

'A Real Say in the Solutions'

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4th NDIS and Mental Health Conference:

Improving Recovery, Capacity Building and Wellbeing

International Convention Centre, Sydney

21 February 2023

Introduction

I would like to acknowledge the traditional owners of the lands on which we meet – the Gadigal people of the Eora nation – and pay my respects to their Elders, past, present, and emerging.

And I want to thank the CEO of Community Mental Health Australia, **Bill Gye**, for inviting me to speak today.

I would also like to say what a privilege it is to be speaking today in the same session as my good friend, Lisa Brophy. Your commitment, passion, research and insights in relation to psychosocial disability and mental health never cease to amaze me!

I'm here to talk about the work of the NDIS Independent Review Panel – which was established last October to evaluate the design, operations, and sustainability of the National Disability Insurance Scheme.

From Day One, NDIS Minister **Bill Shorten** has been very clear about how this review should work.

He has said it should be led by people with disability.

He has said it should not just consult but engage with people with disability and their families and carers.

And he has said its recommendations should be co-designed – meaning people with disability should have a real say in the solutions.

With that in mind, I want to start by reading an excerpt from one of the many 700 submissions the Independent Review Panel has received to date.

The submission is by Mental Health Australia, Community Mental Health Australia, and the Mental Illness Fellowship of Australia and, in my view, it provides a very important and clear summary. It states:

‘The NDIS has been life changing for many Australians. However, some people with psychosocial disability have faced a number of barriers in accessing the Scheme and implementing appropriate NDIS supports. In addition, the focus on individual funding packages has impacted carer and family access to supports. The NDIS has also created significant challenges for the psychosocial support workforce.’

To paraphrase:

the NDIS is a life-changing reform,

but it is not working as it should for many people with psychosocial disability.

I agree with that view.

I would also extend that view.

Based on the feedback we have received:

The NDIS is working well for many, but for some participants and their families the Scheme is not working well at all;

In fact, in some cases, it has been a cause of distress and fear.

That's why the Review is here today.

We are here because we are committed to transforming the participant experience – and to make the NDIS work for all participants.

Ms **Lisa Paul** – my co-chair on the Independent Review Panel – who is here today – and the Review Panel are united in this view.

Lisa is very familiar with mental health issues, through her former role as Chair of Headspace.

Our fellow Panellist, Dr Stephen King, is also here today.

Stephen is of course well known to you because of his role as the Presiding Commissioner on the Productivity Commission Inquiry into Mental Health.

But Lisa, Stephen and I are not here to lecture you. We are here to listen to you.

We want to benefit from your understanding, knowledge, and experience.

That's why we will hold two workshops today – one later this morning and the other this afternoon.

I hope you can attend the workshops because they are important.

Very important.

They are important because they are your opportunity to tell us the best ways to ensure the NDIS delivers better social and economic outcomes for people with psychosocial disabilities.

And, make no mistake, we are here to listen.

We also have members of the NDIS Review Secretariat with us – and they will ensure that your ideas and suggestions are recorded and can then be taken into the heart of the Review.

We want to find the best ways to deliver better outcomes – and we need your lived experiences of what is, and is not, working.

And – given the tight timelines of the Review – we don't have a moment to lose.

The purpose of my speech is to prepare the ground for today's workshops.

With that in mind, I will

brief you on the state of the NDIS;

outline the work of the Independent Review Panel;

detail two very important initiatives that will create the data and research we need to make long-term reform decisions;

and – most importantly – I will answer any questions you might have so that we hit the ground running in the workshops.

But first, let me say a few words about mental health and the NDIS.

Mental health and the NDIS

Professor Pat McGorry has told me he believes psychosocial disability and mental health conditions should stay in the NDIS.

Professor McGorry is right, of course.

Mental health does belong in the NDIS.

Psychosocial disability does belong in the NDIS.

But – and this is important – that does not mean everyone with a medical diagnosis of mental illness will automatically be eligible for the NDIS.

That's because, under the NDIS, eligibility is defined by need – not disability type or medical diagnosis.

It does not matter what kind of significant disability a person has.

It does not matter whether they have a psychosocial, physical, sensory or intellectual disability – or a combination of disabilities.

What matters is whether that person has a significant disability and an individualised funding package of disability-specific supports provides the best way for them to participate in the life of their family or community – or the economy.

That means no particular disability or medical condition is automatically in – or out – of the NDIS.

For example, there have been calls for Attention Deficit Hyperactivity Disorder or ADHD to be covered by the NDIS, but that thinking puts the cart before the horse because the NDIS is all about need – rather than a medical diagnosis.

The NDIS is also based on a social model of disability not a medical model.

My focus on need may sound like semantics, but it is fundamental to the purpose and sustainability of the NDIS.

Further, the fact that eligibility for the NDIS is based on need was foundational – and fundamental.

Back in 2008-2009, before the Productivity Commission Inquiry into Disability Care and Support, the Disability Investment Group – or DIG – stated that the NDIS ‘...would fund on the basis of each individual’s needs...’.

And so – from Day One – all disability types, including psychosocial disability, were included in the access criteria of the NDIS.

The focus on need is one of the great reform breakthroughs of the NDIS.

It goes to the heart of the Scheme.

Having said that, I should acknowledge a point well-known to everyone in this room: the fact that the NDIS eligibility criteria requires disability to be permanent.

At first glance, the language of permanence is at odds with the language of recovery that underpins psychosocial disability and mental health supports.

But recovery approaches and capacity building – which are fundamental to psychosocial disability and mental health care – are fundamental to the NDIS as well.

After all, as a lifelong insurance scheme, the NDIS should be investing in people today to increase independence tomorrow.

That's why the Scheme has much to learn from the experiences of people with psychosocial disability.

As at 30 June 2022, there were 56,559 NDIS participants who were designated as having a primary presentation of psychosocial disability and a further 35,157 participants with a secondary presentation of psychosocial disability. Together, these participants were 17.2 per cent of all participants in the Scheme. Many more have mental health issues.

The challenge we face is to ensure that the NDIS fits the needs of people with psychosocial disability and mental health.

The opportunity we face is to use the experiences of participants with psychosocial disability and mental health to improve the design and operationalisation of the NDIS for all participants and their families – not just those with a psychosocial disability.

This is the approach the Review is taking, consistent with our terms of reference and Minister Shorten's instruction to put participants first.

So, in the workshops later today, I am hoping we will be able to begin to explore and co-design how the experiences of participants with psychosocial disability could shape all aspects of the NDIS in the future.

Let me now brief you on the state of the NDIS.

State of the NDIS

The NDIS was not designed to individually cater to every Australian with a disability.

It was designed to be part of an ecosystem of disability and universal services.

Its purpose is to provide funding to the group of Australians who have permanent and significant disabilities ...

.. and – through what the Productivity Commission called Tier 2 – to support all Australians with disability, as well as their families and carers.

Following the commencement of the NDIS, Tier 2 supports were renamed Information, Linkages and Capacity Building – or ILC – and then implemented through a small annual grants program.

However, as highlighted in the submission the Review has received from Orygen:

‘The ILC Tier 2 stream of psychosocial services has failed to be developed in a way that aligns with the intent of the Scheme. ... Tier 2 services are particularly critical for young people as many will not meet the current criteria of permanence.’

In addition, those community-based supports through ILC were supposed to be supported by a foundation of accessible universal services – delivered by state, territory and local governments.

Local Area Coordinators were also meant to play a role in Tier 2, but, as is well-known, they have spent almost all of their time on access and planning for NDIS participants.

So the intent was clear: the NDIS needed to be built on a firm foundation of Tier 2 supports, so that Australians with disability not eligible for the NDIS were well supported in the community ...

.. and so that there was equity between the last person to become eligible for the NDIS and those not eligible.

However, the reality is very different.

There is a cliff – not a ramp – between the NDIS and Tier 2.

This cliff has been documented by my colleague at the Melbourne Disability Institute, Dr **Sue Olney**, in a report entitled *The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding* and which Sue spoke about yesterday.

That report, which Sue authored with Dr **Amanda Mills** and **Liam Fallon** from the Brotherhood of St Laurence's Social Research and Policy Centre, revealed a shocking picture of avoidable human costs, which is totally at odds with the purpose, philosophy and sustainability of the NDIS.

There are 300,000 Australians who experience persistent, severe and complex psychosocial disabilities, but 154,000 of them receive no support from the NDIS or Tier 2 ...

.. because at the time that the NDIS was introduced governments poured their resources into the NDIS and weakened or abandoned their responsibilities to provide Tier 2 services to Australians with disability – including those with psychosocial disability.

Since then, governments have made additional investments under the National Mental Health and Suicide Prevention Agreement outside the NDIS. This has mainly been directed at community mental health supports but it is not sufficient given that more than 150,000 people with persistent, complex and severe psychosocial disabilities receive no supports, today.

Governments have also used the NDIS as an excuse to weaken the rights of people with disability to access universal services.

And that neglect of need is creating a crisis that – unless action is taken – will undermine the long-term sustainability of the NDIS.

It risks undermining the sustainability of the NDIS because – contrary to the design of the Scheme – it is increasingly seen as the answer to every disability-related issue.

Or, as Minister Shorten has put it, the NDIS is the only lifeboat in the ocean.

These systemic issues must be addressed.

Therefore, some of the key questions for the workshops will focus on Tier 2.

We'll be asking you questions like what should Tier 2 look like? How should it best support people with psychosocial disability? And how can mainstream interfaces,

such as with health, justice and housing, work in concert with the NDIS rather than in silos?

There are other unresolved issues in relation to the implementation of the NDIS that are particularly important to people with psychosocial disability, and their carers and families – and will be discussed at the workshops.

For instance, we have heard,

The Scheme is not focused enough on evidence-based practices and its workforce lacks skills and churns staff;

The National Disability Insurance Agency has a poor understanding of psychosocial disability;

The Agency's planning process is too stressful;

NDIS supports are not focused on enabling people with disability to take charge of their lives and participate in the community;

There is a need for a more recovery-orientated approaches to supports in the Scheme;

The Scheme does not adapt to fluctuating levels of need;

Related life-style issues – such as alcohol and drug abuse – are not adequately addressed;

Connections with the health system need to be strengthened and rather than seeking to draw boundaries between health and disability, which encourage cost-shifting, their needs to be more shared responsibility and accountability;

Outreach and pathways into the Scheme are poor;

And carer and family supports are fundamentally lacking.

The good news is that the NDIA is working to overcome these issues by developing the Psychosocial Disability Recovery-Oriented Framework.

That's a start, but we must do more to improve outcomes for people with psychosocial disability.

And that is where the Independent Review comes in.

Independent Review Panel

Minister Shorten– when he appointed the Independent Review Panel – said the NDIS is the 'best thing' Australia has done since the establishment of Medicare.

'But,' he said,

‘For too many people accessing support though has become problematic.

‘For too many people the Scheme has developed into a source of stress and anxiety. We need to make sure that it delivers on its promise. ...

‘The Review will identify ways we can improve the NDIS to get it back on track, so it's more effective, empathetic and stands the test of time.’

Those are our riding instructions.

As co-chairs, Lisa and I have committed to ensuring the Review puts people with disability at the centre of the NDIS.

Our ambition is to restore trust and confidence in the NDIS – and the best way we can begin to restore trust and confidence is to go out into the community and listen to people.

We are here to find ways to make a measurable improvement in social and economic outcomes for people with psychosocial disability.

What kind of outcomes?

- We want to see a significant improvement in social and community access.
- We want to see a reduction in social isolation.
- We want to see improvements in rates of employment.

- And we want to see objective measurements of satisfaction with the NDIS among people with psychosocial disability – so we can track improvements.

All of which brings me back to the submissions we have received from people with psychosocial disability, their carers and families.

An initial analysis of the submissions we have received which refer to mental health has come back with the following insights:

- 49 per cent of submissions said dealing with the NDIS had negative mental health impacts.
- 29 per cent said those negative mental health impacts included stress, frustration, burnout, depression, anxiety, and/or the escalation of a pre-existing condition.
- 25 per cent said the NDIS's processes and requirements could be psychologically or emotionally damaging.
- 12 per cent said the negative impacts of dealing with the NDIS affected their whole family.
- And 10 per cent said the NDIS made them less able to participate in or feel a part of the community.

Here are what some of those submissions think of the NDIS in their own words:

- 'The NDIS is a punitive system. Every time my child's plan is reviewed, I am terrified that his funding will be cut. ... It shouldn't be this way.'

- ‘I voluntarily help a person who was evicted. ... I can’t get the help needed due to limited access to services [and] a reluctance on the person’s behalf to be assessed by a GP or psychologist due to past trauma/abuse. She needs a high level of care due to escalating mental health issues in conjunction with intellectual disability. ... She is afraid. She will soon be on the street due to her core funding running out.’
- ‘My whole experience with NDIS from start to finish has been stressful.’
- ‘Complex mental health issues like schizophrenia are invisible.’
- ‘Aside from the challenges I have had with the NDIS ... it has also been a blessing for myself and my loved one. ... It has improved our lives.’
- ‘It’s a great system when it works.’

The last comment says it all for me: the NDIS is a great system when it works.

The challenge we face is to make it work for everyone – every day.

In order to do that we need better data, evidence, and research.

Building the Evidence

The good news is that building blocks are being developed to complement the NDIS and make Australia a world-leader in disability research, analysis and policy.

For the past several years, the Commonwealth, States and territories have been working together to establish a National Disability Data Asset (www.ndda.gov.au).

When it is finished, the Data Asset will be an extraordinary platform for research, as it will bring together NDIS, social security, tax, employment, medical, health, education, justice, and housing data from across the Commonwealth, state and territory governments.

This is essential infrastructure and the Independent Review has already recommended to governments, through Disability Reform Ministers, that this work should be prioritised further. It is urgent.

In addition, over the past three years, people with disability and colleagues from other universities have been working with the Melbourne Disability Institute to establish a National Disability Research Partnership (www.ndrp.org.au).

The Research Partnership will provide a new source of research funding directed to improving disability policy and practice – and the research it commissions will be by, with, and led by people with disability.

Australia is therefore well placed to become a global leader in disability research, but ultimate success will require deep engagement by people with disability, their families and carers and so I would encourage you to become involved in these exciting and vital initiatives, so that the voices of people with psychosocial disability, their families, carers and representative organisations are clearly heard.

Conclusion

Let me now make some concluding observations, before I invite Lisa Paul to join me and Lisa Brophy at the microphone, open up to your questions and have a conversation.

The NDIS – as Minister Shorten has said – was and is a monumental socio-economic reform on a par with Medicare.

It has changed the lives of hundreds of thousands of Australians with disability – including Australians with psychosocial disability – and its impact will only grow in the decades to come.

But we cannot take the future of the NDIS for granted.

Nor should we be satisfied with the current state of play just because it is better than what we had before.

We can and must do better.

We must do better because we owe it to the hundreds of thousands of Australians who – through Every Australian Counts – tirelessly campaigned for the NDIS.

We owe it to those activists to strengthen the Scheme:

To streamline its design and operations;

To improve outcomes for people with disability;

To secure its sustainability.

That is the task at hand.

And we need your help to get the job done.

Thank you very much.