



**Proposals Paper on
Participant Safeguarding:
Independent Review of the
National Disability Insurance Scheme
Consultation Paper**

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002 with a focus on the private sector. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both.

Our core business is to advocate for systemic change to improve mental health care (including psychosocial disability) across the whole Australian health system, including within State and Territory jurisdictions. This includes advocating for empowerment of people with mental health lived experience (people with mental health conditions and their family, carers and kin) in the broad range of issues that impact their mental and physical health, and their lives more broadly. It includes empowering them in their own care and contact with health and social services, promoting their engagement and inclusion within system design, planning and evaluation and most importantly, advocating for systems that promote choice, inclusion, justice and fairness, and address abuse, violence, exploitation, neglect, stigma, discrimination and prejudice.

Our current feedback on the questions posed by the NDIS Independent Review Panel comes from the perspectives and experiences of consumers with lived experience of psychosocial disability, and from the perspectives of their families, carers and supporters. We welcome the opportunity to provide this feedback to the NDIS Independent Review Panel and wish you well in providing its recommendations for improvements in safeguarding for NDIS recipients.

The Consultation Paper

From the document:

This consultation paper is the second step in the NDIS Independent Review Panel's conversations about quality and safeguards in the NDIS. The first step was a discussion on updating the [NDIS Quality and Safeguarding Framework](#). LEA provided input to a submission about the Framework as part of its membership of the National Consumer & Carer Mental Health Forum.

This paper focuses on the contribution of effective natural safeguards and strong participant capacity in how the NDIS can best promote the safety of participants, while supporting them to exercise choice and control and engage in the dignity of risk.

This paper brings together what the NDIS Independent Review Panel have heard in their engagement to date, what has been said before in other reviews, and other observations they have made.

This paper focuses on how the NDIS supports participants to be safe. This includes building capacity and natural safeguards to empower participants to recognise and manage potential risks to their safety wherever possible, and providing more intensive safeguarding support to participants who may face more significant risks of harm than others.

The NDIS is a large system, and everyone has a role to play in supporting participants to be safe. The different actions that parts of the NDIS take to do this are called 'safeguards'. Safeguards can be natural (for example, skills, confidence and support from family, friends and community to speak up if you are unhappy with a support or service) or formal (for example, rules that providers and workers must follow, actions taken by organisations with formal responsibility for the safety of people with disability, and other supports such as advocacy, visitation and outreach, and support coordination). These safeguards work together to keep people safe.

This paper sets out three draft proposals for change to better promote the safety of participants, drawing on what the NDIS Independent Review Panel has heard so far. Feedback on these proposals will inform its recommendations to governments.

- The first idea is creating an NDIS-wide strategy on participant safeguarding, so that everyone has a clear idea of how to support the safety of participants.
- The second idea is to explore options for how participants and their supporters can communicate about risks and safeguards and develop a proactive plan of supports and actions to manage the individual risks they face.
- The third idea is to have a better variety of safeguards available that prioritise building and strengthening natural safeguards.

Our Feedback on the Review Questions

1. What does safety and safeguarding mean to participants?

a) When do participants feel safe and unsafe? What helps participants to feel safe?

People tell us that they feel unsafe when they are forced to navigate a maze of systems of assessment, particularly where they must repeat their story and information over and over again, and where there is a focus on psychosocial deficits in order to prove their need for NDIS. A recent NDIS quarterly report indicated that 51% of people with psychosocial disability have their application rejected. Our experience is of many people who have spent months or years sometimes with very limited or no real support other than within very clinically dominated illness focused systems. Consumers and their family carers may have little 'experience' of talking a new language of capacity, strengths and goals, particularly if their former experiences have been of coercive care, exclusion, stigma and marginalisation. To then have their claims rejected or made more difficult with multiple bureaucratic hoops to jump through can be overwhelming and make people feel very unsafe, overwhelmed and disillusioned about any hope for change. There are many 'unknowns' within NDIS and a lack of transparency for people to understand what to do and how to navigate this system.

People tell us they feel safe with they have consistent and reliable support, when support workers are on time, when those workers are more spontaneous with making new events to go to, informed by and in collaboration with the person, so that the person doesn't just feel like one in a long list of people to visit that day and tasks that the worker is 'getting through' on their schedule. We know that life can be very isolated for many people with psychosocial disability. Having someone to visit (anyone to visit!) can be a significant event in a person's day. For some people, there is anxiety and expectation before the person arrives and return to loneliness or 'sparse days' in between NDIS worker visits. Recognition of and more empathy and understanding of these 'lived' circumstances can help people feel more safe, build their confidence and self-worth, and build hope.

2. What is working well, and not well, to promote the safeguarding of participants?

What works well is Local Area Coordinators (LACs), others such as Occupational Therapists (e.g., who perform functional assessments), specialists, and other mental health and disability professionals who take a holistic view and truly understand what the person's day is like, how they actually live with their psychosocial disability. This includes people who clearly understand what the person's life would be like if their natural supports were not there. For example, we hear from many family carers who, because they have always 'just been there' and sometimes for decades, assessors and health professionals fail to see the

full extent of a person's psychosocial disability. But a major concern of family carers is 'who will care when I'm no longer able to do so?'

Related to this above issue, there seems to be little in the NDIS assessment that takes a longer-term view of the person's life and actively plans for that. Plans are made for a year (or a little more if the person is lucky) that can somewhat superficially cover 2-3 goals. We recently heard of a disturbing interaction where a person's needs changed, and their health deteriorated which also had impacts for their psychosocial disability. Rather than recognising the longer-term view and the reality that people's needs change, the NDIS did not seem to really account for 'real world' interactions between psychosocial disability, mental and physical health over time. Arguably it is a system that 'pretends' that mental and physical health needs are someone else's responsibility. Whereas the person lives their day making sense of all of these issues together. The only solution provided to the individual we heard about was for them to be placed in a nursing home. So, it seemed that the NDIS was saying 'It's all about giving the person choice, until it's not'.

The detail of people's lives may be difficult to describe in ways that are more meaningful to them; many descriptions are reduced down to tasks to be performed by a support worker. So, the system is already geared for people being 'recipients' of care and support rather than being seen upfront as contributing community members. The conditions are then ripe for many of the concerns around safeguarding that are raised in this document with regard to abuse, violence, exploitation and neglect because the person is by default, already in an unequal power relationship from the outset, despite the rhetoric.

3. Do you agree with the issues about participant safeguarding identified in this paper?

- a) Are there other issues about participant safeguarding that the Review should consider? If so, what issues?

The Independent Review Panel has stated that they have heard from participants, carers and families about their desire for safeguards to:

- Support participants to uphold their rights
- Ensure support and services are safe and high quality
- Recognise each participant's circumstances
- Be psychologically safe, and
- Respond when circumstances change.

We agree that these issues are central to participants feeling safe. We would add that participants, carers and families also want greater accountability across many aspects of the NDIS. Lack of accountability seems to be connected with many of the issues that then lead to problems with safeguarding such as exploitation, poor quality skills of workforce and boundary crossing problems, support that is more about what the worker wants to do than what the person has actually said they want to achieve in their plan, and so forth.

The discussion document talks about the NDIS Quality and Safeguarding Framework developmental, preventative and corrective safeguarding measures working together (pp.12-13 of the document). We are concerned that this 'working together' is not the experience of many people who are NDIS participants or their family carers. The failure to work together can often be at the heart of concerns expressed by them. Some family carers tell us that they feel more not less supported because many processes are still fragmented, inconsistent and not working together; and the person or their family carers must do the monitoring to ensure safeguarding is working.

The discussion document talks about the importance of natural safeguards (p.6). We agree wholeheartedly because where natural safeguards are present and strong in a person's life, then they are truly experiencing equity and citizenship, genuine relationships and so forth. Natural safeguards are part of people feeling and being 'normal', having diversity recognised as just how it should be in the community. People need natural safeguards to be highly visible, otherwise, their main experiences are of being 'recipients' of care and support, which are somewhat 'artificial'. When a person's life is dominated by service provided safeguards,

they may not be able to identify as readily with and call out abuse, neglect and exploitation; they are hidden and less visible to their community.

The discussion document also mentions state and territory governments' responsibilities for safeguarding (p.14). We would like to see their responsibility also being for investing in community resources and infrastructure that improves access to community and therefore to meaningful and genuine community connections. Currently, this section of the document focuses on issues like authorisation of restrictive practice, managing guardianship, and so forth. That is, the focus is on protection and correction, not building the structures and have a positive impact on capacity and community building, more broadly.

4. What do you think about the draft proposals for change identified in this paper?

- a) What is good about these proposals? Is the balance right between the dignity of risk and supporting participants to be safe? What could be different or better?
- b) Is anything missing from these proposals? If so, what?
- c) Do you have different ideas to improve participant safeguarding? If so, what?

These three draft proposals are a good start. The challenge and the important thing now will be to ensure they are broad enough yet individualised enough to ensure consistent and cohesive safeguarding occurs for all. We know that safeguarding within the NDIS cannot occur in a vacuum, because people live their lives 'beyond' their NDIS plans, in a larger community and this is the way it should be. Therefore, wider safeguards that are afforded to everyone should take particular account of people with psychosocial disability. Currently they do not do this very well, we believe. Protection from scams is one example. Affirmative action in the workplace for people with disability is another, young carers continue to be largely invisible, real access and connection to community can improve.

5. What could be done beyond the NDIS to improve the safeguarding of people with disability?

We have made brief reference to this in our comments above.

6. What should an NDIS-wide participant safeguarding strategy cover?

All the elements named in the discussion paper would be important to cover. Accountability could be elevated. Community and natural safeguards could be elevated and strengthened for the reasons given above.

7. When and how should participants and their supporters be engaged in communication about risk and safeguards in the NDIS? Why would this be the best approach?

Communication about risk and safeguards should occur when the person feels ready and safe to engage in discussion about these, and when the people they trust the most are able to share in this communication with them in ways that are constructive and solution focused. This would be the best approach because it would acknowledge the importance of the person being fully included and respected as part of this discussion. It would also ensure supporters are not co-opted into talking about the person in ways that demean or define the person according to what they are unable to do. We recognise the tension between engaging in this communication early and giving everyone concerned time to feel connected, trusted and open to having these conversations on the person's terms, rather than as part of a bureaucratically driven paperwork process which can reinforce 'clienthood'.

8. Who should communicate about these concepts with participants, and why? What skills or attributes are required to best support this?

The person to communicate these concepts should ideally be someone chosen by the person to ensure they feel safe in having sometime difficult conversations. The person should ideally have a holistic knowledge of the person so that things that are important and most relevant to the person are highlighted.

9. What helps build natural safeguards in participants' lives? What makes this harder?

Genuine connections with community build natural safeguards. Access to employment or other occupation that give the person a sense of purpose, value and worth, and that gives them expression and opportunity to maximise their skills and strengths.

Ableist attitudes make it harder, as do patronising support structures.

10. What can be done to support participants in decision-making?

Time and great skills development for all of the workforce in how to undertake supported decision-making would be useful to support participants in decision-making.

Having NDIS plans that are more nuanced rather than the focus seeming to be on 2-3 very task-oriented Goals that may or may not have been drawn fully from the person's expressed preferences would also be useful.

More active inclusion of families, carers, friends and other natural safeguards, where the person has indicated a preference for their involvement, would be useful.

11. How should information sharing between government agencies to promote safeguarding be balanced with privacy considerations?

Our experience is that when people have sufficient information in formats that they can access and understand that information, then they are more likely to be less worried that the information will be used in ways that they do not agree with. Our recent survey on My Health Record and Advanced Care Planning (conducted for Mental Health Australia and the Australian Digital Health Agency) clearly found that many people with mental ill-health and their family carers wanted to know more about how and how to use these systems more effectively, to have more control of their information.

12. What kinds of support and advice might participants need to effectively advocate for their right to be safe or to support safeguarding? In what circumstances would this be valuable?

People with lived experience tell us over and over again that they feel safest when they can identify with and are supported by others with lived experience who can take the time to listen and understand, walk alongside, help them find the words, be present so that others remain more accountability and include the person, and so forth. These circumstances now have a clear and growing evidence base for effectively in

helping people be heard, helping their engage, helping others take more notice of their person's preferences and therefore help the person for more safe and respected.

13. What options for outreach and visitation or other support can be provided to participants in different higher-risk settings and circumstances? What benefits would this provide?

This role should be undertaken by individuals with significant experience and alignment with the values of positive and respectful approaches to safeguarding, and with the preferences of people with psychosocial disability at the forefront. Ensuring a high level of skills and credibility of those providing outreach and visitation would help address any power differences, whereas less experienced people may be co-opted, overlook or not see concerns in some settings, especially where more institutionalised stances may minimise autonomy for the person with psychosocial disability.

14. How should any model for outreach and visitation operate for participants living in private homes? Should this be based on participants opting into or opting out of receiving visits or other forms of outreach?

Our concern about an opt-in system is that it requires significant effort put into communication that reaches every NDIS participant and provides sufficient information to them in order for them to make a decision. If they are experiencing a difficult circumstance where others may be exerting undue influence, exploiting or abusing them (i.e. particularly involving implications for safeguarding), an opt-in only system may fail to protect the very people who may benefit most from it. Their situation may remain hidden from view and scrutiny (the Anne-Marie Smith case is an example of this).

An opt-out system offers greater accountability, arguably, but again there would need to be significant planning and design in consultation with the lived experience community to determine how this should look and how it should be delivered.

Contact

We thank the NDIS Independent Review Panel for the work it is doing. We wish you every success with the next steps and would be keen to be involved in any future discussions about this important topic.

Your sincerely

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