
HONEST CONVERSATIONS

Episode 3 - Data Collection, Public Surveillance And Research

HOST: Ally Garber

SPEAKERS: Dr. Deepa Singal, David Nicholas, Dr. Mackenzie Salt

You are listening to the third 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 and thank you, Deepa, Mackenzie and David for joining us today for honest conversations about Canada’s Autism Strategy. And today, we’re going to be discussing priority area three, which is data collection, public health surveillance and research, topics which obviously the three of you are very well versed within. So the vision for priority area three is a Canada where public health surveillance and research support action to improve health outcomes for Autistic people.

A few of the tactics that are outlined within this priority area is support for National Autism surveillance, including the development of new data and reporting on indicators beyond prevalence, such as demographics, diversity and equity, co-occurring conditions and including Indigenous health, as well as all jurisdictions and age ranges, children, youth, adults, where possible, support autism research through the federal health portfolio and establish a National research network that would support information sharing and collaboration across sectors and jurisdictions, enable improve data collection and promote research on autism. But I want to turn it to our guest today, and maybe what I’ll do is just have each of you introduce yourselves and provide a bit of background in terms of how you are involved with the Autism Alliance of Canada, and any sort of personal connection you may have to the topic of autism. So Deepa, if it’s okay, I’ll start with you.

Dr. Deepa Singal 01:52

Sure. Thanks, Ally, thanks so much for having us today. My name is Deepa Singal and I am the scientific director of Autism Alliance of Canada. Super proud to work for this organization and work for our members, ensuring that Canada has a National Autism Strategy.

Ally Garber 02:09

Thank you so much. Mackenzie. I’ll head over to you.

Dr. Mackenzie Salt 02:11

Thanks, Ally. My name is Mackenzie Salt, and I am a research associate at the Oxford Center for Child studies and an embedded research associate at the National Center for Autism

collaboration, which is a joint initiative by Autism Alliance of Canada, Hamilton Health Sciences and McMaster University. And I am an Autistic autism researcher.

Ally Garber 02:33

And David.

David Nicholas 02:34

I'm David Nicholas Professor and Associate Dean of Research and Partnerships in the Faculty of Social Work at the University of Calgary, and I serve on the board of the Autism Alliance of Canada, and I bring lived experience as a caregiver in the autism community.

Ally Garber 02:52

Thank you so much. And again, I you know all three of you are such, have such a wealth of expertise in this area, so I'm really excited to to get into the conversation, I think the first question I want to ask now that you've had an opportunity to review the Strategy after many, many years of advocacy from the Alliance to get the Strategy delivered. How does it sit with you? How are you feeling about what's in it? Your first thoughts upon reading through it. So, Mackenzie, I'm going to start with you this time. We'll just kind of play a game, if I'll make you guess who I'm going to go to.

Dr. Mackenzie Salt 03:29

Sure. Thanks. Ally, in general, I think that what we saw in this pillar, in the data collection, public health surveillance and research section of the National Autism Strategy, I think we saw pretty much what we expected, and that is that the government only has so much ability to guide the research agenda and what's going on the ground and things like that. But I'm very happy with much of what I saw in this pillar. Deepa would be well equipped to sort of go into a little bit more detail on what we saw, because I think, generally, we're all in agreement on this point. Deepa,

Ally Garber 04:16

Naturally, I'm going to go to you now after Mackenzie offered that up.

Dr. Deepa Singal 04:22

Sure. Yeah, so Ally, what we know is one of the most powerful tools that the federal government has is its ability to fund research. And we know that federal funding can drive collaborative, high impact studies that can address the most pressing issues facing our community. And we also know that government backed research can also potentially scale innovation solutions across provinces and territories. So overall, as Mackenzie said, you know, we were pretty pleased with this pillar. I think it's actually one of the strongest pillars in the Strategy. But as with the whole Strategy, you know, we still have quite a lot of work to do, and some of the things that we're hoping that this pillar can address or catalyze, is more meaningful engagement with Autistics and their families within the research landscape in the country, more training for Autistic researchers so that they can lead studies and set priorities that are most important to them and their peers, the importance of evaluation of policy and programs that may be either funded from the National Autism Strategy or supported by it.

You know, we really need more efforts to track how well services are working for where and for whom and where improvements are needed, reliable data helps identify disparities and advocate for equitable access to resources across diverse communities and more emphasis on the spreading and scaling of innovative solutions across the country, especially in rural, remote areas that don't have some of the services that we see in bigger centers. But essentially, you know, the underpinnings of the measures and the actions in the Strategy and the framework would lead to building a more robust research ecosystem, bringing the advanced work that's happening across the country together and laying the groundwork for the government to implement policies that are evidence-based and address real world challenges.

Ally Garber 06:31

Thanks for that. Deepa, David, I'm going to go to next to ask what your first impressions were of the pillar itself, but also if you have any thoughts more broadly on the Strategy, but Deepa, you know, we talk about the research ecosystem and, and certainly some of the complaints that Autistic Canadians and caregivers have had and I join you in also being a caregiver of an Autistic son. You know that some of the criticism is that the research that is being conducted has not historically always been what the community feels needs to be researched, that we invest a lot of time and money into initiatives that we don't feel are going to have a tangible positive impact. So, you know, I'll throw that out for everybody to weigh in on to after David talks about his initial observations. But David, what were your first thoughts on reading this pillar?

David Nicholas 07:32

Sure. Well, I would concur with my colleagues in terms of the kind of the overall perspectives on this pillar. And I think what we need to think about is the detail, and how do we move forward with that, in terms of resources to advance that Strategy, and really moving forward with those lofty, aspirational aims relative to intentionality and resources to make that happen in terms of Strategy, and as you spoke about Ally, really thinking carefully about what are the priorities of the Autistic community in terms of moving forward and moving the needle in terms of knowledge and its rapid impact on action and catalyzing shifts in a good way.

Ally Garber 08:28

Thank you so much, David. Mackenzie, do you? Do you have any thoughts in terms of, you know the research being, you know how we're prioritizing research and whether this Strategy will help with that, or at least provide a more context in terms of what we're focusing on and what we're prioritizing, and why?

Dr. Mackenzie Salt 08:47

Sure, so autism as a research topic is quite broad. There's health research, there's social sciences research, there's the basic science. There's lots of different aspects that you can look at. So one of the things that really stuck out to me from this pillar is the idea of advancing guidelines for researchers on inclusive and participatory research approaches. So these are approaches that I like to use. I did a national survey of Autistic adults age 30 plus last year, including Autistic adults across the country. We had representation from every province and territory with this and

one of the things that I think really helped that was we had a group of lived experience partners of different ages, genders, abilities, who helped design the survey. Helped come up with questions, come up with topics, what should we be asking about? And in that survey, we asked about 11 different areas of life. It was 97 questions, so not for the faint of heart, so to speak, but including Autistic people, and including other people with lived experience in the design of the research is so critical to make sure you're getting the priorities that they want, that the community wants. And there's a very old expression in the autism community, when you met one Autistic person, you've met one Autistic person, because lots of Autistic people are all different, and they have different experiences. They bring different different lived experiences, different backgrounds to the table, different living situations and more. So you want to do sort of broad engagement, if you can, some studies can do broader engagement than others. It depends a lot on the research infrastructure. So we talked a little bit about the research ecosystem. So it depends on the funders and the timelines and things, but ideally we should be including people with lived experience at all stages of research, so that we can help with the we can learn about what's needed, we can learn about what's desired, what are the topics that are important. And this is something that I've thought a lot about, because, like, my experience as an Autistic person is very different than other people's experiences of being an Autistic person. So I can't just put myself out there and say 'Oh, I know what's best. Because I'm Autistic' it's no that I represent one experience. So that's why you try to bring together a diverse group of people to try and learn about what those priorities are, and different people have different priorities. That's okay. It's about figuring out, how can we incorporate that information, and we also need to make sure that we have research studies that can be feasibly done like, it might be that, hey, we're learning something came up from one of our lived experience partners. This is really interesting, but it's not it's not something that this project is focused on. But you know what, I want to make a follow up project on that.

Ally Garber 12:04

Right.

Dr. Mackenzie Salt 12:04

Or I know someone else who's working in that area. Let's see if we can connect those people.

Ally Garber 12:09

Well, I think it speaks, Mackenzie, to, you know, the survey that you referenced that was done last year, which was incredible, and I know so much work goes into that. You know, the Alliance itself has done numerous studies, provided numerous documents to inform partners and the federal government, such as, you know, the framework or the blueprint for a National Autism Strategy. There was the needs assessment that was done. So you know that certainly the outcomes and the research that was collected and consultations for the Canadian autism partnership project so Deepa, like, I think maybe many people might be concerned about, like, are we just starting from scratch again? Like, it's, I think sometimes when people within the community, and, you know, I'll speak myself as a parent, I feel exhausted because I feel, you know, my son is 14 now. I've been, you know, joining 1000s of others advocating for a National Autism Strategy since the day of his

diagnosis. And now we're talking about, okay, well, we're going to do some more research, and we're going to do some more, you know, and it's just what happens to all the research that has already been accumulated. And what is your hope for that? Like, is that going to be kind of a launching pad?

Dr. Deepa Singal 13:24

Yeah, I think that's a great question. So much, so much to say. You know, I really validate and recognize the frustration that families and our members feel, but change is historically incremental when we're looking at government change. So what we really want is our members and our families, and you know, Autistic people in Canada, to celebrate this moment. Even though we didn't get everything we wanted or change to happen as fast as we wanted, this is still quite a historically significant moment that Canada Health Autism Strategy right and now, how can we as the Alliance, as a community, as a research community, leverage what's going to come from this, the good that's going to come from this, and move it forward to address sort of the issues that you're talking about, right? And so two things that you mentioned, and that my colleagues mentioned, you know, I hope that this Strategy and the network that gets formed from it will be community-driven, we know it will be, historically, research has really primarily been academic driven, researcher driven, and so it may not have always hit the mark or met the needs of Autistic people and their families.

Emphasis on the Strategy being community driven, lived experience, we hope to see that shift in research priorities. And I know that David can speak quite eloquently to this as well, and then also picking up on David's point and resources. I think a lot of the frustration we've seen when the Strategy has been released is sort of the lack of commitment around the resources that it's going to take to implement, as David said, and act on these lofty goals. And you know, the big ambitions that have been set forth. And the Strategy, and so, you know, our work continues in terms of, how do we allocate or get the government to advocate for those resources so that those actions can be taken that the community needs and knows the next stages and the implementation of the Strategy?

David Nicholas 15:16

Yeah, I think that we're at an important juncture where we are invited to kind of leverage our research relationships and the work done, and I appreciated your question around really building on the work done, not starting from the beginning, but also critically thinking about theoretical presumptions in that research, and how do we move forward in a way that is respectful of the Autistic community and and it has, as Mackenzie spoke to is really in partnership in a proactive way together and in moving that forward. I think there is an opportunity to work together well. And I, and I personally feel like in Canada, we have this rich camaraderie of researchers who have and continue to to work together well. And really this is a moment to build on that work and and to think deeply about things that my colleagues have already spoken about things like representation of who's at the table in that research, and whose voices, whose perspectives, I should say, are being heard or not heard, across the diversity of autism and across other areas of intersectionality, other communities that well.



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l'autisme

Ally Garber 16:37

Yeah, I'm sorry. I didn't mean to interject there, but I was, I was rudely searching something up on my phone because, you know, just on the topic of building on research. And as you said, David, you know, leveraging the partnerships, and what's happening in other communities that have similarities is, I do know that there was the Canada's epilepsy community, for example, recently, I think in the last couple of years, worked on a collaboration with the James Lind Alliance and the Ontario Brain Institute over a two year process that saw Canadians submit and prioritize their most pressing questions related to epilepsy and seizures. And this was, you know, essentially an exercise to listen to the community's voice to help shape the future of epilepsy research. And so if we look at examples like that, you know, my hope is that we could take, you know, examples of best practices and initiatives that were successful and, you know, perhaps integrated into what we're doing here. Deep, it looks like you -

Dr. Deepa Singal 17:38

I swear we did not plan this.

Ally Garber 17:42

I don't think we can show a video of me searching really on my phone.

Dr. Deepa Singal 17:45

It's just so, it's so great, because just as we're speaking right now, Mackenzie and myself and David, we're bringing you into this project as well. Are just sketching out a concept note of us doing this for the autism community in Canada to help priorities set for each of the five areas of the National Autism Strategy. So that is a project that the Autism Alliance of Canada is undertaking right now. It you know, we're looking into whether we're going to do it with James Lind or a different party sending exercise, but it's very much similar to what you just described, and a huge opportunity for our members and for our community to set those priorities that are going to come from that are aligned with the National Autism Strategy. So incredible example, and -

Ally Garber 18:33

Great minds Deepa.

Dr. Deepa Singal 18:34

This is sort of the opportunity that I think we're all talking about now. So yes, we're frustrated that things haven't moved as quickly as we have wanted, but together now, with new refreshed energy and momentum from this Strategy, we can present these opportunities to our community and shift and move the dial; right? We want the work that all of our incredible researchers are doing across the country to impact our lives and change lives. And so to have more folks with lived experience at those tables, with intersectionality: moms, caregivers, Autistic people, fathers, families saying, you know, this research isn't really going to impact our lives, or we don't need this right now. What we really need is X, Y and Z. Let's put the focus there is really going to help shift our needle.

Ally Garber 19:25

I think too, you know, and I appreciate what you're saying, because you're right. You know this, this absolutely is an opportunity. It is a milestone. And I do think the federal government seems to be receptive of, you know, people are tired. They've been advocating for this for a very long time. And while it may not be, you know, everything we had hoped for it is that start that we needed. One of the challenges is, of course, as a family member or as an individual, you know, you are constantly asked, 'Can you be a part of this research program? Can you?' You know, and I think you know what, we're also circling around the same point is that we want to know, you know, ultimately, how that translates to real life supports and resources. Not all of it has to, I think there's absolutely, you know, benefit, but it's with the gaps that we have in service delivery.

Dr. Deepa Singal 20:15

Yeah

Ally Garber 20:16

It's very difficult for families to find time. And yeah, sorry, Mackenzie. I'd love to get your thoughts.

Dr. Mackenzie Salt 20:22

So it's funny, you mentioned services, because we just released a report from a project we did looking at mental health and community based social support services, looking at recommendations from Autistic adults for what they need in terms of mental health and community based social support services. So that was just released on Friday on the Autism Alliance of Canada's adult needs website. I wanted to touch on the piece. So not only yourself, but David mentioned it as well. The being asked again and again to participate in research. And this is something that I've run into quite a bit, and it's people who either want to participate in everything, which is great, but then there are people who are asked too much and they don't want to participate anymore. And I think one of the things that could help that, and one of the things that's mentioned in the data pillar of the Strategy is so it mentions a National Research Network for information sharing and collaboration. Now I don't know the specifics around the National Research Network. I'll leave that up to my colleagues to talk about that specific construct, but I think that more information sharing and collaboration is really important to the work that we're doing, and with the survey I did last year, we are preparing that data set for sharing with other researchers.

And it's really important, because when you have people who spend a lot of time telling you exactly what they need when they're filling out a survey, when they're doing whatever type of research you're doing, when they're taking their time to do this, the instinct for a lot of academics is just to sit on it that like, this is stuff. I'm gonna deal with this. I'm gonna do this. But you may have too much data to deal with it, or you may not get to certain parts, you may run off and do other things. And then people find that, especially caregivers and people who participate, might go, 'Hey, I told them all about these issues, and I haven't seen anything about it. What's going on?' So one of the things that and this sort of data sharing is newer in the health sciences. It's going on for a bit longer in the social sciences. But I think it's really important to be able to share that data, because, for example, in the survey we collected information on housing. I'm not a

housing researcher, but I know some housing researchers who have an interest in autism. So if I can share that data with them, maybe they can do something with that. And then, rather than recollecting where we're sending people off to their expertise, and then they have the data to work with, and then hopefully we can get some faster progress, faster innovation.

Ally Garber 23:23

I think that's, you know, data sharing is I, you know, I've seen it kind of increasingly been being talked about more, even in kind of the traditional media spaces, because there is an interest in, okay, with all this research going on, you know, and I know I'm with a number of academics on the call right now, but in very plain language, it's like, if I'm a researcher in Australia, and it's like, I'm missing that one puzzle piece to kind of put together my perfect puzzle of the initiative that I'm researching, and somebody in Canada maybe has data that could provide that puzzle piece, but there's no opportunity or ability or platform to share it, you know, again, you know, I think that that this concept needs to be explored more. And I'm now giving a second shoutout to Ontario Brain Institute. But they do have brain code, which is that neuro-informatics platform, I believe it's called, where they are, you know, is a place where data is being collected, curated and shared. So I guess you know, David, if it's okay, I'd love for you to provide your perspective on that and where we can go from here.

David Nicholas 24:32

Yeah, well, it's an emerging question that is so important in terms of really building and leveraging on good work that has been done across the world and certainly in Canada, while also respecting ethical bounds and issues of confidentiality and privacy related to certain methodologies and approaches. So I think there's this balance, but at the same time leveraging data for learning is so crucial and shortening that continuum of going from data collection and analysis to actually using the data for practice and policy change is so critical. So I think part of that is being really strategic and effective around how we use data and move it forward for use.

Ally Garber 25:25

Thank you for that, Deepa, I'm going to maybe throw you a little bit of a curveball, because I know the term evidence-based when it comes to research and practices can be a little bit contentious, like when we talk about different early intervention strategies. And even, you know, our approaches to, you know, co-occurring issues, there is a, you know, I think people are looking to see, you know, a little bit more clarity on what defines evidence-based, if you know what I mean. And so, you know, because we can say evidence-based research, but I know in speaking with a number of people in the community, there's just, like, this wariness of, like, oh well, you know, there's a number of things that are evidence-based, but they're evidence-based for one individual, or, like, one segment of, you know, a very vast spectrum. So again, throwing you a bit of a curve ball, but what are your thoughts on, kind of how that narrow definition of potentially narrow definition of evidence-based?

Dr. Deepa Singal 26:27

Yeah, so you know, evidence-based usually refers to practices, decisions, policies that are grounded in what researchers call this, the best available, reliable, systematically gathered evidence so research that is conducted in a really methodologically rigorous way, but I think you speak more about the importance of including the entirety of the spectrum or the entirety of the population, or making sure to include vulnerable populations or intersectional identities, so that the research base that is evidence-based or best practice research includes the diversity of our population, which historically, it may not have, and so that the results that are generated through that methodological research, or that rigorous research reflects more of our population versus segments of the population who are more likely to participate in research, or, you know, that kind of thing. Is that sort of what you're getting at?

Ally Garber 27:25

It's slightly humbling how you just articulated that so perfectly. That's exactly what, yes, that is exactly what I was, you know, trying to get a little more perspective on or clarity, because that is exactly it. You know, there is kind of one segment or one demographic that kind of is more, has the ability, perhaps, is, you know, in the position to volunteer for research initiatives a bit more. You know, I certainly as an advocacy I've said a number of times that being educated, being middle class, I have more ability to advocate for my child than somebody who has more limitations. And so yes, thank you. That is exactly what I was getting at.

Dr. Deepa Singal 28:10

No and I think it's really important for, you know, resources or supports that come out of the National Autism Strategy to support paying people for their time, and that can be one of the barriers that can help support folks to take time out of their busy schedules and really value the expertise that they bring. Right so the Alliance, we really are advocating and pushing hard for ensuring that it's not a volunteer offering, but people are paid for their time and expertise in participating. I know that's just one of the many, many, many barriers in participating in research and advocacy work and policy work, but we're super open to hearing more solutions from our members in the community and how we can use policies or the work that we do to reduce some of those barriers.

David Nicholas 29:04

It strikes me that, along with that, we need to think carefully and critically about the barriers that...

Ally Garber 29:10

Right.

David Nicholas 29:11

...may stand in the way of some segments of our population being less involved in research, and how do we address that in a proactive, inclusive way. And so I think such an important issue in moving forward and in thinking deeply about representation, so whose perspectives are being heard and whose are not, and then, and for what reason, and how do we change that to be more inclusive?

Ally Garber 29:37

It does seem as though, you know, the within this pillar that is acknowledged, that, you know, there's work to do, and, you know, steps in place to address it. David, I'll ask you, what's missing in this pillar? Was there anything that stood out that you felt should be there?

David Nicholas 29:56

It's a good question. Well, I think, as I've said earlier, I think. Yeah, just thinking through the how to, as opposed to aspirationally, what we want to think about. And I think, you know, thinking about some of the tension around the precision and research, sometimes methodologically, we think about precision, to study what we study well and use robust approaches, but also to think in terms of breadth and what are areas that warrant a broader spotlight, in terms of really building capacity in Canada and elsewhere. And so I think, thinking about areas of marginalization, of the lifespan. So autism is lived over the life course. And so to think about, what does that mean?

What are key moments of transition, or junctures of imposed challenge in community life or in society and so to think of some of those areas in a broad based way, but also bringing some focus and precision on that and thinking carefully about whose voices or perspectives are being brought to that discussion, and that research is so critical and moving forward, I think the other piece is we've talked about in terms of resourcing, inclusion and research and focusing on areas for development that inherently requires resources, and that's where the federal government can be quite helpful in thinking about focused opportunities and calls for research that really invite targeted advancement in some of the priority areas that Autistic Canadians and the community hopefully will identify and really moving that forward.

Ally Garber 32:05

Well thank you for that. Mackenzie. We have, you know, just a little bit over two minutes left, and I want to make sure I get to you and Deepa. What were you very happy to see? And I'll get your thoughts too. Do you agree with David on what's missing?

Dr. Mackenzie Salt 32:20

Yeah, in general, I'm very happy with what came out of this pillar. And I think David is exactly right in terms of, we've sort of got the goals listed, but not the sort of how we're going to get to those goals. And one thing, I think that, one thing that I'll add to what David was saying in terms of things that are needed is, I think we need to start thinking about flexibility in the research ecosystem. If you want a study that is going to be really impactful, if you want to get a large sample of people from a very wide population, you're not only going to need resources in terms of money and staff, you're going to need time, and a lot of the grants are time limited, and so you don't necessarily have a large amount of time to build the relationships that you might need to build trust with areas of with people who are in parts of the spectrum that are not routinely seen in research, or are asked to participate in research. So I think time is one of the things that we need. We need a little bit more flexibility in the research ecosystem around resources and especially time. That would be one of the things that I think we definitely need.

Ally Garber 33:38

Thank you, Mackenzie and Deepa, if there's anything else you wanted to add in terms of what's missing, but I'm also, you know, knowing you, I'd love to hear, where do we go from here? What, next?

Dr. Deepa Singal 33:52

Yeah, I echo both Mackenzie and David's really amazing comments. What was missing for the whole Strategy was the specificity, right? It was very high level, very aspirational. And what the community is looking for is that, who the what, the how and what resources are going to help us get to the who the what and how. And that goes for all pillars, including this one. Where do we go from here? Well, we look at this as an opportunity, another opportunity to work together. We're stronger together as a community, both in research and in all other areas, and so we continue to do that. We continue to advocate for the people that we love. We continue to advocate for this community.

And now the National Autism Strategy gives us that platform to do it with the more focused intention and some mechanisms that the government hopefully will deliver on. So they're going to invest in the National Autism Network. Okay. They're going to invest in interfacing with the National Autism Secretariat. What does that look like? Right? They're going to have to go back to the Senate committee in five years and say, what impact did the National Autism Strategy have? Staff, and so these are opportunities for our community to put forth solutions, priorities, solutions, innovations, and hopefully government supports in a way that it historically hasn't before. So that's where we go from here continuing to work together and supporting the people that we love across this country.

Ally Garber 35:21

That's a perfect statement to wrap up on. Thank you to the three of you for sharing your perspectives and your experience and expertise on this particular topic and on the Strategy as a whole. It's really appreciated. And as we've been doing this podcast, I'm just, I'm really, you know, taken aback at just the caliber of talent that's on the Alliance's board, and it makes me feel so we're in very good hands for advocacy efforts moving forward. So thank you to the three of you, and really, really appreciate your time today. You can learn more about our [Summit](#) in April, where 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.