



DANA

Disability Advocacy
Network Australia

Submission on the National Disability Advocacy Framework

[July 2022]

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Introduction

Disability Advocacy Network Australia (DANA) is the national peak body for the independent disability advocacy organisations across Australia. Our goal is to advance the rights and interests of people with disability by supporting advocacy organisations in their targeted advocacy as well as engaging in systemic advocacy on a national level to further these objectives. DANA works to a vision of a nation that includes and values people with disabilities and respects human rights for all.

DANA welcomes the opportunity to make a submission on the draft for a new National Disability Advocacy Framework 2022-2025 (the Framework). In particular, our organisation welcomes the increasing recognition by Governments of the vital role that advocacy plays in promoting and protecting the rights, interests and well-being of people with disability and in contributing to the proper functioning of systems established to provide services and supports for people with disabilities. This includes the leadership of the Commonwealth government in developing high-level principles and definitions in this draft Framework.¹

We note positive undertakings, also listed under the Safety Targeted Action Plan of Australia's Disability Strategy 2021-2031, to improve access to disability advocacy from the:

- New South Wales Government²
- Victorian Government³
- Queensland Government⁴ and
- Western Australian Government (to engage with and present views of people with disability to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability)⁵

DANA has recently held discussions with and collected input from advocacy organisations specifically about the Framework, and also to collect their perspectives and ideas about independent disability advocacy to inform our recommendations to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission). (See [Section 5: What is needed](#) for the resulting draft high level recommendations.)

¹ Australia's Disability Strategy 2021-2031: Safety Targeted Action Plan, Action 3.3 on p9, and Action 5.3 on p11. See [Safety Targeted Action Plan | Disability Gateway](#)

² Ibid, p14, p16.

³ Ibid, p20, p22.

⁴ Ibid, p27.

⁵ Ibid, p28.

Additionally, over the years since the development and introduction of the National Disability Advocacy Framework in 2012, DANA has carried out many face-to-face and online consultations with disability advocacy organisations in all the states and territories of Australia,⁶ attended many sector meetings and liaised with many advocates and their managers and other staff to hear about the challenges faced in the disability advocacy sector, including:

- inadequate and insecure funding;
- the need for increased sector development and support, including training, peer support and networks for sharing expertise between disability advocates;
- the need for increased evidence of demand and need for advocacy, and to demonstrate the impact and positive outcomes achieved through independent advocacy; and
- reaching people with disability who are most in need of independent advocacy and/or at risk of violence, abuse, neglect and exploitation in small institutional and domestic settings, due to gatekeeping, isolation and lack of independent support.

This submission thus reflects a broad range of matters of importance to disability advocacy organisations across the country. DANA strongly support many aspects and elements included in this draft high-level Framework. We believe it is vital that the agreed Framework and the supporting disability advocacy work plan will be strongly supported by Federal, state and territory governments and by the disability advocacy sector to ensure its principles and envisaged outcomes are realised.

This submission identifies some of the key issues and challenges, proposes changes to the draft Framework,⁷ and suggests directions for the disability advocacy work plan,⁸ informed by our consultation with the disability advocacy sector.

Framework Rationale and Objective

We are pleased to observe that the language of the Framework, including the Rationale and Objective, reflects understandings of the social model of disability and intersectional discrimination and disadvantage, and specifically refers to being

⁶ Throughout this Submission, DANA has included deidentified quotes from discussions with advocates, including from a discussion series to provide input on important issues in relation to the Disability Royal Commission: See [Voices of Advocacy | Disability Advocacy Network Australia \(dana.org.au\)](https://dana.org.au).

⁷ Find **proposals for amending Framework included in bold** throughout this document.

⁸ See [Section 5: What is needed.](#)

underpinned by a “person centred and rights based approach”. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) must inform the agreed Framework and the supporting disability advocacy work plan. The CRPD and other United Nations documents provides valuable guidance on interpreting international human rights law as it applies to people with disability and their needs. We are pleased that the Framework reflects the strong rights-protection and safeguarding functions of independent disability advocacy and includes reference to the role that disability advocates can play in supporting the decision making of the individuals for whom they advocate.

Independent advocacy plays a vital role both in protecting the rights of individuals and in ongoing systemic quality assurance and improvement. By scrutinising and challenging the disability service system, advocacy adds to its accountability. Access to independent advocacy fosters greater wellbeing, autonomy and community participation of people with disability, and thereby strengthens safeguards against abuse, violence and exploitation.

1. DANA's vision of advocacy

The Submission Guide asks: *“Do you believe the new NDAF encompasses your vision of advocacy?”*

DANA’s vision of independent disability advocacy in Australia is expansive and nuanced. Having consulted and liaised across the sector over the last decade, our organisation is familiar with the breadth and depth of the work performed by disability advocacy organisations around Australia. We see strength in the diversity of organisations funded to provide disability advocacy, and other grass-roots organisations and their responsiveness to local needs and communities. Although we strongly support the development of purposeful consistency in some important aspects of data collection, reporting obligations and other processes and standards, this should be achieved in consultation with sector and people with disability and their supporters and advocates. We perceive brilliant outcomes being achieved efficiently on limited funding by both larger and small agile organisations, as they have grown from, and developed to fulfil the needs of, their local community.⁹ DANA believes the sector can be strengthened and developed in ways that allows for

⁹ See Anne Daly, Greg Barrett and Rhiân Williams (2017) *A Cost Benefit Analysis of Australian independent disability advocacy agencies* – Report commissioned by Disability Advocacy Network Australia, August 2017, Canberra available at [Publications | Disability Advocacy Network Australia](#); Deloitte Access Economics (2013) *Identifying and measuring the outcomes of advocacy*- Report commissioned by ACT Disability, Aged and Carer Advocacy Service

certain levels of flexibility and accommodates differences among organisational styles and advocacy models, and doesn't impose an insistence on sameness for its own sake.

In some funding decisions, we have seen valuable expertise lost from the sector because of bureaucratic preferences for large organisations with extensive “service provision” experience, and polished grant applications, which ignores the achievements and extensive expertise of truly independent and/or dedicated organisations that have developed to solely advocate for people with disability and/or to meet the needs of specific groups of people with disability.¹⁰ DANA strongly cautions governments against any “reforms” or other policy decisions that would sacrifice or dispense with the incredible value and skills of agile, responsive grassroots disability advocacy organisations (that are frequently “punching above their weight”) from currently funded advocacy (and information, peer support and disability representation) programs.

Safeguarding rights, enabling control

[Advocacy is the] crucial, critically important part of the whole process of protecting, safeguarding and helping people with disability who are being abused or have been abused to make a complaint or work their way through the system and in the first place to protect people against some of the things that happen.

DANA CEO Mary Mallett¹¹

Disability advocacy is about promoting and protecting the rights, interests, and wellbeing of people with disability. In many cases it needs to be proactive work, seeking out those who are most isolated or are experiencing or at risk of abuse, neglect or discrimination and working to change the circumstances of their lives so that these things are less able to occur.¹² It is also about working to ensure that the

¹⁰ One advocate from South Australia describes a State Government funding decision as “wrong-headed... if they're going to fund advocacy...it would be our view that they need to fund... advocacy organisations - not advocacy that's tacked onto service provision... it's really about... trying to separate out advocacy efforts from service... and maintain actual and observed independence of advocacy...” DANA Advocacy Catch Up, 2 June 2022.

¹¹ Mary Mallett quoted by the Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, Final Report 188.

¹² See discussion on proactive outreach work, below in [Section 5: Improving access to advocacy](#).

policy settings and practices of services, governments and business tend towards the creation of a culture and environment in which people with disability experience safety and fulfilment in their lives.¹³ In this way advocacy operates as an early intervention and safeguarding mechanism particularly in respect of those people with disabilities who are at most risk of harm.¹⁴ Thus the aims of advocacy are strongly aligned with those of any government that seeks to keep their citizens safe and operating at their full potential.¹⁵

“[Independent disability advocacy] allows people with disability to understand their full entitlements and not be pushed into making decisions that do not fully enhance their life, or that will put them in harm's way. Very important for all to have this essential access.”

QLD Family member of a person with disability¹⁶

“I think [individual advocacy] builds capacity for people... to help access the NDIS for internal reviews or to tell their story with the Disability Royal Commission. People are sometimes at their lowest ebb and they don't know where to go and it's helping them build their own capacity and showing them a way forward and helping them submit applications, whatever that application may be...”¹⁷

“...if a person has had an experience with an advocate, they're more inclined to understand their own rights and be empowered. And there's that word, to Self-Advocate. And that's the purpose of having a disability advocate... is to build capacity and [help] someone to understand ... that they have rights. They are entitled to be treated as all citizens are treated, equally, equitably. I'm not saying that that actually happens on the ground and in real life, but yes, with an advocate by their side - if they've had that, they will be more...they will have more capacity to understand their rights and self advocate.”¹⁸

¹³ Research literature indicates that advocacy improves the attitudes of professionals in service delivery systems: Alison Macadam, Rich Watts and Rob Greig (2013) *Impact of Advocacy for People who Use Social Care Services*, NIHR School for Social Care Research, London School of Economics and Political Science.

¹⁴ Social Care Institute of Excellence (2011) Report 41: *Prevention in Adult Safeguarding*: scie.org.uk/publications/reports/report41/index.asp;

¹⁵ Townsley R, Marriott A and Ward L, 2009, 'Access to Independent Advocacy: An Evidence Review', Office for Disability Issues.

¹⁶ DANA's 2015 *Quality and Safeguards* survey - Response from QLD Family member of a person with disability

¹⁷ WA Advocate November 2020 Zoom workshop with DRC

¹⁸ ACT Advocate, October 2020 Zoom workshop with DRC

Disability advocacy should as far as possible be about enabling people with disability to take control of the direction and form of their lives to the same extent as is available to the general population.¹⁹

Solving problems, preventing harm

“...over the years the people I've worked with have said, how important it was knowing we were available and unconditionally on their side for as long as 'it took'; we are able to intervene, call it out for what it is, and support people to constantly have their services improved or changed. Advocates ...can be heard when the person with the disability is not being listened to.”²⁰

“Once trying all avenues, being bullied, abused and discriminated, it's time to find an advocate, just knowing that safety net is there is a life saver, not an exaggeration for some, an actual life saver just to get through the issues we are faced with all the time.... listen intently, treated as an individual, validated, supported, follow up, no judgement, and got satisfaction. Helps give encouragement, ideas, tools to try a new issue on our own. Builds self esteem.”²¹

Advocacy organisations often solve problems and prevent harm, working both to:

- respond to and support people in crisis, including through seeking remedies and redress for harms against people with disability,²² and
- engage in the developmental and preventative safeguarding work that contributes to the avoidance of harm or escalation to crisis.²³

However, due to chronic under-funding, exacerbated by the strains created by COVID-19 and other emergencies, and the high demand on the NDIS Appeals stream of the National Disability Advocacy Program (NDAP),²⁴ advocacy

¹⁹ Disability Advocacy Network Australia (2010) Comments on the Draft National Disability Advocacy Framework.

²⁰ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

²¹ DANA's 2015 *Quality and Safeguards* survey - Response from WA Person with disability

²² Scottish Independent Advocacy Alliance (2014) *“Advocacy changed my life”: Research into the impact of independent advocacy on the lives of people experiencing mental illness.*

²³ See explanation of Safeguarding domains: Department of Social Services (2016) *NDIS Quality and Safeguarding Framework* pp13-16.

²⁴ See Disability Advocacy NSW, Your Say Advocacy Tasmania and Villamanta Disability Rights Legal Service Inc. (2022) *National Disability Insurance Scheme appeals at the Administrative Appeals Tribunal* p 9.

organisations have increasingly been forced to prioritise crisis response work over the preventative and developmental work of rights education and awareness raising, capacity building and early stage problem-solving and dispute resolution, in turn leading to increased demand and greater strain on organisations. One advocate in NSW noted during discussions about the draft Framework:

“With regard to the objective of the Framework... we could easily argue that it’s not being met purely because of the capacity issue of advocacy organisations at the moment, and people are missing out because of that.”

Advocacy support should be considered essential to any system of services and supports designed to assist people to a life of full and effective inclusion, participation and freedoms equal to others. Whenever a service or system is created, advocacy support should be made available to those for whom the service is constructed and particularly to those who are most at risk within it.²⁵

In many cases the necessary advocacy will come from friends, family or other supporters. It will be undertaken voluntarily out of a commitment to the person’s rights and wellbeing. Volunteer advocates come from all walks of life and with a wide variety of skills and knowledge. Family Advocacy and Citizen Advocacy organisations in particular harness their expertise and offer human and other resources to assist them in their advocacy efforts. All advocacy organisations tend to provide some level of information and/or advocacy support to community members undertaking advocacy for people with disability.²⁶

Independent paid advocates more often become involved when the issues are complicated, where the systems or services are intransigent to people’s wishes or needs, where the person with disability is at risk of violence, neglect or another form of harm, where the person does not have family or friends able to assist them or where a supporter has competing personal or organisational interests.²⁷ Systemic advocacy also contributes to solving systemic problems on a larger scale, though governments often perceive advocacy as adversarial and creating problems. As FPDN CEO Damian Griffis observed:

“There is still such a sensitivity on the part of some governments of the term “advocacy”, it’s often viewed as perhaps adversarial and I think we need to change the way government systems think about it. It’s not necessarily about

²⁵ Disability Advocacy Network Australia (2010) Comments on the Draft National Disability Advocacy Framework.

²⁶ Ibid.

²⁷ Ibid.

adversarial outcomes, it's about support-providing to a person with disability so they can participate in community life. That's a long title for a job, but that's really what advocates do, they provide support to community members so they can have their rights met. I think we need to --- governments still have a, "Here comes an advocate, look out, this is going to be another fight" sort of thinking, when what we need to be thinking about thinking is, "No, this is what a person requires, support required to think about participating in life". Then we might get less adversarial stuff that can sometimes be the perception of government".²⁸

Realising the right to advocacy...

We can envision an Australia in which people with disability have a genuine right to access independent advocacy when and where they need it. Unfortunately, the existing under-resourced sector cannot guarantee this support will be available in practice. There are also a range of systemic barriers preventing this access.

We would like the agreed Framework and the supporting commitments of governments to result in real progress towards this aspiration becoming a substantial reality, so that future versions of the Framework can frame the right to access independent advocacy support as a human right of all Australians.

Definitions

The draft Framework includes a short section of "definitions", that do not fully represent the six advocacy models or capture fully the activities of independent advocacy.²⁹

There is often overlap across these different models of advocacy – as DANA explained in our 2010 submission on the original draft NDAF:

"The current approaches to advocacy are complementary and address different component parts of the total advocacy effort. ... Some forms of advocacy logically flow into others when the need arises.... Without separate

²⁸ Damian Griffis at Public Hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices. Transcript of proceedings - Day 1, Monday 8 November 2021.

²⁹ For explanations of the six advocacy models see [National Disability Advocacy Program | Department of Social Services, Australian Government \(dss.gov.au\)](https://www.dss.gov.au) and Jenny Pearson and Associates (2009) *Research of the Models of Advocacy funded under the National Disability Advocacy Program Final Report*, 14 September 2009.

recognition within the Framework of the value of the different advocacy approaches it is too easy for later decision-makers to take a very narrow view of individual advocacy thus losing the benefits accruing from the different approaches.”³⁰

In our submission to the 2016 Review of the NDAP (endorsed by Australian Federation of Disability Organisations or AFDO), DANA reflected that:

Describing the models of advocacy separately can imply that they are all done very separately by different organisations. The reality is that many advocacy organisations already provide two, three or four models of advocacy. The models are not interchangeable as they are used by different organisations working in different ways with different people. Some advocacy organisations have developed deep expertise in working with the particular target group they are funded for. If organisations were expected to provide all models, there is a risk of diluting and losing the detailed knowledge and expertise that is within the advocacy sector... Having specialist, expert organisations is not a drawback. What is possible is to resource advocacy organisations so that they have time to network and collaborate with other advocacy organisations, providing more seamless referral processes for the person needing advocacy.³¹

The section of Definitions needs to be redrafted so all six models of advocacy are included and accurately represented.

Disability advocacy

This definition focuses on enabling people to participate in decision making – this is certainly an aspect of advocacy but does not encompass the full breadth and scope of what advocates do. Participation in decision making processes that safeguard and advance the rights of people with disability is extremely important under to realising the rights envisaged in the CRPD. However, this statement that “disability advocacy enables people with disability to participate in the decision-making processes that safeguard and advance their human rights”, thought true, does not fully encapsulate the work of disability advocates to act on the decisions and preferences of the person with disability, in order to achieve outcomes, solve

³⁰ Disability Advocacy Network Australia (2010) Comments on the Draft National Disability Advocacy Framework.

³¹ Disability Advocacy Network Australia (2016) *Response to Department of Social Services Discussion Paper: Review of the National Disability Advocacy Program* June 2016 (Endorsed by Australian Federation of Disability Organisations), p12.

problems and safeguard their rights, interests and wellbeing. **The definition of disability advocacy should be adjusted to fully reflect its scope and purposes.**

We are pleased that the equal right to make decisions is strongly reflected in the listed Outcomes and in the Principles section, under Presumption of Rights and Capacity (including for children and young people) and under Access to Supports and Person-Centred Approach. (See further discussion of individual decision making in [Section 5](#).)

Individual Advocacy

Although this definition of individual advocacy is sufficiently general to accommodate the work of ‘professional’ paid advocates, volunteer advocates like Citizen Advocates, and the advocacy of family members, relatives or friends, it does not specifically refer to the support provided by Citizen Advocacy, family advocacy and other advocacy organisations to enable these one-on-one approaches to be undertaken. DANA is concerned that this lack of recognition fails to reflect the important work of organisations to facilitate advocacy support through the provision of training and resources, and the building of relationships, networks and communities.

Advocates have stressed the importance of preserving diversity in the models and forms of advocacy available around Australia:

“...we have to keep the diversity in advocacy. We need all forms of advocacy, the crisis responses, individual... advocacy, we need the systemic. We need all of those aspects of advocacy to be available for people including those freely given natural relationships which we know are fantastic safeguards for people.”³²

References to Citizen Advocacy, family advocacy and legal advocacy should be included, with their own definitions or at very least as examples of individual advocacy that are included under this broad definition of individual advocacy.

Self Advocacy

The definition of Self advocacy as “undertaken by someone with disability who speaks up for and represents themselves”, **should be adjusted to additionally reflect the collective work of Self Advocacy groups to make change.**

³² SA Advocate, DRC Advocacy Recommendations Meeting 3, 31 May 2022.

“Self-advocacy groups are groups that are run by people with disability who join together to support each other to listen, hear and learn from each other. Self-advocacy groups provide opportunities for members to learn and speak up about their rights, have a say about the services they use and want, and collectively work together to make changes happen.”³³

Advocates have expressed concern that the definition of Self Advocacy in the draft Framework does not actually fully reflect the advocacy of Self Advocacy groups that is encompassed in the shorter definition in current NDAP funding agreements, which describes Self Advocacy as supporting “*people with disability to advocate for themselves, or as a group*”. Although the draft Framework includes a specific sentence noting that “support and training for self-advocacy is available through community-based groups” this explanation does not adequately reflect the significant capacity building, advisory and leadership work undertaken by Self Advocacy groups and the organisations supporting them, which often extends far beyond individuals advocating for their own needs to considerable systemic advocacy for the needs of those in the group and others with similar experiences.

A disability advocate from Victoria commented:

The long history of group self advocacy by people with intellectual disability is not reflected in the Advocacy Framework at all. This is despite the fact that both State and Federal governments have and do fund group self advocacy. It’s a glaring omission.

See further discussion of Self Advocacy, leadership and representation under [Section 3: Self advocacy and representation](#) and [Section 5: Representation and Participation](#).

2. Framework Principles

The Submission Guide asks: “*Are the principles of the NDAF appropriate for guiding the delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS?*”

³³ Description of Self Advocacy from NDIS Companion Paper: Supporting you to make your own decisions (2021) p5.

The draft NDAF Principles are rightly informed by CRPD understandings of disability and human rights.

DANA is strongly supportive of the principles described as guiding the provision of independent advocacy for people with disability, under themes of:

- Presumption of Rights and Capacity
- Access to Supports (including communication and decision making supports)
- Participation and Inclusion (See further discussion in Section 3: Active involvement of people with disability) and Section 5: Representation and Participation)
- Justice
- Person-Centre Approach
- Respect for Intersectionality and Diversity
- Safeguards

DANA is also strongly supportive that specific principles in-line with the Closing the Gap National Agreement guide the development of improvements to meet the needs of Aboriginal and Torres Strait people with disability be included.³⁴ Partnerships and shared decision making with First Peoples Disability Network (FPDN) and the Aboriginal and Torres Strait Islander community controlled sector in the design and implementation of disability advocacy is absolutely vital.

In the first paragraph under Principles, the Framework specifically mentions the NDIS Quality and Safeguarding Framework and the NDIS Information Linkages and Capacity Building (ILC) program as informing and being supported by the Framework. DANA suggests that intergovernmental commitment and cooperation to provide independent disability advocacy are crucial not only to the safeguarding, quality and capacity building goals and components of the NDIS, but to the broader scheme's overall success. Therefore, **the *National Disability Insurance Scheme Act 2013* should also be listed in the Framework.**³⁵

³⁴ See [National Agreement on Closing the Gap | Closing the Gap](#)

³⁵ The *NDIS Act 2013* specifically acknowledges the role of advocacy in Section 4, Subsection 13: *The "role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:*
(a) promoting their independence and social and economic participation; and
(b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
(c) maximising independent lifestyles of people with disability and their full inclusion in the community."

While it is appropriate that the National Disability Advocacy Framework is guided by the principles and priorities of the CPRD it is important that guidance is also drawn from other relevant human rights treaties. Persons with disability are also women, indigenous, children and from diverse cultures. Application of the UNCPRD should not be to the exclusion of consideration of the way in which rights are framed and promoted and achievements are measured by the United Nations for these specific population groupings. Depending on the issue involved it is highly likely that one of the other United Nations treaties will be of equal or more value in guiding the advocacy to be delivered for people belonging to these groups.³⁶ The other relevant United Nations human rights treaties are:

- the International Covenant on Civil and Political Rights (ICCPR)
- the International Covenant on Economic, Social and Cultural Rights (ICESCR)
- the International Convention on the Elimination of All Forms of Racial Discrimination (CERD)
- the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW)
- the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT)
- the Convention on the Rights of the Child (CRC)³⁷
- the Declaration on the Rights of Indigenous Persons (UNDRIP)³⁸

Therefore, **other relevant international human rights treaties should be included in the list of documents in the Principles section of the Framework.**

In relation to the right to pursue any grievance or complaint, “without fear of retribution or disadvantage” should be added. This would recognise the real hesitancy and fear many people with disability experience

See further discussion of the fear of retribution or other consequences of making a complaint under [Section 3: Accessing complaints mechanisms](#).

Under Person-Centred Approach, the principle that “advocacy should be directed by the will, preference and rights of the person with disability” should be added.

³⁶ Disability Advocacy Network Australia (2010) Comments on the Draft National Disability Advocacy Framework.

³⁷ See links to the full text of each treaty, including Optional Protocols: [International human rights system | Attorney-General's Department \(ag.gov.au\)](#)

³⁸ See [United Nations Declaration on the Rights of Indigenous Peoples](#). For an example of targeted resources underlining the intersections between these sets of rights, see FPDN's [Let's have a yarn about advocacy - FPDN](#).

The need for advocacy support to meet the diverse needs of people with different disability types and multiple disabilities should be better represented in the principles.

The needs of people with complex communication support needs could be better reflected in the Principles or elsewhere in the Framework. The “Communication Bill of Rights” has received widespread support in the international Augmentative and Alternative Communication (AAC) community.³⁹ This document offers guidance on how to fully support the rights of people with complex communication support needs to receive information, make choices and be supported to communicate effectively.

In addition to the above suggestions, DANA would like to draw attention to certain aspects of the “changing disability environment” that have significant impacts on the delivery of advocacy for people with disability by Australian disability advocacy organisations. This includes a brief examination of independent advocacy “in the context of the NDIS” and the current disability services sector.

The importance of advocacy in individualised schemes

Independent advocacy performs crucial functions in ensuring quality, and in safeguarding the rights of people with disability in complex systems:

“...individual advocacy is more important, now than ever, when we have a service system that is increasingly individually focused. It's much harder, through the system, to navigate - individual advocates play a crucial role.”⁴⁰

Dr John Chesterman – Public Advocate (QLD)

Without advocacy, individualised schemes such as NDIS have the potential to maintain power imbalances between service providers and people with disability that

³⁹ (American) National Joint Committee for the Communication Needs of Persons... (2016) [Communication Bill of Rights \(asha.org\)](https://asha.org/resources/communication-bill-of-rights/) from Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Ronski, M., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, 121(2), 121–138. See also Scope’s poster version: [Free Resources to Download](#)

⁴⁰ Royal Commission into Violence Abuse, Neglect and Exploitation of People with Disability (2022) *Transcript of Roundtable – Best Practice Models of Guardianship*, Wednesday 1 June 2022, p15 (See [Supported decision-making and guardianship - proposals for reform roundtable](#))

existed under block funding.⁴¹ DANA, along with advocacy and disability representative organisations have frequently called for the design and implementation of the NDIS to more effectively take into account the needs of NDIS participants who require advocacy support to effectively raise or communicate concerns, resolve issues before they escalate, or participate meaningfully in complaints resolution processes.⁴² Researchers contend that advocacy organisations play an important market stewardship role in social care quasi markets like the NDIS.⁴³

The role of independent advocates is sometimes to ensure that the grievances of a person with disability are not dismissed too quickly, without proper consideration and due process. However, the timely involvement of an independent advocate to assist a consumer in identifying and articulating the issues of concern, will often result in problems being addressed and resolved more swiftly.⁴⁴ Therefore, automatically granting access to independent advocacy when a complaint is made is one of the methods supporting the early resolution of complaints.

As noted in the Quality and Safeguarding Framework Consultation Report:

“Many stakeholders (including people with disability and their families, as well as advocates) said that while family members will often play an important role in supporting people with disability, independent advocacy services and peer support networks also have important functions. These services were identified as particularly, but not only, important to people with few natural supports and people with cognitive disability. In the workshops, people with disability talked about the need for ‘someone in my corner’ who is independent of the NDIA and of providers... The consultation also identified an important role for self-advocacy supports to empower people to make choices and advocate for their rights, and for systemic advocacy to identify trends and issues at the system level”⁴⁵

⁴¹ Laragy, C., Fisher, K., Purcal, C., & Jenkinson, S. (2015). Australia's Individualised Disability Funding Packages: When Do They Provide Greater Choice and Control. *Asian Social Work and Policy Review*, 9(3), 282-292.

⁴² Joint DANA and AFDO *Submission on National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017* (2017), p 15.

⁴³ Celia Green, Gemma Carey & Eleanor Malbon (2022): Advocacy as market stewardship in social care quasi-markets, *Public Management Review*, DOI: 10.1080/14719037.2022.2084771

⁴⁴ *Ibid.*

⁴⁵ The Consultation Report of the Quality and Safeguarding Framework (December 2015) in Section 3.2.2

More recently, the Disability Royal Commission has reiterated the important role of disability advocacy and representation:

“Advocacy and representation enable people with disability to have their voices heard at all levels of society and to influence issues of deep concern to them.... We have heard from many advocacy and representative organisations that increased advocacy is a key measure to address violence, abuse, neglect and exploitation and would lead to a more inclusive society. We have also heard that there is a lack of advocacy services, including for First Nations people with disability and people with complex needs, and that existing advocacy services are under-funded.”⁴⁶

The NDIS and advocacy demand

Prior to the enactment and implementation of the NDIS, DANA explained that independent advocacy would remain extremely important under the new scheme of disability supports, stating:

“the demand for advocacy is likely to grow and change in the proposed new system.”⁴⁷

Because of reasons outlined above and others, this position paper by DANA correctly predicted that there would be increasingly high demand for advocacy, including because many people with disability found it difficult to navigate the new scheme or wished to challenge or appeal Agency decisions about their eligibility or plan. With the introduction of a new stream of advocacy funding dedicated to assisting people with “External Merits Review” or NDIS Appeals to the Administrative Appeals Tribunal, some of this increased demand was specifically addressed by the Federal Government. However this stream of funding has not kept pace with the significant increased demand for advocacy support for people taking appeals to the AAT.

In 2015 DANA ran several surveys of advocacy organisation; collecting information about organisational issues, advocacy and the NDIS, and the independent advocacy workforce.

⁴⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), p18.

⁴⁷ Disability Advocacy Network Australia (2012) *Independent Advocacy and the NDIS*. See also Disability Advocacy Network Australia (2013) Federal Election Call to Parties

What are the main triggers for a person needing an advocate in regards to NDIS participation?

Not understanding processes and what NDIA can do; Not being provided with enough knowledge/info to make choices; feeling overwhelmed by the guidelines/legislation; feeling they are not listened to or respected for their lived experience

What difference has it made to the outcome for the client to have an advocate involved?

The client's confidence to make complaints improved as well as consideration of how the client might use the funding to achieve a better outcome (i.e. leave the unresponsive service provider and pursue different options).

Has your organisation experienced any barriers to providing advocacy to clients who are participants in NDIS?

... people are not receiving information about how to get support and advocacy. The NDIS and other key websites do not mention how to go about appealing decisions in clear enough language.

We have no capacity in [our region]. We were already at full capacity prior to NDIS

We are doing extra work with no extra funding.

DANA has heard from organisations around Australia who deliver NDIS Appeals advocacy this stream of funding has been completely overwhelmed by recent levels of demand.⁴⁸ The current high level of demand for support with NDIS appeals has been well-documented in this joint submission representing a network of advocacy and representative organisations NDIS Appeals advocates and lawyers, which was jointly authored by Disability Advocacy NSW, Your Say Advocacy Tasmania and Villamanta Disability Rights Legal Service.⁴⁹ This submission is an example of the the systemic overview that advocacy organisations can present to government decision makers, including practical solutions and improvements to service systems, which will strengthen the outcomes for people with disability.

⁴⁸ See further information and links to media: [National Disability Advocacy Program funding announcement | Disability Advocacy Network Australia \(dana.org.au\)](#)

⁴⁹ See Disability Advocacy NSW, Your Say Advocacy Tasmania and Villamanta Disability Rights Legal Service Inc. (2022) *National Disability Insurance Scheme appeals at the Administrative Appeals Tribunal* p 9. See [Policy and Law Reform - Villamanta Disability Rights Legal Service](#)

Rachael Thompson of Rights Information and Advocacy Centre (RIAC) told ABC Radio, that so many people with disability are appealing their NDIS funding cuts advocacy organisations are having to turn them away.

“We’re turning away people that we would never have said no to before, but we just don’t have any more capacity.”⁵⁰

Segregation and Isolation

A major barrier to complaints or to the reporting of abuse, violence or neglect, is the fact that many people with complex and significant disabilities continue to live institutionalised and “shut in” lives in segregated settings such as group homes, boarding houses, hostels or aged care homes.⁵¹ This is particularly acute where a provider delivers all support for an individual, eliminating any opportunity for person with disability to seek help from someone who is independent of that provider.

“Many services have ‘whole of life’, so [people with disability] don’t have any opportunity to make a complaint.

...can list the services who have whole of life, and who go to the planning meeting with them, so no option of changing services in the face of their [service provider]”⁵²

“I have seen it frequently in residential aged care facilities, so I’m talking about older people who have disabilities, and I think the common denominator tends to be people who are very isolated who don’t have an advocate or a family member or someone close to them looking in on them and checking that things are okay. That’s where I believe, abuse tends to flourish or can flourish.”⁵³

The Disability Royal Commission stated in their Interim Report:

“Independent advocacy and self-advocacy emerged as key factors in promoting the safety of people with disability living in group homes. If people with disability are aware of their rights and how to exercise those rights, they

⁵⁰ See further: [Disability advocates forced to turn people away as appeals to NDIS cuts grow - ABC Radio](#)

⁵¹ See joint campaigns against segregation in 2020 and 2011: [#EndSegregation – Over fifty disability rights and advocacy organisations call for an end to segregation](#) and [Shut In campaign – People with Disability Australia \(pwd.org.au\)](#).

⁵² TAS Advocate, November 2020 Zoom workshop with DRC

⁵³ ACT Advocate, October 2020 Zoom workshop with DRC

are more likely to recognise and report threats to their safety or wellbeing. The safety of residents is further protected when family members or other trusted supporters advocate on their behalf.”⁵⁴

One advocate from Victoria proposes:

“there needs to be explicit recognition (perhaps in ‘Respect for Intersectionality and Diversity’) of how social isolation increases risks for individuals and so warrants advocacy effort to reach and support these groups.”

Refer to [Section 5: Improving access to advocacy](#) for consideration of strategies to strengthen the capacity of independent advocacy organisations to reach people who are segregated and isolated.

3. Framework Outcomes

The Submission Guide asks: “*Are the outcomes of the NDAF clear and achievable? Should different ones be included?*”

The draft NDAF outcomes are rightly informed by CRPD principles and understandings. DANA is strongly supportive of the Framework including these identified Outcomes, reflecting:

- human rights principles
- civil and political rights
- economic, social and cultural rights;
- understandings of diversity and multiple disadvantage; and
- the need to strive towards quality independent advocacy support being available and accessible from all locations across Australia, (including in regional, rural and remote areas).

Comments on outcomes

DANA has some insights and further comments regarding what is needed to achieve specific draft Outcomes, including that people with disability:

⁵⁴ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), pp253-255.

- “can access a complaints mechanism and independent support and advice when providing feedback or making a complaint in relation to the supports and services they purchase or engage.”
- “have the opportunity to be actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them.”
- “are supported to have effective interactions and access to disability supports and services and/or mainstream services and facilities including supportive, flexible and timely access to justice and legal advocacy”

Accessing complaints mechanisms

Consumers who have been isolated and mistreated may struggle, not only to voice a complaint, but to even identify and recognise what they have experienced as abuse, exploitation or neglect. The 2015 Senate Inquiry Report noted that one of the challenges for advocacy services is “having regular access to institutions and residential settings to assist people with disability in identifying and reporting abuse”.⁵⁵ The Committee also expressed particular concern at evidence suggesting that people with disability are actively prevented from accessing Self Advocacy services.⁵⁶ This is consistent with many advocates observations of “gatekeeping” around people with disability.⁵⁷ These themes have also emerged in Disability Royal Commission hearings and forums.⁵⁸

DANA’s 2015 consultation with advocates, people with disability, carers, family members and support workers found that many consumers experiencing poor quality supports and/or unsafe environments often struggle to make complaints, or choose not to even try, for a range of factors. As Reinforce Self Advocate Colin Hiscoe articulated at the Living in Group Homes hearing in December 2019:

“I think you need to get there into the group homes. The biggest problem might be that no matter what you do, the people there are going to be really scared, they’re going to be afraid, they’re frightened of retribution, they’re

⁵⁵ The Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, 194.

⁵⁶ *Ibid*, 201-202.

⁵⁷ Joint DANA and AFDO *Submission on National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017* (2017), p 16.

⁵⁸ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), p18, pp180-181 p253, p387. See also Report of Public hearing 3, p113, pp317–318.

*frightened of being in trouble, they're frightened of being hit, whatever, and they're really scared."*⁵⁹

Advocates are very mindful of the genuine fear of retribution or reprisals that make it difficult for people with disability to speak up and voice complaints or report abuse. They are also aware of the fear of other consequences that may arise from voicing a complaint including facing legal processes, changes to relationships, or loss of community connections. This was articulated well in responses to our 2015 survey and in a 2020 workshop:

*"It's too hard. There might be retribution. I could lose the service all together. I will hurt people's feelings. The police won't believe me. Mum or Dad will be upset with me. In a small community, everyone will hate me for rocking the boat..."*⁶⁰

*"Without independent advocacy there is a lack of reporting back to the client and the client is also vulnerable to reprisals by individual support staff if the quality of service directly relates to them."*⁶¹

"I just wanted to bring it back to that setting where the service providers are saying that for this to be financially viable, we have to provide you with all of your supports and your support is tied to your accommodation and I guess there comes that risk of 'if I piss off my service provider, I'm going to lose my house, you know, so I will put up with being potentially abused, neglected, exploited, having restrictive practices put against me because I'm really worried about my housing and where I'll go or if I can find another place in another home –'

*[Colleague: "Or I'll lose my community. It's not just that they will not have a home because even if they are moved to another home because they're unhappy with the service provider, they've lost their community and it can be very challenging for people to rebuild that and it can be very challenging for people to get to that if they've moved"]*⁶²

DANA has long argued that accessible and effective systems of complaint management and resolution are critical to the protection of individuals with

⁵⁹ Hearing on Living in Group Homes - Transcript of proceedings - Day 4, Thursday 5 December 2019, Melbourne.

⁶⁰ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

⁶¹ DANA's 2015 *Quality and Safeguards* survey - Response from WA Advocate

⁶² WA Advocates, October 2020 Zoom workshop with DRC

disability.⁶³ The experience of the advocacy sector is that well-functioning accessible complaints mechanisms can effect change and improvements in the disability service system and other systems. However, far too often the capacity to pursue a complaint through existing mechanisms has been hampered by inadequate access to independent advocacy or even a lack of awareness among consumers of their right to complain.⁶⁴

Existing complaints processes have often been ineffective in protecting individuals with disability who have lodged a complaint, leaving people vulnerable to intimidation and abuse. The power imbalance that exists between the consumer and service provider prevents people from pursuing their rights, instead resorting to finding ways of surviving within the system.⁶⁵ During recent consultations, advocates have expressed fear that the barriers to making complaints and ineffective oversight mechanisms mean that many people with disability (especially those experiencing restrictive practices) are effectively blocked from accessing an independent advocate:

“...we don't know what we don't know and the case that we're looking at, the use of chemical restraints and the over-prescription of medication used incorrectly in some of the group homes, they're certainly not going to be seeking an advocate for the resident. So I just think we don't - I think the problem is probably worse than we think in a lot of senses because again, as everyone said, the NDIS Commission is a toothless tiger, so people don't even bother going to report to them. So where do you go? I think that's a real issue that we don't know - we can only speculate how big the problem is because the person themselves is not in a position to seek out advocacy.”⁶⁶

“Many people who are subject to RPs [Restrictive Practices] have significant intellectual disabilities and cannot speak up for themselves. If their family/SIL [Supported Independent Living] provider all want RPs to make life easier, the person subject to RPs needs an independent advocate to speak up on their behalf as their interests do not always coincide with the interests of those caring for them”⁶⁷

⁶³ For instance, 2011 *Position Statement: NDIS Complaints and Review* and 2013 *Federal Election Call to Parties*.

⁶⁴ The Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, Final Report 194-197.

⁶⁵ Bill, H. (2015) *A Missing Piece: The need for independent advocacy in the NDIS Quality and Safeguarding framework* (Honours Report).

⁶⁶ VIC Advocate, February 2021 Zoom workshop with DRC

⁶⁷ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

“As an advocate I have been to guardianship hearings to support clients but not ever contacted by a service regarding restrictive practices.” “I have had some providers make referrals to advocacy but other providers are clearly wary of advocacy services.”⁶⁸

Active involvement of people with disability

To achieve the outcome that “People with disability have the opportunity to be actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them”, there must be adequate funding to Disabled peoples, representative and advocacy organisations to support individual and group capacity building and meaningful participation in co-design, advisory groups and other consultative activities. According to the United Nations Special Rapporteur on the rights of persons with disabilities:

“The ability of representative organizations of persons with disabilities to access funding and resources is an integral and vital part of the right to freedom of association. Funding stability is essential to ensure effective and sustainable work programmes, enabling organizations to grow...”⁶⁹

Too often we see lip service to this principle, without dedicated funding to facilitate the inclusion and meaningful participation of people with disability, especially those with intellectual disability, acquired brain injury or other cognitive impairment. DANA recommends funding to advocacy and disability representative organisations to enable the provision of individualised support, for instance with meeting preparation, and during and after meetings, including Easy English materials.⁷⁰ These supports should be provided by people who are independent and skilled in supporting decision making without influence.

The strength and expertise that Disability Representative Organisations contribute needs to be valued and adequately funded by governments.

See draft recommendations in [Section 5: Representation and Participation](#).

⁶⁸ NSW Advocate, March 2021 Zoom workshop with DRC

⁶⁹ United Nations Special Rapporteur on the rights of persons with disabilities, delivered to Human Rights Council at its 31st Session, 4 March 2016: [OHCHR | A/HRC/31/62: Report on the rights of persons with disabilities to participate in decision-making](#)

⁷⁰ See training and resources from Voice At The Table project: [Voice at the Table - State Government funded training with resources for Government and Peer Advisors](#)

Addressing intersectional disadvantage

DANA strongly supports the inclusion of Outcomes focused on multiple disadvantage and responding specifically to the needs of First Nations people with disability and Culturally and linguistically diverse people with disability:

- People with disability, including those experiencing multiple disadvantage, are supported to have effective interactions and access to disability supports and services and/or mainstream services and facilities including supportive, flexible and timely access to justice and legal advocacy.
- Aboriginal and Torres Strait Islander peoples with disability will have a greater say in how advocacy is designed and delivered; have access to culturally and linguistically appropriate, and culturally safe, disability advocacy, including access to community controlled organisations delivering disability advocacy; and have access to, and the capability to use, locally-relevant data and information.
- Culturally and linguistically diverse communities, have access to culturally and linguistically appropriate, and culturally safe, disability advocacy that features the engagement and input of relevant local communities.

DANA perceives great scope for increased work to better meet the needs of First Nations people with disability and culturally and linguistically diverse (CALD) people with disability:

“Advocacy is critical for people with disability in remote indigenous communities. Most people with disability in our region have English as a second or third language and literacy levels are very low. It would be almost impossible for people with disability to manage all the requirements of Government without advocacy support.”⁷¹

This work must occur in close collaboration with FPDN and National Ethnic Disability Alliance (NEDA). Damian Griffis, FPDN CEO told the Royal Commission:

“the demand certainly from a First Nations perspective is so great that it's impossible to meet individual advocacy needs...”⁷²

⁷¹ NT Advocate, April 2021 Solutions focused workshop with DRC

⁷² Damian Griffis at Public Hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices. Transcript of proceedings - Day 1, Monday 8 November 2021, p64.

June Riemer, Deputy CEO of FPDN also underlined that:

“The funding of the NDAP program needs to be further monitored and supported, there’s currently not enough advocates nationally.... There is not enough First Nations advocacy groups, and we need more work around supporting self-advocacy for people with disability.”⁷³

In a 2020 DANA workshop, one advocate from Queensland highlighted that building relationships of trust with local First Nations communities takes time:

“We identified in one of our rural/regional areas, it was not being covered and there was a lot of people missing out on NDIS access. There were a lot of First Nations communities. We were able to get funding for one year for supporting NDIS access, but the barriers were still there, and that took a lot of building those relationships.

Some of those areas still weren’t covered and there is a massive concern out there that in remote and rural areas where a lot of communities are, that the supports are not there. ...It takes a long time and a lot of the areas are not covered. That’s the barriers I feel that we face”⁷⁴

A Self Advocate from NSW highlighted the importance of responding to the diversity of First Nations people and of building local connections:

“... every Aboriginal community is not the same. We are very different, we are very diverse, we have different needs and different resources. We have different aspirations and different interests as well.

We cannot do a blanket cover for everybody, you know? Everyone has to be looked at individually throughout Australia. You have got traditional people, you have got urban people, who all have different needs. Some are isolated, socially isolated as well as geographically isolated. One solution does not cover all.”⁷⁵

⁷³ June Riemer at Public Hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices. Transcript of proceedings - Day 1, Monday 8 November 2021, p68.

⁷⁴ QLD Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

⁷⁵ NSW Self Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

Significant access issues affect multicultural communities:

“Making sure that CALD people have equity and access to the NDIS is really important, but there is still a big lag time and CALD people are still finding it hard to engage,”⁷⁶

“... in [our area], it's a very multicultural area and we come across people with disabilities and their families that are not connected to services, don't even understand, never heard of advocacy. We've met somebody recently who's 45 years old, intellectual disability, not on the NDIS, being cared for by his 95-year-old mother from a CALD background that is no longer able to look after this person. So I think the Government needs to - and even advocacy organisations maybe have a little bit more funding to go to have more of an impact on people from cultural and linguistic backgrounds in a point of view from providing information, basic information, as to what services are out there and how to access advocacy organisations.”⁷⁷

Some jurisdictions have one or two advocacy organisations that specifically address the needs of CALD people with disability and the issues they face, but culturally appropriate support is not available everywhere. Targeted approaches are needed, but most organisations have limited time to build relationships of connection and trust with each cultural community:

“We are really aware of our lack of reach into other communities. We have made some gains in the local Sudanese community, but COVID-19 made that enormously difficult to maintain supports in in terms of accessing interpreters in a timely way... we are very aware that different community groups have different ways of working...”

One advocate from Victoria suggests that what's needed is to:

“Ensure trained culturally and linguistically diverse people are employed in advocacy, promoting disability advocacy within the communities from a human rights perspective,”⁷⁸

In addition to the work outlined in in the Outcomes regarding First Nations and CALD Communities, to address the experience of intersectional or “multiple disadvantage”,

⁷⁶ Dwayne Cranfield, NEDA CEO quoted by SBS News, 28 August 2020: [Advocates for culturally diverse Australians with disability cautiously welcome new NDIS reforms \(sbs.com.au\)](https://www.sbs.com.au/news/article/2020/08/28/advocates-for-culturally-diverse-australians-with-disability-cautiously-welcome-new-ndis-reforms)

⁷⁷ VIC Advocate, April 2021 Solutions focused workshop with DRC

⁷⁸ DANA's 2020 survey, Advocacy for people from culturally and linguistically diverse communities - Response from VIC Advocate

advocacy sector collaboration must occur with other disability representative organisations including Women With Disabilities Australia (WWDA), Children and Young People with Disability (CYDA), Older Persons Advocacy Network (OPAN) and Council on the Ageing (COTA) to ensure gender and age dimensions of disadvantage are addressed. There is currently inconsistency between jurisdictions and different regions as to whether independent advocacy organisations with a specialist focus are available. In relation to individual advocacy for children and young people, CYDA has indicated:

“The absence of child and youth specific individual advocacy services in various states and territories has real impact on our community, and we are often fielding calls from families who are at a loss in those parts of Australia as to where they can turn to for specialised support. This is particularly the case for education.”

In keeping with the stated principle of ‘Respect for Intersectionality and Diversity’, considerable work is needed to address the gap for systemic representation of the needs of LGBTIQ+ people with disability. There also needs to be funding for the development of training and networking structures to support advocacy organisations to meet the needs of all people with disability regardless of sexuality or gender identity. Collaboration with LGBTIQ+ organisations both nationally and locally is crucial.

Across different demographics, the envisaged collaboration, networking and development of training resources should include organisations with expertise in particular cohorts, particularly people with intellectual disability and people with autism. These organisations must also receive resourcing to contribute their knowledge and participate in advocacy sector development and training.

Refer to our high level draft recommendations for developing tailored advocacy approaches in [Section 5: Targeted Advocacy](#).

Access to Justice

As the Community Affairs References Committee recognised during the 2015 Senate Inquiry, violence, abuse and neglect often thrive in institutional and residential settings and people with disability experience significant barriers in seeking access to justice.⁷⁹ More recently, the Disability Royal Commission has

⁷⁹ The Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related*

received information and evidence of the considerable barriers people with disability face in accessing justice systems and processes and to the reporting and investigating of violence, abuse, neglect and exploitation.⁸⁰

“...in terms of what we found, just getting access to the justice system can be frustrated by, particularly in closed environments such as group homes, a particular mechanism of internal investigations. If the perpetrator of the violence or abuse is a group home staff, there is a lot of, ‘we investigated ourselves and found nothing wrong’. Often without external support, which can be physical in terms of having access to a phone to report, or going to a police station, they can’t further escalate to the justice system and the support providers are unlikely to provide support to do themselves in.”⁸¹

See further discussion about the barriers to accessing independent advocacy support for people with disability in segregated settings in [Section 5: Improving access to advocacy](#).

There is significant scope for advocacy on an individual level to contribute to the achievement of people with disability experiencing “supportive, flexible and timely access to justice” including through legal advocacy and non-legal advocacy. Advocates frequently support people with disability in legal matters, whether supporting them in tribunal process or in other ways. However, systemic advocacy will also be vital for achieving the relevant structural reform for realising accessible and responsive justice systems and processes.

At the Disability Royal Commission hearing on the experiences of people with cognitive disability in the criminal justice system, Janene Cootes, Executive Officer of Intellectual Disability Rights Service (IDRS) explained their approach to legal advocacy:

“I think one of the features of the way that we felt was important to do this work was to build a person’s capacity, and a big way of doing that was to involve them in the decision-making. Too often in court processes, decisions are made for people, but the more somebody can learn the way things happen and make their own decisions and have their decision respected,

dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability, Final Report, Chapter 6, p149-181.

⁸⁰ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) *Overview of responses to the Criminal justice system Issues Paper*, pp10-12.

⁸¹ SA Advocate, "Advocates Zoom In On... Criminalisation" October 2020 Zoom discussion

I think that makes a very big difference to how the person goes forward and to their skills to cope better and do better.”⁸²

Non-legal advocacy organisations have also contributed to capacity building in the legal sector and justice systems, and sometimes play a role in translating legal information to ensure the person with disability can understand and participate in justice processes:

“...one of the recommendations from the UN was that all police, lawyers, magistrates, everybody have disability training and it absolutely needs to happen because we do support people through the legal process and that's because solicitors largely don't know how to talk to people. And so people can't make an informed decision about their legal issues because they don't actually understand what their choices are because of the way that the legal fraternity communicate with them. I think we've built the capacity of a number of law firms over the last few years and so they're our go-to solicitors and they've done a fabulous job in modifying their language and making sure that people are actually understanding information. But again, where is the proactiveness in terms of where is the money to do that? There's been a lot of time and effort working with those firms and with clients over the years to get them to that stage. But the court process is so inaccessible to people. They don't understand what's happening when they get there. Half the time they can't hear because it's just the way that the courts are set up. It's really inequitable for people.”⁸³

“...there's just such a huge reliance on literacy, isn't there? So whenever I've had anything to do with the legal system and when I've been supporting people, a lot of it has been about being a point of contact because everything is via email now. If you don't have literacy, if you don't have an email address, and if you don't understand what the next step is or why it might take a little while, then that's an access issue. That's massive, it's really massive. And I guess the other thing is...just being there to be able to reframe or interpret for people so they can have a really clear understanding and also having no skin in the game saying do you need five minutes time out for people to know that they have time to consider their options and to be able to think about things.”⁸⁴

⁸² Hearing on the experiences of people with cognitive disability in the criminal justice system - Transcript of proceedings - Day 7, Thursday 25 February.

⁸³ TAS Advocate, November 2020 Zoom workshop with DRC

⁸⁴ TAS Advocate, November 2020 Zoom workshop with DRC

However significant improvement in realising equal access to justice will require major cooperation on ongoing systemic reform efforts through Federal policies, State and Territory disability justice strategies and related initiatives. Advocates often tell us about people with disability facing intractable barriers to justice:

“...a lot of our clients are finding... communicating with lawyers to be extremely difficult as they're not necessarily willing to kind of make the effort or are not trained in how to actually communicate with people with disabilities and often times the lawyers will get frustrated and either not act in the most optimal way or withdraw completely because they're unable to communicate with the client. I've had an example where the lawyer themselves was actually trying to do so by communicating through a third party at the client's direction and the lawyer was then charging the client double for that time. So they would charge for the original communication with the client and then the client would need the information communicated to their third party so then it could be explained in proper, understandable terms to the client and then the lawyer was charging them for that again, which didn't seem very fair to them at the time... there's definitely a lot of problems and there seems to be a very large gap in the support system for people with disability to engage in not just criminal justice legal services, but just legal services in general.”⁸⁵

“There are so many stories where: ‘I got given this label by a police officer, or child protection services, somewhere and that label has continued to follow me. Because I have that label the courts, police treat me this way, and that’s where there needs to be the ability to have an independent reporting process, assessment, so that I don’t walk into every court room or police station wearing the same clothes. I’m able to go to somebody who can help me to have different clothes or have someone speak for me in a way that means I’m not tainted by that report my abusive husband put in about me 25 years ago that has followed me ever since.’ That independent reporting can be the circuit breaker that allows somebody to start to be free of the system.”⁸⁶

“For people with intellectual disability, it starts from the very beginning, often not having the support they need to help them keep out of trouble and the assumption that if someone gets into trouble it is inherently their fault, as opposed to the lack of appropriate supports being provided through the NDIS or otherwise. The police all too often do not have the skills or willingness to

⁸⁵ TAS Advocate, November 2020 Zoom workshop with DRC

⁸⁶ NSW Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

respond to a person's intellectual disability, assuming they are aware of it in the first place. And that all too often leads to problems escalating: a person is having a blue with a neighbour, the police get called, the police arrive and use formal language that the person does not understand. The person gets agitated and anxious and police respond to that in an authoritarian way. The person gets more anxious and agitated and before you know it the person is in trouble not just for the general issue but for resisting arrest and assaulting a police officer as well. The court system, especially in the local courts, is so rushed and legal aid solicitors have enormous caseloads and often wouldn't recognise or respond to a person's disability or provide appropriate communication and support and so on through the system. At all levels there are major issues of disadvantage and I would argue that is a matter of systemic neglect and in some cases, abuse by police, correctional officers, or whoever."⁸⁷

"I think one of the biggest issues we have seen in our region is that somebody can identify very clearly with an intellectual disability, yet the police will go ahead without giving that person any form of support, with police interviews and carry on without that. A lot of the time [people with intellectual disability] don't really understand what they are getting charged with and they agree with what the police say. One of the biggest changes needed is to ensure that people, if they are going to be interviewed by the police, there needs to be a firm support network for that person before being interviewed. That is one of the biggest things we have come across, that there is no support for that person when the police are interviewing them."⁸⁸

"...sometimes it comes down to the individual police officer and the station. If there is a culture at a police station, there is very little we can do to change it and to get inside to help educate and upskill etc, but other stations are fantastic. And that is huge, that could just be within a couple of catchment areas. Police stations within the one LGA [Local Government Area] could all be different. I have had instances where I have said: 'don't go to that police station to lodge your family violence application, go to this other one because you will get more sympathy there'. We should not have to be doing that, we want more consistency."⁸⁹

⁸⁷ NSW Advocate, "Advocates Zoom In On... *Criminalisation*", October 2020 Zoom discussion

⁸⁸ QLD Advocate, "Advocates Zoom In On... *Advocacy for First Nations People*", November 2020 Zoom discussion

⁸⁹ VIC Advocate, "Advocates Zoom In On... *Criminalisation*", October 2020 Zoom discussion

One of DANA's draft recommendations included in [Section 5: Service Capacity Enhancement](#) is to introduce a legal advisory service for funded advocacy organisation to seek information and consult on the operation of laws and legal processes. This idea came from advocates:

"I notice some people have legal representation within their organisation, which is great, but some small groups don't have it. From our point of view, it's actually being able to access better legal representation and advice, if we're going down those lines. Because sometimes that's very difficult. We are calling on lots of different organisations or people that we know, for some legal advice. Sometimes when you do have a case, and you think there needs to be some sort of legal representation, some small advocacy groups don't have that access on hand. It would be great if we could have something like that."⁹⁰

"It would be great to have a free confidential legal call service!"⁹¹

This legal advisory service would need to have specific expertise on the various areas of law that affect people with disability and how relevant Federal and State and Territory laws operate and interact across Australia's jurisdictions. This is one simple initiative that might address some of the barriers described above, through supporting advocates to be informed on relevant legal matters relevant to the individual with disability for whom they are advocating.

Outcomes to include

Self Advocacy and Representation

Although it is positive that Self Advocacy is included under Definitions and in the Principles section, under Person-Centred Approach, DANA would support the inclusion of an Outcome that is focused on building the capacity of people with disability to self-advocate, and/or specifically mentions the work of advocacy organisations in supporting Self Advocacy groups and activities. One advocate from Victoria suggests:

⁹⁰ QLD Advocate, "Advocates Zoom In On... *Advocacy & Abuse Prevention*", December 2020 Zoom discussion

⁹¹ VIC Advocate, "Advocates Zoom In On... *Advocacy & Abuse Prevention*", December 2020 Zoom discussion

“Add self-advocacy as an “Outcome”, e.g. ‘people with disability can self-advocate by speaking up and representing themselves by increasing/building their capacity’.”

Although there are self advocacy groups and training opportunities delivered around Australia, Victoria’s Reinforce Self Advocacy group and Self Advocacy Resource Unit (SARU) have been instrumental in building and maintaining strong networks and expertise in that state.⁹² At the Disability Royal Commission hearing on living in group homes in December 2019, AMIDA Projects Co-ordinator Pauline Williams explained:

“So the Self Advocacy movement – and it’s a civil rights movement, really, that grew up at the time that people were fighting to have institutions closed, and self-advocacy groups around Victoria and Australia are, you know, very poorly funded, I would have to say, but people have fought over the years to come together because they know that their voices are stronger when they come together, ... it provides that sense of, “I’m not alone and I can maybe do something about this and get some support.” And we – we think that it plays a big role in sort of safeguarding people’s rights if they’re – if they’re strong self-advocates who stand up they’re less likely to have their rights infringed. And it would be really great if that model could be rolled out across Australia. I think it’s been very successful in Victoria.”⁹³

Self Advocacy and its role in “empowering people with stick up for themselves” can play a crucial role in safeguarding the rights of people with disability to live free from violence, abuse, neglect and exploitations and to access quality supports. Building personal capacity to self-advocate goes beyond strengthening individual safety. One Victorian advocate explained the potential roles that trained Self Advocates can play in oversight and protection of other people with disability:

“...about accessing closed environments because the people who need to be accessing those environments - Advocates are important but Self Advocates are even more important. They see the things we don’t see and know what they mean. They see the micro aggressions, they see the closed door. They understand the context in a way that somebody who has never lived or worked or spent significant time in such a setting doesn’t understand it. We

⁹² Prof Christine Bigby (2015) *Self-Advocacy and Inclusion – A Summary of the Study ‘What can be Learned from Speaking Up over the Years?’* Living with Disability Research Centre, La Trobe University, Victoria.

⁹³ Hearing on Living in Group Homes - Transcript of proceedings - Day 4, Thursday 5 December 2019, Melbourne.

need to be breaking down the barriers between who is a trusted person and who is some charitable object of a service provider and see people with disabilities as having useful and valuable experience that they should be able to be paid to provide to others and get out in the community and do that...”⁹⁴

One Tasmanian advocate also highlighted the preventative role that Self Advocacy training can play, in influencing the quality of supports provided to people who are “connected to advocacy”:

“...the preventive, so it's been really strongly evident... we co-facilitate Self Advocacy meetings monthly around Tasmania with members, and support workers say to us that just the fact that they have.. that... clients have or members have an invitation to attend a Self Advocacy meeting with [our organisation] on a monthly basis is a prevention and they say this person in a four-bedroom group home who attends gets better treatment, because the staff are aware that they're connected to us, than the other three people in the group home.

So that's a really absolute stark example of the value of when they know people are connected to advocacy, that they're actually... they're a bit more aware and a bit more conscious and it's unfortunate for the other three people in the home, but it's fairly strong evidence that it actually works and it is a prevention.”⁹⁵

In recent years, some excellent Self Advocacy, and disability representation and advisory projects have been funded through the NDIS Information, Linkages and Capacity Building funding stream and other sources. This funding has largely been project-specific and short term. In terms of recurrent core funding Self Advocacy has limited resourcing, as Mary Mallett told the Senate Community Affairs References Committee in 2015:

“Time and time again, what the advocates are telling us and what they see is that people do not complain—for many reasons. In the first place, they do not know their rights. They do not know they have a right to complain, and one of the few groups who educate people with disability about what their rights are is advocacy organisations... That really important arm of advocacy, which is Self Advocacy by and for people with disability themselves, almost does not

⁹⁴ VIC Advocate, February 2021 Zoom workshop with DRC

⁹⁵ TAS Advocate, April 2021 Solutions focused workshop with DRC

exist. It is done off the side of the desk mainly. Advocacy in general is badly funded; Self Advocacy has nothing really.”⁹⁶

“It happens relatively well in Victoria because the Victorian government fund a small Self Advocacy resource unit. It is the only one in the country and it makes a big difference in Victoria. It is one of the reasons Self Advocacy exists much stronger there than anywhere else and almost not in the rest of the country.”⁹⁷

DANA would like to see intergovernmental commitments to increased funding for Self Advocacy training and groups, to teach people with disability about human rights, speaking up and advocacy. Advocacy organisations should also receive secure ongoing funding to maintain ongoing Self Advocacy groups and networks, so that Self Advocates can attend regular meetings to share knowledge about rights and support each other to protect these rights.

The Framework should include an Outcome about building the capacity of people with disability to self-advocate.

See draft recommendations about enabling more Self Advocacy training, leadership and representation under [Section 5: Representation and Participation](#).

Systemic Advocacy

Whichever model or models of advocacy they are involved in, DANA has heard that disability advocates deeply value the role of systemic advocacy in working for change “to ensure the collective rights and interest of people with disability are served through legislation, policies and practices”:

“...I do feel sometimes very frustrated when I am challenged with a systemic issue with a service that just basically - like I've heard so far... ‘it's too hard’, ‘we've done what we can’, and the onus of responsibility is always back on the client who is in a very vulnerable position...”⁹⁸

⁹⁶ Mary Mallett quoted by Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, Final Report p197.

⁹⁷ Ibid, p 198.

⁹⁸ VIC Advocate, February 2021 Zoom workshop with DRC

“Individual advocacy is important, but where there is a systemic/cultural problem in an agency, then this needs to be addressed at a higher level rather than just chipping away at each case one by one...”⁹⁹

“...for example, someone comes to me with a communication issue and then we identify they haven't had an aged care assessment and then when I'm talking to the communication provider, there's just no access for people with disabilities and then I'm putting a systemic issue to them and trying to get that changed within the provider so that for other people in the future they will never have to use an advocate to resolve this issue, the provider can resolve it themselves. I think that the role of systemic advocacy is so important in this sort of ...preventive of abuse and neglect... and if we just had more time and more funding for systemic advocates, that would be amazing because we've got all of these clients that have crisis issues. And if I have the time I can put together these files, but they're really time-consuming... but I think systemic advocacy is just so important.”¹⁰⁰

There is a definition of “systemic advocacy” included and a reference in the Outcome about improving coordination and communication between relevant entities that this includes “promoting linkages between individual and systemic advocacy”. However, the important role played by systemic advocacy is not well represented in the draft Framework. An advocate from Victoria commented:

“...as we are well aware, systemic advocacy can reduce the barriers for individuals, and so reduce the demand for individual advocacy. It needs to be included/recognised/supported as part of an holistic approach.”

The Framework should include an Outcome about systemic advocacy, such as “there are systemic improvements reducing the barriers and disadvantage experienced by people with disability”.

Strong commitments to funding systemic advocacy and representation activities would also be investments in identifying and remedying systemic barriers that drive the current high levels of demand for advocacy on an individual level. In 2014, the Productivity Commission recommended in relation to the civil justice system that:

⁹⁹ DANA's 2020 *Child Protection Systems* survey, Response from QLD Advocate

¹⁰⁰ SA Advocate, April 2021 Solutions focused workshop with DRC

“Australian, State and Territory Governments should provide funding for strategic advocacy and law reform activities that seek to identify and remedy systemic issues and so reduce demand for frontline services.”¹⁰¹

Furthermore, the Productivity Commission considered that *“strategic advocacy and law reform that seeks to identify and remedy systemic issues, and so reduce the need for frontline services, should be a core activity of [Legal Aid Commissions] and [Community Legal Centres].”* Similarly, all advocacy organisations should be additionally funded so that they can contribute to and inform broader systemic advocacy efforts, whether or not they are a systemic advocacy organisation.

The Framework should have a stronger focus on the valuable functions of systemic advocacy, and include commitments to increase funding for organisations performing systemic advocacy in each jurisdiction. One advocate working at a national disability representative organisations commented:

“considering the sheer amount of requests we get from federal and state and territory governments to provide guidance and help connect them with the community and ensure [the relevant group’s] voices are included in various reform/projects, etc., investment in the sustainability of the [systemic advocacy] sector is really an investment in their cross-portfolio outputs.”

In our draft recommendations in [Section 5: Target Advocacy](#), DANA has highlighted that, as systemic advocacy organisations, national disability representative organisations, both cohort-focused (e.g. age, gender, cultural identity) and disability-specific (e.g. autism, deafness) should be adequately funded to engage in their systemic advocacy and representation activities, in addition to other roles that they play in providing information, linkages and leadership development. DANA is hopeful that the newly established “National Coordination of Systemic Advocacy” function (to provide coordination and secretariat support to funded national disability representative organisations) will help evidence the demands, workload, activities, and outcomes of these organisations, and provide the federal government greater visibility of their achievements and value.¹⁰² Disability representative organisations need to be equipped to play complex roles in facilitating the [‘Active involvement of people with disability’](#) (as discussed above), information provision, linking and networking, and systemic advocacy and representation. These organisations have been under-funded and inadequately staffed to perform these roles. Disability-

¹⁰¹,Productivity Commission (2014) *Access to Justice Arrangements Inquiry Report*) Recommendation 21.1, Chapter 21.

¹⁰² See Media Release announcing secretariat funding: [Increased funding to uphold the rights of people with disability | Former Ministers and Parliamentary Secretaries \(dss.gov.au\)](#) and job description: [Coordinator - Secretariat on National Systemic Advocacy](#)

specific representation, (including for people with physical disability, people who are blind or Deaf and people with intellectual disability or brain injury) has been especially under-resourced under current funding arrangements.

As mentioned above under [Addressing intersectional disadvantage](#), there is a gap in systemic representation of the needs of LGBTIQ+ people with disability. A 2020 report from Deakin University focused on their experiences in healthcare and community concludes:

There are no easy, simple solutions to the complex ways in which LGBTIQ+ people with disability experience social exclusion and marginalisation, including in using or trying to access a host of health and advocacy services. Meaningful inclusion means from design to delivery, LGBTIQ+ people with disability work at all levels of planning and management, which values their expertise appropriately, and commits to outcomes that offer meaningful transformations in policy and practice to LGBTIQ+ people with disability.¹⁰³

Although some project work has been funded in this area,¹⁰⁴ there is no LGBTIQ+ organisation that receives ongoing funding to represent the specific concerns of Australians with disability who face intersectional discrimination because they are lesbian, gay, bisexual, trans/transgender, intersex, queer or other sexuality, gender, and bodily diverse. This systemic gap should be addressed.

4. Responsibilities, "reform" and policy directions

The Submission Guide asks: *Are the responsibilities, reform and policy directions of the NDAF relevant or should different ones be included?*

DANA respectfully suggests that the word "reform" inaccurately captures the work that is needed in relation to independent advocacy in Australia. Overall, we see a highly efficient sector that needs investment, strengthening and supporting. We perceive scope for:

¹⁰³ O'Shea, A., Latham, J., Beaver, S., Lewis, J., Mountford, R., Rose, M, Trezona, A., Frawley, P. (2020). *More than Ticking a Box: LGBTIQ+ People With Disability Talking About Their Lives*. Geelong: Deakin University.

¹⁰⁴ See joint NEDA and LGBTIQ+ Health Australia project Our Voices, Our Lives, Our Way: [Disability Inclusion - LGBTIQ+ Health Australia](#) – In 2017, MindOUT and People with Disability Australia worked together to create a webinar resource targeting LGBTI people who are or will be accessing the National Disability Insurance Scheme (NDIS): [LGBTI people and the NDIS - YouTube](#)

- streamlined reporting and compliance burdens on organisations;
- better data quality and collation in consultation with the sector; and
- improved coordination between the Federal and State and Territory levels of government

Rather than “reforming” the provision of disability advocacy, DANA would prefer the focus to be on strengthening, developing and expanding a sector that has often delivered strong outcomes on individual, group and wider systemic levels.

Responsibilities

Federal and state and territory governments must stay committed to joint funding responsibility. There needs to be a strong commitment from both national and state and territory governments to fulfilling these responsibilities and to not engaging in disputes, stand-offs or battles over funding responsibilities or the scope of funded advocacy supports.

The Framework should specify a commitment to fully funding disability advocacy organisations to meet demand and need. This commitment should include ensuring sustainability and stability of the disability advocacy sector.

It is extremely problematic to limit the scope of advocacy funding to being focused on the systems delivered at a particular level of government. People who need advocacy often present to advocacy organisations with a tangle of sometimes inseparable issues created by the barriers of overlapping systems at federal, state and territory and local government levels. Limiting funding to only advocating about systems delivered at a State or Territory level, for instance, would be nonsensical, inefficient and go against principles underlying the “no wrong door” approach to service organisation that provides or links individuals with appropriate service interventions, regardless of where they enter a system. This limit would only compound the existing complexity that advocacy organisations operate in, requiring advocates to attempt to identify and separate out problems that are not within their funding body’s jurisdiction to refer an individual to receive parallel advocacy through another program for those specific issues. People with disability often come to advocacy organisations with multiple overlapping issues, and advocates need to sort through, prioritise and address comprehensively – the effects of different government systems on their lives are often practically indivisible and advocacy solutions must consider the whole life of a person. Imposition of such a limit would likely result in greater strain on advocacy organisations, less holistic and efficient advocacy and harmful outcomes for people with disability.

DANA has heard advocates express concern about the implication that governments will continue to separately make decisions about the development, funding and management of advocacy organisations - potentially allowing for further fragmentation, disunity and uncertainty for independent disability advocacy organisations. Although we acknowledge that policy areas of shared responsibility between governments can present political and bureaucratic complexity and logistical challenges, we urge all governments to make strong commitments to work together towards harmonisation, consistency and cooperation, ensuring the disability advocacy sector is enabled to meet the needs of people with disability, (thereby living up to their commitments and promises under *Australia's Disability Strategy 2021-2031*.)

Strengthening and Developing the Advocacy Sector

The independent disability advocacy sector needs to be strengthened and developed. In areas of specific gaps of unmet need, the sector needs to be expanded, with additional funding allocated to:

- existing funded advocacy organisations to cover additional areas or new purposes, or
- organisations with specific expertise, for instance Aboriginal community controlled organisations (in collaboration with FPDN) or Autism advocacy organisations.

DANA is pleased and encouraged that after much advocacy, our organisation will receive funding from DSS to establish and develop a National Centre for Advocacy from July 2022. This represents an initial investment from the Federal Government to commence some national coordination of sector development activities, in consultation with NDAP organisations. However, for the sector co-design, networking and training development activities DANA has proposed over the next three years to achieve optimal outcomes, organisations will need to have time to thoughtfully contribute and participate in co-design and other efforts to develop and strengthen the advocacy sector.

DANA plans to continue coordinating and collaborating with the Disability Advocacy Resource Unit funded by the Victorian Government, which has provided relevant training, networking and resources for that jurisdiction. To achieve a stronger, more developed sector across all Australian advocacy organisations, it will also be important for state and territory governments to resource the National Centre for Advocacy to include advocacy organisations that are funded solely from their government to participate in these sector development activities.

In Section 5, DANA outlines high-level draft recommendations reflecting what we see as priority actions to develop and strengthen the sector. We note that these activities should be undertaken in consultation with the sector and with people with disability, their advocates and supporters.

Independent advocacy organisations have always worked to avoid, minimise and manage conflicts of interest. NDAP organisations are independently certified under a Quality Assurance process that has just completed the first 3 year cycle of audits. The organisations are audited against the National Standards for Disability Services and a strong focus in the audits is demonstrating awareness of and management of potential conflicts: detailed policies; conflict of interest registers for staff, Board members, volunteers; processes for dealing with conflicts if they arise.¹⁰⁵

DANA has been liaising and collaborating with Older Persons Advocacy Network (OPAN) on the development of an Advocacy Standard that could apply to both disability advocacy and advocacy for older people. The Standard is based on work done by OPAN to develop standards for the advocacy organisations that provide the NACAP (National Aged Care Advocacy Program) including mapping equivalence to all other applicable standards. The proposed Standard would allow advocacy providers to be accredited against a nationally recognised, objective set of quality criteria relevant to their Advocacy work rather than standards that have been designed for service provision.

The new Standard which would be used across the Aged Care Advocacy and Disability Advocacy sectors would fit well with current government intentions to improve Regulatory Alignment across departments, sectors, and programs. Once the Standard has been accepted by Standards Australia, there will be consultation with the disability advocacy sector to build consensus about practice examples that are relevant to disability advocacy.

Policy directions

DANA is strongly supportive of commitments to:

- shared responsibility for disability advocacy funding and development between Commonwealth and State and Territory governments in each jurisdiction

¹⁰⁵ Disability Advocacy Network Australia (2016) *Response to Department of Social Services Discussion Paper: Review of the National Disability Advocacy Program* June 2016 (Endorsed by Australian Federation of Disability Organisations), p14-15

- building an effective network of disability advocacy across Australia
- person-centred approaches
- policy co-design with people with disability at the centre
- supporting capacity building of disability advocates
- the development of more nationally consistent guidelines
- building awareness across the disability sector and the community of the rights of people with disability and the importance of disability advocacy
- funding accountability, equity and transparency
- evidence based data informing advocacy planning and administration
- evidence based data informing improvement of services systems
- improving coordination and communication
- implementing advocacy in-line with Closing the Gap implementation

DANA has further comments and insights to contribute on some of the elements listed in the draft Framework policy directions.

Building awareness of disability rights and advocacy

DANA is strongly supportive of intergovernmental commitments to “Building awareness across the disability sector and the community of the rights of people with disability and the importance of disability advocacy.”

In a range of consultation activities, advocates have stressed the lack of awareness of human rights, including the right to complain or to access independent advocacy support:

“...the majority of vulnerable people are unlikely to complain... Some may have no mechanism for complaining due to limited communication options or severity or complexity of their disability. Some may be complaining by way of behaviour which is not being listened to effectively. Many are unaware that they can complain or that the way things are is not the way things should be. Those few people who can complain often having difficulty negotiating the bureaucratic and limited complaints processes available to them.”¹⁰⁶

“I think many of them are so institutionalised. They wouldn't know that they have a right to complain. They wouldn't know where to go to. I mean, some work has been done in that area to improve it, but there's a long way to go, and that's why advocates are so essential to the whole process.”¹⁰⁷

¹⁰⁶ DANA's 2015 Quality and Safeguarding Survey - Response from SA Disability advocate

¹⁰⁷ ACT Advocate, October 2020 Zoom workshop with DRC

“There is a case that I'm working on to take to the Royal Commission. A person in a group home who had no outside supports. She had nowhere to speak up for her. So that capacity first of all to recognise that she was being treated badly, and secondly, what to do about that. Like... not even knowing who to speak to about that. That is part of the failure in the system, there is a reliance on people who don't necessarily have the skills and resources and understanding of those issues to speak up for themselves. That is why advocacy is so important.”¹⁰⁸

“I think people with a disability don't talk, they're not given the chance to have input into little things... how do they stand up to people and say we've been abused or neglected or exploited when they're too scared to say 'I want to have that support worker' and they're told no. If they put in something to say 'this has happened', who's going to listen to them?”¹⁰⁹

“I think that the nature of restrictive practices is that either there's an ignorance of rights, so the staff are not aware of what they're doing, or maybe they're ignoring someone's rights, and so that person is isolated... And so if there's not really a great knowledge about people's rights, they're not really going to know about advocacy either or about when to refer to advocacy. So it's sort of like a double isolation chamber.”¹¹⁰

As DANA has heard repeatedly from advocates around Australia, and has been often highlighted in Disability Royal Commission hearings, training for disability services staff in human rights principles and what constitutes abuse needs to be strengthened. However, education and awareness raising about disability rights also needs to extend across different service systems and throughout the wider population to be truly effective. One Self Advocate in New South Wales explained:

“Not just the person with a disability ...teach people about their rights and basic rights as a human being, but the people they are working with, they are the ones who need to know... You are working with a person with particular needs and particular challenges and particular concerns, so you have to think outside the square for a while and put yourself in their shoes for a while. Some workers think they know everything, but unless you work with a person with a disability, unless you walk in their shoes, you don't know anything.

¹⁰⁸ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

¹⁰⁹ TAS Advocate, November 2020 Zoom workshop with DRC

¹¹⁰ TAS Advocate, November 2020 Zoom workshop with DRC

I can speak on that from a personal point of view, some of you may know, because I am blind. I can take that experience. Speaking from that point of view. And I certainly get treated differently. Unless I stand up and tell them my rights.”¹¹¹

Proactive outreach activities into congregate or closed settings are needed. Advocacy organisations have often engaged in this human rights education and capacity building work, but have been increasingly limited by overstretched capacity and funding constraints, and also by gatekeeping and lack of access into those settings. Increased capacity for advocacy organisations to coordinate and deliver rights education and awareness-raising is a critical component of preventing violence, abuse, neglect and exploitation.

“Primary prevention in the form of community education is essential to begin the process of changing attitudes about violence and abuse... It is important to ensure that people understand their rights and have support to have their rights championed. Advocacy is a critical aspect of educating and supporting people to access their rights.”¹¹²

The achievement of this Outcome requires a focus on education/training for the disability sector and the community. Advocacy organisations are ideally situated to deliver this training and it needs to be provided by local advocacy organisations in the regions they cover, so that people with disability and support workers develop a connection with local advocates and are more comfortable to contact them when an advocate is required.

Refer to our draft recommendations to increase community awareness of, and enhance access to, advocacy for people with disability, in [Section 5: Awareness and Access](#) and the subsection on [Improving access to advocacy](#).

Evidence-based data

As DANA raised in our 2010 submission, the data currently collected by government from funded advocacy agencies has often had limited usefulness or opportunity to

¹¹¹ NSW Self Advocate, "Advocates Zoom In On... *Advocacy for First Nations People*", November 2020 Zoom discussion

¹¹² NT Advocate, April 2021 Solutions focused workshop with DRC

influence government policy and decision making, due to inconsistent reporting requirements and inadequate guidance on data collection and quality:

“Disability advocacy data collection varies greatly depending on the program under which the advocacy is funded and thus is not able to be aggregated and is not directed to delivering systemically useful information on a national level. The quality of the data collected is also variable arising from the difficulties advocacy organisations face in resourcing ongoing database development and the staff reporting development. DANA would like to work with government to address these issues so that the data collected can both provide useful information about the effectiveness of the advocacy programs and about issues that might be addressed systemically and by governments.”¹¹³

During the DSS consultation about NDAP and “Enhancing Collection and Actioning of Systemic Information” in 2013, DANA underlined that not all demand or need for advocacy is generally captured in reporting structures:

“DANA supports the notion of improved data collection including to enable stronger links between individual and systemic advocacy. We note however that this only represents one side of the relevant information, as this information naturally is derived only from clients of advocacy agencies and not from those people with disabilities who are turned away from agencies due to lack of capacity or those who cannot access advocacy because they are unaware of their right to access such support or because the gatekeepers in their lives make it impossible for them to access an advocate or for advocates to seek them out to offer support. DANA members regularly lament the difficulties in accessing people living in institutions, whether these are called residential care facilities, group homes, congregated living, or otherwise.”¹¹⁴

Over the past decade, DANA has continued to work with the Department of Social Services and others on improving the quality of advocacy data collected and published. We are currently working on a project focused on intake, prioritisation and referral processes, with a view to evidencing the unmet demand for independent disability advocacy in Australia. In our submission to the 2016 Review of the NDAP, DANA observed:

¹¹³ Disability Advocacy Network Australia (2010) Comments on the Draft National Disability Advocacy Framework.

¹¹⁴ Disability Advocacy Network Australia (2013) *Response to Draft NDAP Options Papers – Better Collaboration & Enhancing Collection and Action of Systemic Information*, p3.

“The data collected from the advocacy organisations annually through NDAP reporting could be shared widely by DSS to facilitate awareness of advocacy and the specific systemic issues that are being addressed by the advocacy agencies.”¹¹⁵

Further, that submission recommended that DSS work with the advocacy sector to plan for relevant data collection and use, stating that *“organisations need to know in advance what pieces of information are required, and be able to plan to build it into their systems.”¹¹⁶*

With the introduction and transition to using “SCORE” and the Partnership Approach to measure client satisfaction through the DSS Data Exchange (DEX),¹¹⁷ DANA has provided feedback on the inadequate adaptation and limited guidance for NDAP organisations in fulfilling their reporting obligations. Frequently, clients may not feel satisfied with the outcome of an advocacy issue, often due to intractable systemic problems and discrimination, but nonetheless have had a good experience with the support and help provided by the advocacy organisation. The system for measuring Community Outcomes “SCORE” is often a poor fit for recording advocacy outcomes.

During this project, and previously we have heard that advocacy organisations often find that requesting significant personal information can undermine relationships and trust that they build with people with disability. Advocacy organisation staff often feel it is inappropriate to ask for personal information when the person is distressed, in the middle of explaining their advocacy issue, or scared about the repercussions of speaking out.

Through focused cooperation between key stakeholders, DANA believes a better approach can be developed and implemented: refer to [Section 5: Data and Information Improvement](#) for draft recommendations.

Data collection should not create an excessive administration burden and should be relevant to the outcomes being measured under the Framework. As DANA submitted in 2010, advocacy organisations:

¹¹⁵ Disability Advocacy Network Australia (2016) *Response to Department of Social Services Discussion Paper: Review of the National Disability Advocacy Program* June 2016 (Endorsed by Australian Federation of Disability Organisations), p13-14.

¹¹⁶ Ibid.

¹¹⁷ [Home | Data Exchange \(dss.gov.au\)](https://www.dss.gov.au/home)

“recognise the importance of improving their administrative, management and governance systems but wish to do this in a way that enhances rather than diminishes their advocacy effort..”

All governments must agree to work together to streamline and build capacity for the collection of data and to remove administrative and financial burdens on organisations in complying with multiple data collection and reporting systems and ensuring effective data collation and analysis of trends. Any data collection that is undertaken should include a transparent process for sharing the aggregate data to inform systemic advocacy. Disability advocacy organisations and DANA must be consulted when interpreting advocacy program data. (When data is interpreted in vacuum poor policy decisions are made). Improved outcomes reporting and measurement should be co-designed with disability advocacy organisations and the people with disability who access their supports.

Improved coordination and communication

The Outcome about improving coordination and communication should specifically refer to the NDIS Quality and Safeguarding Commission.

The Commissioner of the NDIS Quality and Safeguards Commission has a legislated obligation:

In performing his or her functions, the Commissioner must acknowledge, recognise and respect the role of advocates (including independent advocates) in representing the interests of people with disability.¹¹⁸

Currently the draft Framework mentions the NDIS Quality and Safeguarding Framework as a key document included in the list under Principles. Despite the NDAF being informed by and supporting the implementation of the Quality and Safeguarding Framework, any mention of the NDIS Quality and Safeguarding Commission is absent. As one advocate from Victoria observed:

There is no explicit reference to the NDIS Commission and I think this is needed in the ‘Improving coordination and communication’ point under ‘Responsibilities, Reform and Policy Directions’.

One advocate noticed marked improvement following the introduction of the Quality and Safeguards Commission in their jurisdiction of Tasmania:

¹¹⁸ NDIS Act 2013 - Section 181D (3A)

"I also think it has changed a bit in Tassie now we have the Quality and Safeguards Commission. There is a clearer process for organisations and for support staff..."

"...also the pressure from organisations, because they might be aware of what they have to do to report, and they seem to be getting us in earlier. That's my experience anyway."¹¹⁹

However, more commonly DANA has heard advocates express disappointment with the level of oversight and monitoring and lack of collaboration or respect for the disability advocacy sector in the actions and approaches of the NDIS Quality and Safeguards Commission:

"...from our experience, we're finding that [Quality and Safeguarding Commission is] in the favour of the service provider rather than the participant. It's educating and hand-holding and they forget that there needs to be compliance and there's nobody coming and actually checking from the Safeguards Commission to actually visit the person and actually spend some time actually getting to know what the issues are and what's going on in the houses."¹²⁰

"...with regards to the Quality and Safeguards Commission, my impression is that most of the dialogue... if there's a complaint or reportable incident that it is between the service provider and the agency. So the service provider has the opportunity to control the narrative, so to speak and it seems as if there isn't... a proper investigation, at least according to this one case. Not reaching out to the family and doing site visits to speak with the participant... That is really a lack of proper information gathering to understand what is going on."¹²¹

"Complaints to the Quality and Safeguards Commission ...have gone nowhere and in one case we've even had to complain about the Commission because there are no outcomes and no tangible sort of investigations, you know. Even on our advice ... saying this is what you need to look at..., it's just like a chat. It's pretty toothless. I don't know if it's because they haven't got the resources..."¹²²

¹¹⁹ TAS Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

¹²⁰ VIC Advocate, February 2021 Zoom workshop with DRC

¹²¹ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

¹²² VIC Advocate, February 2021 Zoom workshop with DRC

“Quality and Safeguards is mediation. It's great if you have some kind of service agreement dispute with your provider and the outcome you want is for them to do something. But it really, really doesn't work in the cases of abuse. I had people that in lockdown, nobody set eyes on for three months other than the group home provider. I know a number of them were subject to physical abuse during that time. But when it is a service that doesn't keep records of incidents, proving that is virtually impossible.”¹²³

“...the service itself is doing the initial investigation. And then, if you do get to the Quality and Safeguard Commission, sometimes you hear language like ‘Well, it depends what the others view has taken place.’ You are not always finding that they are using the power that they have and the authority that they have to actually do something about this. In the end, people don't complain, because they won't be believed or other residents in the house see what happens when one person spoke up.”¹²⁴

“...we've experienced an issue where one of our protégés experienced some issues and because he had a guardian under the Guardianship Act, we had a lot of trouble getting an advocate in for him and we got literally told that we could not have an advocate for him. Because we have a lot of trouble with Citizen Advocates - getting them recognised... that's one thing that we'd like to see changed at some level moving forward with the Quality and Safeguards Commission.”¹²⁵

In relation to improving sector coordination and communication, during the DSS consultation about “better collaboration” among NDAP organisations in 2013, DANA emphasised that:

- *“collaboration already happens quite extensively, although to varying degrees in different states and geographical areas;*
- *...that inclusion of non-NDAP agencies and stakeholders in collaboration, whether in the individual advocacy or systemic advocacy sphere, is almost by definition essential to effectively pursuing outcomes; and*
- *...that to enhance collaboration it is necessary and essential to ensure the existence of adequately resourced bodies or structures charged with facilitating and coordinating collaboration – both at state and*

¹²³ NSW Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

¹²⁴ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

¹²⁵ WA Advocate, October 2020 Zoom workshop with DRC

national levels – as well as ensuring individual advocacy agencies have the required resources to invest in collaborative relationships.”¹²⁶

DANA sees great potential for the National Centre for Advocacy to play a significant role in proactively promoting, supporting, and facilitating “linkages between individual and systemic advocacy”, particularly if the Centre receives access to advocacy data and sufficient ongoing funding to coordinate collaboration, networking and communities of practice around specific issues and cohorts.

Refer to our draft recommendations for what is needed in Section 5, especially [Awareness and Access](#), [Sector Development](#), and [Commonwealth/State and Territory Coordination](#).

Funding accountability, equity and transparency

As discussed above under Responsibilities, Framework commitments should include ensuring sustainability and stability of the disability advocacy sector. Commonwealth, state and territory governments in addition to ensuring funding is transparent, equitable and accountable, should commit to increased funding to adequately meet demand and need for disability advocacy

Advocacy organisations need security and certainty of funding for organisational planning and sustainability. DANA frequently hears from CEOs and managers of disability advocacy organisations that short term grants of one or two years length, and last minute extensions, do not support capability building in the sector, and can result in challenges attracting and retaining qualified staff to funded programs.

For DANA’s high-level draft recommendations on what is needed to increase the capability of advocacy organisations. See Section 5, especially [Service Capacity Enhancement](#).

5. What is needed

The Submission Guide asks: *“Does the NDAF identify what is needed in the current and future disability environment? If not, what changes are required?”*

¹²⁶ Disability Advocacy Network Australia (2013) *Response to Draft NDAP Options Papers – Better Collaboration & Enhancing Collection and Action of Systemic Information*, p3.

Current disability environment

DANA has grouped high-level draft recommendations we have formulated for the Disability Royal Commission under the following themes:

- Awareness and Access
- Representation and Participation
- Service Capacity Enhancement
- Sector Development
- Targeted Advocacy
- Commonwealth/State and Territory Co-ordination
- Data and Information Improvement
- Safeguarding Mechanisms
- Sector Coordination

These draft recommendations capture DANA's current thinking and efforts to identify what actions are needed in the current and future disability environment in relation to independent disability advocacy. We note that the development of the disability advocacy work plan will require further co-design and consultation with advocacy organisations, disability representative organisations and people with disability and their supporters. However, these draft recommendations reflect recurring themes and priorities that we have heard from the sector.

AWARENESS AND ACCESS: Increase community awareness of, and enhance access to, advocacy for people with disability.

- Establish a national public information and awareness raising campaign about advocacy support for people with disability that:
 - clearly articulates the links with upholding human rights
 - highlights the need for community support for people who are endeavouring to self-advocate
 - explains conflict of interest and when an independent advocate is needed
 - is widely available in accessible formats, Plain English, diverse languages
 - highlights the role of independent disability advocacy in abuse prevention and response, including potential for earlier intervention in high risk situations

- clearly explains that anyone with disability can access advocacy support, whether or not eligible for or receiving NDIS supports or the DSP
- Include specific information about disability advocacy services, rights to advocacy, roles of advocates and benefits of access to independent advocacy in all relevant government-produced or government-funded information resources for people with disability, their families and supporters
- Strengthen awareness of the right to independent advocacy among all staff within the National Disability Insurance Agency, Services Australia, and other government agencies including at the State and Territory level (e.g. Public Guardians/Advocates, Child protection, Justice, community visitor schemes,)
- Strengthen awareness of the right to independent advocacy among all staff of disability services, including support coordinators, health, mental health and allied health, community legal sector, domestic and family violence services, financial counsellors, etc.
- Develop and fund a comprehensive outreach communication strategy specifically targeted to reach people who have barriers accessing existing advocacy services: e.g. First Nations peoples, people of CALD background, people in locked premises, people who are socially isolated, people with complex communication support needs, in rural and remote settings, experiencing homelessness etc.

See also proposed strategies for [Improving Access to Advocacy](#) below.

REPRESENTATION AND PARTICIPATION: Strengthen the inclusion and involvement of people with disability in decision making, co-design and organisational governance.

- Provide dedicated funding for advocacy and disability representative organisations to support building increased capacity of people with disability in
 - self-advocacy and advocacy skills
 - leadership and representation
 - advisory and decision making processes, including in community, public and private sectors at local, regional and national levels

- Provide funding that supports advocacy organisations to strengthen the participation of people with disability in their organisational decision-making processes and program co-design to ensure the needs of the local population are being met and their voices being heard.
- For the above activities, include resourcing that facilitates the inclusion and meaningful participation of people with intellectual disability, acquired brain injury or other cognitive impairment, through the provision of individualised support, for instance with meeting preparation, and during and after meetings. These supports should be provided by people who are independent and skilled in supporting decision making without influence. (See Voice At The Table project¹²⁷)
- Recognise and strengthen the oversight and capacity-building role of independent advocacy organisations in building understanding of supported decision making practice and safeguarding the rights of people with disability to make decisions with support, according to their own will and preferences.

SERVICE CAPACITY ENHANCEMENT: Increase the capacity of disability advocacy services to meet demand and support clients in a timely and consistent manner.

Funding enhancement to increase reach, efficiency and quality of advocacy services

- Provide additional funding to advocacy services funded by Federal and State and Territory government programs to support increased workforce capacity to meet unmet demand, address complex needs, reach people who find advocacy hard to access, reduce waiting times and waiting lists:
 - apply a robust funding formula that accounts for client complexity
 - so that people with disability who are greatest risk receive prioritised support
 - face to face support is available to those who need it
 - include support for staff training and ongoing professional development, supervision, counselling and staff wellbeing support etc.
 - include allocations for assertive outreach (and in-reach) and culturally appropriate support to people and communities who may find advocacy

¹²⁷ See training and resources from Voice At The Table project: [Voice at the Table - State Government funded training with resources for Government and Peer Advisors](#)

hard to access e.g. First Nations people, CALD community members, people with complex communication support needs, socially isolated, closed settings etc, rural and remote areas. (Funding level needs to enable organisations to engage in the collaboration, expertise-sharing, and training described under point 5: Targeted Advocacy)

- Provide consistent funding that is CPI indexed and supports advocacy service continuity and sustainability:
 - funding grants with 5 year timeframes to enable organisational planning and development, enhance staff retention (offer stable contracts)
 - apply an agreed funding formula (see #5 below) to grant allocations to adequately cover service staffing to meet demand, on costs and related non client direct services e.g. consultation/liaison with other service providers (lawyers, educators, therapists etc).
 - reduce administrative burdens on funded services of reporting etc to multiple agencies (see #5)

- Provide additional targeted funding to improve advocacy organisations system capacity and efficiency
 - streamline functions and free up resources for direct client support
 - implement nationally consistent/compatible CRM (Customer Relationship Management) systems – including funding to support tailoring/adaptation and workforce development

- Provide additional targeted funding to enable all advocacy organisations to (with DANA acting as a conduit)
 - flag systemic issues at local, regional, state and territory and national levels
 - participate in opportunities for intersectoral liaison and awareness raising and broader systemic advocacy activities

- Establish a legal advisory service that funded advocacy organisations can consult about the operation of Federal and state and territory laws they are encountering in their individual casework

SECTOR DEVELOPMENT: Develop the disability advocacy sector to enhance professionalism and consistency of advocacy support for all people with disability.

Workforce training and development

Provide funding to the National Centre for Advocacy to work in collaboration with relevant organisations and agencies to:

- Develop nationally consistent professional competencies for disability advocates drawing on existing work in development
- Develop nationally consistent tools and resources to support high quality disability advocacy practice across the spectrum of need and settings
- Explore opportunities for articulating disability advocacy specialisation e.g. complex communication support needs, supported decision making skills, people who are communicating unmet needs through “challenging behaviour” etc.
- Establish a national peer workforce network that draws on collective skills, knowledge and expertise and disseminates knowledge and evidence nationally
- Support establishment of disability advocacy communities of practice
- Explore and develop models of peer and lived experience advocacy training/qualifications and support mechanisms

Increase recognition and awareness of disability advocates

- Develop a promotional strategy to raise the profile and roles of disability advocates to disseminate across related professionals, services, communities etc.
- Increase community awareness of different models of independent advocacy, including Citizen Advocacy, (and the opportunity to volunteer and train as a Citizen Advocate), Self Advocacy groups and family advocacy supports

Disability advocacy service standard

- Implement the proposed new National Disability and Older Persons Advocacy Standard (currently being developed by OPAN and DANA)¹²⁸
- Ensure equitable staff wage levels for disability advocates
- Develop a national benchmark for disability advocacy case loads

Cross-sector development and awareness and profile raising of disability advocacy and the role of advocates

- Establish an information and awareness program for service providers/related professionals to raise awareness and understanding about the importance of advocacy for people with disability, roles of advocates, advocacy services and benefits of advocacy.

TARGETED ADVOCACY: Support the development of tailored advocacy approaches to increase access and support for identified high risk population groups to address their specific needs.

Support identified population groups with disability that are at higher risk of violence, abuse, neglect and exploitation

- Provide funding for National Centre for Advocacy to work in collaboration with relevant peaks and specialist advocacy organisations to develop tailored advocacy approaches for specific groups such as:
 - First Nations people with disability
 - Culturally and Linguistically Diverse people with disability
 - LGBTIQ+ people with disability
 - Children and young people with disability
 - Older people with disability
 - Women, girls and non-binary people with disability

¹²⁸ Older Persons Advocacy Network and DANA have been collaborating on the development of a new Advocacy Standard which is currently with Standards Australia for acceptance as a Standard

Support identified population groups with disability that require specifically tailored approaches

- Provide funding for collaborative work between the National Centre for Advocacy and relevant peaks and specialist advocacy organisations to develop tailored advocacy approaches for:
 - Specific and/or multiple disabilities (such as people with intellectual disability, people with acquired brain injury, people with autism, people with psychosocial disability or mental illness)
 - People with disability in segregated settings e.g. group homes, jails, schools etc.
 - Children and young people with disability
 - Parents and carers with disability
 - People with disability living in rural and remote areas
 - People with complex communication support needs
 - People who can behave in challenging ways when they have unmet needs
 - People with chronic health conditions

- Provide funding for both cohort-focused and disability-specific national disability representative organisations and other organisations with specific expertise to engage in:
 - their systemic advocacy and representation activities
 - consultation and collaboration to support the development of resources, training and communities of practice to support relevant tailored advocacy approaches
 - the provision of training, resources, advice and other supports directly to on-the-ground advocacy organisations, as required

This would support all advocacy organisations to effectively meet the needs of the individuals from specific groups or demographics. (With adequate ongoing funding, DANA through its role delivering the National Centre for Advocacy and National Coordination of Systemic Advocacy could play a linking and facilitating role)

Address issues arising from intersectionality that impact people with disability i.e. housing, poverty, mental health, justice, abuse, vulnerability

- Provide funding for National Centre for Advocacy to collaboratively develop with other relevant stakeholders comprehensive advocacy approaches for

addressing impacts of intersectionality that provide early support and continue across the lifespan

- Provide funding for National Centre for Advocacy and others to develop and deliver training and workforce development resources to support effective advocacy for people with disability experiencing intersectional impacts

COMMONWEALTH/STATE & TERRITORY COORDINATION: Streamlining of Commonwealth and state and territory funding and administrative systems to increase access, efficiency, improved outcomes and so that “no door is the wrong door” for people with disability

- Establish a national series of roundtables focused on disability advocacy including federal and state and territory funders, representative organisations, peaks and other key stakeholders (including people with disability who have accessed advocacy support) to:
 - review current barriers and identified gaps and systemic issues for people with disability accessing advocacy
 - develop a joint/collaborative strategy and road map to address barriers and fragmentation in access to disability advocacy support to reflect population demographics
- Establish an expert taskforce to design a disability advocacy funding model that can be applied at federal, state and national levels to enable equitable, population based allocation to address needs
 - consider collaborative funding models that support people with disability who experience multiple factors of disadvantage and intersectionality
 - consider options to streamline funding and reporting to reduce administrative burdens on disability advocacy services
 - evidence the social and economic benefits of funding increased preventative work by disability advocates

DATA AND INFORMATION IMPROVEMENT: Strengthen data and intelligence/information systems to enable collection, analysis and utilisation of high quality accessible data and evidence

Establish a National Disability Advocacy Data Taskforce with relevant expertise to:

- Developed agreed national and jurisdictional data collection systems to:
 - identify optimal approach for outcomes measurement across sector
 - enable greater efficiency and consistency of data collection
 - define agreed priority data sets
 - yield robust data with potential for aggregation, cross-system data linkages and systemic analysis
 - implement agreed processes for data release and protection of confidentiality
 - enable transparency and public sharing of high level information
 - support building an evidence base of effective disability advocacy models, approaches and systems
- Incorporate mechanism for collecting and disseminating data at federal and state and territory levels on systemic issues that adequately reflects on-the-ground experience

SAFEGUARDING MECHANISMS: develop effective systems for ensuring access to advocacy as part of safeguarding rights of people with disability

- Promote recognition of the protective role of disability advocates with all safeguarding institutions, including the NDIS Commission, human rights, anti-discrimination and complaints commission
- Strengthen organisational policies and processes for referral to independent advocacy from relevant staff within the National Disability Insurance Agency, Services Australia, other government agencies including at the State and Territory level (e.g. Child protection, justice, community visitor schemes, public guardians or advocates)

See potential strategies to strengthen safeguarding included below under [Future disability environment](#).

SECTOR COORDINATION

- Fund DANA as peak representative body to advocate for the advocacy sector (all of the recommendations would be strengthened by ensuring strong consultation with and representation of the whole advocacy sector)

Our 2016 submission to the review of the NDAP argued for recurrent funding for DANA as the national peak body for independent advocacy organisations:

The government funds a national representative organisation for disability service providers recognising that the voice of the industry needs to be heard and to have a place in policy development. Equally, the legitimate, collective voice of the independent advocacy organisations requires ongoing funding that acknowledges the value of this specific, detailed, and wide-ranging perspective.¹²⁹

Through funding commencing in July 2022 to establish and develop the National Centre for Advocacy, some of these sector development functions will be undertaken, in preliminary and initial forms, under the management of DANA.

However, our organisation has largely survived in recent years on project and/or specific funding in relation to the NDIS and the Disability Abuse Royal Commission, rather than being:

“funded sufficiently to build and develop capacity within independent advocacy organisations, disseminate information, collaborate in research, provide human rights-based analysis relevant to disability issues, participate in consultations and raise awareness of the value of independent advocacy.”¹³⁰

Future disability environment

There is scope to significantly enhance the safeguarding potential of independent disability advocacy. There is also potential for independent advocacy programs to play significant roles in relation to Australia realising the vision for equal recognition before the law envisaged by the CRPD Article 12, possibly in providing formal “decision support”, and/or Supported Decision Making training, support and referral.

Improving access to advocacy

“...there are those people who are never going to access an advocacy program of any type because they can't. They either can't speak, they don't

¹²⁹ Disability Advocacy Network Australia (2016) *Response to Department of Social Services Discussion Paper: Review of the National Disability Advocacy Program* June 2016 (Endorsed by Australian Federation of Disability Organisations),

¹³⁰ Disability Advocacy Network Australia (2016) *Response to Department of Social Services Discussion Paper: Review of the National Disability Advocacy Program* June 2016 (Endorsed by Australian Federation of Disability Organisations), p14.

*have access to communication. Some people who don't even know they are being disadvantaged, exploited...*¹³¹

In relation to safeguarding, DANA proposes there is considerable potential to strengthen the proactively preventative and protective functions of independent disability advocacy. We note that disability advocates have frequently suggested the following methods to strengthen safeguarding and improve access to independent advocacy for people with disability experiencing, or at risk of, violence, abuse, neglect and exploitation:

- Investigate legislative options to provide disability advocates with the right to access clients in closed settings (in line with NACAP older people advocates,¹³² Official Visitors/ Community Visitors¹³³)
- Explore additional funding for provision of increased proactive outreach by disability advocacy sector to identify people who are at risk of violence, abuse, neglect or exploitation
- Develop mechanisms for people with disability who are at particularly high risk to be allocated a designated independent advocate supported by adequate funding, for instance people under guardianship, and people with intellectual disability and complex communication support needs, without family or informal support, living in closed or segregated settings

As part of investigating how the safety of people with disability living in group homes or other supported accommodation can be enhanced, the Disability Royal Commission has stated that it will consider:

- *“the measures, including increased funding, needed to ensure that all residents of group homes and other supported accommodation have access to individual advocacy*
- *programs to develop the capacity of residents of group homes and supported accommodation to act as self-advocates*¹³⁴

¹³¹ SA Advocate, DRC Advocacy Recommendations Meeting 3, 31 May 2022.

¹³² National Aged Care Advocacy Program (NACAP) is funded by See also [NATIONAL AGED CARE ADVOCACY FRAMEWORK \(health.gov.au\)](#)

¹³³ Department of Social Services for the Disability Reform Council, Council of Australian Governments (2018) *Community Visitors Scheme Review – Final Report* (Authored by WestWood Spice) See [Community Visitors Schemes Review | Department of Social Services, Australian Government \(dss.gov.au\)](#)

¹³⁴ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), p257.

A legislative basis...

The *NDIS Act 2013* requires “registered NDIS providers to implement and maintain a complaints management and resolution system that”:

- (aa) *acknowledges the role of advocates (including independent advocates) and other representatives of persons with disability; and*
- (ab) *provides for cooperation with, and facilitates arrangements for, advocates (including independent advocates) and other representatives of persons with disability who are affected by the complaints process and who wish to be independently supported in that process by an advocate or other representative...*¹³⁵

In theory, registered providers have an obligation to allow a person with disability to receive support from advocates during a complaints process.¹³⁶ However, this legislative provision for independent support for people with disability affected by complaints process doesn't address that some people will need considerable advocacy support to initiate a complaint. As described above under [Accessing complaint mechanisms](#), people with disability may:

- experience fear or hesitation to voice complaints;
- lack awareness of their rights to complain;
- lack trust or confidence in complaints mechanisms; and/or
- be segregated or isolated without support to speak up.

In practice, advocates have observed providers who engage in ‘gatekeeping’ and little indication that there is meaningful access to advocacy facilitated by many providers.

“...where a SIL [Supported Independent Living] has such strict access to the premises that you have to request two weeks prior to the appointment and you're not necessarily guaranteed access. ... or you have to arrange to meet them external to the premises. It's something that occurred, that started about a year ago here ...basically around controlling - like attempting to control... the ins and outs of those group homes. At first ...we thought it was like a safety thing for the clients, but then it can be used to restrict the client from

¹³⁵ Section 73W, See [SECT 73W Complaints management and resolution system--registered NDIS providers \(austlii.edu.au\)](#)

¹³⁶ See also [NDIS Practice Standards and Quality Indicators \(January 2020\) Version 3](#). These standards include three indicators that mention the right to access advocates under the outcome headings of ‘Independence and informed choice’, ‘Violence, Abuse, Neglect, Exploitation and Discrimination’, and ‘Feedback and Complaints Management’, including some mention of providing information about that right.

*communicating with their advocates or with their coordinators of support. ...So most of the clients that this would apply to, they don't have capacity to use their hands or they have limited capacity to use their hands [to talk on a phone], so what we've relied on is just showing up to see them or they'll have a hospitalisation and the hospital will contact us and then we'll go down and visit them at the hospital. Or we make the application to go visit and then we're able to see them."*¹³⁷

*"One of the things I think we have all experienced is one of the difficulties of obtaining entry to some of the places. ... being able to visit places like aged care homes, group homes, some of them have very closed doors and they don't want you coming into see. That's one of the barriers we have. You hear little concerns. You might have a support worker who says these things about the place and it rings alarm bells, but they won't allow you access to just go and say hi. So that's one of the barriers I always find... being able to even start the process to see if things are okay in some of these places. When they won't even allow you entry."*¹³⁸

*"One of the issues in terms of the Disability Royal Commission is that access to people who are experiencing restrictive practices. ...we've had difficulty accessing people in supported accommodation settings to tell their stories because the service providers do act as the gatekeepers and I think they would have concerns about issues that might be reported by residents."*¹³⁹

*"I was just going to say that unless the workers or the organisation or the service provider with the day services is actually going to offer advocacy and actually explains to people that they can access advocacy, then it's controlled by the dog at the gate. They're not going to - I find organisations that invite advocacy in, I think that's transparent and it can be a very good thing. It can be a ...working collaboratively with. But I find that very few and far between, especially with day services. They're very protective"*¹⁴⁰

DANA believes disability service providers should not only be required to facilitate access to independent advocates once a person with disability has made a

¹³⁷ NT Advocate, November 2020 Zoom workshop with DRC

¹³⁸ QLD Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

¹³⁹ SA Advocate, December 2020 Zoom workshop with DRC

¹⁴⁰ VIC Advocate, February 2021 Zoom workshop with DRC

complaint, or after a reportable incident,¹⁴¹ but to ensure that independent advocacy is accessible for people with disability who may need support to voice a complaint or to report abuse, neglect or mistreatment in the first place. In discussions about improving safeguarding and/or about independent advocacy, many advocates have raised this idea of disability advocates having a “right of entry” to disability service premises:

“I think advocates should have right of entry and particularly around people who have no family. The services that I’m thinking of that have whole of life, they have so many people there who have no family or no other significant other and yet they do everything. They go to their planning meeting, they determine who their coordinator of supports is, and usually that’s someone who gets along with the provider and they make decisions for the person as opposed to them being part of making any of those decisions. So there needs to be some definite safeguards for those people who have nobody alongside them that can help them understand their rights and actually have a real meaningful say in things, in decisions. ... They go along with their service provider to their [agency] planning meeting and they’re not going to say in front of them, “Yes, I want...” - they don’t even know they can change services or what that might mean. So absolutely it shouldn’t be - the power shouldn’t be ...depressingly this seems like the power is moving back to the providers from what we see...”¹⁴²

“...advocates need to be able to attend the home and have a relationship so that the people in the homes are not solely reliant on the staff that care for them. They live in fear of discipline and not having someone else to speak too isolates them and leaves them to the mercy of their staff. Who do they complain to? The people who they look to for care and fail them.”¹⁴³

In the *Aged Care Act 1997* Chapter 4 which lists the responsibilities of approved providers, in requiring providers “to allow people acting for bodies that have been [funded to perform advocacy under the Act] to have such access to the service as is specified in the *User Rights Principles*.”¹⁴⁴ These principles provide further detail on the obligation of services to grant advocates access, and list, as one of the rights of

¹⁴¹ See *NDIS Act 2013*, Sections 73W, 73X and 73Z.

¹⁴² TAS Advocate, November 2020 Zoom workshop with DRC

¹⁴³ DANA’s 2020 *Segregated settings* survey, Response from VIC Advocate

¹⁴⁴ *Aged Care Act 1997* (Cth) Sections 56-58

care recipients, the right “to have access to advocates and other avenues of redress”.¹⁴⁵

A legislative basis for independent advocacy services to enter institutional, residential and service settings would allow for isolated consumers to be educated about their rights and be assisted to report incidents of abuse or neglect and make complaints.¹⁴⁶ For instance, Self Advocacy training can play an important role in assisting people with disability to identify abuse and inappropriate behaviour.¹⁴⁷ In the 2015 inquiry, the Senate Community Affairs References Committee highlighted the importance of “access to facilities for advocates” and independent Self Advocacy programs.¹⁴⁸ These themes have also been reiterated during the Disability Royal Commission.¹⁴⁹

Allocation...

People with high support needs, people who face communication barriers and people who do not have much or any informal supports, are often the people with disability supported and prioritised by advocacy organisations in triaging demand and managing limited resources. They are also often the groups of people that advocates fear do not have the means of accessing support from an independent advocate, as this may be needed to even initiate a complaint or report abuse, violence, neglect or exploitation. Advocates often voice this fear that they “*are only seeing the tip of the iceberg*” and are not able to reach those people who need support to speak up.

There is also uncertainty about whether current systems are adept at identifying who needs additional support. For instance, there is little clarity about the internal processes of the NDIA in flagging which participants (or applicants) may need additional support and whether and how they are referred to independent advocacy organisations or to other relevant safeguards.

¹⁴⁵ *User Rights Principles 2014* (Cth) made under section 96-1 of the *Aged Care Act 1997*. See also Older Persons Advocacy Network website: [OPAN - Your aged care rights](#)

¹⁴⁶ Joint DANA and AFDO *Submission on National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017* (2017), pp16-17.

¹⁴⁷ The Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, 196.

¹⁴⁸ *Ibid*, xx, 195-202.

¹⁴⁹ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020), p18, pp180-181 p253, p387. See also Report of Public hearing 3, p113, pp317–318.

"...we deal a lot with people in supported accommodation who do not have any relatives and what I have found and what other advocates have found in our organisation is that these people are extremely vulnerable. They often have no choice in the care that they have. They often have no overseeing person to look after them and, in fact, one person got moved from one house to short-term accommodation and the only reason they knew about it was because the person who was running the house rang me and said that they needed an individual advocate for this person, she didn't want to move. And I think it's really important that people who are in supported living accommodation who do not have any relatives are allocated an advocate (that has no vested interest either in accommodation or service provision) to look after their needs because it's quite obvious to us from our experience that they are often left very vulnerable..."¹⁵⁰

"...if you have someone who has a significant disability or who has communication needs, then they actually rely on their support or someone to actually contact an advocate. And that's the assumption, that they actually know what abuse is because I had one just a couple of days ago who was thrown in the shower with her... by her support workers, fully clothed. She thought they were just having a bit of mischief. So there's real... [problems with] understanding around what is abuse, but also there's a dependence on support workers to actually contact an advocate, that doesn't always happen."¹⁵¹

"...the problem is that there are so many people living in supported accommodation that don't have anyone to refer them to an advocate, that don't have an awareness of it or access to it. And if they did, it would improve the quality of their life..."

"...there needs to be a cultural change in the way advocates are viewed in a lot of settings, that the input from an advocate isn't to create trouble or to make someone's workplace more difficult, but the actual reason that we're there and engaging in the work we are engaging in. So a bit of education for the sector as well as having people assigned an advocate. If someone's got a public guardian assigned to them and no-one else in their life, no level of informal supports, or if they don't have a guardian, I think it's absolutely a requirement that they should have an advocate appointed."¹⁵²

¹⁵⁰ NSW Advocate, March 2021 Zoom workshop with DRC

¹⁵¹ TAS Advocate, April 2021 Solutions focused workshop with DRC

¹⁵² NSW Advocate, March 2021 Zoom workshop with DRC

Proactive outreach and in-reach...

Advocacy organisations have often engaged in proactive disability rights education and capacity building work in the community and in congregate or closed settings, but increasingly this outreach-type work has been limited by overstretched capacity and funding constraints, and by gatekeeping and lack of access into relevant premises.

“...because of often our long wait lists and our long - our capacity is directed towards helping individuals, we're not able to get out and do as much outreach as we would like to. So the people who may need support - if they don't know that support exists, they can't access it. So as an organisation, and I imagine as a sector, we would like to see more people being made aware that these services exist and then us being actually available to assist them without huge wait lists...”¹⁵³

“Outreach” into segregated institutional and closed settings may sometimes more accurately be described as “in-reach”. Advocates around Australia have described the incredible vulnerability and isolation created by segregated settings like group homes, day services and prisons:

“Evidence suggests those most vulnerable to abuse and neglect are those who are surrounded by paid supports 24/7, and that having other responsible adults involved in their lives, provides for strong safeguards against abuse and neglect. Many people with disabilities are abused and neglected in care because no-one from 'the outside' is ever present in their lives to bear witness and take action.”¹⁵⁴

“...I do know of a few services in particular that have sort of grown really quickly, but also while they say that - they actively discourage other services coming in to group homes to provide day service, so for somebody who perhaps needs the infrastructure of their home, it means that they don't have another organisation coming in and being a witness to how things are for them within the home.”¹⁵⁵

“Advocates... investigate allegations of abuse and can instigate protective measures to either relocate the person away from harmful situations and to advocate for improved supports, services, housing options. However, this can only occur when the person with disability themselves can be contacted and

¹⁵³ WA Advocate, October 2020 Zoom workshop with DRC

¹⁵⁴ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

¹⁵⁵ TAS Advocate, November 2020 Zoom workshop with DRC

give consent and authority for the advocate to act or a family member who has guardianship or recognised authority. Advocates can be hampered when an allegation of abuse or exploitation or restriction and control is reported if the person either does not have capacity to give consent for the advocate to act or is in a situation where the advocate cannot gain access to speak with the person.”¹⁵⁶

“...in terms of general access of advocates into prisons, I don't think prisons promote disability advocacy services. We do get contact from prisons but it's really hard to get in contact with people in prisons, it's really hard to be able to facilitate that support, and a lot of the stuff that's come through that we have got, most of it is around issues with NDIS and getting appropriate supports within the prison.”¹⁵⁷

A concept that emerged in recent discussions is “assertive outreach”, which has been used to describe some government programs delivering specific community supports like:

- specialist homelessness services;¹⁵⁸ and
- drug and alcohol services.¹⁵⁹

In Victoria, the phrase “assertive outreach services” has also been used to describe supports targeted to people with disability engaged in, or at risk of entering the criminal justice system to assist with building connection to community and support services, strengthening relationships and independence, and developing “pro-social behaviours and life skills”.¹⁶⁰

A ‘mobile outreach’ services model was developed to support people experiencing homelessness and mental illness in the 1970s and onwards.¹⁶¹ In conceptualising

¹⁵⁶ DANA's 2020 *Advocacy and Abuse Prevention* survey, Response from QLD Advocate

¹⁵⁷ WA Advocate, October 2020 Zoom workshop with DRC

¹⁵⁸ Rhonda Phillips and Cameron Parsell (2013) [What role does assertive outreach play in ending homelessness for people who are sleeping rough?](#) (AHURI Research and Policy Bulletin) See, as part of Victoria's Homelessness and Rough Sleeping Action Plan: [Reaching Out And Supporting Vulnerable Victorians | Premier of Victoria](#) (October 2018) and [Assertive outreach guidelines \(dffh.vic.gov.au\)](#); See also Homelessness NSW's Assertive Outreach Good Practice Guidelines and Resources: [Assertive Outreach Good Practice Guidelines and Resources – Homelessness NSW](#)

¹⁵⁹ Roger Nicholas, (2021) *Evaluation of the Assertive Outreach Services Program Pilot*. See [Drug and Alcohol Research Connections](#)

¹⁶⁰ Residential & Outreach Services | Australian Community Support Organisations ACSO

¹⁶¹ Morse GA, Calsyn RJ, Miller J, Rosenberg P, West L, Gilliland J. (1996) *Outreach to homeless mentally ill people: conceptual and clinical considerations*. Community Mental Health Journal. 1996 Jun; 32 (3) pp261-274. See also development of Assertive Community Treatment model in mental health services: L Stein and M Test (1980) [Alternative to mental hospital treatment. I. Conceptual model, treatment program, and clinical evaluation](#)

“outreach”, psychologist and researcher Gary Morse defined this type of support as referring to:

“contact with any individual who would otherwise be ignored or un-served in non-traditional settings for the purposes of improving their mental health, health, social functioning or to increase their human service and resource utilisation”¹⁶²

Some advocates have suggested the assertive outreach model has great potential to be adapted to a disability advocacy context:

I am in the Disability Royal Commission coordinator role - trying to engage people in this, we are [finding] assertive outreach is the best thing we are utilising at the moment to reach out to people... Those groups that don't or can't access services, haven't heard about [advocacy], don't know they have the rights to engage. So assertive outreach - we are going out, sitting at community centres and libraries. Having cups of coffee and starting to try to bring people into the program by means of the funding ...[for DRC Advocacy], we also trying to bring them into our organisation as well. It is an important point to reach the people that commonly slip through the gaps.¹⁶³

As Damian Griffis of FPDN explained to the Disability Royal Commission:

“...our advocates must have capacity to get out into regional and remote Australia. I think that still remains an untold story in many ways... The situation for many First Nations people with disability in regional and remote Australia, to be blunt, is one of abject poverty. The only way to get meaningful support to our community members out there is to go see them on country and try and seek support. So the National Disability Advocacy Program is inadequate in funding...”¹⁶⁴

Advocates have also described how additional funding for specific purposes like Disability Royal Commission Advocacy or the Decision Support pilot has sometimes enabled greater participation in the types of proactive capacity building and human rights education and awareness raising (described above in Section 4), both to work directly with people with disability, or those supporting them. These activities are

¹⁶² Gary Morse (1987) *Conceptual Overview of Mobile Outreach for Persons who are Homeless and Mentally Ill* p9.

¹⁶³ VIC Advocate, DRC Advocacy Recommendations Meeting 3, 31 May 2022.

¹⁶⁴ Damian Griffis at Public Hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices. Transcript of proceedings - Day 1, Monday 8 November 2021, p68.

sometimes described as “outreach” and can result in an increased awareness of the availability of independent advocacy and improve access for those people with disability who may not otherwise be engaged in advocacy (or other supports for which they are eligible):

“...as part of our promotion of the DRC we've actually managed to meet with service providers and that's actually been a really, really good connection in various regions and locations in terms of I guess getting them to understand about the Royal Commission. But as a side issue they know that advocacy is available and whether it be for SACAT matters or other matters they are learning about the fact that they can refer clients to our services across the board. So that outreach is really important, that letting those providers know about our advocacy services has been really valuable.”¹⁶⁵

“We do community outreach about once a fortnight but, as with all things DRC, the response is a slow burn, not a heated rush to share. We are interested in reaching street people and people in prisons. I would be particularly interested to gain access to the people in our disability justice centre.”¹⁶⁶

“Working through the NDAP program gives us an opportunity to 'discover' people's stories they may not think are relevant to the DRC - but quite often they are very relevant. Likewise it helps people learn about advocacy. It also gives us an opportunity to spread the word about the DRC.”¹⁶⁷

“I think if you look at the experience of the decision support pilot and the number of - and the identification of unauthorised restrictive practices that came with that, it actually again shows that - it's evidence of the benefits of having that kind of outreach and tapping into people in that more proactive productive way.”¹⁶⁸

“We've been doing a bit of outreach and I've been on Kangaroo Island fairly recently and there isn't much choice there with the service providers and what I'm seeing a lot of is people going to their GP and the GP suggesting perhaps

¹⁶⁵ SA Advocate, December 2020 Zoom workshop with DRC

¹⁶⁶ WA Advocate, July 2021 DRC Advocacy Check-In Survey response

¹⁶⁷ TAS Advocate, August 2021 DRC Advocacy Check-In Survey response.

¹⁶⁸ TAS Advocate, November 2020 Zoom workshop with DRC

they should look into NDIS and they have quite serious disabilities that they've just been managing on their own on their farms and things like that, and also people having strokes and injuries later in life and then trying to access NDIS. But there's nothing there that assists them to help, so we're coming in and trying to do as much as we can, but there's also really low literacy because there's few jobs so people leave school early. So they can't really just be given forms to fill out. We've got to go... it's a big time commitment to read through with them, to make sure that they know what they're going into and even if they do get NDIS, they have such a slim choice of providers and... a lot of people know everyone. If they don't want to go with that provider, they choose not to engage and then they're just not getting any services or support.”¹⁶⁹

Developing guidance and good practice standards for proactive outreach (including in-reach into segregated settings) in consultation with the advocacy sector, is a potential area of work for the soon-to-be-established National Centre for Advocacy. The “assertive outreach” tools, resources and practice guidelines developed in mental health, homelessness, justice and drug and alcohol services may provide useful approaches and insights but would need to be comprehensively adapted to the significantly different context of disability advocacy.

(Given the broad-ranging and less-defined nature of independent disability advocacy, outreach has arguably always been a component of most models of advocacy performed on an individual level, but lack of sector development and investment has increasingly curtailed organisations capacity to engage in outreach proactively and develop their practice in this area.)

As noted above advocacy outreach work can be complex and resource intensive but has the potential to reach at risk populations who may not otherwise find advocacy support accessible. DANA therefore advocates for governments to explore options for allocating additional funding for advocacy organisations to provide of increased proactive outreach by disability advocacy sector to identify people who are at risk of violence, abuse, neglect or exploitation.

Supported Decision Making

“Advocates work hard to develop trust and relationships with people, and we have the time and recognise the importance of doing that, particularly with

¹⁶⁹ SA Advocate, April 2021 Solutions focused workshop with DRC

people from culturally and linguistically diverse backgrounds where English may be their second language. If people had more access to independent advocacy and support for decision-making, we might see less need for the appointment of guardians for individuals around some decisions.”¹⁷⁰

Maureen Fordyce - Amparo Advocacy (QLD)

We understand considerable work is happening to operationalise “supported decision making” within different parts of Government, and there has also been research commissioned by the Disability Royal Commission. As described above advocates providing advocacy on an individual level often support the decision making of the people with disability they are advocating for, by providing information and explaining options in an accessible way and listening to what they want.

DANA believes the role of providing formal “decision support” is distinguishable from that of providing independent advocacy. However, given disability advocacy organisations’ independence from service provision, system of quality assurance, human rights focus and expertise in supporting people with complex communication support needs, we recommend the exploration of establishing a Supported Decision Making stream of funding.

“...individual advocates strike me as having the capacity to be able to play that role quite well if we ensure that there is that clarification of the distinction between advocate and a supporter. But there are many ways in which advocates could play that role of a paid supporter. They have governance arrangements. They have codes of practice and so on that wouldn't be too hard to change - to enable them to play their role.”¹⁷¹

Dr John Chesterman – Public Advocate (QLD)

Therefore, we recommend that researchers, policy and decision makers should:

explore and evaluate potential for disability advocacy sector to:

- deliver decision support to people with disability
- provide training on supported decision making practice
- play a supportive and linking role in ensuring access to decision support

¹⁷⁰ Royal Commission into Violence Abuse, Neglect and Exploitation of People with Disability (2022) *Transcript of Roundtable – Best Practice Models of Guardianship*, Wednesday 1 June 2022, p12.

¹⁷¹ Royal Commission into Violence Abuse, Neglect and Exploitation of People with Disability (2022) *Transcript of Roundtable – Best Practice Models of Guardianship*, Wednesday 1 June 2022, p15.

This work would require a comprehensive Supported Decision Making funding stream.

Conclusion

DANA encourages all governments to fulfil their responsibility to the citizens of their jurisdictions and agree to strong commitments to disability advocacy to ensure there is access to advocacy services for all people with disability across Australia.

Implementing these commitments would go a long way towards the Safety, Rights and Justice Outcome Area of Australia's Disability Justice Strategy: *'the rights of people with disability are promoted, upheld and protected, and people with disability feel safe and enjoy equality before the law'*.

The current inadequate funding levels, opaque and inconsistent data collection and lack of sector support and investment means that a meaningful right to access to independent advocacy is not currently the reality for all Australians with disability. All federal and state and territory governments need to undertake to invest in Australia's disability advocacy sector, taking a collaborative and coordinated approach to funding and administration that provides real certainty for organisations in planning activities and retaining staff. In some areas the sector will need to be expanded and better connected to meet the needs of specific groups experiencing intersectional disadvantage and discrimination.

Above we have identified what we think is needed - these actions need to occur in close consultation with the sector, with governments listening and responding to input and feedback from advocacy organisations and the people with disability they support. DANA looks forward to working collaboratively with DSS and other stakeholders on developing a disability advocacy work plan that will truly strengthen and develop the disability advocacy sector, while preserving and valuing its diversity and unique strengths in achieving outcomes for people with disability, and defending and safeguarding their human rights.