

Report on Consultation - NDIS Bill No. 2 (Quality and Safeguard)
Amendments

23/12/2024



The National Mental Health Consumer Alliance (the NMHCA) has prepared this submission in response to the consultation on the National Disability Insurance Scheme (NDIS) Bill No. 2 for Quality and Safeguard Amendments (NDIS Bill No 2).

The NMHCA is the national mental health consumer peak body led by and representing the voices of people with direct lived experiences of mental health challenges. This report is based on a consultation with people with mental health challenges who have experience receiving funding from and/or services through the NDIS held 19 December 2024.

All references to 'consumer' and 'lived experience' and 'psychosocial disability' in this submission refer to Mental Health Consumers with lived experience of mental health challenges. The term 'Mental Health Consumer' includes people who identify as having a psychosocial disability, who identify as having lived experience of mental health challenges, and who identify as mental health consumers. We use these terms interchangeably.

We <u>do not</u> include family, carers or kin in our definition of lived experience as it appears in this report.

The NMHCA

The NMHCA is the national peak body representing mental health consumers. We work together with the state and territory consumer peak bodies to represent the voice of mental health consumers on national issues. We are the people experiencing mental health issues/distress; at the table advocating with government and policy makers; and working with a robust network of grassroots communities. More information is available on the NMHCA's website: nmhca.org.au.

Acknowledgement of Country

We acknowledge Aboriginal and Torres Strait Islander Peoples as the traditional custodians of the land on which we work and pay our respects to Elders past and present. Sovereignty was never ceded.

Contents

National Disability Insurance Scheme Bill No 2 – Quality and Safeguard	
Amendments	4
General Concerns	5
NDIS recipients should not be forgotten in the penalty framework	5
Impact on smaller providers	e
Supported understanding of NDIS conditions	e
Potential loss of providers	6
Co-design	7
Penalty framework and statutory requirements	7
Safeguarding	8
Information gathering	9
Information held overseas	10
Key recommendations	12
Recognition of Lived Experience	13

Report

National Disability Insurance Scheme Bill No 2 – Quality and Safeguard Amendments

The proposed legislative reforms to the National Disability Insurance Scheme (NDIS), as outlined in the NDIS Amendment (Getting it Back on Track No. 2) Bill, aim to strengthen the regulatory powers of the NDIS Quality and Safeguards Commission (NDIS Commission). These changes, designed to address ongoing issues of quality and safeguarding in the NDIS, have important implications for NDIS participants, especially those with psychosocial disabilities. While the reforms are intended to improve the safety and quality of services provided to people with disabilities, there are potential challenges and unintended consequences for individuals with psychosocial disabilities that need to be considered.

The National Mental Health Consumer Alliance (NMHCA) facilitated a national consultation on Thursday 23 December 2024 to discuss the National Disability Insurance Scheme Bill No 2 – Quality and Safeguard Amendments. The Consultation paper on Bill No 2 for quality and safeguard amendments¹ was used as a structure to facilitate the consultation with six current NDIS recipients with lived experience of mental health challenges selected by their respective State and Territory consumer peak body to provide their expert opinion on the proposed legislation changes. The following report is based on the consultation.

The participants at our mental health consumer consultation expressed ongoing concern over the complex nature, speed and number of changes being made to the National Disability Insurance Scheme (NDIS). Consultation participants told us that the speed of the process introducing changes to the NDIS, along with the variety, scope and number of changes being made are confusing and difficult for consumers to remain confident in their understanding of what services they can and cannot access. The lack of true codesign – one of Bill Shorten's promises regarding NDIS changes – or at the very least coproduction, is also of concern and may result in new policy decisions likely to require further work after implementation.

While consumers recognise the need for the quality and safeguard amendments, several concerns were raised with the ten key proposed measures that form the NDIS Bill No 2 –

¹ NDIS Act, Rules and Standards | NDIS Quality and Safeguards Commission

Quality and Safeguard Amendments (NDIS Bill No 2) which will be covered in this report. Some of the concerns cross all key areas, including the impact of the proposed measures on smaller providers and on the person receiving services. Throughout the consultation, consumers emphasised that the key focus of the reform process should be on ensuring that the care and safety of the person receiving services through the NDIS are front and centre of any decisions made.

General Concerns

NDIS recipients should not be forgotten in the penalty framework

Mental health consumers expressed concern that the proposed framework and statutory requirements were very vague when it came to the impact on people, and especially people with lived experience of mental health challenges. Paying a fine or facing regulatory consequences doesn't directly compensate the individual whose support was compromised.

The focus of the Back on Track Bill No 2 appears to be on the prevention of inappropriate billing from the NDIS and does not adequately consider the impact on people receiving the services. When NDIS providers engage in unethical or improper practices, paying fines alone is often insufficient to address the harm caused to participants as they do not don't necessarily correct the immediate negative impact on the individuals who rely on these services. True accountability requires the provider to actively make things right for the affected participant which could include offering financial restitution, ensuring proper services are provided retroactively, taking steps to repair the relationship and regain trust, revisiting the participant's care plan, compensating for any lost or missed services, or making structural changes within the organisation to ensure that mistakes aren't repeated.

As well as being personally impacted by incorrect advice and poor or dangerous service provision, people with lived experience of mental health challenges will also be affected by the proposed penalties as they will potentially be left without services when their service provider is removed from the system.

Consumers identified measures of support are needed in the case of a provider being removed from the system including:

 replacement services for the services paid for that were not delivered/delivered incorrectly, at no further cost to the consumer; and immediate access to new service providers if the service provider is forced to exit the NDIS.

Impact on smaller providers

Consumers were particularly concerned that the impact of these ten measures on smaller, not for profit, independent providers could see them driven out of the market, with the larger commercial service providers surviving, limiting consumer choice of service provider. This was particularly the case for the additional data requirements and information changes which would have a greater proportional impact on smaller providers.

Supported understanding of NDIS conditions

Consultation participants told us that when a person is accepted to receive NDIS supports, they need adequate support to understand NDIS conditions, especially in relation to keeping their information private. Consumers want to know exactly what information about them can be shared with different government departments or not for profit organisations at different times, as well as in what circumstances. This support and focus needs to be offered more than once, and documentation should be submitted to the NDIS Commission to prove it has happened.

Potential loss of providers

Consumers want to ensure that it is as easy as possible for providers to embed all the changes and understand the new penalties.

There is general concern that providers may think the costs and associated time of implementing the changes and meeting the new requirements outweigh the payments received, which may see them leaving the sector. Consumers are most concerned about small providers, such as not for profit community managed organisations leaving the sector, reducing choice for consumers. Consumers are also concerned about the impact on people living in rural and remote areas, where service providers are already limited, which may result in consumers losing access to appropriate care providers altogether.

Additionally, consumers are concerned that the new measures may have the unintended consequence of turning providers away from consumers requiring greater support as they are seen as 'more difficult' or 'high risk'. This attitude can increase discrimination and further

marginalise mental health consumers.

Co-design

Consumers insist that they be involved in the co-design of policy and programs to ensure that the voices of the people that will be impacted are heard and considered. Including consumers will reduce the number of unintended consequences and ensure services appropriately meet the needs of consumers.

Penalty framework and statutory requirements

Consultation participants requested the documents to clearly identify what constitutes harm, noting that people often think about physical harm but rarely think about what happens when a person experiences less obvious, hidden effects of poor services such as trauma, psychosocial harm or the denial of decision making.

These less visible effects are an important human rights consideration, and as such the NMHCA would like the NDIS Bill No 2 to be screened against the human rights laws in Australia to ensure it is fully compliant and will not infringe on peoples' human rights.

Consumers were concerned about the impact on the individual services they receive if their service provider or support worker is removed from the system due to the penalty framework. This was particularly concerning when specific support is necessary to sustain and support consumers to live well in society. There must be a system whereby a consumer is not left without services, which can have disastrous implications.

Consultation participants expressed concern that some of the smaller providers, such as self-employed allied health therapists, may get caught up doing the wrong thing in terms of submission of paperwork or advertising of services no longer funded under the NDIS, due to confusion caused by the number of changes that have, and are, occurring in a short period of time. Consumers want to see a difference between getting something wrong and intentionally doing the wrong thing. They recommended that there should be some flexibility when mistakes are made, suggesting that having a grace period after the new legislation comes into effect could reduce this risk.

The intent behind a mistake should be considered when penalising a provider. Consumers agreed that some service providers have exploited consumers, with the focus on profit rather than care, and they agree that the penalty framework and statutory requirements are

needed to stop this practice. However, consumers identified the need for nuance in the implementation of the penalties and a greater focus on the consumer who is harmed by such activities.

For some wrongdoing by service providers, consumers recommend the consideration of a penalty system, whereby it is initially about identifying breaches and providing support workers, coordinators and care provider organisations with the time to correct any issues that may arise through notices and training. Involving people living with mental health challenges to codesign the implementation of the framework would allow likely issues to be identified early and corrected before any harm is done.

Additionally, consumers recommend the consideration of a system where penalty amounts are calculated based on the size of the provider to ensure diversity within the NDIS is maintained. A fine for a sole trader is very different for a multi-million-dollar organisation and this should be considered in terms of penalties being applied.

The hierarchies that exist in NDIS service provision, where providers hire support workers who provide hands-on support and care, need to be considered in the penalty framework. Consumers noted that sometimes a staff member gets away with causing harm as the provider is blamed for the action, and sometimes a provider gets away with not training staff appropriately and the staff member that causes harm is penalised. These intricacies in the way the NDIS market operates need to be considered in any new safeguarding and quality legislation to ensure that whoever is the cause of the harm is removed from the service market.

Safeguarding

If personal information is to be released to the courts, consumers want the individual affected to be advised of the pending release, what it means, who will see the information, and advised of their rights of appeal. Assistance to make a decision regarding making an appeal should be provided with consumers noting that the NDIS has not always acted in favour of participants.

Education and training should be included as part of a penalty matrix along with the proposed fines and incarceration. A large provider can easily pay multiple fines as fines may be cheaper than providing education and training for their staff. One person incarcerated for doing the wrong thing does not improve the service if everyone is doing the wrong thing due to lack of training or poor organisational culture.

Information gathering

Consumers agreed with the proposed changes providing more power to the NDIA Commissioner, but they noted that as with any form of power it can be misused and want to see the inclusion of checks and balances. This could be provided via a governance framework that holds the Commissioner accountable for their decisions.

As stated earlier, it is the recipient of the service that bears the cost of these proposed legislative requirements as it will take their support worker/coordinators additional time to do the additional paperwork. This will result in the consumer receiving less support time so the paperwork can be done in the allotted service segment of time OR the consumer may be charged an additional paperwork fee. This would reduce the amount of support they receive through the NDIS and not be beneficial to the participants who will be paying for the additional administrative tasks.

One consumer identified that this had happened already, with their support worker no longer providing one hour of support but 45 minutes, with the other 15 minutes spent on administrative tasks. Consumers recommend that the time needed to comply needs to be supported in another way so it does not impact the services they receive.

Again, the main concern was regarding the impact the additional administrative requirements would have on the smaller, not-for-profit businesses with the support staff often doing the paperwork and administrative tasks.

Consumers also questioned whether the NDIS portal was sufficient and quick enough to allow for the additional paperwork to be submitted without overburdening support staff and coordinators.

The additional powers for the NDIS Commissioner in relation to access to documentation and tabling these documents in court were welcomed. However, consumers did ask for the following additional information and inclusions to be incorporated.

There should be an opportunity for a consumer to request that their documents be deidentified when making a complaint. Consumers shared genuine concern that they could be targeted as a 'trouble maker' and may not be able to obtain future services if identified information is provided regarding a complaint they have made

If the NDIA Commission is going share the information of NDIS recipients, consumers recommend that the consumer(s) whose information is being shared (and therefore will be impacted by the decision), be provided with support to understand what information will be shared, how the information will be used, and what the implications for them will be. This needs to be explained as many times, and for as long as necessary, for the consumer to understand.

Freedom of information was identified as a key requirement by consumers. If something has happened during the provision of a service, and it has reached the courts for a compensation hearing, consumers advised that having the notes to provide a perspective of what happened is essential.

In summary, consumers stated that it should be clear from the very beginning of a therapeutic relationship what information will be collected and by whom and how that information could be shared, and that this information should be provided in an easy to comprehend document rather than as fine print.

Information held overseas

Consumers are unclear why holding information overseas is an issue, noting that a lot of organisations, businesses and individuals are holding information overseas. For example, consumers noted that emailing services MailChimp, mailing lists stored in DropBox, and survey tool Survey Monkey are all used widely and store data overseas. Additionally, consumers were again concerned about small businesses providing services, such as a local gardener whose mobile phone data that includes information about their NDIS client is stored on icloud.

Consumers were more concerned about the number of places their sensitive and personal information was stored and the security of these storage places rather than where the storage was geographically located. Consumers recommended that information should be able to be kept overseas but a proforma statement be introduced for providers to identify where they store information, including the security in place for more sensitive information. This statement should be kept on the participant's NDIS file as well as provided to the participant so they know what is happening with their data. Discussions regarding where

data is stored should be clearly explained to the participant at the beginning of the therapeutic relationship and if the consumer is unhappy, they can choose another provider. Again, every other part of a therapeutic relationship is negotiated upfront so why should it be any different when it comes to information.

Key recommendations

That the NDIS and/or NDIS Commission:

- 1. Co-design the implementation mechanism of the changes to legislation with mental health consumers to ensure that the new laws have a positive impact on consumers and focus on the provision of care and support.
- 2. Introduce a grace period after the implementation of the new legislation so penalties for errors made without intent are not as severe as for errors made with intent.
- 3. Recognise that smaller providers will be more impacted by the new legislation than the larger providers and should therefore be provided with some leeway, and fines should be imposed on an incremental basis depending on size of organisation to ensure that smaller, independent service providers are not all forced out of the market.
- 4. Consider a penalty system whereby it is initially about identifying breaches and providing support workers, coordinators and care provider organisations the time to correct any issues that may arise, through notices and training.
- 5. Provide additional finances to cover the time needed to comply with the new information requirements so the cost does not fall on the consumer in the form of less time per service or additional cost to service.
- 6. Advise consumers each and every time their information is going to be disclosed, and provide the consumer with the opportunity to deidentify the information.
- 7. Provide support to consumers each and every time their information is going to be used in court proceedings to ensure they understand what information is being shared, how it will be shared, why it will be shared and what is hoped to be gained by sharing their information.
- 8. Develop a proforma for suppliers/providers to use as a basis for advising a consumer where their information is stored as part of the therapeutic relationship, allowing for updates when necessary. The completed proforma should be stored with the NDIA Commission.

As a final recommendation, the NMHCA would like the NDIS Bill No 2 to be screened against the human rights laws in Australia to ensure it is fully compliant and will not infringe on peoples' human rights.

Recognition of Lived Experience

As a consumer lived experience-led organisation, the National Mental Health Consumer Alliance values the skill and expertise of consumers with lived experience. We pay tribute to those we have lost for the work that they have done to advocate for our rights. We acknowledge that we stand on the shoulders of giants who have paved the way for the rights we have today, and we will continue their work today and every day until the mental health system recognises and upholds our human rights. Nothing about us without us.



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National Mental Health Consumer Alliance.

See nmhca.org.au for more information about the NMHCA.

For questions about this submission, please contact us at policy@nmhca.org.au.