

DANA Submission to the NDIS Review

NDIS Quality and Safeguarding Framework issues paper

June 2023



Introduction

Disability Advocacy Network Australia (DANA) is the national peak body for disability advocacy in Australia with a membership comprising over eighty organisations that are funded to provide disability advocacy across all jurisdictions. Fifty-nine of these advocacy organisations receive funding from the National Disability Advocacy Program (NDAP) and other funding is received from various state and territory disability programs.

The following responses to questions in the <u>NDIS Review Issues Paper on the NDIS Quality and Safeguarding Framework</u> present key themes and insights from our engagements with the disability advocacy sector, during the last several years of the Royal Commission into Violence, Abuse, Neglect and Exploitation against People with Disability (Disability Royal Commission) and previously.

The footnotes of this document include links to relevant material and indicate relevant sections from several of our submissions to the Disability Royal Commission:

Attachment A: Independent disability advocacy – DANA submission

Attachment B: Rights, Safety, Quality - Voices of Advocacy

Attachment C: Advocates on Quality and Safeguarding – April 2021

We would welcome opportunity to further discuss these matters with the NDIS Review panel and/or other representatives. DANA will continue to work on the topics of safeguarding and quality as we progress our NDIS Review Engagement Plan to consult with disability advocates on these challenges and potential solutions.

Summary of Recommendations

Recommendation 1: That the Framework guarantees access to independent advocacy by increasing funding to organisations in line with increasing funding for the NDIS.

Recommendation 2: That the Framework includes significant resourcing increases to all complaint mechanisms so responses are timely, proportionate, and focused on proactively reducing the rates of violence, abuse, neglect and exploitation against people with disability.

Recommendation 3: That a national public information and awareness raising campaign about human rights and advocacy support for people with disability be established that:

- is developed through co-design with people with disability;
- emphasises that anyone with disability can access advocacy support;
- highlights the need for community support for people who are seeking to selfadvocate;
- explains conflict of interest and when an independent advocate is needed;



- is widely available in accessible formats, Plain English, diverse languages;
 and
- highlights the role of independent disability advocacy in abuse prevention and response, including potential for earlier intervention in high risk situations.

Recommendation 4: That awareness of and access to advocacy for all people with disability be enhanced by:

- establishing an information and awareness program for disability and other service providers and related professionals;
- strengthening awareness of the right to independent advocacy among all staff within the NDIA, Services Australia, and other government agencies including at the State and Territory level e.g. Public Guardians/Advocates, Child protection, Justice, community visitor schemes;
- strengthening organisational policies and processes for referral to independent advocacy from relevant staff within government agencies; and
- promoting recognition of the safeguarding role of disability advocates with all safeguarding institutions, including the NDIS Commission, Human Rights, Anti-Discrimination and Complaints Commission.

Recommendation 5: That the future Framework establishes clear responsibilities within Federal Government for its implementation and coordination, with regular and effective monitoring of progress under Australia's Disability Strategy (ADS) 2021-2031.

Recommendation 6: That the next iteration of the ADS Safety Targeted Action Plan from 2024-2025 will strengthen and clarify accountability for implementing and coordinating the revised Framework across the relevant actors, and evaluating the outcomes achieved over time.

Recommendation 7: That the Deregulation Taskforce undertake a review of complexity of NDIS complaints mechanisms, and implement a timetable, with people with disability, for simplification and reform.

Recommendation 8: That the NDIS Quality and Safeguards Commission provides an initial response to complaints within 7 working days, and for urgent matters of violence and abuse against a person with disability, within 1 working day.

Recommendation 9: That the role of independent disability advocacy is acknowledged and included in the Framework as part of the safeguarding mechanisms and funding is provided to fulfil these functions, particularly for people with disability in closed or restricted settings.

Recommendation 10: That the Framework addresses the different roles that are needed and provides direction to address significant gaps for people with disability including:

• the feasibility of an independent consumer voice;



- a separate body for market regulation and price setting; and
- a stronger focus on violence prevention, including being able to address systemic issues, for the existing Commission.

Recommendation 11: That an immediate injection of additional funds to address the existing crisis in lack of independent advocacy support availability be provided by enhancing the workforce capacity of disability advocacy organisations to meet current demand and to support clients in a timely and consistent manner.

Recommendation 12: That unmet need for advocacy be addressed by expanding reach through targeted advocacy to increase access and support for identified high risk population groups and to address specific needs including issues arising from intersectionality that impact people with disability.

Recommendation 13: That all governments (with the advocacy sector) work collaboratively to develop a robust disability advocacy funding model in order to guide distribution of funding to address client complexity, meet current and unmet advocacy needs and to support organisational responsiveness and sustainability.

Recommendation 14: That the Framework includes the importance of building capacity for people with disability in violence prevention, and choice and control in using a variety of providers, including unregistered providers.



Question 1 – What is and is not working well to promote safeguards and quality of supports

DANA has heard from disability advocates around the country that there are inconsistencies and gaps in safeguarding frameworks applied across Australia. In their daily work, disability advocacy organisations work to safeguard the human rights of individuals with disability to be included in the community, live free from violence, abuse, neglect and exploitation and access quality supports. Disability advocates possess extensive insights about what is and, mostly, what is not working well in the NDIS Quality and Safeguarding Framework and other Federal, and state and territory mechanisms designed and implemented to promote safety and quality across a range of service systems used by people with disability.

In DANA consultations, advocates have spoken at length about the barriers people with disability experience when accessing or interacting with complaint mechanisms, whether this is fear of retribution or other consequences of making a complaint, lack of rights awareness or effective complaints responses, or segregation and isolation from the community. Advocates have also described failures of accountability, reliance on restrictive practices, systemic power imbalances, and problems of profit driven services and providers delivering both support and accommodation.³ The current arrangements relating to quality of service provision and violence are fragmented and difficult to understand and navigate. Further, the onus is often on people with disability to take action or complain when things go wrong.

As acknowledged by the NDIS Review Issues paper on the NDIS Quality and Safeguarding Framework:

There has been insufficient focus on developmental safeguards to support individuals in the NDIS, including participant capacity building, the provision of information, the development of natural safeguards (such as family, supporters and community), and initiatives focused on supported decision-making and advocacy.

Bolstering inclusion in all domains of life strengthens natural safeguards.⁴ Independent advocacy organisations themselves can play a vital role in strengthening informal safeguards and developing the personal capacity of people with disability to safeguard themselves, including through their work building human rights awareness and supporting self-advocacy skills. This can also occur through peer support, supported decision making and other forms of education and capacity building.⁵

¹ See Attachment B: Rights, Safety, Quality, pages 21-26

² See Attachment A: <u>Independent disability advocacy – DANA submission to the Disability Royal</u> Commission

³ See explorations of these themes in Attachment B: <u>Rights, Safety, Quality</u> and <u>'Advocates Discuss'</u> transcripts of 2022 discussion series

⁴ See for instance in relation to inclusive schooling - Attachment B: <u>Rights, Safety, Quality</u>, page 59; <u>Advocates Zoom In On... Access to Education</u> 2020 discussion transcript.

⁵ See Attachment B: Rights, Safety, Quality pages 40- 59, 78- 89.



Recommendation 1: That the Framework guarantees access to independent advocacy by increasing funding to organisations in line with increasing funding for the NDIS. ⁶

Recommendation 2: That the Framework includes significant resourcing increases to all complaint mechanisms so responses are timely, proportionate, and focused on proactively reducing the rates of violence, abuse, neglect and exploitation against people with disability.

(See greater detail on the funding of independent disability advocacy below in **Recommendations 9**, **10**, and **11**.)

Question 2 – The need for, role and monitoring of a Framework for safety, quality and rights

Despite the operation of the current NDIS Quality and Safeguarding Framework, advocates have observed a range of service settings operating with limited or insufficient oversight or active monitoring for signs of abuse, violence, neglect or exploitation of people with disability. Advocates have described a range of systemic failures to ensure quality, promote safety and protect human rights.⁷

To improve the current arrangements, disability advocates believe ensuring the accessibility and integrity of complaints mechanisms and improved access to independent advocacy for people with disability at risk are vital challenges for the Framework to encompass and directly address. These improvements require ensuring the independent advocacy sector is resourced, networked and supported to meet the needs of all people with disability. There also needs to be cross-sector efforts to focus on human rights across all service settings and government investment in disability rights awareness and education across the community.⁸

Recommendation 3: That a national public information and awareness raising campaign about human rights and advocacy support for people with disability be established that:

- is developed through co-design with people with disability;
- emphasises that anyone with disability can access advocacy support;
- highlights the need for community support for people who are seeking to self-advocate;
- explains conflict of interest and when an independent advocate is needed;

⁶ See details of Recommendation 4: Enhance safeguarding mechanisms - Attachment A: <u>Independent disability advocacy – DANA submission to the Disability Royal Commission</u>

⁷ See our submissions to the Disability Royal Commission across a range of topics: <u>Voices of Advocacy | Disability Advocacy Network Australia (dana.org.au)</u>

⁸ See Attachment B: Rights, Safety, Quality, pages 13-20, 32-56, 71-85



- is widely available in accessible formats, Plain English, diverse languages; and
- highlights the role of independent disability advocacy in abuse prevention and response, including potential for earlier intervention in high risk situations.

As DANA explored in our submission to the Disability Royal Commission, there are multiple gaps and inconsistencies in the availability and accessibility of disability advocacy supports due to fragmented and inadequate funding for organisations across states and territories.⁹ Organisations are of varying size, focus and capacity for provision of disability advocacy for the increasing numbers of people seeking advocacy support. Currently, many people with disability miss out due to a range of factors including:

- Lack of knowledge of their rights, lack of proximate or accessible organisations, complexity of the service system and overburdening of the advocacy organisations that exist;
- Lack of awareness or education among disability support workers and professionals about, the rights of people with disability, the role or availability of disability advocacy and how or when it is important to refer people with disability to independent advocacy; and
- Limited access to independent advocacy, due to lack of awareness, gatekeeping or exploitative practices in some specific settings including closed, institutional and family contexts.

Without access to disability advocacy people with disability are at greater risk of experiencing violence, abuse, neglect and exploitation and of experiencing entrenched exclusion.

Recommendation 4: That awareness of and access to advocacy for all people with disability be enhanced by:

- establishing an information and awareness program for disability and other service providers and related professionals;
- strengthening awareness of the right to independent advocacy among all staff within the NDIA, Services Australia, and other government agencies including at the State and Territory level e.g. Public Guardians/Advocates, Child protection, Justice, community visitor schemes;
- strengthening organisational policies and processes for referral to independent advocacy from relevant staff within government agencies; and
- promoting recognition of the safeguarding role of disability advocates with all safeguarding institutions, including the NDIS Commission, Human Rights, Anti-Discrimination and Complaints Commission.

⁹ Attachment A: <u>Independent disability advocacy – DANA submission to the Disability Royal Commission</u>



Particular attention must be paid to identifying and reaching people who need additional supports, including those who face communication barriers and people who have limited or no informal support networks.¹⁰ To address intersectional disadvantage and discrimination, improvements must also meet the specific needs of groups who have been identified at higher risk of violence, abuse neglect and exploitation, including First Nations people with disability, culturally and linguistically diverse communities, children and young people, non-binary people, women and girls.¹¹

A comprehensive human-rights focused Framework is needed to play a central role across the NDIS and the supports and services relied on by people with disability. This requires more effective oversight and protections and considerable investment in quality improvement mechanisms and in empowering people with disability to:

- access independent information about the services and support options available;
- make active informed decisions about these options, with support where needed;
- · complain about poor quality and mistreatment; and
- report violence, abuse, neglect and exploitation.

The onus for high quality services or supports should be on the provider (whether mainstream or specialist) and not the person with disability. Organisational measures for quality and prevention of violence should include independent auditing and complaints processes which are fit-for-purpose, carefully designed and easily accessible. Standards for service providers need to be enforceable to ensure accountability.¹²

The Australian Government needs to actively monitor implementation and ongoing effectiveness of the future Framework to ensure it operates as intended to protect rights, ensure safety and promote quality.

Recommendation 5: That the future Framework establishes clear responsibilities within Federal Government for its implementation and coordination, with regular and effective monitoring of progress under Australia's Disability Strategy (ADS) 2021-2031.

Recommendation 6: That the next iteration of the ADS Safety Targeted Action Plan from 2024-2025 will strengthen and clarify accountability for implementing and coordinating the revised Framework across the relevant actors, and evaluating the outcomes achieved over time.

¹⁰ See Attachment B: Rights, Safety, Quality, pages 71- 78, 85- 89

¹¹ See Attachment A: <u>Independent disability advocacy</u> and Attachment B: <u>Rights, Safety, Quality</u>, pages 89- 98, 242- 247.

¹² A New Act to Replace the Disability Services Act 1986: A joint submission from Disability Representative Organisations (A submission by Australian Federation of Disability Organisations, Children and Young People with Disability Australia, Disability Advocacy Network Australia, First Peoples Disability Network, Inclusion Australia, National Ethnic Disability Alliance, People with Disability Australia and Women with Disabilities Australia)



Question 3 – Coverage of supports, services and actors

There needs to be an integrated approach across the NDIS and all disability and mainstream supports and systems. Government needs to work cohesively to develop an improved Framework through co-design with people with disability and their representative organisations.

The current complex landscape is fragmented and often inaccessible and ineffective for people with disability seeking remedies, recognition or resolution of their complaints or negative experiences with disability supports.

The burden of this complexity falls on people with disability, their families and supporters, who then often turn to independent advocacy organisations to support them to navigate that system.

Government needs to take on this complexity and undertake reform that ensures that people with disability can access timely, effective and adequate mechanisms to address violence, abuse, neglect and exploitation. A research report commissioned by the Disability Royal Commission found that an independent, trustworthy and effective complaint processes is needed.¹³

Recommendation 7: That the Deregulation Taskforce¹⁴ undertake a review of complexity of NDIS complaints mechanisms, and implement a timetable, with people with disability, for simplification and reform.

In consultations in 2020 and 2021, recurrent themes and frustrations emerged in advocates' commentary about pursuing complaints with the NDIS Quality and Safeguards Commission. Recurrent experiences and concerns included:

- Complaints go nowhere;
- Lack of outcomes for complainants;
- Lack of enforcement or consequences for providers;
- Reputation as "toothless";
- Bureaucratic and technical;
- Risk of power imbalance; and
- Overly trusting of service providers who can "control the narrative".

Disability advocates expressed dissatisfaction with the role currently played by the NDIS Quality and Safeguards Commission in ensuring compliance with relevant service standards of quality and safety. Recurrent experiences and concerns included:

¹³ <u>Disability complaints processes need major overhaul - The University of Sydney</u> - Dinesh Wadiwel, Claire Spivakovsky, Linda Steele (2022) *Complaint mechanisms: Reporting pathways for violence, abuse, neglect and exploitation* - Research Report commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

¹⁴ See https://www.regulatoryreform.gov.au/

¹⁵ See Attachment C: Advocates on Quality and Safeguarding – April 2021, pages 2-5.



- Inadequate oversight and monitoring;
- Lack of action on systemic issues identified by advocacy organisations;
- Lack of measurement of people's rights and wellbeing; and
- Disconnect between glossy organisational brochures and policies and reality "on the ground" within group homes.¹⁶

The multiple functions residing in the NDIS Quality and Safeguards Commission has been problematic in relation to integrity, independence and effectiveness. There is a need to clearly separate some of these functions and to improve the performance of those functions.

Recommendation 8: That the NDIS Quality and Safeguards Commission provides an initial response to complaints within 7 working days, and for urgent matters of violence and abuse against a person with disability, within 1 working day.

There are currently few avenues for people with disability to obtain independent information about the services they use for NDIS supports, alongside the rights they have in using those services. Many independent advocacy services are performing this function, without adequate resources to do so. DANA believes that this role for independent advocacy organisations needs to be formally included in the Framework to both acknowledge this essential work that is already occurring, and to address the significant resource gap for independent advocacy.

Recommendation 9: That the role of independent disability advocacy is acknowledged and included in the Framework as part of the safeguarding mechanisms and funding is provided to fulfil these functions, particularly for people with disability in closed or restricted settings.

Question 4 – Roles, responsibilities and coordination

A new Framework needs clearer accountability, improved coordination and to connect more strongly with the National Disability Advocacy Framework, implementation of the National Decision-Making Principles and realisation of Supported Decision Making for people with disability.

The Australian Government plans to repeal and replace the Disability Services Act 1986 represents a significant opportunity to provide the vision and direction for the rights of people with disability in Australia for years to come. As recommended in the joint submission of Disability Representative Organisations on A New Act to Replace the Disability Services Act (1986), there needs to be cohesive interaction between legislation and policy reform agendas and responsibilities, compelling government to be bear responsibility for multi-system integration and coordination. A lack of accountability and clarity has hampered the implementation and monitoring of the current Framework. There is no mechanism within government to provide this

¹⁶ See Attachment C: Advocates on Quality and Safeguarding – April 2021, pages 5-9.



oversight and monitoring of the Framework, nor of those charged with its implementation.

(See above **Recommendation 4** in relation to strengthening and clarifying responsibilities and monitoring).

As part of the Safeguarding Framework, there needs to be acknowledgement and resourcing for the different roles that are needed to ensure that people with disability can exercise full choice and control over their NDIS supports, alongside being free from violence and abuse.

The Framework needs to include:

- Violence prevention and responses, including complaints;
- Consumer voice, independent information and capacity building; and
- Market oversight and regulation, including price setting, action on consumer law and predatory conduct.

The new Framework needs to set out these diverse functions and address the gaps in the current systems. DANA urges the NDIS Review to make strong recommendations to address these three areas.

Recommendation 10: That the Framework addresses the different roles that are needed and provides direction to address significant gaps for people with disability including:

- the feasibility of an independent consumer voice;
- a separate body for market regulation and price setting; and
- a stronger focus on violence prevention, including being able to address systemic issues, for the existing Commission.

Question 5 – Changing the Framework

Disability advocacy supports individuals with disability (and their family and supporters) in a range of ways - to be aware of and assert their rights and to facilitate their access to services and support that enhance their capacity to participate fully in society across multiple domains of life. The introduction of the NDIS has seen a significantly increased demand for advocacy to support people in navigating its inherent complexities. A range of government consultations, reviews and inquiries have reiterated the importance of independent disability advocacy in relation to quality and safeguarding in the NDIS and other government systems.

Despite the significant increase in disability services funding through the NDIS, this has not been met with proportionate additional funding for disability advocacy organisations to deliver the coordinated support people with disability require for the goals of the NDIS to be achieved. Multiple recommendations for increased investment in and certainty of disability advocacy funding have not been acted upon.



As argued above, the safeguarding role of independent advocacy needs to be embedded in the Framework with dedicated funding to support the advocacy sector to fulfil important functions across the developmental, corrective and preventative domains of safeguarding outlined in the current Framework. In our submission to Disability Royal Commission, DANA called for an immediate injection of additional funds to address the existing crisis in the short term and made detailed recommendations for Australian governments to work together to:

- Enhance disability advocacy service capacity;
- · Improve and develop sector quality;
- · Improve national co-ordination and data; and
- Enhance safeguarding mechanisms.¹⁷

Recommendation 11: That an immediate injection of additional funds to address the existing crisis in lack of independent advocacy support availability be provided by enhancing the workforce capacity of disability advocacy organisations to meet current demand and to support clients in a timely and consistent manner.

Recommendation 12: That unmet need for advocacy be addressed by expanding reach through targeted advocacy to increase access and support for identified high risk population groups and to address specific needs including issues arising from intersectionality that impact people with disability.

Recommendation 13: That all governments (with the advocacy sector) work collaboratively to develop a robust disability advocacy funding model in order to guide distribution of funding to address client complexity, meet current and unmet advocacy needs and to support organisational responsiveness and sustainability.

Balancing protection from harm and promotion of control and choice

Generally, efforts to uphold independence, choice and control in service contexts contribute to the quality of services and safety of people with disability. Implementing safeguards like ensuring access to independent advocacy and ensuring provision of capacity building and training in human rights awareness, supported decision making and self advocacy for people with disability, will contribute to independence, choice and control. Although scenarios are imaginable in which regulations to keep people with disability safe may restrict their autonomy or choices (for instance, by preventing them from choosing a harmful service provider), the values of independence, choice and control are largely not in tension with or needing to be balanced against promoting the right to live in freedom from violence, abuse, neglect and exploitation. Rather, these values strengthen one another.

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¹⁷ See Attachment A: <u>Independent disability advocacy</u>, Pages 19-20 and Attachment A for detailed recommendations.



Driving improvements in quality of supports and services

Through the nature of their work, disability advocates are generally more exposed to the characteristics of poor quality disability services. 18 Yet they can describe and articulate the features of high quality services, including that they:

- give attention to the needs, will and preference of the individual with disability;
- support autonomy, control and choice;
- · train staff in human rights principles;
- · recognise 'behaviour' as communication;
- strive to be trauma-informed;
- lead cultural change at all levels; and
- ensure access to independent advocacy and support to make complaints.

During the Disability Royal Commission, disability advocates have shared many ideas in DANA forums about how to drive quality improvement and responsiveness in the systems of support that people with disability rely on.¹⁹

Ensuring effective regulation

There needs to be more effective safeguarding measures and protections to ensure people with disability who use NDIS supports are not victimised or neglected. However, flexibility, choice and control for people who use NDIS supports, supported by individual and sector capacity-building, and independent information, advocacy and decision-making support all contribute to the prevention of violence, abuse, neglect and exploitation. Efforts to increase oversight and safety through more stringent regulatory measures should not restrict the autonomy of individuals with disability to choose supports from unregistered providers and workers. As confirmed by the evidence before the Disability Royal Commission and the NDIS Quality and Safeguards Commission Own Motion Inquiries, registration of providers has not prevented appalling instances of mistreatment, violence or neglect.

Independent advocacy organisations around the country hear about shocking levels of violence and abuse by registered providers every day. There is strong evidence that building the capacity of people with disability, their families and supporters, alongside the community, to have control over their own supports, is a significant preventative measure against violence and abuse.

Research from the NDIA has looked at self-management, and discussed the evidence about violence prevention. That research found that:

¹⁸ See Attachment B: Rights, Safety, Quality, particularly Section 12, pages 99-154.

¹⁹ See <u>DANA Submission – Solutions-focused workshops with DRC</u> and Attachment B: <u>Rights, Safety, Quality</u>, particularly Appendix A, pages 199-246.



"Self-management has been found to lead to beneficial outcomes for the budget holder and their families. These include higher satisfaction with access to needs-led supports and improved quality of life, health, social and community participation, choice and control, empowerment, independence, and relationship quality. Family members also report increased participation in paid work. Moreover, fewer adverse events have been reported. However, the positive effects of self-management are only realised when people are able to creatively and flexibly use their funding, and they have timely access to appropriate information, supports and tools to manage the administrative aspects of self-management."²⁰

Finding the balance between building capacity of people with disability and regulation is vital to delivering on the promise of the NDIS, and to prevent violence against people with disability. However, the elements that will build the capacity of people with disability are still missing from both the NDIS architecture and the broader legislative frameworks underpinning services and supports for people with disability.

Recommendation 14: That the Framework includes the importance of building capacity for people with disability in violence prevention, and choice and control in using a variety of providers, including unregistered providers.

²⁰ National Disability Insurance Agency (2022). *A narrative review of self-directed disability budget management*, National Disability Insurance Agency, Australian Government. Prepared by Research and Evaluation Branch NDIA.