



NDIS 2.0

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Geelong community meeting

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I want to acknowledge the Traditional Owners of the lands on which we are gathered – the Wadawurrung People – and pay my respects to their Elders, past, present, and emerging.

I also want to extend that respect to any First Nations people joining us today.

It's great to be back in Geelong – the home of the National Disability Insurance Scheme.

Before I start, I want to thank everyone who has made contributions – in writing and in person – to the NDIS Review.

So far, the Review has received more than 3,000 submissions and we have engaged directly with thousands of people.

The overwhelming message from those engagements and submissions is the extraordinary positive change that the NDIS is making in the lives of people with disability and their families.

At the same time, we have received invaluable advice on how the NDIS and the eco-system around it could be improved – and this is guiding the Independent Review Panel as we finalise our recommendations.

Those recommendations will be made to Disability Ministers at the end of October.

With that deadline approaching, I want to take this opportunity to tell you some more about the Panel's current thinking and answer your questions.

Before I talk about where the Panel is up to, let me go back to where we started.

Last October the NDIS Minister, the Hon. Bill Shorten, established the NDIS Review to evaluate the design, operations, and sustainability of the NDIS.

I was asked to co-chair the Review with Lisa Paul, who cannot be here, but is with us online.

Minister Shorten gave the NDIS Review three core tasks:

Find ways to improve the experiences of participants and families;

Find ways to ensure the NDIS is sustainable; and

Find ways to restore trust in the Scheme.

These core tasks – outcomes, sustainability and trust – are connected and must be considered jointly.

They're connected because the NDIS can't achieve sustainability without improving participant outcomes – and because the NDIS cannot earn trust without delivering better outcomes.

Now, I know people are worried about the Review.

Some people – understandably – are anxious about the future of the NDIS.

I also understand, while everyone wants the Scheme to work better, this also means that there will be more changes – and changes always bring uncertainty.

As many of you know, two of my adult sons are participants in the Scheme. So, I understand the worry and the fear, because I feel it at every planning meeting.

With that in mind, let me start by addressing those concerns.

The NDIS is here to stay. It is not going anywhere.

That is what Minister Shorten has said.

That is what the Treasurer has said.

And that is what the Prime Minister has said.

The Federal Budget backed up those words with a \$910 million investment in the National Disability Insurance Agency's capacities, capabilities, and systems.

This is a very significant down-payment from the Commonwealth Government towards better outcomes and restoring trust.

In addition, every government in Australia continues to back the NDIS.

My point: the promise of the NDIS is secure.

But – and this is vital – that promise does not mean the work of the disability sector is done ...

.. because the onus is now on us to realise the full, transformational potential of the NDIS.

That means everyone in the disability sector shares a responsibility that is both an opportunity and a challenge:

An opportunity to take the vision that drove us all those years ago – a vision of human rights and inclusion – and see that vision realised in practice;

And a challenge to do that in a way that ensures the Scheme is sustainable and continues to enjoy the high level of public support it has always enjoyed.

Let me unpack that challenge for you.

The national roll out of the Scheme began in July 2013 and only finished in July 2020.

That means we are only three years into a nation-building project designed to deliver social and economic benefits over the lifetime of each and every participant.

That's why, according to the *Intergenerational Report*, future cost growth must be contained and the full benefits must be delivered.

Put it this way: the NDIS – once it reaches maturity – will deliver social and economic dividends for generations.

As I said, the initial rollout of the Scheme was carried out between 2013 and 2020 – and focused on getting participants into the Scheme.

That was the individualised stage of the NDIS build.

Going forward, in the 2.0 version of the NDIS, we need to focus on the community-wide stage of the build.

What do I mean by 'community-wide stage'?

I mean that we should be inclusive and, as a community, we should care as much about people outside the NDIS as we do about those who are in the Scheme.

Roughly one-in-five Australians live with disability – but only one-in-fifty Australians receive an individualised support package from the NDIS.

The vast majority of people with disability are not in the NDIS – and never will be – because they do not need an individualised package to meet their needs or fully participate in the community if attitudes change and mainstream services are accessible and inclusive of people with disability.

Every government in Australia – including local councils – agreed to make their mainstream services more accessible to the community before we started rolling out the NDIS to individuals.

This was set out in the first National Disability Strategy, which ran from 2010 to 2020.

But, more than a decade on, the promised rollout of community-wide services and supports has barely started – because all governments prioritised the rollout of individualised NDIS supports.

The great challenge we now face is to finish the job by finishing the community-wide rollout of disability supports, which were always intended to sit side-by-side with individualised NDIS supports.

There have been many different names for that community-wide rollout.

It's been called Tier 2.

It's been called ILC – or Information, Linkages and Capacity building.

As a Panel, we have been thinking deeply about the concept, too.

We've decided to call them community-wide foundational supports, because they are supports that should – by right – be available to all people with disability.

The Panel's position is clear.

We believe foundational supports should include such things as information and peer support and – for a smaller number of adults – should also include assistance with shopping, cooking, and cleaning.

We also believe that foundational supports must include much better support for children with emerging developmental concerns and delay – and those supports should be primarily delivered where children already are – in existing services such as maternal and child health, integrated child and family centres, early childhood education, and schools.

We believe that all children with emerging developmental concerns and delay must be supported in ways that best meet their needs.

For many children, foundational supports will best meet their needs.

For other children, individualised supports will be needed on top of foundational supports.

Let me make the Panel's position even clearer:

The Review strongly believes that the fairness, trust, and sustainability of the NDIS depends on the delivery of community-wide foundational supports to the one-in-five Australians with disability.

In other words, the sustainability of the NDIS depends on foundational supports.

Foundational supports are fundamental – and, like preventative healthcare, the smartest investments governments can make.

Let me now move to the sustainability of the NDIS – which was the focus of a report released last week by Dr Simon Duffy and Dr Mark Brown.

In their report, Duffy and Brown argue that the costs of the NDIS need to be brought under control – otherwise the Scheme will lose political and public support.

Duffy and Brown also said that sustainability is fundamental to the human rights of people with disability.

I think that is an important insight.

It's important because it means those of us who champion disability rights should also champion sustainability.

After all, a human right that cannot be sustained is a human right that, in effect, has been denied.

As I said, the NDIS is not going away.

But the future of the NDIS – and the realisation of its full promise – is in all our hands. And everyone has an important role to play.

As a movement, we have agency. We also have responsibility.

All of which begs a question: How will we use our power?

I firmly believe we must use our power to work together to improve the Scheme.

In their report, Duffy and Brown also talk about the importance of people with disability and their families having a central role in the ongoing design and operation of the NDIS.

I could not agree more.

There has already been some positive change. For example, for the first time, people with disability are in the majority on the NDIA Board.

That's a good start – but there is so much more to do be done.

We need to work together, including with the Agency, in a spirit of shared endeavour and responsibility to solve the current challenges.

We may not agree on everything – but open and respectful dialogue is essential.

One key issue to be resolved is clarifying the eligibility criteria for the NDIS.

The Panel's view is that eligibility for the NDIS should be based first and foremost on significant functional impairment and need – and only secondly on medical diagnosis.

This was always a key design feature of the NDIS and it remains as important today as when the Scheme was conceived.

The principle focus on functional impairments arising from one or more disabilities is important because it allows for multiple disabilities to be considered, which – when taken together – result in significant functional impairments.

Another key issue we need to work together on is clarifying the definition of reasonable and necessary supports.

I've said that an item-by-item approach to reasonable and necessary supports is not in line with the original intent of the Scheme.

This point has raised questions.

With that in mind, let me explain more about the Review's thinking.

The current planning approach is clearly not working. That is what you have told us.

People are trying to squeeze their lives into lines in the NDIS price guide. They spend precious time and money arguing with Local Area Coordinators or the NDIA about what they need – line by line – instead of focusing on building connected and inclusive lives.

This flawed approach is extremely stressful and leads to constant disputes. Despite the name it isn't really planning – it's a budget negotiation.

That was never what was intended. The intention was that reasonable and necessary supports should be set at a whole-of-budget level, allowing for people's individual needs and preferences to determine how a budget is spent.

That is why the Panel thinks that – in order to provide individualised, fair, consistent, sustainable and certain funding for participants based on transparent and valid processes – we need to separate the current planning process into three distinct steps.

The first step would be information gathering. The focus here would be on support needs rather than the price guide.

What activities do you do? How much support do you need to undertake them? And how often do you need those supports?

A suitably well-trained and qualified person would spend time gathering all this critical information from the participant and their family, as well as, where appropriate, professionals who work directly with the participant.

As part of this information gathering phase there would be an assessment. The assessment would be personalised and comprehensive and focused on your support needs.

There will be three important sources of information:

- Information from participants,
- Information from the professionals in their lives, and
- Information from the needs assessment.

Unlike Independent Assessments, there would be no shortcuts – because we know that this information gathering step is crucial to ensuring the budget is right. It would also be transparent and designed with the disability community.

The information from these three sources would then all be combined using consistent and transparent processes to set an individualised budget. And – because the budget is reasonable and necessary and has not been built line by line – people will have much more flexibility in how they use their funds.

Only big items like equipment and Specialist Disability Accommodation and Supported Independent Living will need to be used for a pre-agreed purpose.

The final step will be getting that budget off the page and into action.

Here we want to make sure people have much more support to use the funds in a way that makes sense for them – and gets them out in the community doing the things they choose to do.

We have heard loud and clear from many people that they want better support and advice and so we are thinking about all the ways that help might be provided.

We think that by separating out these three steps the process will be fairer, clearer, and more predictable – and therefore less adversarial and stressful.

And the final step – getting budgets into actions – will help everyone work more effectively together to get the best outcomes for participants.

That is our current thinking.

But, as you can already see, there is a lot of design and implementation work that needs to be done to finalise exactly what each of these steps should look like.

I want to be clear – the detailed design and implementation work will not be done by the Review. And nor should it.

The design and implementation work should be done by the Agency or independently, in conjunction with people with disability, their families and their representative organisations.

That point is important, so let me repeat it.

The Review will not be the final word on eligibility and reasonable and necessary supports.

Rather, the Review's work should create a platform for ongoing engagement and collaboration between the NDIA and disability stakeholders.

The Review will come up with a considered position – including a direction and clear recommendations.

Ultimately, though, the responsibility for these big decisions needs to be shared by governments, the disability sector, and the broader community.

Ten Big Reform Directions

I want to now come back to the Review's final report.

As I said, we will deliver our recommendations to Disability Ministers at the end of October.

It will then be up to Australia's governments – Commonwealth, State, Territory, and Local – to respond to those recommendations.

At the moment, we are still carefully reading your submissions and finalising our recommendations.

There is still a lot of work to be done, but I do want to share ten key areas the report will focus on.

The first big reform direction should come as no surprise given what I have already told you.

The Panel believes that community-wide foundational supports are non-negotiable. They must be rolled out nationally to secure the fairness, trust, and sustainability of the Scheme.

Allied to this, mainstream services – health, education, housing – must become universal services and meet their obligations to all people with disability.

At the same time, these systems and the NDIA must work much more closely, so that the NDIS is not an island.

This will require a new inter-governmental agreement between the Commonwealth and States and Territories, with responsibilities clearly set out through multilateral and bilateral agreements.

Our second big reform area relates to improving the participant experience, which is central to our Terms of Reference.

The Scheme needs to become more person-centred and respond better to intersectional disadvantage.

For instance, we need to improve outcomes for participants from First Nations, including those living in remote communities, and culturally and linguistically diverse backgrounds.

We also need to take gender into closer consideration and better understand and support participants with complex needs through initiatives such as supported decision making.

Our third big reform direction is access to the Scheme.

The assessment of access to the Scheme should be based primarily on significant functional impairments – and not a purely medical or diagnostic approach.

Our fourth big reform direction is that the NDIS needs a clear, fair, and consistent definition of reasonable and necessary supports.

Our fifth big reform area relates to early childhood.

Children with developmental concerns and delays should be identified as early as possible in mainstream settings ...

.. and early intervention needs to be based on best-practice evidence and principles.

We want to maximise the benefits of early intervention and give children and their families every opportunity to lead ordinary lives in their communities.

Our sixth big reform direction relates to home and living.

Reforms in this area need to focus on current and future housing needs.

We are thinking about ways to ensure that decisions about housing and living are more consistent and provide more certainty to participants. There is also a need to better utilise staff while delivering more individualised solutions to participants.

Our seventh big reform area relates to intermediaries and the current confusion and gaps between support coordinators, Local Area Coordinators, complex case managers, community connectors and plan managers.

There is also confusion about whether these roles are agents of the participant or the Scheme.

Our eighth big reform direction concerns the NDIS market.

The market is not delivering enough of the right supports in the right locations, let alone creating value or innovation.

The Panel believes that government needs to step in and steward the market. We also believe that participants need to have a greater say in how the market and services are shaped.

Our ninth big reform direction involves the workforce.

Here, the bottom line is that positive outcomes from the NDIS depend on a diverse, well-trained, engaged workforce, working with people with disability.

Our tenth big reform direction concerns quality and safeguards.

We need proportionate regulation and we need a better quality and safeguards framework – and those regulations and that framework need to be updated and expanded to include foundational supports as well as the NDIS.

There also needs to be better information sharing between regulators – and much more work needs to be done to build developmental safeguards.

If implemented together, these reforms will improve outcomes for participants, ensure the NDIS is sustainable, and restore trust, confidence, and certainty in the Scheme.

For the Panel and for me, to be involved in this work is an enormous privilege.

We, therefore, very much hope our recommendations will lay the foundation for a Scheme that will deliver for people with disability and the broader Australian community for decades to come.

In conclusion, let me come back to our shared responsibility to deliver the promise of the NDIS.

One of the lessons of climate change and the pandemic is that everything and everyone is connected.

The NDIS may be operating as an oasis, but no one in the disability community is an island.

Almost every part of every government, for instance, is connected to the NDIS.

Put it this way – the NDIS cannot be all things to disability and so you cannot fix the NDIS without fixing everything that sits around it.

It is in the national interest that governments should finish the job of building the NDIS and its eco-system, as was envisaged in 2013.

For service providers, the sustainability of your enterprises is directly connected to the fairness and trust of the NDIS.

Your business imperatives, therefore, mean that you should focus on delivering innovative, quality services that are of greatest value to people with disability and Australian taxpayers.

As for participants and their families, it is in our interest to understand what reasonable and necessary supports are – to demand value for money from our service providers – and to hold the NDIA and governments to account.

Make no mistake, the NDIS is here to stay.

That is why our unifying purpose must be to ensure it realises its potential and keeps its promise to people with disability and their families.

Thank you.