



# NDIS Participant Safeguarding

Proposals Paper on
Participant Safeguarding
Independent Review of the
National Disability Insurance Scheme
May 2023



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# **Foreword**

People with disability have a right to be safe from violence, abuse, neglect and exploitation, including when they participate in the National Disability Insurance Scheme.

All members of the community have the right to be safe. For people with disability, this right is reinforced by the United Nations Convention on the Rights of Persons with Disabilities, but not always realised. This has become clear through the experiences shared with previous reviews and inquiries, including the ongoing Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

The 2016 NDIS Quality and Safeguarding Framework stresses the importance of balancing formal safeguards, such as rules for providers and workers, with efforts to build natural safeguards for participants that support and promote their rights and safety.

There has been insufficient focus on implementing supports to build the capacity of participants and strengthen their natural safeguards. Effort here is critical, and needs to be supported by targeted safeguards for participants facing higher risks and for whom building natural safeguards is more challenging.

This proposals paper provides some background on participant safeguarding and describes our aspirations for empowering participants to exercise their right to be safe. These aspirations reflect what we have heard so far from participants, carers, families, and other interested parties, as well as issues identified in previous reviews and inquiries.

It is clear that more must be done to empower participants to build their capacity and natural safeguards, as well as to support participants facing higher risks. We have developed some ideas for changes to achieve this. We want to hear from you about your views on these ideas and other things we should consider. If you have limited time, we encourage you to focus on the key messages and questions for consultation.

Yours sincerely

El anfrady.

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# Content advice

This paper contains material that may be emotionally impactful for some readers.

If you need support at any time, you can contact the following confidential services which are available 24 hours a day, 7 days a week:

# **Beyond Blue Support Service**

#### 1300 224 636

or https://www.beyondblue.org.au/

Phone, webchat or email. Provides immediate, short-term counselling, advice and referral services.

# Lifeline Crisis Support

#### 13 11 14

or https://www.lifeline.org.au/

Phone or text with a crisis supporter. This is a confidential service providing you with support for when you feel overwhelmed, for when you have difficulty coping, or are thinking about suicide.

# 1800Respect

#### 1800 737 732

or https://www.1800respect.org.au/

Phone or webchat. Supports people impacted by sexual assault, domestic or family violence and abuse.

### 13YARN

#### 13 92 76

or <a href="https://www.13yarn.org.au/">https://www.13yarn.org.au/</a>

Provides crisis support for First Nations people.

# NDIS Quality and Safeguards Commission

If you would like to report a specific incident involving an NDIS provider or worker, visit NDIS Quality and Safequards Commission or call 1800 035 544 or TTY 133 677.

### **Summary of key messages**

- Participants have the same right to be safe as other members of the community, including
  when they use NDIS supports and services. We are looking at how the NDIS can better
  support participants to be safe.
- 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 support people to be safe.
- We have started hearing from participants, carers and families. They have so far told us that they want their safeguards to:
- support participants to uphold their rights
- ensure supports and services are safe and high quality
- recognise each participant's circumstances
- be psychologically safe
- respond when circumstances change.
- We have identified that building strong natural safeguards is important, that risk and safeguarding processes need to be fit-for-purpose for participants, and that more intensive safeguards may be needed where participants might have more difficulty accessing or building natural ones.
- This paper outlines three complementary ideas we have about how safeguarding in the NDIS could be improved. Any changes should be participant-centred and focused on empowering participants to exercise their rights and be safe.
- 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.

# Questions for consultation

We want to hear from you about how to improve the safeguarding of participants. These questions are posed to guide you in providing feedback. However, you do not need to answer each question individually, or at all. You can respond to these questions and the issues identified in this paper in a way that best suits you.

- 1. What does safety and safeguarding mean to participants?
  - a) When do participants feel safe and unsafe? What helps participants to feel safe?
- 2. What is working well, and not well, to promote the safeguarding of participants?
- **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?
- **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?
- **5.** What could be done beyond the NDIS to improve the safeguarding of people with disability?
- **6.** What should an NDIS-wide participant safeguarding strategy cover?
- **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?
- **8.** Who should communicate about these concepts with participants, and why? What skills or attributes are required to best support this?
- **9.** What helps build natural safeguards in participants' lives? What makes this harder?
- **10.** What can be done to support participants in decision-making?
- **11.**How should information sharing between government agencies to promote safeguarding be balanced with privacy considerations?
- **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?
- **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?
- **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?

# Introduction

### **Key messages**

Participants have the same right as other members of the community to be safe, including when they use NDIS supports and services. We are looking at how the NDIS can better support participants to be safe. Many people have shared their thoughts, ideas and experiences of participant safeguarding with us and previous reviews and inquiries, including the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

This paper is focused on what we and other reviews have heard about how participant safeguarding can be improved, including outlining some ideas for change. It is our second step in considering quality and safeguards in the NDIS, following an <u>issues</u> paper on the NDIS Quality and Safeguarding Framework.

### Overview

People with disability who participate in the NDIS (participants) have the same right as other members of the community to be safe, including when they use NDIS supports and services. Participants should also be supported and empowered to exercise choice and control, and to engage in the dignity of risk. For many people with disability, the NDIS has been leading to better, safer outcomes. However, for other people, the NDIS has not worked well enough to support them to be safe.

We will develop recommendations to better promote the safeguarding of participants. In doing so, we are considering submissions made to, and the findings from, previous reviews and inquiries that have looked at safeguarding – as well as monitoring relevant developments in active inquiries. This includes:

- The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) was established in April 2019. A range of issues relating to the safety of people with disability, including NDIS participants, have been identified through submissions and public hearings.
- The Independent 'Robertson Review' into the circumstances relating to the death of Ms Ann-Marie Smith made recommendations to improve the safety of participants.
- The Joint Standing Committee on the National Disability Insurance Scheme has conducted several relevant inquiries, including an inquiry into the NDIS Quality and Safeguards Commission in 2021. Submissions to this inquiry identified a number of issues related to the safeguarding of participants.

 The NDIS Quality and Safeguards Commission's Own Motion Inquiry into Aspects of Supported Accommodation in the NDIS identified a range of safety issues.

Figure 1 gives examples of recent statements on safeguarding for people with disability:

### Too compliance focused

'Service systems focus their resources too narrowly on compliance and managerial approaches in responding to, instead of preventing, abuse.... It is essential to have preventative measures, to complement safeguards.'

(Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2021)

### People can be more and less vulnerable over time

'... being vulnerable, or being at risk of harm or neglect, is not static: a person with a disability may become vulnerable or may be vulnerable at one point but cease to be vulnerable. It is also worth saying that being a person with a disability does not by any means make you vulnerable.'

(Independent review into circumstances relating to the death of Ms Ann-Marie Smith, 2020)

### Natural safeguards should be strengthened

'A number of submitters emphasised the role of support networks and community inclusion to assist in ensuring people with disability are not subject to abuse or neglect... The committee recommends that the Australian Government specifically consider... in its review of the NDIS Quality and Safeguarding Framework how to improve access to and strengthen natural safeguards for all people with disability.'

(Joint Standing Committee on the NDIS, 2021)

### Barriers to accessing safeguards

'... individuals who experience, or are at risk of, violence, abuse, neglect and exploitation, face significant barriers to accessing and engaging with service systems designed to support them including those that take corrective action to address abuse and neglect. These barriers largely exist because these service systems often rely on individuals to seek out information, communicate and advocate for their needs, make informed decisions, and navigate within and across systems, to deliver services and supports effectively.'

(Safety Targeted Action Plan, 2021)

#### Relationships are important

'Seeking and sustaining 'right relationships' in communities and in services can centralise a high value on respecting the person and ensuring this is reflected in daily practice across services and bureaucracies. In the end, mentality (respect and high expectation) is more important than mechanisms.'

(South Australian Minister's Disability Advisory Council, 2011)

# Planning is a key risk management tool

'Effective planning is a key element of quality support in a person-centred system. Participants should be supported to identify and manage risk as they interact with the NDIS through access to the level of assistance they need to develop and implement their plans.'

(NDIS Quality and Safeguarding Framework, 2016)

Figure 1. Examples from recent reports on safeguarding for people with disability<sup>1</sup>

# Purpose of this paper

We want to ensure that participants are safe, empowered and aware of their rights, and that all parts of the NDIS work effectively to promote this.

Many factors contribute to how participants experience safety, as shown in Figure 2.



Figure 2. Examples of factors contributing to how participants experience safety

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 work will be complemented by other work across the review looking at these other factors.

This paper brings together what we have heard in our engagement to date, what has been said before in other reviews, and other observations we have made.

We have heard views on safeguarding arrangements for people with disability who are NDIS participants, as well as for people with disability in universal and mainstream services more broadly. This paper focuses on how the NDIS supports participants to be safe. We recognise these broader dimensions of safeguarding, and will also give consideration to interactions with safeguarding arrangements outside of the NDIS.

Our engagement to date, as well as other reviews and inquiries, suggest more needs to be done to support 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.

This paper also sets out draft proposals for change to better promote the safety of participants, drawing on what we have heard. It seeks ideas and feedback on these proposals to inform us in providing recommendations to governments.

### A note on terminology

Having disability is not inherently risky, and we cannot assume the level of risk in a person's life simply by knowing that they have a disability. In many cases, risk arises due to the attitudes and behaviour of other people, and the failure of others to provide suitable supports and environments for people with disability to be safe.

We are conscious that terms such as 'risk', 'safety' and 'vulnerability' can have negative connotations for many people, and acknowledge that not everyone's experience is properly captured by these terms.

We choose to respectfully use these terms in this paper, recognising that a range of circumstances can create risks to the safety of people with disability. These risks have eventuated for some participants. We consider it important to have a conversation about how to support people with disability to make decisions about what risks are acceptable to them and how to manage those risks.

This paper is the second step in our conversations about quality and safeguards in the NDIS. The first step was a discussion on updating the NDIS Quality and Safeguarding Framework.

We will also look at other aspects of quality and safeguards, and provide opportunities for engagement on these areas. These include:

- Regulatory approach: We will consider opportunities to ensure the regulation of
  providers, workers and intermediaries is effective, proportionate and risk-responsive.
  This will include considering the regulatory approach of the NDIS Quality and
  Safeguards Commission (NDIS Commission) and other Australian Government and,
  state and territory agencies that play roles in regulating for, or otherwise upholding,
  quality and safety in NDIS supports and services, as well as interactions with
  safeguarding arrangements for supports and services outside of the NDIS (mainstream
  and universal supports).
- Restrictive practices: We will consider issues in relation to restrictive practices and
  Positive Behaviour Support, including opportunities to make meaningful progress on
  reducing and eliminating the use of restrictive practices.

# Participant safeguarding

### **Key messages**

People with disability can face risks to their safety, including when they participate in the NDIS. Risks to their safety could arise from intentional actions (on purpose) or unintentional actions (by accident). Each participant is the expert on what safety looks and feels like to them.

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.

# Participant safety

All participants have a right to be safe when they use NDIS supports and services. Safety generally means being free from injury or danger.<sup>2</sup>

Injury or danger could be:

- physical (for example, injury or danger to a person's body, health and wellbeing)
- psychological (for example, injury or danger to the health and wellbeing of a person's thoughts, feelings and mind)
- social (for example, injury or danger to a person's connections to their friends, families, partners, and communities)
- economic (for example, loss of finances due to exploitation or fraud)
- cultural or spiritual.<sup>3</sup>

Injury or danger could be caused by:

- **Abuse** includes any behaviour that involves the ill-treatment of a person.<sup>4</sup> Abuse overlaps with violence, exploitation and neglect. For example, verbal abuse may also be considered a form of violence, and financial abuse may be a form of exploitation.
- **Violence** includes any behaviour by a person that coerces or controls another person, or causes the other person to be fearful.<sup>5</sup> Examples of violence a participant could

experience in the NDIS include physical or sexual assault, use of restrictive practices, verbal abuse, humiliation and harassment, financial abuse, and significant violations of their privacy and dignity.

- **Exploitation** is when a person takes advantage of someone else. An example of exploitation a participant could experience in the NDIS could be a person taking advantage of them financially and fraudulently claiming funding in their plan.
- Neglect includes acts by another person that are intentional (on purpose) and
  unintentional (by accident). Examples of neglect a participant could experience in the
  NDIS include being deprived of reasonable and necessary supports and services, as
  outlined in their plan, or not having supports and services delivered in the manner
  needed to keep them well.

Acts causing injury or danger exist on a continuum from minor transgressions causing disquiet or discomfort to significant violations of rights, and can be cumulative in their effect (for example, significant harm arising from repeated minor transgressions).

Participants have a right to be safe. It does not matter if the injury or danger is intentional (on purpose) or unintentional (by accident). Participants have a right to be safe from intentional and unintentional injury or danger.

The rights of people with disability are reinforced by the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). It says that people with disability have the right to be safe from violence and abuse. It also says that people with disability have the right to the same quality of life as other people in the community.<sup>6</sup>

The *National Disability Insurance Scheme Act 2013* (NDIS Act 2013) also sets out key objectives and principles in relation to the safety and rights of participants. For example, the NDIS Act 2013 says that the NDIS should:

- Protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the NDIS.
- Ensure that people with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation.
- Support people with disability to exercise choice, including in relation to taking reasonable risks, in the pursuit of goals and the planning and delivery of supports.

Participant rights are not always respected, and participants are not always safe. Research shows that people with disability are more likely than people without disability to experience all types of violence. 47% of people with disability aged 18 and over report experiencing violence since the age of 15, around 11% more than adults without

disability.<sup>7</sup> Women, children, and First Nations people with disability in particular are at further heightened risk of experiencing all types of violence.<sup>8</sup>

People think about and experience safety in different ways, influenced by factors such as:

- disability
- age
- sex, gender identity, sexual orientation and intersex status
- cultural and linguistic circumstances
- location
- experiences
- risk appetite.

These factors form a unique set of circumstances for each individual. The overlaps and intersections between these circumstances shape each person's experience of safety.

The broader physical and social environment around a person will also influence how they think about and experience safety. There are many different situations in the NDIS where people may think about or experience safety differently, including when they:

- are in the community or a public place
- are in their home
- are at work or educational settings
- need to make decisions
- need support
- need to communicate with other people
- need to find information
- are in crisis situations.

Regardless of their individual situation, participants may feel more or less safe depending on where they are, what they are doing and who they are around.

Access to family, friends, community and cultural networks – as well as the capacity of these supporters – may also impact how a participant feels about safety. For example, a participant may feel safer when they are with trusted people who will support them to identify risks in their environment, and to speak up if something happens. They may feel unsafe if they are in an unfamiliar environment with people they do not know well.

### **Questions for consultation**

- 1. What does safety and safeguarding mean to participants?
  - a) When do participants feel safe and unsafe? What helps participants to feel safe?

# How the NDIS approaches participant safeguarding

Safeguards are 'actions designed to protect the rights of people to be safe from the risk of harm, abuse and neglect, while maximising the choice and control they have over their lives.' Safeguards can be both formal and natural, and can be categorised as developmental, preventative and corrective measures. 10

In the NDIS, safeguarding is everyone's business.

### **Types of safeguards**

Formal safeguards are rules and the actions that are taken by organisations with formal responsibility for the safety of people with disability. In the NDIS, these include:

- the NDIS Code of Conduct, applied to all providers and workers
- NDIS provider registration requirements and the NDIS Practice Standards
- NDIS worker screening requirements
- complaints processes and investigation and monitoring of reportable incidents;
- provider systems and procedures to ensure safety
- worker training and education
- funded advocacy programs (e.g. the National Disability Advocacy Program)
- formal outreach (e.g. Community Visitor Schemes in some states and territories)
- funded support coordination
- disability discrimination and consumer protection laws
- quardianship.

Natural safeguards (also called informal safeguards) are actions and features that are part of people's day-to-day lives and that support them to live safely. These include:

- things that help people with disability to make informed decisions such as accessible information, or training to build their confidence and skills
- a trusted network of people to support, look out for and possibly help advocate for the participant, such as family and community networks
- civil society organisations and paid advisers who support people with disability.

The NDIS Quality and Safeguarding Framework also talks about developmental, preventative and corrective safeguarding measures.

- **Developmental measures** strengthen the capability of people with disability, workers and providers to reduce the risk of harm and promote quality.
- **Preventative measures** proactively regulate providers and workers to reduce the risk of harm and promote quality.
- **Corrective measures** resolve problems, enable improvements to be identified and avoid the same problems recurring.

These different types of safeguards work together to promote the safety of participants. Natural safeguards help people to understand and exercise their rights, and support their communities to protect their rights. Formal safeguards set up mechanisms to create safer environments and to take action where rights are violated. When people have good natural safeguards, they are able to manage risk more effectively themselves and are also able to engage earlier and more effectively with formal safeguards where the need arises.

### Responsibilities for participant safeguarding

- Participants self-advocate about how supports are delivered and raise concerns about supports and services.
- Families, carers and community may support participants to engage with NDIS supports, and advocate for quality and safety for participants when required.
- Providers, intermediaries and workers deliver safe and quality supports to
  participants, both direct supports and intermediary services, including engagement
  with participants about what supports are delivered and how; and raise and act on
  concerns about the quality and safety of supports.
- National Disability Insurance Agency (NDIA) assesses risks to participants
  throughout the NDIS planning pathway to determine the reasonable and necessary
  supports that a person needs; ensures the quality of plans and reasonable and
  necessary funding for supports and services, including to mitigate risk; and supports
  informed decision-making and capability development of participants.
- NDIS Quality and Safeguards Commission (NDIS Commission) regulates the NDIS provider and worker market to reduce risk to participants, drive quality in the delivery of supports and exercise market oversight; responds to and investigates complaints and incidents; regulates the use of restrictive practices; and promotes positive behaviour support strategies to reduce and eliminate restrictive practices. In order to deliver its regulatory functions, the NDIS Commission also has a role in directly supporting participants to uphold their rights to safe and quality supports.
- Australian Government Department of Social Services (DSS) advises on policy and legislative frameworks for the NDIS (including quality and safeguarding policy), and funds advocacy services and other programs including the Information, Linkages and Capacity Building (ILC) program.

• State and territory governments implement worker screening arrangements, authorise restrictive practices, manage guardianship arrangements, manage community visitors schemes (where available), ensure quality and safety in the delivery and regulation of mainstream services (such as hospitals and schools), and operate protective and corrective arrangements, such as emergency services, police, and family services. States and territories also have a role to play in the regulation of state or territory funded disability supports outside of the NDIS.

### **Recent developments**

A number of changes have been made in recent years to improve the safeguarding of participants. Some of these changes have been targeted to supporting participants at higher risk and were made in response to issues identified through previous reviews and inquiries, most prominently the 'Robertson Review' into the circumstances relating to the death of Ms Ann-Marie Smith.<sup>11</sup> Key recent changes include:

- Changes to the NDIS Act 2013 to strengthen the banning order powers of the NDIS Commission, and provide greater clarity about the compliance and enforcement and provider registration provisions.
- A new approach to identifying at-risk participants by both the NDIA and the NDIS
   Commission, including NDIA officers conducting participant welfare checks, NDIS
   Commission officers visiting providers to monitor compliance, and joint protocols that detail how the two agencies will work together on shared matters.
- Improved sharing of information between the NDIS Commission and the NDIA where necessary to keep someone safe.
- Introduction of new quality standards on specific areas of identified risk, such as disaster and emergency response and meal time management.
- New conditions that require registered NDIS providers to make sure they have good oversight and protections in place where a person is being supported in their own home by a single provider.
- Provisions for plans to be varied when participants need emergency funding.<sup>12</sup>

In addition, under <u>Australia's Disability Strategy 2021-31</u>, the Australian Government published a <u>Safety Targeted Action Plan</u>. The Safety Targeted Action Plan sets out the key actions governments will take to enable people with disability to receive high quality and safe services. Several key actions under the Safety Targeted Action Plan are specific to the NDIS, including work to 'develop a framework based on factors that create, contribute to, or reduce the risk of harm and enable proactive safeguards for participants'.<sup>13</sup>

The research agenda for the National Disability Research Partnership will also look at a range of issues linked to this topic, including research into how capacity for self-advocacy

can be further developed among people with disability.<sup>14</sup> It will be important for the NDIS to learn from these initiatives.

The NDIA has also recently developed two new policies on Participant Safeguarding and Supported Decision-Making.<sup>15</sup> The NDIA worked with members of the community, including people with disability, to co-design different elements of these policies. The Participant Safeguarding Policy sets out four focus areas for action: proactive and individualised approach to identifying, assessing and managing risks; developing the workforce and capability of people with disability; working with people with disability to proactively develop safeguards; and effective corrective measures in response to incidents.

### **Question for consultation**

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

# What we have heard so far about participant safeguarding

### **Key messages**

Participants, families and carers have started sharing their experiences and views on what safeguards should look and feel like in the NDIS. So far, they have told us that safeguards should:

- help participants to uphold their rights
- ensure supports and services are safe (physically and culturally) and high quality
- recognise each participant's circumstances
- be psychologically safe
- respond when circumstances change.

We have identified that building strong natural safeguards is important, and that more intensive safeguards are needed where participants might have more difficulty accessing or building natural ones.

Many participants, families and carers, as well as other supporters have shared their experiences, thoughts and ideas with us. They have raised similar themes elsewhere, such as through the Disability Royal Commission and the NDIA co-design and consultation processes to develop Participant Safeguarding and Supported Decision-Making policies.

There are some key things that we have heard to date about what participants and their supporters would like safeguards in the NDIS to do for them. These are only the early

things we have heard so far – and we encourages you to have your say about how the NDIS should support participants to be safe.

# Safeguards should be focused on protecting and promoting participants' rights, particularly their rights under the UN CRPD.

Participants have told us that the NDIS should help them realise their rights.

- Upholding the rights of people with disability is a key objective of the NDIS.<sup>16</sup>
- Despite this, there continue to be incidences of rights abuses. For example, 2,289 reports of alleged abuse and neglect and 1,471 reports of serious injury were made to the NDIS Commission between 1 October and 31 December 2022.<sup>17</sup>
- Participants want safeguards to help ensure they can exercise these rights, including safeguards to prevent abuse, and to support them to make their own decisions, even when the decisions come with risk.

Safeguards should ensure participants have access to safe, high quality and skilled supports and services, and that participants are heard in the design and delivery of supports.

Participants have told us that they want to access quality supports and safeguards that meet their individual needs.

- Participants, families and carers want safeguards to ensure they are both physically and
  psychologically safe, as well as culturally and socially safe, when they use supports and
  services. For example, some people from diverse backgrounds have shared with us
  experiences they have had engaging support workers that share their cultural
  background, and how this has positively supported their ongoing connection to family,
  language, spirituality and culture. Safeguards should support delivery of safe and
  quality supports and services, without reducing access to culturally safe services.
- Participants, families and carers want safeguards to be adaptable to their needs, but need more information to help them make decisions – for example, more information to support them when they are choosing providers.
- Participants would like clearer information about who they can contact and how when they have a complaint, or when an issue occurs that they need to raise with somebody. Nearly 25% of complaints received in 2021-22 by the NDIS Commission were about matters referred to other regulators or oversight bodies more appropriately placed to respond to the identified issues.<sup>18</sup> While people can submit complaints about NDIS supports and services to the NDIS Commission, it is less obvious who they can complain to about other supports or services (for example, universal or mainstream services they might use), or about the NDIA.

 Participants and their supporters seek help from various people if they have an issue with a provider, like talking to family or friends. They value the relationships they develop over time, whether informal or with their support workers. They do not always think of agencies like the NDIS Commission as the first place to go for information and advice.<sup>19</sup>

# Supports in plans are an important part of safeguarding, and should be designed with participants taking account of their varying circumstances.

Participants have told us that they can feel like the NDIA and NDIS Commission do not understand them, and that this can create situations where they feel unsafe. Participants want plans to take account of what they need to be safe. For example:

- Participants do not only face risks in the NDIS. Participants want the NDIS to work with the rest of the systems in their lives for example, education and health.
- Participants value how the supports in their plans help keep them safe in their homes and in their communities for example, a wheelchair can be a safe place to eat, and a trusted support worker can be a good safeguard for a participant when they are socialising out in the community.
- Participants, families and carers would like to see the NDIS do more to ensure supports are available to build their capacity to self-advocate, make their own decisions and manage risk. Only around 37% of participants feel able to advocate for themselves in the current system.<sup>20</sup>
- Intersectional factors like a participant being culturally and linguistically diverse (CALD),
  First Nations, gender, sexuality and intersex status can interact in a way that can create
  higher risks for participants. In a scheme where many participants identify with these
  factors, cultural awareness and specialised resources like translation services should be
  available.<sup>21</sup>
- Participants with sensory or intellectual disabilities want important information to be consistently available in accessible formats such as Auslan and Easy Read resources.
- Participants have told us about the importance of online communities to their wellbeing, and would like more support to be able to access the digital environment. This aligns with research suggesting people with disability are some of the most digitally excluded groups in Australia.<sup>22</sup>

# Supports and safeguards should be psychologically safe, trauma-aware and healing-informed.

Participants have told us that where they experience safety issues, they would like to be supported to not just manage the issue but also to heal.

- Participants want NDIS processes that recognise their psychological and emotional needs when they raise an issue or make a complaint, such as being heard and feeling their complaint is being responded to. This mirrors feedback received by the Joint Standing Committee on the NDIS that the NDIS Commission needed to better demonstrate to participants what steps it had taken in response to complaints.<sup>23</sup>
- Participants want NDIS processes to support them to talk about their experiences as people with disability in ways that feel empowering.
- Participants, families and carers want processes to be more straightforward, as
  complex processes and decisions that are difficult to understand have impacts on their
  safety, health and wellbeing. Family members and carers also observe that the
  complexity of processes can impact upon their capacity to support participants.

### Safeguards should be responsive when participants' circumstances change.

Participants have told us that when their circumstances change, they may need more help from the NDIS to ensure they are safe.

- Participants would like more support to stay safe when their circumstances suddenly change for example, when an informal carer or support becomes unavailable, or their personal or domestic circumstances change due to separation or loss of a job.
   Participants, families and carers have also stressed the importance of timeliness in responding to a change in circumstances, so that they can access supports as soon as possible when their needs change.
- Participants have also asked for an approach that is tailored to their immediate needs, like referrals to appropriate housing in natural disasters. Existing research has suggested that inflexible approaches to planning in crises can mean that supports do not meet the participant's needs.<sup>24</sup> This can create risks to their safety when they have lost key supports or are facing an active risk like a natural disaster. This also highlights the need to ensure continued service delivery by providers during a crisis.

# Other observations about participant safeguarding

We have formed further early observations on participant safeguarding, informed by engagement to date, previous reviews and inquiries, arrangements in other social services systems, and analysis of relevant literature and existing NDIS processes.

Natural safeguards are a necessity. Supporting and empowering participants to build their capacity, and building family and social supports in line with their preferences, is critical.

The NDIS has significantly changed how people with disability access services and supports in Australia. A key feature of the NDIS is 'personalisation' – each participant has an individualised plan, and typically is allocated individualised funding to achieve their own goals, and then exercises choice and manages risk in the market to access supports. This involves seeking information, communicating preferences, making informed choices about supports and services, and raising concerns when things go wrong or do not look right.

Personalisation under the NDIS has had benefits for many participants, including by supporting them to exercise choice and control over who provides their services and how. However, to reap these benefits, each participant needs to be able to advocate for their rights and safeguard themselves in a complex system in which there are many organisations and people. A participant needs significant knowledge, skills and resources to do these things. Access to family, friends and other supporters may help to reduce the burden on participants, provided the participant has an appropriate range of supporters with the right ability to provide that assistance and the participant wants their help. The NDIS should support every participant to build and strengthen their natural safeguards, a point acknowledged in the NDIA's Participant Safeguarding Policy. Participant Safeguarding Policy.

Other inquiries have touched on these themes. For example, the Disability Royal Commission asked the public what could be done to strengthen an individual's natural safeguards.<sup>27</sup> Responses noted the importance of mechanisms that build the capacity for participants to help protect themselves, promote their participation and visibility in the community, and enable more accessible advocacy support.<sup>28</sup>

The initial vision for quality and safeguards in the NDIS – set out in the 2016 NDIS Quality and Safeguarding Framework (Framework) – involved a balance of different types of safeguards working together, with a focus on building capacity and natural safeguards for participants. As described in our issues paper on the Framework, this has not happened in a comprehensive way, with implementation of the Framework focused on preventative and corrective measures for providers and workers.

We believe that increased effort must be directed towards building participants' natural safeguards. This will not look the same for all people. For example:

- Participants have the right to make decisions about what kind of, and how much, risk
  they might accept in the context of feeling safe. This is commonly referred to as
  'dignity of risk'.
- Participants live in a range of different family and community environments, and need safeguards to reflect this. What works to safeguard a child living with their family in a metropolitan area may not be what works to safeguard an adult living independently in a rural community and vice versa.
- There are differences in the typical size and composition of the social networks for people with intellectual disability, autism, psychosocial disability, sensory disability and physical disability.<sup>29</sup> Promoting greater participation and visibility in the community, as well as community support networks, requires tailored approaches.
- Not everyone will find the same type of support helpful or necessary. For example, while many people will be more likely to raise concerns if they have knowledge of their rights or access to independent advocacy, other people will remain reluctant.<sup>30</sup> This could be due to a range of complex factors including access to information or fear of having services withdrawn. Having different supports available is vital for responding to varying needs and preferences.
- Participants' feelings about safety and preferences for support to be safe may also change over time, as their circumstances change.

### Participant capital

A way of conceptualising the personal resources available to a participant to support them to advocate for their rights is the participant capital model, as shown in Figure 3 below. Understanding a participant's capital can help to identify where attention should be directed to help them build, or strengthen, natural safeguards.

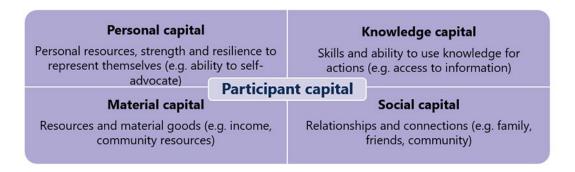


Figure 3. The participant capital model, based on Robbi Williams' 2013 Model of Citizenhood Support <sup>31</sup>

We consider that a model of 'participant capital' would likely offer a helpful frame for considering the needs of individuals to build natural safeguards. A 'capitals' approach also fits with NDIS capacity building and investing in participants.

Participants may benefit from the NDIS taking an approach to building natural safeguards that:

- Actively engages with participants and their chosen supporters about safeguarding, participant capital and natural supports relevant to their individual circumstances.
- Provides them with different safeguarding options to build their participant capital and natural supports, taking into account their individual needs and preferences.
- Monitors for issues that may change or emerge across participants' lives and proactively offers support where needed to maintain natural safeguards, build new circles of informal supports, or intervene with formal safeguards as appropriate.
- Monitors how successful different approaches are to building participant capacity and natural safeguards, and seeks out opportunities to embed innovative approaches that work for participants.

# NDIS safeguarding processes must be fit-for-purpose for participants to empower them to safeguard themselves, with the support of their natural safeguards.

We consider that while participants should be supported to build good natural safeguards, the system must also be straightforward to navigate. Without this, participants will struggle to build sufficient natural safeguards and self-advocate.

Participants will have varying capacity to advocate for their rights and manage risk in the NDIS due to the interaction of personal factors in their lives with the broader NDIS system. Around 60% of adult participants have conditions that could affect their decision-making capacity, such as acquired brain injury, intellectual disability or cognitive impairment, psychosocial disability or other episodic or degenerative disabilities. A2% of participants are aged less than 15 years and will likely need support to be heard in decision-making or may not be old enough to make certain decisions on their own. The complex decisions to be made in access, planning and implementation of plans can present risks to participants being able to exercise their rights and safeguard themselves.

Most participants who have raised concerns about their safety with us so far have focused on how supports, services, aids and equipment helped keep them safe and how the absence of these things made them unsafe. They did not strictly raise violence, abuse, neglect and exploitation. This mirrors findings of research by Purple Orange into the language and vocabulary used by people living with disability, in which significant diversity was observed in the way that different people with disability conceive of safety.<sup>34</sup>

Participants may benefit from the NDIS taking an approach to supporting them and their supporters to act as natural safeguards that:

- Discusses risk and safeguarding clearly, framed by participants' experiences.
- Understands that participants experience risk and safety as a continuum across all areas of their life, and will benefit from a cohesive picture.

Some participants will face higher risks and significant difficulty building good natural safeguards. The NDIS must have more targeted, intensive safeguarding options available to support these participants.

Some participants will face circumstances that place them at heightened risk of harm, due to the way that personal factors in their life interact with the broader environment. This includes difficulty in building natural safeguards that adequately support them to be safe.

The Disability Royal Commission and initiatives under the Safety Targeted Action Plan are considering what factors put a person with disability at risk of violence, abuse and neglect. Work through the National Disability Research Partnership has examined gaps and issues in the systems that support people with disability that can lead to harm.

Vulnerability is not inherent, nor isolated, to the NDIS, and actions to support participants in vulnerable situations need to be alive to this context. For example:

- Lack of support, finances, awareness, trust and gendered barriers to diagnosis may result in some people being vulnerable to not being able to access the NDIS.<sup>35</sup> It is important that the NDIS and other service systems support those in vulnerable circumstances to access the supports they need.
- Some people with disability may be in vulnerable situations but do not meet the NDIS
  access criteria (for example, over 65 years of age, disability does not meet the
  threshold for, 'permanent and significant', do not meet residency requirements).
- Participants interact with and receive services and supports from multiple systems including education, health (including mental health), housing and community services.
   These interactions are increased for certain people at heightened risk of harm, for example participants with active drug and alcohol addiction, mental illness, psychosocial disabilities or who are engaged with the justice system.<sup>36</sup>
- The Royal Commission into Aged Care Quality and Safety identified that many similar factors to those known to contribute to risk of harm for people with disability – such as social isolation, communication challenges and complex needs – also contribute to risk of harm for older people.<sup>37</sup>

Recent changes (described above) have been made by the NDIA and NDIS Commission in their formal safeguarding roles, targeted to supporting participants facing heightened risk of harm. There are also systems within the NDIS to help participants manage NDIS-specific risks around putting together and implementing a support plan, including the ability to access Specialist Support Coordinators and the NDIA's Complex Support Needs Pathway.

A number of reviews have called for more intensive, direct support for participants in complex and more vulnerable circumstances who have very low personal and/or social capital to support them to ensure a proactive and holistic approach to safeguarding their interests and wellbeing. Many have raised that a case management function, grounded in a social work approach, may be needed. Careful consideration needs to be given to who is best-placed to deliver that support, what it should deliver for participants, and how participants retain control. We are interested in views on this issue.

Participants may benefit from the NDIS taking an approach to supporting participants who may face more significant risks of harm that is:

- Aware of the broader issues that create risks of harm to people in our communities.
- Able to look beyond the NDIS-specific parts of a participant's life.
- Tailored to the individual, and able to deploy different safeguards as needed.

### **Questions for consultation**

- 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?

# Draft proposals for consultation

### **Key messages**

We think that any changes to better support the safeguarding of participants should be participant-centred, and should:

- be focused on participants' rights and their capacity to exercise them
- view the NDIS from participants' perspectives
- proactively identify and engage with risk
- be trauma-aware and healing-informed.

This paper describes three complementary ideas to improve safeguarding.

- The first idea is creating an NDIS-wide strategy on participant safety, so that everyone has a clear idea of what participant safety means and how to support it.
- The second idea is to explore options for how participants and their supporters can engage in a discussion 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.

We have developed three draft proposals for changes to better support the safeguarding of participants.

### These proposals are not our final views or recommendations.

This paper seeks ideas and feedback, to inform us in refining these proposals and then providing advice and recommendations to governments.

These draft proposals are complementary, interlinked and mutually reinforcing. This means they should be implemented together.

Together, these draft proposals aim to ensure that:

- Arrangements to support safeguarding involve all government agencies working in the one direction in a way that is coordinated and centred on the participant – rather than having different strategies and arrangements across governments.
- There is a more nuanced understanding of the circumstances and risks faced by individual participants – with responses and supports calibrated to provide the assistance individual participants need to exercise choice and manage risk.

 There is a holistic set of non-regulatory safeguards that can be deployed based on the individual circumstances of participants – with a focus on building participant capacity and natural safeguards wherever possible.

# A participant-centred approach

Changes to the NDIS to better support safeguarding should be participant-centred. While participant-centred does not have a formal definition in the NDIS, the concept is embedded in the rights-based approach of the NDIS Act 2013. Other frameworks from health and social services can help in understanding this concept. For example, National Disability Practitioners define a person-centred approach as,

'ensur[ing] that the focus is on what matters to the people receiving support and their families, and pays attention to how to support staff as well.'38

The Picker Principles of Person Centred Care also provide some guidance on this idea. When something is participant-centred, it,

'... puts people at the heart of health and social services, including care, support, and enablement. It is an approach where users are recognised as individuals, encouraged to play an active role in their care, and where their needs and preferences are understood and respected.'39

As shown in Figure 4, to deliver a participant-centred approach to safeguarding, changes should:

Be focused on participants' rights and their capacity to exercise them	Prioritise empowering participants to understand and exercise their rights and take risks, including by supporting them to build capacity and natural safeguards.  Build capacity among carers, families and broader systems to respect and promote the rights of people with disability.  Be culturally safe and inclusive, ensuring that First Nations, CALD and LGBTQI+ people are supported with approaches that are right for them.
View the NDIS from participants' perspectives	Ensure all government agencies are coordinated and working in one direction.  Be aware of, and cohesive with, the broader systems that participants, carers and families engage with throughout their lifetime (for example, education, health).
Proactively identify and engage with risk	Recognise that each participant will understand and think about safety and risk in their own way, and that this will influence what safeguards feel and work best.  Identify risks, changes and issues proactively.  Address risks before issues arise wherever possible, rather than responding after the fact.
Be trauma-aware and healing- informed	Recognise that as people with disability, participants may have already experienced feeling or being unsafe, and that this will inform what they want and need to feel safe in the NDIS.

Figure 4. A participant-centred approach for changes to safeguarding

### **Questions for consultation**

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

# Draft proposal 1

# An NDIS-wide participant safeguarding strategy

# How does this currently work?

The 2016 NDIS Quality and Safeguarding Framework (Framework) outlines an overarching architecture and specific initiatives to achieve safe and high quality supports in the NDIS. While there has been positive progress in implementing parts of the Framework, other aspects have not been implemented as envisioned, or at all. We have recently published an issues paper on the Framework, which seeks views on how to revise and reset the Framework to be fit for purpose for the future.

Underneath the Framework, the various parts of government responsible for delivering the NDIS (for example, NDIA, NDIS Commission, DSS and states and territories) have different policies and processes for understanding what risks people with disability face, what supports people with disability to be safe, and how and when to take action to ensure safety. There is not, however, a clear articulation of how these individual policies come together to deliver on the strategic objectives of the Framework.

This means that it is not always clear what the different agencies should be doing to support participants when they are unsafe, how they should work together, and how their actions fit with an overarching strategy. It also means it can be difficult to understand how the system as a whole is working together to keep people safe, as reporting on outcomes is fragmented across agencies using different measures of success.

### How could it change to work better?

We think there should be one strategic approach to participant safeguarding in the NDIS. A new NDIS-wide Participant Safeguarding Strategy should be designed with strong engagement from participants, and should include things that participants want to see in it, such as clear guidance on who is responsible for what, and illustrative examples to help them understand what the strategy means in practice for them. DSS should lead the development of this strategy, working in partnership with the NDIA, NDIS Commission and states and territories, and engaging with participants.

The strategy would sit under a revised Framework and be linked to Australia's Disability Strategy 2021-31 and the Safety Targeted Action Plan. It would articulate how all governments coordinate and deliver on participant safeguarding objectives. It would also articulate how the performance of the NDIS system as a whole in safeguarding participants will be monitored and reported on, to ensure accountability. Individual agencies' policies would articulate how they will deliver on their responsibilities under the strategy.

Other people such as providers and workers play critical roles in safeguarding – with these roles and expectations articulated in the Framework and specific regulatory requirements. The strategy would instead focus on coordinating various parts of government.

Under this proposal, everyone would have a different role to play, but they would be guided by the same approach, objectives and understanding. Participants, families and carers would have a single source of truth about what to expect, what their role is, and how NDIS agencies can support them. This would mean that when they ask for help, there would be fewer gaps to traverse in finding support. Likewise, the NDIA, NDIS Commission and other parts of government like states and territories would have a single articulation of expectations and roles, better coordination, and a clearer process to evaluate performance and outcomes on participant safeguarding at a whole-of-scheme scale.

It will be important to ensure that the strategy delivers practical change and outcomes. For example, this could include focusing on specific issues and sources of harm over time, as well as ensuring accountability through frequent, transparent reporting on outcomes.

### **Question for consultation**

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

# Draft proposal 2

# An improved and individualised approach to work with participants to understand risk and build safeguards

### How does this currently work?

The NDIA encourages participants to consider the safeguards, strategies and support mechanisms they have in their lives when developing their statement of supports, deciding on their support requirements, developing their plan and putting their plan into action.<sup>40</sup>

Currently, the planning and assessment conversation is an opportunity to consider risks and safeguards that may be required, and planners are given some information about actions to take where they identify risks. For example, NDIA guidance explains that plans can include more funding to build a participant's support network.<sup>41</sup> The NDIA also see this as a chance to organise regular interactions between participants, their supporters and the NDIA, or NDIS intermediaries, and to check that their providers have appropriate registration for certain supports (for example, restrictive practices).<sup>42</sup>

However, we have so far heard from participants, families and carers that:

- They are not always aware of, or actively engaged in, conversations about risk and safeguarding.
- Where they are aware of these conversations, they may not be aware that what they
  are being asked is part of an assessment of their safeguards and the risks they may
  face. This can mean that their perspectives on the risks and safeguards in their lives are
  not taken into account, and may leave them at heightened risk of harm.

Access and planning processes can be confronting for some people. Some people have also expressed that they have experienced risk assessment processes as confronting.<sup>43</sup> As described above, the NDIA has recently developed a new NDIA Participant Safeguarding Policy. Focus areas in this policy include ensuring a proactive and individualised approach to identifying, assessing and managing risks on an ongoing basis, and working with people with disability to proactively develop safeguards.

The ambitions in the Policy take positive steps to addressing some of the issues with current processes. However, we have formed the preliminary view that there are further opportunities to improve proactive, individualised and participant-led conversations about risk and safeguards, building on the ambitions in the NDIA's policy.

### How could it change to work better?

We think there should be a more comprehensive and individualised approach to understand risk and build safeguards that allows participants and their supporters to lead the conversation, and to speak about risk and safeguards in a manner that reflects their needs, values, priorities and experiences.

This should start with transparent and meaningful conversations with participants and their supporters about risk and safeguarding. It should be supported by a range of safeguarding strategies, and incorporate active and ongoing monitoring for changes.

### **Note**

We are considering the participant pathway more broadly, including the relationships between participants, the NDIA, and NDIS intermediaries. Recommendations relating to participant safeguarding will be integrated more broadly into any recommendations on the participant pathway.

Key features of these conversations and processes could include:

- Working together, led by the participant, to reach a shared understanding of what risks
  might be present in the participant's life in a trauma-aware, healing-informed way. This
  would include considering the protective factors and personal capital available to
  support the participant, and the circumstances of families, carers and community
  supporters (for example, the breadth and capability of supporters).
- Working together, led by the participant, to consider safeguarding options (both formal and natural) that are appropriate to the risks identified and meet the needs and preferences of the participant and their supporters. Proposal 3 will talk about ideas for supports to build or strengthen natural safeguards – as well as targeted safeguarding actions for participants facing higher risks – that could be considered.
- Agreeing a plan to monitor and review risks and safeguards together. This could include defined review points, avenues for participants to raise changes or issues at other times, and use of government data (held by both the Commonwealth and the states and territories) to identify risks and changes. Proposal 3 will talk about some ideas for monitoring risk over time, including information sharing and outreach.
- Recording safeguarding plans in an accessible way as a resource for the participant.

We consider that these conversations and processes should:

- Be led by the participant and focused on empowering the participant.
- Be between the participant (and their chosen supporters) and a trusted person with whom the participant will feel comfortable discussing risk and safety. Consideration

- should be given to ensuring participants have agency to identify their supporters, acknowledging this may not always be family members. This may require someone to work with the participant over time to understand their needs and desires.
- Be personalised to the individual participant and their circumstances, noting that discussions about risk and safeguards will look different for every participant.
- Support each participant to communicate what being safe looks and feels like for them, and prioritise their individual perspectives on risk and safeguards in their lives.
- Prioritise efforts to build and strengthen natural safeguards.
- Be supported by a suite of safeguarding options that could be deployed in different circumstances to uphold the safety, rights and preferences of the participant.
- Incorporate active and ongoing monitoring, including by leveraging government data and information (held by both the Australian Government and the states and territories) to identify issues and changes in a participant's circumstances that may impact the risks they face or the effectiveness of their natural safeguards.

It will be important that conversations and processes to consider risk and safeguards are developed and implemented in the way that works best for participants, including that they happen at an appropriate time and with a person the participant trusts.

### **Questions for consultation**

- 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?
  - Options could include when a participant is granted access to the NDIS; during the planning process; or at another time.
- 8. Who should communicate about these concepts with participants, and why? What skills or attributes are required to best support this?

  Options could include a planner, an advocate, another person, or a self-led process.
  - Options could include a planner, an advocate, another person, or a self-led process undertaken by participants supported by information.

# Draft proposal 3

# Improved safeguards deployed on an individual basis

### How does this currently work?

A range of safeguards are currently available in the NDIS. However, there has been limited investment into developing participants' capacity to manage their safety, support for participants to understand the safeguards available, or support to build natural safeguards.

Existing safeguarding mechanisms include those in Figure 5.

### **NDIS Commission safeguards** - focused on regulating providers and workers

- **Code of conduct** all providers and workers must follow these rules on how to behave when delivering supports.
- **Provider registration** assess suitability and quality of providers, and requires providers to register for certain higher-intensity or higher-risk supports.
- **Complaints process** participants and others can make complaints about the quality or safety of NDIS supports.
- **Worker screening** workers of registered providers working closely with people with disability are required to undergo a check for their suitability.
- **Site Visits** attend places where services are provided to check that providers and workers are complying with the rules.
- **Incident reporting** obligations for providers to report particular events, abuse or neglect.
- **Education** education and capacity building for people with disability, providers and workers.

### **NDIA safeguards** - focused on participants and the planning process

- **Decision-making supports** mechanisms to support participants to make decisions (supported decision-making) or replace their decision-making (substitute decision-making).
- **Check-in calls** calls from NDIA staff to participants to check on their welfare.
- **Complex support needs pathway** specialised support for participants who have other challenges impacting their lives (like mental health issues or homelessness).

### State and territory safeguards - focused on the wellbeing of people with disability

- Community Visitor Schemes (CVS) carry out visits to people living in higher risk environments, including people with disability, in six states and territories. These schemes vary between states and only some cover NDIS services.
- **Authorisation of restrictive practices** authorise the use of restrictive practices by providers, where the relevant requirements have been met.
- **Public Guardians and Public Trustees** make personal and health decisions for people, and manage, where a person is under a guardianship order.
- Public Advocates promote and protect the rights of people with disability
- **Health and Disability Service Commissioners** bodies that can receive complaints about health or disability services, sometimes including supports.

### Figure 5. Existing NDIS safeguards

In addition, DSS provides funding to organisations to deliver projects in the community that aim to benefit all Australians with disability, their families and carers through the ILC program. For example, ILC's individual capacity building stream seeks to enable systemic, nationwide access to peer support, mentoring and other skills building for people with disability and their families and carers, playing a role in building safeguards for both participants and non-participants.

There are also safeguards to support participants to make their own decisions (supported decision-making) or make a decision on behalf of the participant considering their will and preference (substitute decision-making).

The NDIS is complex to navigate, and some participants and supporters are uncertain about how to implement their plans, including how to choose providers to deliver supports and services. Participants express that while there are several options for substitute decision-making (for example, guardianship and plan nominees), there are limited supports to help them to make their own decisions and be heard. This may be a factor in observed increases in applications for guardianship of adults since the introduction of the NDIS, which is undesirable because it limits the participant's rights and autonomy.<sup>44</sup>

### How could it change to work better?

As part of the participant-led process to understand risk and build safeguards described in proposal 2, we consider that all participants should be supported to identify and implement safeguards that will work for their circumstances, supported by accessible information made proactively available to them on:

- the range of safeguards available in the NDIS
- how they work
- what benefits each of them offers to support participants to manage risk and advocate for their rights.

A broad range of safeguards should be available to be deployed in different circumstances. We propose that two categories of safeguards be available to be deployed, based on individual circumstances:

- General safeguards: Safeguards that are available to all participants where they would benefit from them, and are routinely deployed – with a focus on building a participant's capacity and strengthening their natural supports where needed.
- **Targeted safeguards**: Specialised safeguards that are available to those engaging with higher levels, or more complex types, of risk that cannot be adequately mitigated by general safeguards.

We think it is important that these initiatives focus first on capacity-building for participants, carers and families that supports participants to be safe not only when they engage with services and supports funded through their plan, but also when they engage with universal and/or mainstream services (that is, services that are not funded through their plans). In addition, safeguards should prioritise better integrating participants into their wider community, as being a recognised and valued part of their community is often the strongest safeguard available.<sup>45</sup>

We note that these measures would be supplementary to the existing safeguards listed in Figure 4, and any further regulatory measures that may be incorporated over time. We also notes that many of these safeguards currently exist to varying degrees, however there is little information and support available to connect participants to them, and opportunities to improve them.

The list of safeguards will also need to be informed by the work being progressed under the Safety Targeted Action Plan and National Disability Research Partnership.

### General safeguards

General safeguards that should be developed and/or improved include:

### Capacity-building and strengthening natural safeguards

Examples of supports that could build capacity and natural safeguards for participants include:

- Accessible informational supports. For example:
  - The NDIS Commission could co-design with participants, families and carers a revised Participant Information Pack that provides information with the goal of building capacity to manage risk.<sup>46</sup> This could cover topics such as participant rights in the NDIS; how NDIS supports, providers and workers are regulated, and what this means for participants; what to expect from providers, workers and intermediaries (such as support coordinators and plan managers); how to raise concerns and make complaints; how to access advocacy support; and how to access and use the Disability Gateway and Carer Gateway. The NDIS Commission and NDIA could then work together to ensure that every participant is provided with the information pack, and has the opportunity to ask questions or seek independent support to review the information and make decisions about safeguards.
  - Building on recent initiatives such as the Make It Known, Make It Better and Speak
     Up campaigns, the NDIS Commission could co-design other media with

participants, such as scenario-based videos or theatre, that explore risk and safeguarding concepts, which participants could mirror in their lives.

- Connection to Disability Representative Organisations that operate capacity-building programs for people with disability.
- Assistance to build community connections. For example, connection to:
  - Organisations offering support to build social connections and community through initiatives like Circles of Support, Community Circles and Microboards;
  - Peer networks (both in-person and online), that offer shared discussion and mutual support, that the participant, their family and carers might be interested in connecting with; and
  - Social and community activities running in the participant's area (such as sports or clubs), including support to access mainstream rather than disability-specific programs where the participant wishes to do so.

Further work may be required to ensure these types of supports are available in the market for participants to access, including considering workforce capacity.

# **Question for consultation**

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

# Support for decision-making

The NDIA has recently developed a new <u>Supported Decision-Making policy</u> that sets the foundation for better supporting participants to make their own decisions wherever possible. This includes through funding reasonable and necessary decision-making supports in participants' plans.

Funding in plans and/or connections to a range of decision-making supports could be provided. Examples of decision-making supports that participants may consider accessing could include:

- Establishing a Circle of Support or Microboard (noting the broader informal support role that these types of supports can play in a participant's life).
- Training to build their capacity to make decisions about their NDIS supports and services.
- Access to communication supports such as Auslan interpreters or equipment and technology.
- Training for carers or family to build their skills around supporting participants to make their own decisions. This could include learning about how to support

participants in decision-making, or learning practical skills such as Auslan or other alternative methods of communication that would support them to communicate effectively with the participant.

- Trained facilitators or advocates to support them to be heard in decision-making processes.
- Life transition supports like mentoring, peer support or individual skill development.
- Support from intermediaries such as support coordinators (noting that it will also be important to build the capacity of support coordinators to act as decision-making supports).

Further work may be required to ensure these types of supports are available in the market for participants to access, including considering workforce capacity and best practice approaches.

We note that in addition to ensuring access to good options to support (rather than replace) participants in making their own decisions, there should also be efforts to simplify and streamline NDIS processes so that they are more straightforward, and the decisions participants need to make are clear and well-understood. Further, where substitute decision-making has been put in place, steps should be taken to ensure that the participant is still included in decisions made about them and that their will and preference is considered.

# **Question for consultation**

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

# Improving information sharing to identify risk

We think that greater information sharing between government agencies, (including with states and territories) is essential to improve responsiveness to participant needs and provide opportunities for agencies that oversee the NDIS to act when information might indicate a change in risk faced by a participant. Current barriers to better sharing information need to be unblocked, as a matter of high priority.

For example, this could include sharing information based on a change of circumstance or application for a crisis payment submitted to Services Australia, or reports from a state or territory Community Visitor Scheme, ombudsman, health or law enforcement agency. There would need to be strong protections in place to ensure privacy (for example participants consenting to information sharing and that information shared is used for safeguarding purposes only). Participant consent would need to be informed by clear advice and support to make an informed decision.

We have heard, on the one hand, that people with disability want their personal information shared only for the right reasons; and, on the other hand, that some key agencies may be taking an excessively cautious approach to sharing information that is compromising effective safeguarding. We are interested in views on the balance between privacy considerations and effective information sharing to promote safeguarding.

In addition, improvements to the business intelligence and feedback systems of the NDIS Commission and NDIA could support these agencies to identify issues early, engage with participants and apply safeguards as needed. This could include drawing on complaints and reportable incidents to identify risks at the individual and system level.

## **Question for consultation**

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

# Targeted safeguards

Targeted safeguards that should be developed and/or improved, to be used where participants need additional support, include:

## Funding for supports to safely implement plans

In situations where participants may face significant risks to their safety and need more than general support to recognise or respond, funding could be included in plans for:

- **Education on rights, risks and safety:** funding for courses and training that help a participant and their carer(s), family or supporters to understand and protect their rights and manage risks facing the participant.
- Tailored information resources: funding for specific resources to be co-developed with a participant to support a participant to communicate about safety issues.
   Examples of tailored information resources could include a range of media suited to the needs of the participant, including using language specific to the participant, or pictures for eye gaze or picture boards.

Further work may be required to ensure these types of supports are available in the market for participants to access.

#### Support and advice to navigate the system and support safeguarding

The support that participants need to navigate the NDIS and make their own decisions about their supports and services exists on a spectrum of intensity from the provision of information to support for decision-making to formal advocacy services, depending on

their circumstances. We see a need to ensure that participants whose circumstances necessitate it are able to access a range of more intensive advisory services to support safeguarding, particularly in navigating the system and implementing their plans. This type of support is likely to be especially relevant for participants who have limited or no access to family, friends and peers who can support them, and for participants living in certain settings such as supported accommodation. For such participants, access to advisory services could help them to navigate choices in service delivery to ensure their safety, or to resolve complex issues or complaints about service provision.

To some extent, advisory services are available for participants. For example:

- A participant's plan may provide funding for a support coordinator to undertake
  activities such as connecting the participant to NDIS and other supports, brokering
  supports and services in line with the participant's wishes, and building the
  participant's capacity.
- Outside of the NDIS, the Australian Government and some state and territory governments fund independent individual advocacy that participants may access.
   Existing advocacy programs like the National Disability Advocacy Program (NDAP) have been reported to improve choice and control for over 58% of people with disability who use them.<sup>47</sup>

We recognise that some participants would benefit from improved support in navigating choices and challenges in implementing their plans to ensure safeguarding. For example, this could include:

- Incorporating clearer and more explicit expectations for support coordinators to play a
  role in safeguarding participants who face more significant risks and who have more
  limited natural safeguards. This could be integrated with a broader focus on defining
  the role of intermediaries.
- Ensuring improved access to individual advocacy where it could assist participants in navigating choices and challenges, through referrals to advocacy services. This should be complemented by consideration of increased funding for the NDAP and state and territory advocacy programs.

It is important that these advisory services complement and incorporate any decisionmaking supports that the participant may need.

# **Question for consultation**

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?

#### Clear point of contact and warm referrals

Participants and their supporters need a clear point of contact to raise issues about safeguarding. This initial contact when a participant needs help is critical in supporting them to be safe. Participants and their supporters must have a clear understanding of who to contact with an issue, and the people responding need to have the skills and training to effectively triage issues and refer participants to the right places in a timely manner so they get the right help when they need it.

In addition, warm referrals could be offered at various points in the system (for example, during planning and in conversations about risk and safeguards), where a participant, their carer(s) or family indicates that they may feel hesitant to reach out to an organisation or program they would likely benefit from (for example, the NDIS Commission, Disability Gateway or Carer Gateway). A warm referral is where direct support is provided to connect a participant to the organisation or program (for example, sitting with them and exploring a website together, or making a phone call with or for the participant). In some cases, this practice already takes place between the NDIA and the NDIS Commission.

#### Rapid approval pathway for funding for temporary supports critical to safety

We think that there would be value in a rapid approval pathway for requests relating to supports needed to aid a participant's safeguarding in a temporary time of personal crisis such as the incapacitation of a primary carer or a situation involving family or domestic violence. This would involve both providing appropriate funding and working with the participant or their support coordinator (where applicable) to ensure they are appropriately supported to ensure their safety through the crisis period.

It would be important that this pathway is not solely reliant on participants or their supporters letting the NDIA know that they were in crisis. This could be supported by better information sharing between government agencies (including states and territories) to identify such circumstances and then active, timely outreach to participants and, where appropriate, plan nominees or other supporters.

We note that a rapid approval pathway may not be the appropriate approach in a time of community crisis, such as a natural disaster, where supports or services may not be available. A different approach wherein community disaster planning specifically includes

plans for meeting the support needs of people with disability is likely to be more effective in these circumstances.

#### **Outreach and visitation**

Many reviews and inquiries over the years have identified a need for more proactive safeguards in the NDIS, in particular improved outreach and visitation to participants at heightened risk of harm. This includes reports by <u>Westwood Spice in 2018</u>, the <u>2020 Robertson Review</u> and the <u>2021 Joint Standing Committee on the NDIS Inquiry into the NDIS Quality and Safeguards Commission</u>.

These reviews agree that Community Visitor Schemes (CVS) support people with disability to uphold their human rights, support them with decision-making, and work to address violence and abuse in higher risk settings like supported accommodation. This reflects their importance as a safeguard to people with disability.

These reviews have consistently called for a 'national' outreach and visitation function, but have reached different conclusions on whether that means:

- A nationally-consistent service offering delivered by the states and territories through reforms to existing CVS; or
- The standing up of an Australian Government outreach and visitation function, delivered by the NDIS Commission.

However, there has been minimal discussion of what the explicit role and responsibilities of any outreach and visitation function would be. In order to understand who could most effectively deliver an outreach and visitation function, it needs to be clear whether the intention is to:

- Supplement social capital and natural safeguards by providing avenues to check on and promote the wellbeing of participants; or
- Ensure providers and workers adhere to regulatory requirements and obligations.

We note that six states and territories already provide CVS that align with the former (to varying degrees), and that the NDIS Commission already has the power to visit NDIS providers and ensure they are adhering to their obligations, either with permission or under warrant.

Both functions are important, but there is value in the separation of them. For example, the Westwood Spice Review noted the independence of CVS from regulators and complaints resolution roles as valuable, allowing issues to be raised by someone who does not have a stake in maintaining a particular policy or regulatory approach.<sup>48</sup>

We consider that the role of any future outreach and visitation program should be focused on checking on and promoting the wellbeing of participants, particularly those with more limited personal and social capital and natural safeguards, and those in higher risk environments and circumstances such as people living in supported accommodation or living alone without good natural supports. This would be complemented by ongoing monitoring of provider compliance by the NDIS Commission.

We have formed the preliminary view that these outcomes are better delivered through improvements to CVS delivered by states and territories because:

- The CVS are an established function in six states and territories, with knowledge and connections that would be difficult to replicate.
- Current CVS can support participants with a range of issues, not just those related to the NDIS. Because CVS are not NDIS-specific, they are able to assist participants with issues that arise both within and outside of the NDIS system. For example, South Australia's CVS reported helping people with disability living in public housing with numerous housing maintenance issues, while the Australian Capital Territory's Official Visitors Scheme visits and monitors homelessness and prison services that may include NDIS participants.<sup>49</sup> In this way, CVS provide an important safeguard that complements those already offered by the NDIA and NDIS Commission by focusing on participant wellbeing. A Commission-based program risks focussing on NDIS-based problems and solutions, rather than picking up the 'multi-agency approach' that has been identified as a key strength of current CVS.<sup>50</sup>
- CVS do not only visit NDIS participants, and so would need to remain active regardless
  of whether any NDIS Commission-led function was established. Operating different
  CVS at different levels of government could lead to significant confusion, and leave
  gaps for people to fall through where another party is assumed to have oversight of an
  issue.
- The Westwood Spice Review highlighted the importance of the independence of CVS from regulators to ensure people can access support without any agenda or particular approach.<sup>51</sup>

We acknowledge, however, that reform of the state and territory CVS is vital to enhance the role that CVS can perform as a safeguard for NDIS participants (as well as people with disability more broadly) and to better integrate CVS into the NDIS. Any reforms must be co-designed with people with disability who would be likely to be engaged with visitation and outreach services. Some examples of reform that we consider would need to happen include reforms to:

- Allow state and territory CVS to visit any site where NDIS-funded services are provided, including accommodation for people with disability. Consideration could be given to visiting participants in private homes or where they live alone (see below).
- Ensure that the focus of the CVS is on visiting participants to ensure their welfare and promote their rights, not on a provider's compliance with requirements.
- Formalise and enhance the role of CVS in helping participants to develop capacity to raise issues and manage risks themselves.
- Enhance information sharing with the NDIA and NDIS Commission, including warm referrals from the NDIA during the planning process where direct outreach would be helpful, and considering opportunities to improve CVS visibility of the status of previously reported issues and their resolution.
- Ensure that CVS have strategies for ensuring outreach can be regularly undertaken, in a culturally safe way, in First Nations, CALD and remote communities where disability services are provided.
- Evaluate the strengths and weaknesses of the existing CVS models and develop a
  national community of practice to promote best practice approaches to CVS, which
  could support greater national consistency over time. This could consider issues like
  training, reporting and whether existing volunteer CVS programs should be
  professionalised. Greater national consistency in legislative settings, approaches and
  coverage across all states and territories would support participants to have
  confidence that this safeguard is available if needed, regardless of where they live.

It is also important to note that outreach and visitation does not operate in a vacuum. Other safeguards like capacity building, advocacy and supported decision-making will complement outreach and visitation functions so that the issues participants face can be picked up and addressed in a variety of ways.

# Visits to private homes

Some have suggested giving CVS the ability to visit private homes where disability services are provided, to provide outreach and support to participants in these circumstances. We recognise the human rights concerns associated with this, but also recognises potential value in outreach with participants at home.

We would like to hear participants' views on this matter, noting that any reforms to outreach and visitation in the NDIS would need to be further co-designed with people with disability who would be likely to be engaged with these services.

We are also interested in views on possible options for these circumstances, such as allowing state and territory CVS to be able to visit private homes and undertake other forms of outreach with participants (e.g. calls rather than visits) where this is essential to safeguarding the participant. Allowing for participant choice is critical, with a key issue being whether this is based on participants opting into or opting out of receiving visits.

# **Questions for consultation**

- 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?
- 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?

# Glossary

Term	<b>Definition</b>
Choice and control	A participant has the right to make their own decisions about what is important to them and to decide how they would like to receive their supports and who from. <sup>52</sup>
Dignity of risk	Supporting people to take informed risks to improve the quality of their lives. This means rather than seeking to eliminate all risk – which can be highly restrictive and out of proportion to the level of risk involved – the NDIS should work with participants to define acceptable risk levels to achieve their goals. <sup>53</sup>
Formal safeguards	Rules and the actions that are taken by organisations with formal responsibility for the safety of people with disability.
Knowledge capital	A person's skills and ability to use knowledge for actions (e.g. access to information). <sup>54</sup>
Material capital	Resources and material goods (e.g. income, community resources) in a person's life. <sup>55</sup>
Natural safeguards	Actions and features that are part of people's day-to-day lives and support them to manage their safety (also called informal safeguards).
Participant	A person who meets the NDIS access requirements. <sup>56</sup>
Person with disability	A person who has any or all of the following: impairments, activity limitations (difficulties in carrying out usual age-appropriate activities), and participation restrictions (problems a person may have taking part in community, social and family life). <sup>57</sup>
Participant capital	A way of conceptualising the personal resources available to a participant to support them to advocate for their rights, adapted from Williams' Model of Citizenhood Support.
Personal capital	A person's personal resources, strength and resilience to represent themselves (e.g. ability to self-advocate). <sup>58</sup>
Safeguards	Actions designed to protect the rights of people to be safe from the risk of harm, abuse and neglect, while maximising the choice and control they have over their lives. <sup>59</sup>

Term	Definition
Safety	Safety typically means being free from injury or danger. <sup>60</sup> It does not matter if the injury of danger is intentional (on purpose) or unintentional (by accident).
Social capital	A person's relationships and connections (e.g. family, friends, community). <sup>61</sup>

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