autism, autism is going to bankrupt us nationally, and it's going to because I have to support my own family. What are we going to do with these kids as adults? What? There's a huge fear factor of not understanding autism, and we need to break down that stigma and that's what I thought this Autism Strategy was going to help to do.

Ally Garber 21:23

Cyndi, that's exactly the honest conversation that we want to have here. And I, similar in Nova Scotia, and I'm sure, I think across the majority of Canada, is that focus on kids, but you also mentioned when another issue, a co-occurring issue, comes up, you are punted back to the developmental clinic, and they do not have the expertise or knowledge to deal with a co-occurring OCD diagnosis, a co-occurring anxiety, like it, it very much is, well, if it's autism, It's autism, and you have this bucket of resources to kind of figure all of that out.

So thank you again. You very articulately described, you know that, the challenges that a lot of people are facing, and you know, if the goal is to make sure that people are, you know, contributing, people who want to contribute to their communities are able to do so, we have to be able to address what's limiting them from doing so. So, Stacey, did you have anything you wanted to add on to that, you know, in terms of, you know, echoing what Cyndi said, you know, based on kind of the families and people you work with?

Stacey Herperger 22:36

Yeah, um, like we primarily provide services for Autistic adults 18 to 35 but even in that, that's sort of what our funding mandates. But Autistic people still exist after 35 and we do what we can to help support past that age group, if necessary. But I think the strategy really lacked putting it in writing that it needs to address children, young adults, older adults. It really said gap areas and that it would apply to everybody, but there was no specific language around making sure it's available for people of all ages and that the information is developmentally appropriate for adults. So if all the research and all the tools are developed for children. They don't always work for adults. People's skills and abilities change as they get older, and the expectations that society has on people will change as they get older, and so there needs to be different tools for children, adults, and then older adults as well, but it doesn't really speak to that at all.

Ally Garber 24:04

Right, one of the biggest items within this priority area that I didn't mention when we started, because I wanted to dig in a little bit deeper in our conversation, was the establishment of a National Autism Network. And so that National Autism Network, as outlined in this pillar, will have a mandate to put in place advisory committees with representation of Autistic people, their advocates, families and caregivers, to provide experience and expertise on the additional resources and tools needed from a social determinants of health perspective, to provide better support for Autistic people in Canada, their families and caregivers. So the first thing that I thought of when I saw this was that this is very similar to what was proposed many years ago with the Canadian autism partnership project. But also, I know that some people are seeing this as a bit of a let's again, "punt this down the road a little bit by, you know, establishing this network to kind of do the work that a lot of us had hoped would have been done in this strategy". What is your take on that? Stacey? I'll let you answer that first.

Stacey Herperger 25:15

If it's implemented well, I think the network could be very valuable in, especially, for organizations, maybe, instead of taking perspective from individuals, but across Canada, I think a lot of

organizations are duplicating work, and so if we could spend our time and resources and funding on new and innovative things, and so could other organizations, and we aren't always trying to come up with the same information or do the same work, and we could share that in the load of the work. I think it would really help Autistic people in that we could do more things overall with what each organization has.

Ally Garber 26:07

Yeah, it feels like you're saying that, you know, if maximizing skill sets and expertise, you know, instead of duplicating efforts.

Stacey Herperger 26:19

Yeah, it really feels like, organizationally, all these nonprofits are doing really great work. They're kind of in a silo of, they're doing really great work, and they're benefiting the people who are coming to them. But if we could spread that across the provinces, and then even more really good work could be done to support people coming to us for services. It would have to be implemented in the right way, with the right voices speaking for what is needed in order for it to be effective and not just be more for, like, show, like window dressing.

Ally Garber 26:58

Yeah, yeah. Cyndi, what's your take on the network, and are you optimistic that it could, you know, I know that both of you said something similar at the outset, that you know this is a start, but we hope it builds from here. Do you think the network will allow that to happen or enable that to happen?

Cyndi Gerlach 27:23

So for me, the and I echo much of what Stacey was saying, I just want to be cautious that with a network and the advisory committees that they're looking for, one of the challenges that I have with the word "advisory" is you're providing advice. Doesn't mean that anybody has to take it right. And so if we truly want to have a national network that really does listen to the Autistic voice, we need to collaborate. We don't need to continue to advise. We need to collaborate with those that are living with autism, right? I can't, as an Autistic person, I raised two Autistic children. I can't perceive to know how their autism affects them, but more importantly, as non-speakers, or minimal speakers, how is their voice being heard, and often we neglect to look at the continuum of autism and have the whole spectrum being represented and so, when I looked at the advisory committees that the National Autism Network was sort of looking at, again, they left out the very people that my children are, right? They're not even represented. And so I think the National Autism Network will be a good thing, but it needs to listen to Autistic people, because it cannot be neurotypical, able-bodied individuals who presume to think they know what's best for us, and that is what has happened for decades. And I get it.

You know, there wasn't the knowledge that we have now, but I'd like to see a network that collaborates, that agencies are willing to share openly and honestly the things that worked well for them so that they can, because I worry about the silos, I worry about the "I'm going to hold on to the information because I don't want anybody else to have it, because we want to be the leaders in this area", and we have to stop this. Because, I don't really care if the information came out of Nova Scotia. I don't care if it's going to help me here in BC, I'll share it. Be collaborators. Uplift us and the people who are here to support it and provide, uplift each other.

We have to break down the silos. We have to be working collaboratively together, because I want my kids, who have quite significant supports, to be considered as equally as somebody like me,

and that whole continuum needs to be supported. And I think we can do that well, because there are provinces that have great resources, but are we sharing those with the territories? Are we sharing them across with our First Nations and our Indigenous? Are we embracing each other's perspective? Are we culturally aware people who are coming here from other countries, and they turn out that they have a child who's Autistic, or they find themselves at the age of 50 being diagnosed, are we able to support and how do we do that? And we can only do that if we are working together and breaking down those silos.

Ally Garber 31:02

From your perspective, what's the biggest piece that is missing and the piece that you hope does get incorporated, or woven into the strategy in the days, weeks, months, God forbid, years ahead, Stacey, I'll go to you.

Stacey Herperger 31:22

Well, I think we already spoke to some like, some of our feelings regarding what's missing. I think there's just a real lack of detail of what the intent behind some of the actions was.

Ally Garber 31:38

And why do you think that is? Stacey, do you think that, you know, is it that political aspect of, like, "Oh, we don't want to put a target on, because that'll be tied to that will be rated by that, or judged by that"? Why do you think that we're not getting targets?

Stacey Herperger 32:00

Yeah, I think because it is a huge undertaking, and the more you dig into the specifics of it, the more you really see how much has to be done. And I think in an attempt to not overwhelm or overcommit, what really happened was the opposite in under committing and lack of real action that will benefit the community. Again, if you look at the National Autism Network funding, the money that is promised to the organization who ends up taking this on is not really all that much, if you consider that they want the network to address the intersectionality of cultural differences, different ages, across the lifespan. Yet I don't think there's enough behind it for anybody to effectively do that for every single person across the country

Ally Garber 33:09

And I mean, I think it's, you're right. I think it's fair to say that, you know, yes, it's a big issue, for lack of a better word. But this isn't new, you know, and that's what I think a lot of people are frustrated about, is that, you know, there have been calls for a National Autism Strategy. There's been a needs assessment survey, there's been, you know, a number of different reports and documents with tangible proposals from the Autism Alliance of Canada, like the blueprint for a National Autism Strategy. The Canadian Autism Partnership Project put together a lot of information.

So that's, I think maybe what's frustrating is that, yes, it's overwhelming, and yes, they may be nervous to kind of put targets to but I think, you know, Cyndi, if I can go to you for your thoughts on that, you know, how do families and individuals, you know, feel after decades of advocacy to kind of hear that, well, it's very overwhelming. So we don't want to kind of pinpoint ourselves to any specific targets.

Cyndi Gerlach 34:08

It's sad, right? It's sad. I think other nations have a National, you know, have created their own strategies. Yes, we're vast. Yes, I get the federal government doesn't want to step on the toes of the provinces, because, you know, this, technically, we're, you know, this is all under provincial mandates. I think there's a fear, right? A fear of "we're going to decide for you".

So when you ask the question, sort of, what's missing? I think one of the things that when I read the document, it always seems to be just about the children. And please don't get me wrong, that is absolutely key. But there are teenagers, there are adults. There, like, to be an adult to try and get a diagnosis, you have to pay for it out of pocket. Well, what if you don't have that kind of money? A \$3,000 bill to get a diagnosis or more. It fell short by not having any teeth. It fell short by not having concrete, it fell short by not identifying the holes. It was very soft, right? It's a soft document for those of us that live and that have been advocating for decades, it's a letdown. Again, we're trying to get the government to step up and do what's right. Now, if I could be so bold and blunt, if 1000s of people were dying because of autism, they would be throwing money at research to try and make us live and and I don't want to compare, but you know, when AIDS was an issue, look at what they did. They stepped up to find out why. They're not stepping up. This country is not stepping up to find out why there's a huge increase in the diagnosis. They're not stepping up to just admit that you need more help with this. Listen to us.

We're telling you what needs to happen. I'm not doing a make work project. I'm trying to improve the lives of my children, and I'm trying to improve the lives of every single person out there who is struggling. Listen to us. We have the answers. Yes, it's going to be expensive, so figure out how we're going to fund it. I'm not looking for it 100% today, but over the next 10 years, where do we want to be? Where's our five-year plan? Where's our 10-year plan? That's what you do in a strategic plan when you have a business. We can do the same thing for this, and we can actually make this country the most inclusive, Autistic country in the world.

Ally Garber 36:52

That's the standard we should be holding ourselves to. Cyndi and Stacey, I appreciate your time here today so much I could talk to you for hours. I think that we all share the same passions and the same hope. And Cyndi, I love that standard you set for us. And I think the Alliance has proven time and time again that their efforts will not stop to have us achieve that. So thank you for your time. For all of those listening, please go to the show notes. We have a link to the full [National Autism Strategy](#) available, and look forward to your thoughts.

Thank you again to both of you for being here today. You can learn more about our [Summit](#) in April or you can sign up for membership@autismalliance.ca and make sure to share this podcast widely with your friends, family, coworkers and all across your social media networks.