

A voice of our own

Safeguarding the Future

Submission to the NDIS Quality and Safeguarding Framework Issues Paper

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Safeguarding the Future: Submission to the NDIS Quality and Safeguarding Framework Issues Paper

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About PWDA

<u>People with Disability Australia</u> (PWDA) is a national disability rights and advocacy organisation made up of, and led by, people with disability.

The disability representative organisation has a vision of a socially just, accessible and inclusive community in which the contribution, potential and diversity of people with disability are not only recognised and respected but also celebrated.

PWDA was established in 1981, during the <u>International Year of Disabled Persons</u>. It is a peak, non-profit, non-government organisation that represents the interests of people with all kinds of disability.

The organisation of people with disability helps represent the Australian disability community at the <u>United Nations</u>, particularly in relation to the international human rights outlined in the Convention on the Rights of Persons with Disabilitiesⁱ (CRPD).

PWDA's work is grounded in a human rights framework that recognises the CRPD and related mechanisms as fundamental tools for advancing the rights of people with disability.

The disabled people's organisation (DPO) is a member of <u>Disabled People's</u>

<u>Organisations Australia</u> (DPO Australia), along with the <u>First People's Disability Network</u>,

National Ethnic Disability Alliance and Women with Disabilities Australia.

As a DPO, PWDA collectively forms a disability rights movement that places people with disability at the centre of decision-making about all aspects of their lives. This in keeping with the human rights of people with disability to be involved with legislation, policies and other issues relating to them through representative organisations, and right to equal recognition before the law, under articles 4(3) and 12 of the CRPD.

PWDA's work also embraces the <u>Nothing About Us</u>, <u>Without Us</u> motto of members of the international disability community, prioritising inclusion and respect for people's right to legal capacity.



Introduction

People with Disability Australia (PWDA) welcomes this opportunity to comment on the NDIS Quality and Safeguarding Framework Issues Paperⁱⁱ

From March to May 2023, PWDA conducted consultations with people with disability on their experiences of the National Disability Insurance Scheme (NDIS). This involved several focus groups, interviews and online surveys (including an easy read version) which received over 800 responses. The findings from these consultations, as well as feedback from PWDA Individual Advocacy and Policy functions have provided valuable direction and evidence for the development of this submission to the NDIS Review of the NDIS Quality and Safeguarding Framework (the Framework).

In responding to the Issues Paper, PWDA has been careful to distinguish between the roles of the NDIS Quality and Safeguards Commission (the NDIS Commission) and the National Disability Insurance Agency (NDIA). It was clear from the PWDA consultations that many participants, supporters, potential participants and people with disability did not understand the different roles. They told us they found the NDIS system confusing and were anxious about using it.

This brings into sharp focus the importance of capacity building, decision-making supports, accessible information, individual advocacy and national consistency for people with disability to make choices and to exercise control regarding the NDIS and other supports.

Similarly, NDIS supports and effective safeguards need to continually respond to the changing needs and expectations of people with disability. But quality and safeguards should not be limited only to NDIS participants, and the benefits of improvements under the Framework should be extended to other people with disability who use non-NDIS supports.

Accordingly, PWDA has proposed a range of detailed recommendations that will maximise the reach and effectiveness of the NDIS Quality and Safeguards Framework. The submission's headings have been drawn directly from the Issues Paper questions.



PWDA notes that every aspect of using the NDIS for participants can have implications for participant safety and the quality of supports and services provided. However, this PWDA submission has focussed on issues relating to the Framework. Feedback on other issues of participant safeguarding will be furnished in our response to the NDIS Participant Safeguarding Proposals Paper iii in June 2023.



Summary of Recommendations

Recommendation 1 – In order to reduce risks and improve quality supports, the Framework must require and enable national consistency in the following areas:

- 1. authorisation and reporting processes for restrictive practices
- 2. the provision and operation of Community Visitors Schemes across Australia
- 3. information exchange between the NDIS Commission and relevant State and Territory government authorities, and Community Visitors Schemes
- 4. the availability of individual advocacy to support participants and people with disability.

Recommendation 2 – The implementation of Developmental domain strategies and associated training must include the involvement of people with disability at every stage. Developmental strategies must be delivered on an ongoing and regular basis and must include, at least:

- capacity building strategies for participants
- fostering natural safeguards and personal networks
- the provision of comprehensive, plain language, accessible-format explanatory information that is widely available and promoted to participants and their supporters.

Recommendation 3 – The implementation of Developmental domain strategies must be sufficiently resourced so that the strategies can be delivered on a regular and ongoing basis.

Recommendation 4 – Adequate ongoing funding and resources must be provided for individual advocacy to ensure that advocates are available by phone, online or in-person to participants and anyone needing expert advice and assistance to exercise disability rights regardless of their location or mode of communication. This will support people with



disability to navigate and access NDIS and related service systems as well as disability support services and other mainstream services (i.e. non-disability services used by the general public) when required.

Recommendation 5 – Adequate ongoing funding and resources must be provided for the provision of decision-supports to people with disability, including NDIS participants. These decision supports should be provided by organisations that do not also provide direct services to people with disability.

Recommendation 6 – Appropriate increased and ongoing funding must be provided to expand the number of intermediaries and to provide appropriate training.

Recommendation 7 – Without diverting essential resources for Participant NDIS Plans, the Framework should ensure that the NDIS Commission receives increased funding to adequately respond to a growing number of participants joining the NDIS, an escalating provider market, and to collaborate with other related regulatory authorities.

Recommendation 8 – As a fundamental function of NDIS and disability monitoring, the Framework must ensure that Community Visitors Schemes:

- are recognised as an essential monitoring strategy
- are nationally consistent
- are funded to operate in every state and territory of Australia
- receive increased funding to deliver regular visits to an expanded range of visitable services.

Recommendation 9 – It is essential that the Framework acknowledges that mainstream providers must remain an important and available choice for people with disability. Improvements to risk assessment and safeguards must not discourage or prevent mainstream providers from engaging with the NDIS and participants.

Recommendation 10 – Disability Representatives Organisations (DROs) should be appropriately resourced to provide systemic responses, to predict issues and preventable



problems, to raise awareness about systemic and individual gaps, to make connections with non-disability service systems, to advise on policy developments within the disability sector and outside it, to suggest innovation, to ensure the exercise the rights of participants and people with disability outside the NDIS, and to advance the inclusion of people with disability.

Recommendation 11 – The Framework must explicitly require the NDIS Commission to incorporate the genuine involvement and guidance of people with disability in its role, policies, operations and implementation strategies. The best, most effective and efficient way to advance inclusion, develop responsive strategies and promote quality for people with disability with diverse backgrounds and personal circumstances is to involve them in the NDIS Commission's strategy development and implementation.

Recommendation 12 – The Framework should be redesigned to clarify how the Information, Linkages and Capacity Building (ILC) program can provide supports to the people with disability who are not NDIS participants. This redesign should be co-designed with people with disability.

Recommendation 13 – The availability of intermediaries should be expanded for participants who require assistance to find appropriate supports and to implement their NDIS Plans. This expansion must increase the Information, Linkages and Capacity Building program to support other people with disability to access mainstream providers and services in the local community. This will require additional resources and should not come at the cost of existing supports or programs.

Recommendation 14 – To avoid a conflict of interest, the Framework should explicitly require that providers of intermediaries must not also be providers of direct services and supports.

Recommendation 15 – The Framework should require providers to report to the NDIS Commission and other regulatory authorities on any significant changes that could adversely impact the supports, health and wellbeing of each participant or person with disability.



Recommendation 16 – The Framework should include information about how it directs the role and functions of the NDIS Commission. The NDIS Commission should be required to conduct regular reviews on the implementation of the Framework and to publish the review reports.

Recommendation 17 – Under the Framework, the NDIS Commission must be required to publish clear accessible explanatory information that is widely available and promoted to participants and their supporters about the NDIS Commission's role, how to use it or what issues can be raised by whom. Regarding the quality of services, explanatory information must be available to participants about what standard of service a participant can expect, how to raise issues or complain about quality, what issues can be raised, who can raise them, and what happens next.

Recommendation 18 – The NDIS Commission should publish an annual report on actions to reduce restrictive practices across all States and Territories. This information must guide the development of bespoke supports that offer alternatives to restrictive practices for participants and therefore support the goal of reducing and ultimately eliminating the use of restrictive practices for people with disability.

Recommendation 19 – To reduce risks, the Framework must facilitate the coordination and alignment of the powers and practices of all related regulatory bodies and government authorities that can affect the lives of people with disability across Australia.



1. What is working well

Feedback from the PWDA's NDIS Review Survey indicated that many respondents were able to rely on the NDIS for access to the community, to increase independence and for necessary equipment and supports, in ways that were not available to them before the NDIS. Respondents also noted increased choice related to supports as a positive.

PWDA finds the six overall objectives (upholding rights, informed decision-making, personcentred outcomes, safe and fit-for-purpose supports, freedom from abuse, violence, neglect and exploitation and effective monitoring and responses to issues) of the Framework to be sound and worthwhile.

PWDA supports the five principles underpinning the Framework (a human rights approach, choice and control, national consistency, proportionality and risk responsiveness, and efficiency and effectiveness) but recognises that the way in which the principles are implemented requires continuing work and development.

2. What is not working well

PWDA has summarised what still needs improvement and development under the five principles that underpin the Framework. Further detail on improvements and developments is presented under subsequent questions.

2.1 Human rights

While the Framework mentions all people with disability, it focusses on people with disability who are eligible for and use the NDIS, and others who may require extra supports.

The Framework does not clearly acknowledge that a NDIS participant will engage with a range of systems in their daily life outside the NDIS which could require NDIS supports to access and use.



Accordingly, it is critical for the Framework to align and coordinate with other systems and regulatory bodies that are part of the everyday life of people with disability.

2.2 Choice and control and the presumption of capacity

The terms *Choice* and *Control* are separate concepts and have different meanings. The difference between these concepts is not well understood or articulated in the Framework.

PWDA asserts that *Choice* is a decision after the options are presented. No choice can be made in the absence of information about options.

Control is customising the chosen option to respond to the person's individual needs and circumstances. The exercise of control should not be assumed. Participants may have differing readiness, capacity, ability and sometimes willingness to exercise control. This is the same for people without disability in the general community.

In order to improve person-centred *choice* in services and supports, the NDIS moved from grants-based service delivery, where contracts are between government and providers, to consumer-driven market-based supports in which people with disability hold contracts with providers. There has been inadequate information and assistance for people with disability to understand this fundamental change.

2.3 Presumption of capacity

It is important that the *presumption of capacity* of people with disability to make decisions remains an essential principle of the NDIS. However, a participant's ability to exercise choice and to have control can be limited by the understanding and judgement of the NDIS official, worker or provider they deal with. Consequences for the participant can be further aggravated by imposing excessive workloads on NDIS officials and workers, as well as delivering inadequate training on choice and control.



2.4 Supports for decision-making

The provision of decision-making supports to people with disability has been slow to roll out. Measures for people with disability and their supporters to increase their own skills in decision-making are yet to be implemented in any widely publicised and generally known way.

People with disability have differing needs for decision supports, depending on several factors including:

- impacts of the disability
- environment
- background
- lived experiences
- willingness to participate.

As the Issues Paper acknowledges, the provision of individual advocacy is fundamental to assist people to exercise their rights and the expectations of the NDIS (Please see Recommendation 4 and 5).

2.5 National consistency

The Framework works to provide national consistency, but participants continue to have different experiences depending on their circumstances. The provision of quality and safety measures must consistently respond to the individual participant regardless of disability, age, location, identity, background, language, heritage, and personal preferences.

Recommendation 1 – In order to reduce risks and improve quality supports, the Framework must require and enable national consistency in the following areas:

authorisation and reporting processes for restrictive practices



- the provision and operation of Community Visitors Schemes across Australia
- information exchange between the NDIS Commission and relevant State and Territory government authorities, and Community Visitors Schemes
- the availability of individual advocacy to support participants and people with disability.

There must be no loss of standards to any safeguarding measures when working towards national consistency. Actions to achieve national consistency must build on the best possible features of all related programs.

For further explanation on each of these areas please refer to later sections in this Submission.

2.6 When risks change

The Framework should enable nimble responses when there are changes in circumstances or temporary crises that increase the risks for participants, including when:

- participants have an illness or significant health condition
- the impact of the disability intensifies
- people age (as for the general population)
- families are no longer able or willing to support the participant
- there is a crisis in the person's inner personal network.

NDIS safeguarding strategies should respond to the above changes and circumstances from a person-centred, strengths-based approach according to the choices, needs, rights and interests of the participant.

The success of a participant's approved NDIS plan depends on the skill of their Local Area Coordinator (LAC) or NDIS Planner. This presents a real risk for participants without appropriate information and those with no capacity to act.



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2.7 Strengthening development

The Framework sets out the three domains - Developmental, Preventative and Corrective - that describe quality and safeguarding measures for NDIS participants, workers and providers. To date, the NDIS Commission has heavily focussed on implementing measures in the Preventative and Corrective domains, with less attention on Developmental strategies. The Issues Paper describes the Development domain as including 'developmental safeguards such as capacity building initiatives, the development of natural safeguards, and the provision of comprehensive consumer information.'

The Issues Paper also says Developmental measures are designed:

'to strengthen the capability of people with disability, workers and providers' ... 'because they are fundamental to quality and safeguarding.'

PWDA recommends an amplified focus on implementing the Developmental domain, including deliberate resourcing and sustained opportunities for:

- capacity building strategies for participants, including, but not limited to, selfadvocacy and peer support
- promotion and development of natural safeguards and personal networks
- comprehensive, plain language, accessible-format consumer information, including NDIS system navigation tools, for participants and their supporters, available in plain English and other languages, and widely publicised among people with disability.

At a minimum, the successful implementation of the Developmental domain will necessarily involve a range of ongoing information, decision-support and training strategies.

For participants these can include:

self-advocacy



decision-making skills and supported decision-making.

For NDIS staff, providers and workers:

- understanding and facilitating how to support a participant's decisions for providers
- communication of, and understanding disability for, NDIS Commission staff
- disability awareness and disability-specific communication for staff in other regulatory bodies and for staff of other providers.

People with disability must be consulted and involved in designing, establishing and delivering these and other Developmental strategies, as well as in associated training strategies, to maximise relevance and appropriateness.

Recommendation 2 – The implementation of Developmental domain strategies and associated training must include the involvement of people with disability at every stage. Developmental strategies must be delivered on an ongoing and regular basis and must include, at least:

- capacity building strategies for participants
- the fostering of natural safeguards and personal networks
- the provision of comprehensive, plain language, accessible-format explanatory information that is widely available and promoted to participants and their supporters.

Recommendation 3 – The implementation of Developmental domain strategies must be sufficiently resourced so that the strategies can be delivered on a regular and ongoing basis.

2.8 Promoting quality

The Framework contains extensive information about the safety of participants but does not equally set out directions and expectations about quality. It cannot be assumed that



the provision of safety necessarily indicates quality, especially in supports for people with disability. The Framework should require the promotion and publicising of quality supports to providers and participants, including what good quality looks like and the expectations of quality by regulators.

PWDA is concerned that providers widely assume that minimum standards are all that is needed. The Framework should require providers to demonstrate continuous improvement strategies, as a measure of progress on quality.

3. The need for a Framework

The NDIS Quality and Safeguarding Framework is designed to ensure high quality supports and safe environments for all NDIS participants^{iv}. PWDA considers that high quality supports and safe environments constitute an important role and an ongoing obligation for the Framework.

PWDA remains committed to the continuation of the Framework and its stated purposes regarding the rights of people with disability, the market-based provider system for consumer choice, improving consistency, effective monitoring and responses.

3.1 An ongoing Framework

The Framework should direct and guide actions of providers and government in improving quality. It should also ensure that the whole NDIS system provides safeguards and protections and promotes safety in provision of supports and information.

Consistency is important to the provision and improvement of both safeguarding and quality. Respondents to the PWDA NDIS Review Survey have noted that the frequent turnover of Local Area Coordinators (LACs) and NDIS officers has an adverse impact on the approval and monitoring of NDIS Plans as well as the engagement and confidence of participants and supporters in the NDIS.



The issue of inadequate resourcing necessarily impacts the effectiveness of the Framework. In addition to the provision of appropriate funding to support the implementation of the Developmental domain, it is critical that appropriate resources are allocated to support other elements identified in the Framework. Adequate resourcing must be available for:

- individual advocacy to support participants and people with disability at critical times
 where safety and quality of supports is at issue
- decision-supports for people with disability, including in relation to dealings with
 public guardians and trustees in each state and territory (the provision of decisionsupports is a separate function and should be delivered by organisations that do not
 provide direct services. Decision supports must be made available to people with
 disability who are not NDIS participants.)
- expansion and capacity building of intermediaries
 - expansion: to provide more access to intermediaries for participants who need them
 - capacity building: intermediaries must be appropriately trained to deliver the required supports to participants
- the NDIS Commission to capably undertake its functions.

Recommendation 4 – Adequate ongoing funding and resources must be provided for individual advocacy to ensure that advocates are available by phone, online or in-person to participants and anyone needing expert advice and assistance to exercise their rights regardless of their location or mode of communication. This will support people with disability to navigate and access NDIS and related service systems as well as disability support services and other mainstream services (i.e. non-disability services used by the general public) when required.

Recommendation 5 – Adequate ongoing funding and resources must be provided for the provision of decision-supports to people with disability including NDIS participants. These



decision supports should be provided by organisations that do not also provide direct services to people with disability.

Recommendation 6 – Appropriate increased and ongoing funding must be provided to expand the number of intermediaries and to provide appropriate training.

Recommendation 7 – Without diverting essential resources for Participant NDIS Plans, the Framework should ensure that the NDIS Commission receives increased funding to adequately respond to a growing number of participants joining the NDIS, an escalating provider market, and to collaborate with other related regulatory authorities.

3.2 What monitoring is required?

Community Visitors

Community Visitors are fundamental to monitoring services. PWDA notes there are many versions of Community Visitors Schemes across Australia, with differing powers to access and report, differing mandatory obligations and responsibilities, differing visitable services, differing lines of authority, and differing types of employment – some paid, some volunteers.

A nationally consistent Community Visitors Scheme across Australia will support the more effective implementation of the Framework by removing the sole reliance on complaints to raise participant concerns, by undertaking independent monitoring of quality and by reporting on trends in safety and quality supports to participants. Community Visitors Schemes can improve transparency and become nationally consistent by encapsulating the optimum features of each of the existing schemes, aligning lines of authority and reporting, expanding their scope and coverage to address a growing provider sector with increasing variety of services.



Community Visitors must be independent from related government agencies and service providers and have the ability to:

- receive referrals
- enter visitable services without provider permission or consent
- visit all disability services, regardless of funding source, where there is a significant, actual or perceived risk of harm to the people with disability using them
- make observations
- speak with participants who are happy to chat, while maintaining confidentiality
- make confidential reports
- transfer information to other regulatory and safeguarding agencies, where necessary
- be protected from prosecution or other legal action by visited services or others on matters arising from their reports
- be appropriately paid for their work and appropriately trained.

Sufficient Community Visitors must be employed to enable them to make regular announced and unannounced visits to services, and to make return visits as necessary.

Community Visitors must be enabled to provide necessary information to regulatory bodies without process delays or overly bureaucratic paperwork.

Community Visitors Schemes should prioritise their monitoring, outreach and visitation to:

- services to people in higher risk categories such as people with no significant personal relationships/supporters
- people in segregated settings such as supported accommodation, residential services and Australian Disability Enterprises



- people with complex support needs
- people who use only one worker and/or provider
- people with an insecure financial status
- people in insecure housing
- people who request a visit from Community Visitors.

Recommendation 8 – As a fundamental function of NDIS and disability monitoring, the Framework must ensure that Community Visitors Schemes:

- are recognised as an essential monitoring strategy
- are nationally consistent
- are funded to operate in every state and territory of Australia
- receive increased funding to deliver regular visits to an expanded range of visitable services.

4. Framework coverage

The Issues Paper listed roles and responsibilities under the NDIS Quality and Safeguarding Framework for individuals i.e. NDIS participants; providers, intermediaries and workers; natural supports; Department of Social Services; NDIA; NDIS Commission; State and territory governments. PWDA agrees.

Further, the Framework identifies roles and responsibilities for several other actors including people who are not eligible for the NDIS but who require supports in their daily life.

Specific consideration and flexibility should be given to people with disability outside the NDIS who require access to safeguards that respond to their needs. This could involve better coordination of and information on the various roles of regulatory authorities in the



safeguarding system, shared responsibility for safeguards, better information to both providers and people with disability, and importantly, increased access to individual advocacy.

The Framework acknowledges that there has been very little attention to people with disability who are not eligible for the NDIS but may require some supports, formerly known as Tier 2. The <u>Information Linkages and Capacity Building (ILC) program</u> was designed to provide a level of support to people with disability not eligible for the NDIS. The NDIS ILC Policy Framework explains:

"ILC will also ensure the NDIS establishes and facilitates capacity building supports for people with disability, their families, and carers that are **not** directly tied to a person through an individually funded package (IFP)."

The Framework must adhere to the original design intentions of the ILC by enabling Local Area Coordinators to promote inclusion and support people with disability who do not use the NDIS. Local Area Coordinators must be available to make connections in the community, to strengthen personal networks, to make referrals that will benefit people with disability, and to provide appropriate information and support for access to mainstream and community services and activities.

Further, successful and effective projects that were funded and initiated under the ILC must be made ongoing and expanded to support people with disability and their supporters, and to be available wherever there is a need.

Additionally, the Framework should provide information on other roles including:

- non-NDIS disability providers
- mainstream providers (e.g. gyms) must remain an important and available choice for people with disability. Improvements to risk assessment and safeguards must not discourage or prevent mainstream providers from engaging with the NDIS and participants



 Disability Representatives Organisations DROs as are critical to providing systemic responses, to predicting issues and preventable problems, to raising awareness about systemic and individual gaps, to making connections with non-disability service systems, to advising on policy developments within the disability sector and outside it, to suggesting innovation, to ensuring the exercise the rights of participants and people with disability outside the NDIS, and to advancing the inclusion of people with disability. Each of these DRO functions is essential to enabling participant capacity building and to promoting natural safeguards.

Finally, both individual and systemic advocacy have an important role to play to ensure people with disability have access to support – including but not limited to the NDIS. For example, both types of advocacy work to ensure that NDIS participants' supports can be safeguarded against systemic exploitation by other agencies that are obliged to provide universal services regardless of disability, e.g. Health, Education etc. The failure of other government systems to properly support people with disability can lead to an increased need for individual and systemic advocacy, and paid supports.

Recommendation 9 – It is essential that the Framework acknowledges that mainstream providers must remain an important and available choice for people with disability. Improvements to risk assessment and safeguards must not discourage or prevent mainstream providers from engaging with the NDIS and participants.

Recommendation 10 – Disability Representatives Organisations DROs should be appropriately resourced in an ongoing way to provide systemic responses, to predict issues and preventable problems, to raise awareness about systemic and individual gaps, to make connections with non-disability service systems, to advise on policy developments within the disability sector and outside it, to suggest innovation, to ensure the exercise of rights of participants and people with disability outside the NDIS, and to advance the inclusion of people with disability.



4.1 Advancing inclusion

The Framework must expand the provision of tailored strategies for safeguards and quality for the following cohorts of NDIS participants and people with disability:

- First Nations people with disability and their supporters
- People with disability and their supporters from culturally and linguistically diverse backgrounds
- People who identify as LGBTQIA+
- People with disability experiencing homelessness
- People with access to few or only one provider i.e. in thin markets
- People with disability with high, complex and multiple support needs
- People with disability in financial distress
- People with disability with no significant or supportive personal relationships or social networks
- People living in rural, remote and isolated locations and situations.

PWDA notes that many people with disability in any one of these groups can also share the characteristics and circumstances of one or more of the other groups at the same time.

Recommendation 11 – Overall, participants who did not have access to the NDIS or did not have access yet wanted to have access, the primary barriers to access related to support documentation. Participating experienced being unable to get supporting documentation due to financial unviability, due to not having a formal diagnosis, or the access process being inaccessible in various ways (fatiguing, difficult to understand, or a lack of provision of preferred formats for information).



The Framework must explicitly require the NDIS Commission to incorporate the genuine involvement and guidance of people with disability in its role, policies, operations and implementation strategies. The best, most effective and efficient way to advance inclusion, develop responsive strategies and promote quality and safeguards for people with disability with diverse backgrounds and personal circumstances is to involve them in the NDIS Commission's strategy development and implementation.

5. Roles and responsibilities

The Framework must explicitly acknowledge that the primary relationship and contact regarding the NDIS is directly with the person with disability themselves.

5.1 Supporters and personal networks

In respecting the primacy of the person with disability, the Framework can also acknowledge the important roles of non-government actors, especially participants' supporters, including spouses and family, friends and personal networks. However, the Framework must be cautious to ensure the person with disability remains at the centre.

The Issues Paper describes the development of several focus groups, including a focus group for supporters. PWDA advises that the NDIS should never automatically default to supporters about arising issues and must always approach the person with disability first.

Further, The Framework must ensure that the described roles of supporters do not create a mandatory expectation or obligation that can result in incorrect assumptions by NDIS planners when approving participants' NDIS Plans. These assumptions could mean that people with disability risk not receiving the NDIS supports they need if Planners assume that supporters will provide them.

PWDA makes the following comments on these roles as discussed in the Issues Paper.



5.2 Intermediaries

The Issues Paper describes Intermediaries as plan managers, support coordinators and Local Area Coordinators. PWDA considers these roles as essential to enable participants to understand the choices and decisions available to them under the NDIS, to navigate the NDIS system, and to implement their NDIS plan. Structurally, intermediaries may not be available to all participants requiring or requesting them. PWDA contends that:

- the roles of intermediaries are designed to provide critical advice and information to participants. The Framework should better explain the roles of the various intermediaries and how participants can use their supports.
- Local Area Coordinators (LACs) were intended to be a resource to people with
 disability without access to the NDIS. LACs could connect people with disability with
 mainstream and other supports as well as to foster inclusion in the local community.
 The Framework should be redesigned to clarify how the Information, Linkages and
 Capacity Building (ILC) program can provide these supports to the people with
 disability who need them. This redesign should be co-designed with people with
 disability.
- availability of intermediaries should be expanded for participants who require
 assistance to find appropriate supports and to implement their NDIS Plans. This
 expansion must also include support for other people with disability to access
 mainstream providers and services in the local community. Additional resources
 must be provided to increase the availability of intermediaries to participants and
 people with disability.
- To avoid any conflict of interest, there must be a clear-cut separation between providers assisting with participant choices/decisions, and providers of direct services and supports. This means that support coordination, plan managers, Local Area Coordinators and advocates etc. must not be part of an organisation that also provides direct service supports.



- Intermediaries have the same responsibilities to identify risk and to monitor safeguards as any other worker in the NDIS. However, intermediaries should have a greater role in building the capacity of participants to identify and manage risk in the following ways:
 - o providing information, education and advice
 - supporting people to access capacity building initiatives
 - reporting excessive and/or unauthorised use of restrictive practices
 - assisting participants to access specific safety and risk resources and supports, including <u>Person-Centred Emergency Preparedness^{vi}</u> and Domestic and Family Violence information and referrals when necessary.
 Refer to Appendix for more information on domestic and family violence.

Intermediaries must provide information to assist participants to make informed decisions about contracting service providers. This includes what participants need to know about engaging the following for their NDIS supports:

- registered providers
- unregistered providers
- mainstream providers
- workers directly engaged by participants and their supporters.

Recommendation 12 – The Framework should be redesigned to clarify how the Information, Linkages and Capacity Building (ILC) program can provide supports to people with disability who are not NDIS participants. This redesign should be co-designed with people with disability.

Recommendation 13 – The availability of intermediaries should be expanded for participants who require assistance to find appropriate supports and to implement their NDIS Plans. This expansion must increase the Information, Linkages and Capacity



Building program to support other people with disability to access mainstream providers and services in the local community. This will require additional resources and should not come at the cost of existing supports or programs.

Recommendation 14 – To avoid a conflict of interest, the Framework should explicitly require that providers of intermediaries must not also be providers of direct supports.

5.3 Providers

To ensure high quality supports and safe environments for participants, PWDA considers the Framework should expand on the roles and responsibilities it contains.

The Framework must direct providers to

- discuss their concerns about risks and proposed risk management strategies with participants whenever it is relevant and pertinent
- report any significant changes that could adversely impact the supports, health and wellbeing of participants to the NDIS Commission and other regulatory authorities
- report any significant risks that could impact a person or people not using the NDIS who need additional supports.

Recommendation 15 – The Framework should require providers to report to the NDIS Commission and other regulatory authorities on any significant changes that could adversely impact the supports, health and wellbeing of each participant or person with disability.

5.4 NDIS Commission

In addition to describing the roles of the Complaints Commissioner, the Senior Practitioner and the Registrar, the Framework should explicitly encompass the role of the NDIS Commission as a statutory body.



The NDIS Commission is necessary for national consistency. However, some aspects of its coverage and implementation require improvement:

- It is unclear how the Framework directs the role and operations of the NDIS Quality and Safeguards Commission and conversely, how the work of the NDIS Commission relates to features in the Framework. The NDIS Commission should be required to conduct regular published reviews on the implementation of the Framework.
- The role of the NDIS Commission is not well understood by participants and others,
 nor is it widely promoted throughout the disability sector.
- Most providers understand the NDIS Commission's role in provider registration and the regulation of NDIS supports. PWDA is concerned that providers may not fully comprehend the role of the NDIS Commission in complaints by participants, nor do providers appropriately refer participants to the NDIS Commission.
- In order that participants can have confidence in the availability and use of safeguards, the NDIS Commission should coordinate more effectively with other regulatory authorities that provide safeguards in the lives of the community and people with disability. This will also involve more effective and streamlined information sharing between authorities.
- The NDIS Commission can receive complaints about registered and unregistered providers. While not duplicating standards and complaints requirements, the Framework should enable the NDIS Commission to have improved visibility of unregistered disability providers. As a first step, PWDA suggests that the NDIA could provide to the NDIS Commission with the details of unregistered providers that submit invoices for services to agency-managed participants. However, this improved visibility must not involve any disincentives or barriers for unregistered providers to support NDIS participants who choose to use them.
- The NDIS Commission must not rely only on provider regulatory reports and/or complaints from participants or others. The NDIS Commission should be required to



- coordinate with Community Visitors Schemes as an essential monitoring strategy, critical to ongoing safeguards and quality.
- Non-NDIS regulatory authorities are important to NDIS participants who choose services and supports from mainstream providers. The NDIS Commission should better coordinate with non-NDIS regulatory authorities, including Australian Competition and Consumer Commission, Aged Care Quality and Safety Commission as well as related state and territory agencies e.g. Health Care Complaints Commission in NSW. Improved coordination will involve sharing information where appropriate, to streamline safeguarding responses for participants who have experienced harm or unacceptable services.
- There is little or no clear explanatory information that is widely available and
 promoted to participants and their families about how to use the NDIS Commission
 or what issues can be raised by whom. This also ties into the promotion of quality
 and the provision of explanatory information about what standard of service a
 participant can expect, how to complain or raise issues, what issues can be raised,
 who can raise them, what happens next.
- The Framework should enable the NDIS Commission to have a role in relation to
 people with disability outside the NDIS who require access to safeguards that
 respond to their needs. This could involve better coordination of roles and
 information, shared responsibility with non-NDIS regulators for safeguards, better
 information to both people with disability and providers, and importantly, increased
 access to individual advocacy.
- Information sharing between the NDIS Commission and relevant State and Territory government authorities lacks national consistency and requires significant improvement in streamlining and ease of exchange (Refer to Recommendation 7).

Many roles under the NDIS can be confusing for participants, supporters and providers alike. For instance, the difference between the roles and functions of the National Disability Insurance Agency (NDIA) and the NDIS Commission is not well understood.



Clear accessible explanatory information must be made available to participants to avoid unnecessary confusion and anxiety.

Recommendation 16 – The Framework should include information about how it directs the role and functions of the NDIS Commission. The NDIS Commission should be required to conduct regular reviews on the implementation of the Framework and to publish the review reports.

Recommendation 17 – Under the Framework, the NDIS Commission must be required to publish clear accessible explanatory information that is widely available and promoted to participants and their supporters about the NDIS Commission's role, how to use it or what issues can be raised by whom. Regarding the quality of services, explanatory information must be available to participants about what standard of service a participant can expect, how to raise issues or complain about quality, what issues can be raised, who can raise them, and what happens next.

6. Working together

6.1 Restrictive practices

The Issues Paper acknowledges that States and Territories vary on the authorisation and reporting of restrictive practices for people with disability. PWDA calls for the Framework to require and enable national consistency to work towards the stated NDIS goal of reducing, and ultimately eliminating, the use of restrictive practices for people with disability. (Refer to Recommendation 1).

Recommendation 18 – The NDIS Commission should publish an annual report on actions to reduce restrictive practices across all States and Territories. This information must guide the development of bespoke supports that offer alternatives to restrictive practices for participants and therefore support the goal of reducing and ultimately eliminating the use of restrictive practices for people with disability.



6.2 Regulators working together

Current oversight and safeguarding authorities and mechanisms in Australia can be siloed and not well coordinated. The Issues Paper acknowledges that interfaces between all levels of Government require upgrading. PWDA asserts that there is a need for more coordination and cooperation between regulatory and other related authorities.

Improvements to cooperation, coordination and alignment of powers between oversight and safeguarding authorities will ensure:

- better coordination with the NDIA
- clearer and more streamlined roles
- shared understanding and alignment of disability quality and safeguarding
- enhanced communication and coordination of actions and developments.

Improved interfaces and coordination between NDIS regulation and state and territory authorities should involve at least the following departments/agencies:

- Health
- Education
- Child Protection
- Justice and Police
- Housing
- Transport
- Professional licencing and regulatory bodies

The Framework must facilitate the coordination and alignment of the powers and practices of all related regulatory bodies and government authorities. To improve quality, this



alignment and coordination will serve to avoid gaps and duplication, reduce unproductive effort, improve responses to people with disability, and lift quality standards.

PWDA notes that the coordination and alignment of powers can fail within the NDIA itself, when staff unintentionally undermine the role of the NDIS Commission. For example, an NDIS participant told PWDA they wanted to make a complaint against a service provider and they noted:

"I didn't take action because the NDIA planner said not to."

Recommendation 19 – To reduce risks, the Framework must facilitate the coordination and alignment of the powers and practices of all related regulatory bodies and government authorities that can affect the lives of people with disability across Australia.

6.3 Sharing information

Similarly, the sharing of information between Commonwealth and State/Territory regulatory and other authorities can be onerous and overly complex, resulting in delays that could, at times, serve to increase risks for people with disability. With appropriate safeguards for privacy, the exchange of critical NDIS and other information, when necessary, must become smoother, more streamlined and less bureaucratically complex. Consideration needs to be given to:

- any information that is shared must be immediately relevant and germane to the risks under consideration as participants have the same right to privacy as other people
- enabling intermediaries to share relevant information with appropriate regulatory authorities when significant risks arise to the participant's health and wellbeing.
- Please see Recommendation 1.



7. Strategies and measures

7.1 High quality supports

While the overall objectives and principles of the Framework are sound, the implementation of measures for quality must respond better to:

- the choices and needs of participants
- changes in how people are using their NDIS funding and the supports they engage
 i.e. more self-managed, more unregistered, non-NDIS specific services, more
 engagement of mainstream services.
- participants' expectations for increased flexibility, innovation and continuous improvement in NDIS supports and services.

The Framework must be upgraded to include an increased emphasis on quality measures, including:

- people with disability must not be expected to accept service standards of a lower quality because of their disability or additional needs
- the promotion of the importance of continuous improvement and quality excellence
- the need for more monitoring at critical times, on a regular basis and where requested. This could involve active price regulation and monitoring, regular visits and reporting by Community Visitors, and potentially a range of other measures.

7.2 Making a complaint

In considering whether to make a complaint, PWDA NDIS Review Survey respondents indicated they were already feeling disempowered before they considered making a complaint, and that the act and process of raising a complaint could cause further hardship.



"Not my ability. I've spent my life being neglected or abused."

"I'm exhausted by life let alone having to follow things up and do all the paperwork that people continually asked for and keep track of everything.... well [I'm] just trying to live a life".

Fear of repercussions was a concerning factor for participants in deciding whether to make a complaint:

"I have been too scared to speak up when bad things happen because of what will happen if I do...";

"Failed to say anything in case I got punished for reporting".

This fear about retribution can be intensified for participants in rural and regional locations, where communities may be small, and many residents live and work in the town. Living in a close community can be a serious disincentive for participants to raise an issue with their provider or to make a complaint. Consequently, participants may to decide to change providers rather than raise issues or make complaints.

Similarly, participants who experience recurring low-level instances of abuse or neglect or unacceptable quality may also choose to change providers and avoid the fear and emotional challenge of making a complaint. However, when participants change providers for these reasons, PWDA is concerned that the workers and providers in question will be free to continue poor practices with the remaining participants and also with new participants.

One respondent to PWDA's NDIS Review Survey commented:

"..the Commission fails to accurately identify or understand people with disabilities' needs, or to act in the best interest of vulnerable people.

Because this is the case, events are underreported".

Improved monitoring can begin to address some of these issues and provide opportunities to uncover any unacceptable practices by workers and providers. This is particularly



important in thin markets where people have little or no option to change providers and, it underscores the need for monitoring to be sufficiently resourced.

7.3 Balancing priorities

Risk versus choice

The NDIS promotes itself as a person-centred program that tailors supports to the individual participant according to their specific needs, choices and risks.

The Framework should explicitly recognise that risk attaches to the specific person and their circumstances, and should not be standardised, except for risks that may affect all people in the general population.

One of the key messages on page 2 of the Issues Paper proposes that:

"The Framework needs to balance individual choice and control with actions to provide protections for everyone. This requires choices and trade-offs."

In a truly person-centred NDIS, a reduction in risk for one participant should not limit the choices of other participants. Generally, an effective well-structured service will manage the individual needs of participants. This does not mean that all people will get everything they want in the moment they want it. It does mean that the actions to mitigate risks for one person should not restrict the choices and activities of others in any ongoing way. Similarly, the ongoing impact on people with disability of the assumptions and presumptions of others does not align with the NDIS as a person-centred scheme.

It should not be assumed that choice is an obligation. It is important that the NDIS offers real choices, so that participants and their supporters can determine the extent to which they want to exercise choice. Part of the exercise of choice necessarily involves the provision of decision-making supports to the participant.



It is important to identify where risks sit. Participants should not be obliged to be more informed or to better understand the risk implications of using their NDIS services and supports, than any other members of the public in their use of goods and services.

Safety is the responsibility of participants and providers and regulators. Participants must be free to determine what risks are acceptable to them, and what risks they decide to take on. Equally, participants might ask 'what risks do my provider's practices expose me to when I am using their supports?' and 'whose responsibility is this?' Service and support practices are clearly the responsibility of the worker and ultimately the provider. Official regulators must determine and monitor the structure of supports, provide guidelines, implement preventative and corrective actions.

The Framework and NDIS staff and officials must be wary of assuming that a participant's decision about risk is 'inadequate'. Participants will have differing appetites for risk depending on a range of factors and circumstances including disability, age, culture, life experiences, motivations, expectations etc. as is reflected for people without disability in the general community.

Dignity of risk

The Framework gives insufficient attention to supporting participants to exercise their rights to make choices about risk and to take control of how their chosen supports are delivered. People in the general community can make decisions about what is an acceptable risk within the law. People with disability must be afforded the same right and provided with appropriate information and decision-supports to make their choices. This is the dignity of risk.

The participant's ability to manage risk, and to exercise choice and control can be affected by:

- the understanding and effective implementation of supported decision-making
- working with the participant to develop a clear understanding of the positive and negative consequences of choices and decisions



- the participant's interactions with NDIS staff and officials, especially if these are of a lower standard or quality than others would accept
- substitute decision-making where a legal guardian has been appointed. This can
 result in the implementation of priorities that are not the choices of or belong to the
 participant. PWDA is concerned that substitute decision-makers may not take into
 account the choices of the participant or act in their best interests.

7.4 Driving improvements to quality

Personal capacity can drive quality

The presumption of capacity of participants to make decisions and manage risk must remain at the centre of a person-centred NDIS and be explicit in the Framework. The Framework's commitment to improving quality in the NDIS means the practice of presuming capacity must be strengthened in the interactions of NDIS workers and representatives with participants. Consideration should be given to:

- improvements to quality can be advanced by building the personal capacity of people with disability. The Framework lacks action on the development of personal capacity where people are provided with information, education and supports to make choices and decisions
- it should be remembered that many people who entered the NDIS after using state
 and territory disability supports were often simply informed about the services they
 would use, and had never previously been involved in or responsible for making
 decisions about their supports. PWDA fears that many people assume they are
 automatically covered by government systems for protection and corrective action
- further, it may never have been explained to participants, families and supporters
 that using the NDIS is now consumer-focussed, with choices and responsibilities,
 just like for other purchased goods and services by the general public



- similarly, it is possible that many people coming into the NDIS for the first time assume it is a wholly government managed and provided program and therefore safeguards and protections were inbuilt
- consequently, participants and their supporters must not be blamed or
 overburdened by unfamiliar systemic responsibilities, requirements or expectations
 without appropriate information, and assistance where needed, in order to
 effectively use NDIS supports. The act of accessing and using the NDIS must not
 cause more anxiety or result in more effort simply to receive necessary supports.

Monitoring for quality

As stated, there is a clear and urgent need for more monitoring of quality at critical times, on a regular basis and where requested. This could involve:

- · active price regulation and monitoring
- regular visits and reporting by Community Visitors
- a range of other supportive monitoring measures.

To improve quality, NDIS officials and workers must have a good understanding of equity and equality for people with disability, including the application of dignity of risk, personcentred and strengths-based approaches, consent, and supported decision-making for people with disability.



Appendix

Domestic and Family Violence

PWDA observes that violence occurring in residential settings such as supported independent living and group homes for people with disability, psychiatric facilities and aged care facilities is frequently not identified as domestic violence.

People with disability experiencing violence in these settings, whether by co-residents or support workers, may not be given the same kinds of support as other domestic violence victims.

There are circumstances where this violence is not recognised as a police matter, but as a 'service incident.' This can lead to a double standard in providing appropriate support and accessing justice for family and domestic violence: one for people with disability, and another for the rest of the community. vii



Endnotes

¹ United Nations, *Convention on the Rights of Persons with Disabilities*, United Nations, last updated December 2006, last accessed 17 January 2023.

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

ii NDIS Quality and Safeguarding Framework Issues Paper, issued by the Independent Review of the
National Disability Insurance Scheme, April 2023
https://www.ndisreview.gov.au/resources/paper/ndis-guality-and-safeguarding-framework-issues-paper

iii NDIS Participant Safeguarding Proposals Paper, issued by the Independent Review of the National Disability Insurance Scheme, May 2023. https://www.ndisreview.gov.au/sites/default/files/resource/download/participant-safeguarding-proposals-paper.pdf

- v Department of Social Services Australian Government, *Information, Linkages and Capacity Building (ILC)* program https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/information-linkages-and-capacity-building-ilc-program
- vi Person-Centred Emergency Preparedness resources from Collaborating 4 Inclusion https://collaborating4inclusion.org/home/pcep/
- vii, Response to 'A Blueprint for Family and Domestic Violence Response in NSW', PWDA, 2016 https://pwd.org.au/a-blueprint-for-family-and-domestic-violence-response-in-nsw/

