



## WEBINAR: WHAT'S IN THE SENATE INQUIRY REPORT ON AUTISM (TRANSCRIPT)

### **Jenny Karavolos, Co-Chair Australian Autism Alliance (0:03)**

I'm Jenny Karavolos, the Co-Chair of the Australian Autism Alliance. I first would like to do an Acknowledgement of Country. We acknowledge the traditional custodians of the land that we are meeting on today and pay our respects to their Elders past and present. We also acknowledge our gratitude that we share this land today, plus of that sharing and our hope and belief that we can move to a place of equity, justice and partnership together.

This has been a long time coming for the Autism Community and we're hoping this will be a blueprint for real change in terms of what's outlined today. The Australian Autism Alliance is very pleased to have been a part of this historic journey.

For those who don't know, in February 2019, the Australian Autism Alliance went to Canberra to lobby for change for autism, which included a national autism strategy. There, the Alliance representatives met with various members of the Australian Parliament. This included lending our support to Senators Stirling Griff and Hollie Hughes, who at that time was establishing Parliamentary Friends of Autism for a Senate enquiry into autism. The Alliance worked to inform the bill that established the Senate enquiry and thanks Senator Hugh, Senator Griff, Senator (Jacqui) Lambie and Senator (Jordon) Steele-John for introducing the bill, and look where we are now.

And those who haven't seen the report or those who have would know it's 400 pages long, and packed full of recommendations. And the Alliance will be providing our own detailed feedback on the report, but thought it would be helpful to actually receive a briefing from the Senators first.

There will be time for questions after the briefing, but those who don't get to get their questions answered we will follow up with responses, we promise you, so send them through as we go to the Q&A which you will see on the top of your screen. Now the session is also being recorded and will be posted onto the Alliance website.

So, without further ado I'm very pleased to hand over to our MC for this event, Monique Blakemore, who's Australian Autism Alliance partner, an autistic advocate and parent of autistic children who has a wealth of experience overseas and in Australia, is an advisor to Cambridge University Autism Research Centre, and people with disability in Australia, as just a few positions of note. Welcome Monique.

### **Monique Blakemore, Master of Ceremonies (2:28)**

Thank you, Jenny and thank you everyone for joining us today.

So, on the 25<sup>th</sup> of March, the Senate Select Committee's enquiry, history-making report on autism was tabled in parliament. The enquiry's report has the capacity to make a significant and tangible improvement to the lives of autistic people, their families and carers living in Australia. This is the first time there's been such a broad national enquiry into our lives.

### **Monique Blackmore, Master of Ceremonies (continued)**

We now have over 80 recommendations for positive change across diagnosis, education, health care, employment, housing, social inclusion, advocacy, research, justice and rights. Central to the report is a recommendation for a national autism strategy, to be co-designed



with autistic people and the autism community that will coordinate initiatives across government and address our whole of life needs.

The Australian Autism Alliance commenced the committee for recognising the needs of vulnerable sectors of our community, including First Nations, culturally and linguistically diverse communities, people with complex needs, gender diverse, low income and those who live in remote communities. The report contains important recommendations to address our intersectional inequalities.

As an autistic advocate and the mother of two young autistic men, I'm really glad to see the needs of autistic women and girls, barriers to diagnosis, our reproductive and maternal health and the stigma of being an autistic parent was highlighted within the report. As a community, we know that outcomes for autistic people are far worse than they are for the general population and indeed substantially worse than other major disability groups.

Disability policies to date have failed to capture the needs of autistic people. We've fallen through systemic gaps and it's unacceptable. For this enquiry our community made sure that we were heard, with over 180 submissions and many providing testimony at the hearing.

I'd like to take a moment to, to thank autistic people, their parents and carers for their participation in the enquiry process. We've had to revisit incidents of deep pain and inequality, and at times it's been traumatising. The Australian Autism Alliance honours your personal commitment to inform the committee despite the personal circumstances may have had to yourself. We recognise that not every single autistic person and every organisation will agree with every recommendation in this report, but critically, we finally have in front of us a plan to make a real difference for our future. We, the autism and the autistic communities must come together now and be a unified voice to ensure that the recommendations of this report are implemented.

And I'd like to now introduce our Senators, Senator Hollie Hughes who was the chair of the committee and Senator Carol Brown to be able to, to share their presentations with you on the details of the, the report. Thank you.

**Senator Hollie Hughes, Chair of the Select Committee (NSW) (6:12)**

Thank you, Fleur (Monique), and thank you everyone for being here today. It's certainly very exciting for all of us that are members of the autism community that we now have this report tabled and as many of you know, this has never been done before, and we've certainly never looked at the whole of life when it comes to the autistic experience, not only for those with autism themselves, but also their families and those who love them.

**Senator Hollie Hughes, Chair of the Select Committee (NSW) (continued)**

It was a very, very broad ranging report. The committee endeavoured to look at every stage of life, and as those of you who have struggled to find supports who have been part of trying to navigate your way through a variety of systems. We looked at this not through the lens which all too often happens that this is an NDIS issue, but that this is an issue for every level of government and that the NDIS is just one part of that. But there are also issues when it comes to diagnostics and we know that that's an issue across the health system with GPs regularly referring parents to wait and see, and we know that that's problematic right



through to transitions to all forms of education, which we also know state governments across the country. Some worse than others have dropped the ball when it comes to supports in the classroom for our kids.

We know that we have a much higher unemployment rate for autistic people, even when compared to the general disability community. We also know that our kids can enter the justice system sometimes inadvertently, just purely and simply from a lack of understanding of the communications, challenges and behaviours that some people with autism display.

So we have looked across the board; the national autism strategy was a very big part of what we wanted to achieve and I do think with the 81 recommendations we have really started to lay out what that autism strategy can look like.

I would like to thank all of you before we start that have contributed to the enquiry: all the individual organisations, in particular, that put in submissions. With covert we were a little bit challenged for how we were able to get around the country and speak to people, but now that those restrictions have lifted across the board, I've already been in Melbourne meeting with some groups, but look forward to being able to do that more and more in the coming weeks to keep working through this report through the recommendations and getting feedback. I don't think this is the last thing that we'll do; the report's not in and so now we can all close the book and go 'great, let's move on. We've made the recommendations.' I think there will be more to look at and I think there will be more to look at in specific areas as we go through the next parliament.

I would like to thank Carol Brown; she has been an amazing support to me throughout this enquiry. Senator Brown's stepped up as deputy chair when Senator Griff stepped off the committee, so Carol really claiming later in the process but has been unbelievable in the enquiry and the hearings that we have managed to hold.

I don't really want to go through if you like and I'm happy to be guided by you, and I'll go to Senator Brown in a minute, but I would much prefer to hear your questions and any feedback that you've got. I know it is a 400 page report so there's many of you that may not have had the chance to read it yet. It was certainly my summer reading; there was some of it that I actually got to read lying on a beach, so it looked like a little bit, bit worse for wear by the time I finally gave my suggestions and feedback after we got the draft report. So Carol and I spent most of our summer going through the report making recommendations and looking at how we could improve it.

**Senator Hollie Hughes, Chair of the Select Committee (NSW) (continued)**

So if I hand over to Senator Brown if you're happy and then we can go to questions conscious that we don't have that much time to spend together, but as I said we can travel now, so for any of you that would like to organise a sit down or would like to organise a visit in your state to your organisation or as a round table, I'm absolutely more than happy to come and meet with you all.

(10:52)

Senator Brown there?

I can see Carol with a hand up and muted.



Perhaps while we're waiting for Carol to start, Fleur (Monique) did you want to start with, oh no here we go.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

Hello?

**Senator Hollie Hughes, Chair of the Select Committee (NSW) (continued)**

Yep, got you Carol. Can't see you though.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

I've got my hand up, so sooner or later someone will do perform, do some magic like, unlike some of our kids where not it can't provide any, any suggestion on how to do that, but thank you, and thank you to Australian Autism Alliance and Monique for organising this forum here today. I'm Senator Carol Brown, I'm a Labor Senator for Tasmania. I just thought I'd better let you know who I am.

I have been, have a passion in the disability area and have been part of the disability discussion in parliament for a very long time. I'm not autistic, nor do my children, nor are my children autistic, and I have to say being involved in this report in this enquiry has been such a pleasure and to be able to meet such wonderful people, and to be involved with Senators that have a huge passion for this area has been, has been a real pleasure. And it's, it's great to see that what we've been able to put together, I hope, is the start of what needs to, the pathway to change, because, you know, since the tabling of the report on the 25<sup>th</sup> of March, we've had a lot of feedback about, about the report and it's been very positive, and it is a very broad ranging report and it needed to be, it needed to be. It covers areas like employment, health and, health and mental health, housing, justice, advocacy, diagnosis, education, early intervention and supports, and the recommendations go to each of those areas. And they also go, our headline recommendation as you all know is the National Autism Strategy, a co-design national autism strategy and the establishment of a task force to develop the strategy and to monitor and to report to parliament and publicly the strategy, and the strategy must stay true, must stay true to the added nothing about us without us.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

And recommendation 6 also goes and sets up tasks for the joint standing committee on the NDIS, to inquire into the work of the NDIS, to enquire into the work of the NDIS and the NDIA, and it also tasks the Australian Government with work (to) the states and territories and the systems within the states and territories, education system, justice system, health system, and there's a reason for that.

There's a reason for that and that is, because the report when we look back in years to come, the report will be the easiest part of this journey. It's now where the hard work begins.

The report cannot be built from the start, and I want to be looking back and looking at the 25<sup>th</sup> of March as the start of the change and the journey that is absolutely critical to autistic people, their families and their carers, because what this enquiry has shown is that it is absolutely critical, the need is critical, autistic people are falling behind in nearly every area



in this country. And I want to thank you for letting us into your lives, letting us into your family's lives.

It's a huge challenge, but I want to say to you here today I will be, I'm happy to be part of it. I've been on board since day one and I was lucky enough to be asked after Senator Griff, who should be thanked for his work as Deputy Chair and his efforts with Hollie to establish the enquiry I was happy to take on the role of Deputy Chair.

So look, I'm here to help ensure that this is the start and that we now start our journey on the pathway to deliver what the promise of this report gives you. Thank you.

#### **Q & A (16:44)**

#### **Senator Hollie Hughes, Chair of the Select Committee (NSW)**

OK, so Monique, you've got some questions from people?

#### **Monique Blackmore, Master of Ceremonies**

I do. I've got some, thank you everyone for sending through the questions. So the first one I have is: How will the recommendations, particularly the National Autism Strategy, be implemented by the new Federal Government regardless of who wins the federal election?

#### **Senator Hollie Hughes, Chair of the Select Committee (NSW)**

Well as Carol just said as well and if you've heard that the National Autism Strategy is one of our key platforms, so regardless of who wins the election, there will certainly be pressure to bear on whomever is, will be responsible for this. I won't speak to Carol's party but certainly within the Coalition Party Room I have incredibly strong support for this.

#### **Senator Hollie Hughes, Chair of the Select Committee (NSW) (continued)**

We obviously have the Budget tonight, so we will look at what happens there, but there will be a requirement for whomever is most likely the Minister for Department of Social Services to put together a board to set up the National Autism Strategy and I think that's going to be the first step because whoever is on that board is going to need to have the capabilities to negotiate very, very complex situations because it's not just a matter of negotiating with the Federal Government or federal agencies to make improvements. It's going to have to be a board that can negotiate across all different states and territories who can bring people to the table and ensure that the investments are being made in the required areas and that there's responsibility taken for areas that state governments do have responsibility for.

It is something that Carol and I certainly have bipartisan support for. This is not something that we are seeing anyone, certainly from the Labor or Coalition side pushing back against in any way. We also have Jacqui Lambie who is a very, very strong supporter, and so I think regardless of which side of the Chamber Carol and I are sitting on, our work is certainly not done in ensuring that this strategy becomes a reality.

#### **Senator Carol Brown, Deputy Chair of the Committee (TAS)**



So look, at the last federal election I was actually the Shadow Minister and I committed to a National Autism Strategy back then, so I would expect no less of our party to, to also commit to a strategy coming forward. What is going to be critically important is not only a commitment by parties that seek to govern, we also have to get commitments around other recommendations in this report and to that I go to the, the recommendations that look at our recommendations for the Australian Government to talk to states and territories. It's critically important we know this is work, that there has been work done on in this area, but it's been a long time coming in the, in the information being actually completed and put out there for the autistic community.

So I think, and I definitely agree with Hollie, whoever wins the next federal election, that the National Autism Strategy is going to be a critical part of that government, the government going forward, because it actually has the ability to do so much, not only about people's individual lives, but also in the productivity of this country.

**Monique Blackmore, Master of Ceremonies (20:48)**

Thank you, Senator Brown, so the next question comes from ASAN: How do we ensure that the future government is not only committed to a national strategy, but is invested in true code design where the most marginalised voices are not only heard but truly listened to?

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

We have ensured through every recommendation that co-design is a part of it, so that it's actually stipulated in every recommendation that we've made that would require that or is a separate recommendation. Co-design is not only vital to get the buy-in of everyone who needs to participate in this, and so we do need, we are mindful certainly, that when we talk about co-design we talk about the fact that the autism community is a very, very broad one and there are lots of different elements to it. And we know as Temple Grandin says 'if you met one person with autism, you met one person with autism', and so it is about ensuring that we get that representation across the board, that we get the voices of people, not only autistic voices themselves, but that we get the advocacy and the voices of autistic people who cannot advocate for themselves but quite often have very, very challenging needs and we need to make sure that they are represented.

One of the things we found as we travelled around is that there was still a bit of an expectation that all of our kids are some sort of 'Sheldon Cooper' or 'Rainman' and so breaking down those stereotypes is very, very important, and ensuring that we get a representation across the spectrum, but that we get representation from educators, from parents, from carers, from those that specialise working in the autistic community providing supports. So that when we start to put things together, they're not narrowly focused in one area, they're not only going to cover one little section of the community, they're not excluding any part of the community so this is not going to be a simple task. Carol is not wrong when she says, 'this is the work starts now'. The recommendations are the beginning, but it is, it is critical if we are to succeed, that we have that understanding in co-design across the board. We also don't want to create a solution to a problem nobody knows exists and I think when you don't have co-design you very much run that risk, and you know, put something on my own government, independent assessments was a solution to a problem that didn't exist and we needed to not have that go ahead. So that's the sort of stuff that can happen when we don't have effective co-design and, as Carol knows, I'm quite annoying when it comes to stuff, and I can assure you that at no point...

**Monique Blackmore, Master of Ceremonies**



I can tell you that the autistic community gets annoyed when we don't get included in, in decisions that are being made about us and, and it's important that the whole of the spectrum is represented. Too often I find that there's, you know you mentioned the stereotypes of the 'Sheldon' kind of characters, but this can also be an ignoring of the needs of those of us whose autism is more internally presenting and, you know and, and the whole of the spectrum across the lifespan is, is vitally important to have recognised.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

I got a...

**Monique Blackmore, Master of Ceremonies**

Sorry. Sorry, Carol.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

Sorry Monique. I do want to add a few comments to that, that very good question, actually about how we ensure that the future government is committed to the national strategy, but a true co-design, and it, and it's actually critical that, that commitment is given and I think as you go around and, and you continue to lobby the government and the opposition in terms of their, their commitments to the autism community. I think it is also critical that you get an understanding, you get a commitment not only on the strategy itself, but a commitment on the, the task force to be established and a commitment on a true co-design. You should get those, you should advocate for those commitments prior to election day. That is what, that is, this is all about continuous campaigning because once we have a new government installed it is always very good...

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

Or not...

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

to start off on the right... I'm sorry, a new government as in a new parliament, Hollie.

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

Yes.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

I didn't mean, yes I wasn't, you know, taking things for granted because certainly that is not the case. But it is important that we start off on, at the, at the right, on the right foot and that is all of the parties that are, that our stakeholders in this task know where we're beginning from and that is a commitment to a national autism, sorry, a national autism, or a national autism strategy, a task force and a genuine co-design strategy. That's what the autistic community are looking for and that's what should, in my view, be delivered.

**Monique Blackmore, Master of Ceremonies**

Thanks Carol, and I'm really sorry that, that I kind of jumped in there and before you had a chance to respond.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

That's OK.

**Monique Blackmore, Master of Ceremonies (26:38)**



The next question I've got is: The report explicitly calls out the very poor outcomes experienced by the autistic population across areas like education, employment, health, mental health and social isolation. Do you think your parliamentary colleagues understand just how dire these outcomes are compared with other population groups? How can we help you to ensure there is a momentum to implement your recommendations despite other pressing issues like the pandemic, natural disasters and international security concerns?

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

Look, we do call out across the range of areas the fact that there are poor outcomes for a lot of autistic individuals across the board, across a whole range of areas and issues, you know, things like mental health. We saw that there was a real issue when it came to particularly emergency rooms, but medical assistance when people were presenting with issues around anxiety, depression, but the medical profession seemed to think that it was somehow attributable to the autism as opposed to being able to be treated separately to autism. So, we do know that those outcomes have been poor and a lot of that has been due to a lack of understanding across a whole range of areas, which is why we have recommended more training for the medical profession and GPs when it comes to diagnosis, but also understanding mental health presentations, etc, that just because you have autism doesn't mean the depression or anxiety shouldn't be treated as depression or anxiety.

You know, we, we did see that first responders didn't understand a lot about how autistic behaviours could present and challenges around communication. So we saw around a lot of areas school, you know teachers get about a half hour session on autism in their teaching degree. So not only we're looking to increase that learning during the undergraduate degree, but that it become a critical part of their professional development, because there is not going to be a teacher in this country that is not going to have autistic kids in their classroom.

So we want to make sure that those things are better put together. I think it might be a little controversial here, but I think certainly in the past the autism community has had some pretty big schisms in it, and that hasn't helped anybody. And it actually makes it very easy for politicians, for bureaucrats to ignore what we want when you have one group advocating for something and another group goes in and contradicts that and argues that you don't need to do it at all. And, so you know, when and I'm again, I'm gonna say this, it might not make me very popular, but when I meet with the NDIA and I'm told that we have had groups of autistic adults go to the agency and say 'autistic kids do not need early intervention, because we are somehow inhibiting their autism'. That makes it very, very difficult for the rest of us to go in and argue for better funding or effective early intervention for particularly our kids at that level, high level 2, level 3 end of the spectrum. So you know, a lot of people need to stick to their lane and talk about what they know.

A lot of unity within the community or acceptance that not everyone is going to have the same view on everything, but when campaigns have been put together, arguing fiercely against things, it makes it very easy for bureaucrats and for politicians to ignore. Now we all need to come together and stand together, and say 'we know what works, we know what's best for autistic people. They've been around for a very long time, there's lots of international evidence, there's lot of things that we can look to around the world, and bring that, you know, evidence-based policy, bring those best practice to the table without discrediting anybody else along the way, because that is actually, in my view, the biggest danger to ensuring we get the change that we need. And I'm not sure if I answered your question at all there, but probably got a few of you don't like me very much anyway.



(LAUGHTER)

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

The something, I'll go now Monique, OK. So the question went to, about our parliamentary colleagues and I, I personally think that across the board, our parliamentary colleagues have a high level of understanding around the poor outcomes that have been, that are experienced in the 'Old Testament' autism, autistic community. What there seems to be quite a poor lack of understanding is in the broader community and the voices of what the autistic community is getting lost in the broader community, and in the disability debate more broadly. So, the question really asks again, asks about what you can do and I think that again goes back to the, the headline recommendation that the, the report makes, and that is around a national or autistic, autism strategy, which, and the critical part again, has to be a co-design. And if we can get that right, if we get the commitment for that and then we get the co-design strategy right, then some of the other work that still will need to be done will be able to be done from, from the very get-go in a way, in a way that will be suited to, you know, about different positions in the autistic community.

And, and Hollie's right, we had lots of people come and let them, let us into their lives and they came from different views. And that was, and that was really what made this enquiry all the more enriching for me to have that understanding. You know, but this, for these next two months are going to be critical I think in your continuous campaigning to get the commitments out of the political parties to jump on board with these recommendations. I know there are other recommendations within this report that may seem that we're just looking, we're again going to enquire into different parts, but that's also critical work that needs to be undertaken, why a strategy is being developed, but it's all about the commitments that you get in the next couple of months. I would, I would, you know, that's my advice to you.

**Monique Blackmore, Master of Ceremonies**

Thanks Carol. I'd like to say that the Australian Autism Alliance is made up of researchers, service providers and advocacy organisations, and autistic people, and, you know, the way that we're managing to work together and find focus on our common ground, I think, is something that we need to replicate within the community. You know, they're, autistic people don't live in this world as individuals would, you know we must consider their families and, and the needs of parents and carers who, who support them. And I think the co-design process, we've got examples from overseas of how that was done and we need to learn from the international experience, so that we're not repeating mistakes that have been made in the past and we can kind of streamline this to get the best outcome for autistic people here.

I've got one...

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

I understand, I'm from a caring, carer's family. My, I was a sibling of a person with disability; absolutely understand the support that's needed for the whole family.

**Monique Blackmore, Master of Ceremonies (35:13)**

I've got one more question, and can you briefly share with us something that you read in a submission or heard in evidence given to the enquiry that really impacted or influenced your findings and recommendations?



**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

I mean, honestly to be fair, don't know where to start. There was so much that we heard and learnt about, but if I can share two things with you that really in a lot of ways just broke my heart and proved why we need to do so much better.

I spoke to a mum whose son was 20. He had an unsuccessful suicide attempt and presented to an emergency room in Sydney. Because he was 20, she was not notified. He was suffering from significant anxiety and depression (and) had autism, and this emergency room didn't know how to deal with him. Now, had he not had autism he would have been sectioned for sure. He would have been put into a mental health facility and supported. Instead of that occurring, he was discharged, and the first that his mother learnt of this previous attempt was when he had a successful suicide. And that just broke my heart, and we all know that our kids to have a suicide rate 10 times the general population. So, the mental health side and better preparing emergency room doctors, first responders to deal with that and to understand the mental health implications are separate to the autism and need to be treated as such, was incredibly powerful and important.

The other thing that I learned a lot about, and that I have very great concerns for still, are for the children who have very challenging behaviours. We have a case in Victoria of a severely autistic boy being charged with manslaughter. I know of families who have been separated because it is unsafe for the siblings to live in the house with their autistic sibling, because the behaviours are violent, and they cause real harm. And the parents have had to separate and have a separate living arrangement for the autistic child because they cannot, cannot be in a home environment together. And the lack of support for those families, the condemnation that those families have experienced. And I have some very concerns we have gone overboard in the wokeness of restrictive practices and behavioural therapy.

When, if you have autism and are hitting your head on a concrete floor or punching yourself, it is now considered their human right to be able to cause that damage to themselves and restrictive practice to try and stop it. If this person whacking their head on a concrete floor or punching themselves was not autistic and was stopped in a hospital or by the police, they are absolutely able to stop that person from creating that damage to themselves without it being considered restrictive practice.

We need to do better at that end of the spectrum. We need to do better for those kids who cannot verbally express themselves, who cannot advocate for themselves, whose parents are literally trying to survive day by day with their families being separated, and we are not doing enough in that space. And to speak to some of those families to understand the complex needs that some of our kids have, and you know what, they're not the pretty autism. That's not what autism looks like that, you know, people are going to put on a brochure or put in their organisation as 'how good are we employing an autistic person'. This is not pretty autism; this is something that we can put out there publicly and people are going to feel good about themselves. This is the really, really difficult part of autism and I fear some organisations in some places have lost their way, and we do need to be mindful of that. So, that's two things, but I think that one might even burst into tears now after Kimberley yesterday. I'm still now quite 100 per cent not crying, but it's heartbreaking to talk to those families.

**Monique Blackmore, Master of Ceremonies**

Senator Brown?

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**



Oh, thank you. To, to be honest, I don't really think that I could go past and more than one occasion, and, and too numerous to actually articulate here, but the real life experiences that families and autistic people share with the committee, that evidence made our deliberations richer, more focused, and because of that I really wanted to thank everyone that put in a submission, provided additional, additional information, came and presented to the committee and I was, I was particularly wanted to thank the many Tasmanian individuals and organisations that participated in the enquiry (who) came forward to share their experiences, and they were quite varying in, in Tasmania, the evidence that we heard at the Launceston and Hobart enquiries, and, and it was, it has always been though that evidence that, that evidence that makes you realise that, you know, this is the reason why you actually do the work that you do, that you're able to be, put forward recommendations that we'll be able to, you know, right a, a wrong in our society. And if, as I said when I first started the conversation in the forum today, if I can look back on this report in the, in the, a few years to come and say this report started it all, and it's, it developed the pathway that on for the journey that we have to make, because it's critical.

It is critical to the autistic community and it's also critical for the Australian society more broadly, so I again thank you for inviting me to join with Hollie on this forum and, like Hollie, I'm happy to be, come back to other forums or to meet people individually or organisations as well.

**Monique Blackmore, Master of Ceremonies (42:22)**

Thank you, Senator Brown. I've just got one last question regarding the NDIS. There was this, you recommended a separate enquiry by the NDIS Joint Standing Committee to examine the effectiveness of the NDIS for autistic people. Why has consideration of critical NDIS issues been deferred to yet another enquiry? How long would it be before this can occur and what do autistic people and their families do in the meantime?

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

So Carol and I both sit on the joint standing committee that, on the NDIS. As I said earlier in the piece, this enquiry covered off whole of life, not just the NDIS, and you know, we really do need to remember that the NDIS has a role and a very important role, but it is not the sole answer to everything that the community faces.

So the NDIS committee is, so it's, it's called a Joint Standing Committee because it, it consists of members from both the House and the Senate, and the NDIS, you know, obviously then looks at specific NDIS issues. Please don't think this is being passed off to another committee. We have Estimates this week, I'll be there on Friday. These questions are consistently being asked. I'm certainly looking forward to seeing Mr Hoffman on Friday, because certainly some information he gave me last Estimates proved not to be factually correct, and I, this to me is not a partisan issue; they are an agency, they are accountable, and that we are continually asking questions of them.

**Senator Hollie Hughes, Chair of the Select Committee (NSW) (continued)**

I certainly have many, many conversations with the agency about we improve things, autistic people, and it's dealt with... Look, to come back to independent assessments as much as we all hated them, and it was all dreadful there was actually quite a reasonably good intent behind them with regards to levelling the playing field, it just was poorly executed. So, it is important that we look at getting that consistency because too often we see some people with autism getting fantastic plans and then we have other issues with people getting dreadful plans, with kids who present pretty similarly, same age, same city, you know.



**Audience Member**

Only one.

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

I think we have a problem with some of the local area coordinators that don't understand autism, so we've obviously, in the past in the Joint Standing Committee, have recommended disability specific planners. There are a lot of things that are being looked at around the agency and how those things better delivered. We did recommend one of our things was that the NDIS provide support coordination for the very first plan that autistic people get so that there is hopefully some assistance with regards to putting together the supports and teams that you need when you do start under the NDIS.

One of the things I think though that became apparent to us and if you want to look at it, free NDIS entry was when, when people are diagnosed, there's nowhere to go, there's no information, it's all very piecemeal and difficult to find what you actually need, and that was why I was, I am just in love with autism. What next, that was delivered by Autism Awareness Australia but funded by my government through the department, and you know the best thing the department did was outsource it to someone who actually knew what they were talking about rather than trying to write it themselves. So, it is a fantastic resource for diagnostics, but obviously there is more work to do and hopefully I will have something to tell you about very, very soon.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

Yeah, as Hollie's already indicated, Recommendation 6 isn't about, isn't about putting off to another committee the issues that are in this enquiry. The report covers off or attempts to cover off every avenue that the committee members could think of, where work needed to be done. So, the enquiry that you, that is talked about in Recommendation 6 and throughout the other recommendations is really about supporting the work of a strategy, of the strategy to come, because it's important that we know that we have eyes everywhere, really.

We have eyes looking at the NDIS and how that's operating and the NDIA and the work they need to do, and the more transparent and accountable these organisations are, the better it is for everyone concerned, so absolutely it is not about putting, just shuffling it off to another committee. It's about supporting the work of the national autism strategy, which will be developed by a co-designed, co-design development and hopefully with a task force that is also set up with some people on that task force from stakeholders in the autistic community, absolutely.

**Monique Blackmore, Master of Ceremonies (48:02)**

Senator Hughes, Senator Brown, thank you so much for your work. Thank you for this magnificent new beginning for our community to get the supports that we need. I think that it is so long overdue and for the first time in a long time I'm really excited about the future of autistic people in Australia, so heartfelt thanks and I especially thank you for the, for our community for sending through your questions, and I'm sorry that we've not been able to ask the Senators every single one of them, but as Jenny said earlier, we will try to get to get answers for you, and I'll pass over to Jenny now.

**Senator Carol Brown, Deputy Chair of the Committee (TAS)**

I'm sorry but it's, I, I have to leave, but I'm happy to come back at any stage, sorry Jenny.



AUSTRALIAN  
Autism Alliance

**Jenny Karavolos, co-chair Australian Autism Alliance**

Thank you, Senator Brown, but we will be able to send through our video recording. We will thank you in a few seconds. So, thank you.

That was very insightful and I know the entire community, autism community are looking forward to seeing better outcomes soon as Monique said. Thank you for hanging in there. If you can just hang in with, with me for another two minutes. We do absolutely support about accountabilities occurring and many speaking up, and we as a community there are many vulnerable and most marginalised individuals are being supported by organisations led by autistic people and peak bodies, and there's some great user-led design projects occurring that I'm aware of that include non-speaking people and those with intellectual disability and autistic parents of people with high support needs. But to Hollie's point we need more to be happening, and that's why we love this national strategy as one of the strongest recommendations - the national autism strategy. Many people did ask in the questions, what is the top recommendations, and we, as the Alliance strongly support what's being said about welcoming a national autism strategy and supporting the committee's acknowledgement that generic disability strategics have not improved the outcomes for autistic people.

So, you've strongly heard today the call to action is to continue to lobby and get our messages up, and we'll certainly be doing that, and we ask all of those on this call to join us. We will send out information on how you can support us more. Thank you absolutely to Senator Hollie Hughes and Senator Carol Brown for your precious time. As we know with COVID much is being done virtually, and all we can offer at this point is our thanks, so we do hope that you accepted our bouquets sent yesterday

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

They're beautiful and they're on my table here.

**Jenny Karavolos, co-chair Australian Autism Alliance**

Fantastic.

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

Thank you. They made me cry even more yesterday because I got them after I came back from Kimberley's condolence motion, so they were perfect.

**Jenny Karavolos, co-chair Australian Autism Alliance**

That's on behalf of our communities, it's a token of appreciation for your time today and the commitment. Thank you to Monique for being a marvellous MC. Thank you to all the other, well thank you to all the other members of the Senate enquiry – Senator Jim Mullen, Senator Marielle Smith, Senator Jordan Steele-John and all the other participating members and their staff. I'm sure I've missed some who have been involved in the committee report for the substantial effort and commitment to improving the life outcomes of autistic people, and the biggest thank you that's been said already to the autism community for being bold, brave and brilliant in contributing to the Inquiry and being awesome really every moment of every day.

The release of this report has been mentioned is monumental for all of society to enable the shifting of the dial

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**



AUSTRALIAN  
Autism Alliance

I'm so sorry.

**Jenny Karavolos, co-chair Australian Autism Alliance**

I'm sorry, I'm nearly done...

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

Yeah, OK I have to go, but thank you so much for having me.

**Jenny Karavolos, co-chair Australian Autism Alliance**

No problem, thank you every one, big wave.

**Senator Hollie Hughes, Chair of the Select Committee (NSW)**

Look forward to seeing you all soon.

**Jenny Karavolos, co-chair Australian Autism Alliance**

Thank you. And just to wrap up, what we want to say is as I was saying, the release of the report is monumental for all of society to enable that shifting of the dial on autism to improve the life outcomes of the estimated autistic population of 650,000 Australians.

Now we do recommend that you look at the Alliance pre-election statement of the website. We are very much looking forward to hearing all parties' response to the report and are calling on all major parties to support urgent action on advancing priority recommendations, and we would be encouraged to see the government providing this funding in this year's Budget for the key recommendations in the report. So, we're going to keep working on this, and we are looking forward to working with the next federal government to implement the recommendations.

**Jenny Karavolos, co-chair Australian Autism Alliance**

As mentioned earlier, we will publish responses to all questions we didn't get through today and get them to you. I do know that I've seen a number of hands up, but the way this has been set up, we couldn't pull up those hands. If you'd like to stay behind, I'm happy to take your questions live and we'll make sure we get back to you.

So on that note, thanks for joining us, and bye from us for now.

TRANSCRIPT END