Thank you for the opportunity to appear today on behalf of the Australian Autism Alliance. My name is Jenny Karavolos. I am the independent co-chair of the Australian Autism Alliance.

I'm a parent of an autistic young adult and I'm also the CEO of DAXA, but as stated today, I'm here for the Australian Autism Alliance. And that's Australia's national autism peak body and a recognised disability representative organisation, bringing together autistic people, autistic-led organisations, families, researchers, service providers, and autism organisations from across the country. Before turning to our evidence, I would like to acknowledge what appears to be a common position across much of the disability sector.

While organisations might differ in emphasis, there appears to be a broad agreement on three points. We support reform. We support sustainability.

However, the bill should not proceed in its current form or timeframe. And the Alliance shares this view. The Alliance's concern is not whether reform is required.

The question is whether Parliament can be confident that the reforms will deliver the outcomes intended. Australia did not establish the NDIS because previous systems were working. Many autistic people entered the NDIS, not because it was easy.

It was because too many were excluded from education, employment, community participation, and opportunities to contribute their talents and potential. Poor outcomes across the lifespan. This bill significantly increases reliance on those systems outside the NDIS.

The Alliance is also concerned that disability reform is proceeding without the level of implementation oversight, accountability, and harm monitoring that government has considered necessary in other major reform programs. Yet disability reform is proceeding without those equivalent implementation safeguards. Why is disability being treated differently? The bill creates powers, but it does not create a corresponding positive duty on government.

People also do not experience change one at a time. People experience them cumulatively. Parliament should assess these changes cumulatively, but we have not seen modelling on this.

The Alliance is also concerned that some of the projected savings appear to rely on costs and responsibilities being absorbed elsewhere. A cost removed from the NDIS does not disappear if it reemerges in health systems, education systems, housing systems, justice systems, community services, or within families themselves. A further concern is the increasing reliance on assumptions regarding parental responsibility and family capacity.

Reform should reduce pressure on families, not simply redistribute it. Need does not disappear because responsibility is shifted. Need does not disappear when parents disappear.

But the bill says very little about what happens when those supports disappear. And yes, financial sustainability matters, but financial sustainability alone cannot tell Parliament whether reforms will succeed for the people expected to live with its consequences. Cost tells only half the story.

The other half is potential, potential to participate, to contribute, to belong and to thrive. Even NDIS reports about the positive outcomes. But the impact modelling does not appear to consider the gains for Australia.

So the question is not only what support costs today, it also is what Australia pays tomorrow if support is withdrawn too early. That is why the Alliance has been developing its systems that work framework, including a readiness index and an accountability index. Government's own implementation pathway recognise connections and support coordination functions are critical to support transition, yet they're not to be delivered until June 2028, while major transition occurs earlier.

When you step back from the detail, the scale of what is proposed is extraordinary. It represents a fundamental redesign of how support is accessed and provided. The Alliance therefore urges Parliament to ensure that readiness, accountability and outcomes are demonstrated before people with disability and their families are asked to carry the risk of implementation.

If systems are not ready, reform is not ready. A system that works is not measured by how many people it moves, it is measured by whether people arrive somewhere better. Ultimately, that is how reform should be judged.

Thank you and I welcome the committee's questions. Concept of early intervention has been evidenced for years and even the NDIA created an early childhood path. So this risks delaying support during critical development periods and may reduce future participation, independence and wellbeing.

Effectively, it's a loss of life chances. So it's interesting that that will actually lead to increased costs in the future for these short-term savings. Senate inquiry on autism identified that very thing, that generalised systems do not work for autistic people, which is what led to a national autism strategy.

Unfortunately, the national autism strategy is just being implemented. So this is what we mean. Reforms need to be delayed until systems can be improved.

Otherwise, we're going to go to a treatment compliance lens and we're worrying about the fraud and whatever that's happening now. Instead, we're going to create another market that's called the treatment market and we need to regulate that and the exploitation that might happen there, instead of allowing people to continue on their paths and get early intervention. Can I just ask to you, Ms Karabolas, from an alliance perspective, the changes in the bill around parental responsibility, what are your concerns about the impacts that that could have on autistic folks and families? It will have a profound effect.

A lot of families are holding it together with a little bit of support, as was mentioned by some of the other presenters. A parent effectively wants to be a parent. They should not be required to also be the therapist, the support coordinators, the case managers, the bookkeepers, the system navigators.

Often families currently, because systems are broken, also are the fallback mechanism for when education isn't working, so you need to pick up your child. I will say to you myself, I was a full-time CEO position and I needed to step down so that I could support my child. We've talked about that.

There's families, if you've got multiple children with disabilities, if you're looking after others, so you might have elderly parents, staying in the workforce, being able to not live on the poverty line and supporting your family, taking that stress load off, because that stress is what breaks families. We can't have this. It seems to be this expectation that there's unlimited capacity for parents or guardians to be able to support their loved ones.

I am going to put to you, unfortunately, and just a trigger alert, that, as I said before, when the needs don't disappear, unfortunately there are many parents who are elderly looking after their children. When the parents are no longer available, the need is still there. This reform doesn't take any of that into account.

Thank you. We'll go to Senator Little. I'd just like to go to one of the key messages that's in a submission here, and that is the one that makes reference to reform should be judged by outcomes, not savings.

You go on to say that it should be about what the NDIS achieves, what future costs it prevents, and what potential it unlocks. Would you like to say a little bit more about that particular reference? Absolutely. What we've seen, interestingly enough, is in the explanatory memorandum and associated materials there's a heavy focus on expenditure growth, participant numbers, scheme sustainability and whatnot.

When you look at why the NDIS was set up, and even the NDIA themselves report on a quarterly basis about the outcomes they get, people being employed, people being able to attend school, people being able to hold it together, family units, not be on a mental health path. So, it's what wasn't there and what was less visible. I actually created a list because this interested me.

It didn't have comprehensive modelling of avoided future health costs, of avoided justice costs, of avoided homelessness costs, of workforce participation gains, carer workforce participation gains, taxation revenue gains, productivity gains, social participation gains. This is the impact of we make short-term savings and we end up with long-term costs. Currently, I know of a number of individuals, and I'm de-identifying, but there are individuals that have had enough significant support, or enough support, not significant support, to be able to run their own business.

Now that their plan has recently been cut, they're no longer able to run their own business, of which they were running their business to a level they were contributing to tax, a taxpaying citizen, they're now sitting at home socially isolated. On top of that, this is what I meant by the cumulative lens, if social participation gets cut. For autistic people, that was identified as a key issue, which again creates costs, mental health, employment, because everyone knows if you've got something meaningful that helps your mental health and your contribution to society, they're sitting at home.

The mum who was just about to start a business herself, because the child was at an age that she can now have her career, has put that on the back burner, so again, she can support her child. They're the consequences. This is what I mean about future costs prevents and what's the potential that Australia is missing out on.

All Australians should be able to meet their potential, but we're also saying we've got a productivity issue in Australia, and yet we're tying up a $79 billion informal carer economy.

What red tape or regulation do you think can be removed without impacting outcomes for participants? Can you provide one that's really obvious and I'm sure you have a bundle which you're happy to put on notice. But give me one where it's almost comical. It's sitting right there in front of you.

It's just. Yeah, go. We will take that on notice cause we'll, and we'll have to get back to you on Friday.

But an obvious one is the repeat of getting the reports for a lifelong disability. It's been assessed, you've got people and it's their scope of practice. Nothing's going to change.

And if for some reason people do think that people have now been delivering, we've had the NDIS scheme in place since 2013. It, you know, for some people, it's just the constant report every year and it says exactly the same thing cause that's their life circumstances. That is just a ridiculous amount of money that people pay to say the same thing.

That could just be a quick verification. If really something has to be shown to show that that person is still live and eligible, but it is a ridiculous amount of money. And the concern is we're moving to the world of, if we move to a world where it's about show that you've explored all the treatments.

Imagine the reporting that goes with that to get that validated. Again, as I said, we're going to create another market that runs in parallel to the NDIS market that we've talked about. There isn't enough stewardship.

Imagine what that will present in itself. So that's a really obvious, easy thing to get rid of. In terms of the changes that are proposed in the bill and these changes I'm referring to specifically in this case around governance, review processes and safeguards.

Can you tell me how is that going to change the experience of a participant? An inquiry, a joint Senate inquiry, capacity and capability. All of us have put all these examples forward about how all the savings that could be made and smarter ways. And yet that hasn't been implemented.

So there was the ART grassroots level with the workforce. We heard before about inconsistent decisions. You have to upskill, you have to lift the tide and upskill so that the actual people, the delegates and that are making the consistent decisions.

It's not about the individual becoming standardised. It's about them being able to interpret it. But we could send that forward too if we take that on notice.

There were a number of savings in our submissions. Okay, we'll go to Wendy and then we'll have Hannah. I just wanted to go back to where you were talking earlier about one of the biggest impediments is the red tape required around having to provide repeated reports for lifelong disabilities.

We received evidence yesterday, late this afternoon from the GPs and physicians who were saying that they're basically being pushed out in the consideration of any of the patients or participants' planning and assessments. Would that be something where they would be able to just do sort of a tick and flick annually because they would be seeing all the participants on a regular basis. That would be something that would be a quick time saver that they would be able to implement.

That each year that there's, if there's been a deterioration or whatever, they would be able to put some, because they would get copies of specialist results as well. Absolutely. What are your thoughts on that? Absolutely.

We need to use that entire ecosystem and effectively verify a source of truth. And I'm sure the professions can come up with something and to that point before also even about the reports on the DACSA side that I live with, that's Disability Access and Complaint Services. Often you have to mentor the GPs to be able to work out what it is they're supposed to submit because it's really hard when it's, you get a response unfortunately from the NDI that says, hasn't got enough, I need more.

What does that mean? But if we could standardise some of that, then you can definitely use those channels to make it more effective and it's been clinically validated. I mean, it was said before about the profession. They have to keep to certain integrity and ethics, but we're not influencing on that to make sure that we get the best out of it and then NDIA can get that validity that they need instead of about, we're doing all these other changes to manage fraud.

It's not that, that's not the area where the fraud is. Pamela, I just wanted to make a comment and I'm probably saying the most obvious thing, but a lot of this is built on, we've been here before. All of us have been here before that the systems were broken, they weren't working, the NDIS came about after years and years of looking at broken systems.

There was even an early childhood path and then it was said that we are flying the plane while we're actually designing it at the same time and when I go on about and you see the systems that work, I think what you hear across the disability sector is no one is fighting reform. Everyone wants sustainability. We just want to get it done right and that means design upfront and I'm pretty confident because I actually came from private defence industry and I used to actually roll out, develop, design, mission critical systems, they're all about saving lives, but the reality is that if you design upfront, you avoid 85% of the costs and look where we are because we didn't design upfront.

We've got fraud, we've got this. We're just saying, I think pretty much the sector is saying we spend a little bit of time together designing upfront, hearing from lived experience, getting in the right voices and we will get a better scheme, more sustainable scheme and a more sustainable Australian economy. That's what I think everyone is about and never have I seen in any other sector or anywhere else I don't think where I suppose effectively parliament's approving things that haven't been developed.

The safeguards to your question before aren't in place. Usually you would have harm monitors, fast resolution mechanisms, oversights. No one has seen any of that and yet for other major reforms and reviews, all of those things have been identified and put in place.

The Disability Royal Commission was really clear and it has all the elements here about fragmented systems, broken, not enough funding because don't forget the funding that's going in is all capped, has said what the outcomes are. So that's the path that we're on.