# Response to:
# Australian Government
# Department of Social Services
# National Disability Advocacy Framework 2022-25

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## About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and/or
- That are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

## Introduction

Carers Australia and the National Carer Network appreciate the opportunity to provide feedback on the draft National Disability Advocacy Framework 2022-25 (NDAF).

Carers Australia and the National Carer Network endorse the United Nations Convention on the Rights of Persons with Disabilities (CRPD), of which Australia is a signatory, and believe that families and informal carers can play an important role in supporting the rights of people with disability in line with the CRPD, where they have been nominated to do so.

This submission acknowledges and supports the primary focus of the draft NDAF on the needs and aspirations of the person with disability and welcomes the intent of this review, in light of changes to the disability advocacy landscape over the past decade, but Carers Australia and the National Carer Network are deeply concerned that the extent of these changes and diverse nature of disability advocacy have not been fully realised within the draft NDAF. These concerns and subsequent recommendations for improvement are expanded on in the feedback below.

## Carer Recognition and Support

Recognition, identification and inclusion are significant issues for many carers across Australia, adversely impacting on a carer's ability to both perform their caring role to the best of their ability and be appropriately supported whilst doing so. Whilst these issues have shown some improvement over the past 15-20 years with the adoption of Carer Recognition Acts at State, Territory and Federal levels, much work remains to be done to ensure inclusion and recognition of carers, which is especially needed within significant legislation and frameworks such as the draft NDAF. In a survey conducted prior to the 2022 Federal Election, the Albanese Labor Government committed to reviewing the operation of the *Carer Recognition Act 2010* (Commonwealth) and consolidating coordination of carer policy across governments;[1] these actions intend to improve the visibility of carers in all relevant government policy, programs and practices.

As a demonstration of the inclusion of carers in relevant government documents, Policy Priority 3 of the Personal and Community Support Outcome in *Australia's Disability Strategy 2021-2031* (the Strategy) states that the role of informal support is to be acknowledged and supported, recognising the importance of carers for many people with disability.[2] Informal supports are recognised within this Policy Priority as important to supporting and enriching the lives of people with disabilities, with subsequent acknowledgement and support of these informal supports also able to lift the participation in community life of people with disability.[3] Further, the role that informal advocates such as carers can play is also recognised, with the Strategy noting:

> '*In addition to providing practical and emotional support, those providing informal support can represent the interests and rights of the person they support*' and the inclusion of a quote from Carers NSW '*informal carers can also be key sources of information and often play the role of advocate for the person they care for*'.[4]

Given the above inclusion of informal supports and recognition of this and other typologies of advocacy within the Strategy, Carers Australia and the National Carers Network are deeply concerned as to the lack of inclusion of these aspects within the draft NDAF. This is representative of a significant step backward from the Strategy in the recognition of the role carers can play in supporting a person with disability who has nominated them to do so. The 2012 version of the NDAF states *'consideration of the role of families and carers will be taken into account'*[5] while

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[1] (Carers Australia, 2022)
[2] (Commonwealth of Australia (Department of Social Services), 2021)
[3] (Commonwealth of Australia (Department of Social Services), 2021)
[4] (Carers NSW, 2015)
[5] (Australian Government, 2012)

ensuring the needs and aspirations of the person with disability are maintained as the first priority.[6] While people with disability must remain at the centre, it is critically important to go beyond 'considering' the carers in that person's life. Where a person with disability has nominated or identified carer(s), advocacy services must also regularly check in to ensure the informal carer themselves is appropriately supported and able to continue in their caring role. Caring often has significant impact on and cost to the carer's own life and wellbeing; if they are insufficiently supported and therefore unable to continue caring, this will flow on to having significantly adverse impacts on the person with disability.

Carers are 2.5 times more likely to have low wellbeing, and are twice as likely to have poor health than the average Australian, have significantly higher levels of psychological distress, and are three times as likely to experience loneliness.[7] A significant proportion of carers (44.7%) also report their caring role regularly or always negatively impacting on relationships with family and friends.[8] Carers are often in a lower socio-economic position with poorer financial wellbeing than the typical Australian, are less likely to be employed, and have ongoing challenges to their financial and economic security.[9] On average, a carer will lose $392,500 in wages to age 67 and a further $175,000 in superannuation. Carers most affected financially (top 10%) will lose $940,000 in lifetime income and $444,500 in superannuation.[10] Meanwhile, the value of informal care provided by carers in Australia was valued in 2020 to be $78 billion per annum.[11]

Given this, it is recommended that any advocacy for people with disability also include assessment of supports available for and utilised by the carer, inclusive of individual rights, health, wellbeing and financial security. Further, the deflection of, or assignment of tasks onto the carer as part of an advocacy outcome should be based on Carer Assessments (such as the Carer Gateway 'Carers Star™' assessment) and a stated agreement elicited by the carer.

### Recommendations:

1. Include carers and other informal supports within the draft NDAF, with recognition of the role that these supports can play in supporting people with disability who nominate them to do so.
2. Reflect and codify the rights of carers through the addition of the following Outcome:

   > *'People with disability have access to advocacy services that recognise the capacity, rights and freedom of any informal/unpaid carers involved in their care'.*

3. Update the NDAF to include phrasing which ensures carers are also supported and able to continue in their caring role through the inclusion of the following Outcome: 'People with disability have access to advocacy services that recognise the capacity, rights and freedom of any informal/unpaid carers involved in their care'.
4. Review the operation of the *Carer Recognition Act 2010* (Commonwealth) to strengthen it into a rights-based Act.
5. Consolidate and coordinate carer policy across government under a Minister for Carers, Commissioner for Carers and Office for Carers.

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[6] (Australian Government, 2012)
[7] (Centre for Change Governance and NATSEM, University of Canberra, 2021)
[8] (Centre for Change Governance and NATSEM, University of Canberra, 2021)
[9] (Centre for Change Governance and NATSEM, University of Canberra, 2021)
[10] (Furnival & Cullen, 2022)
[11] (Deloitte Access Economics, 2020)

## Diversity of Disability Advocacy

The vision of advocacy presented by the draft NDAF does not align with that of Carers Australia and the National Carer Network as it does not capture the diversity of disability advocacy, and requires further clarity and definition in several key areas.

While broad definitions and use of the terms 'disability advocacy', 'individual advocacy', 'systemic advocacy' and 'self advocacy' are made use of within the draft NDAF,[12] the document does not incorporate forms of informal advocacy, despite these being often integral aspects of being a carer for a person with disability where advocacy support has been requested. In the present form of the NDAF, much more diverse definitions are embraced and clearly outlined within 'individual advocacy', inclusive of: self advocacy, family advocacy, group advocacy, citizen advocacy, legal advocacy, parent advocacy and peer advocacy.[13] For the draft NDAF to illustrate a more accurate and clear vision of advocacy, it is also essential that informal advocacy is recognised, with carers being included as part of this definition and these previous terms included and explained. It is recommended that these additional forms of advocacy be recognised and defined within a glossary in the draft NDAF, to assist in the provision of clarity and refinement around a more accurate vision of advocacy.

As per the aforementioned Policy Priority 3 in *Australia's Disability Strategy 2021-2031* (the Strategy), the informal support role is stated as needing to be acknowledged and supported.[14] The present form of the draft NDAF does not leave space for or recognise carers being able to be nominated by people with disability to offer support as informal advocates, through supported decision making and as a support person even when formal advocacy services are involved, acting as advocate to the advocate. Carers and other informal supports can offer valuable insight and experience through these roles, which can be of great benefit to the quality of care and life for people with disability.

Further, supported decision making can be described as a best practice approach aiming to enhance the ability of people with disability in making their own decisions.[15] Carers Australia and the National Carers Network recommend that supported decision making be considered and included as a fundamental contributing aspect of disability advocacy. It is critical to highlight the importance of ensuring the ongoing application of supported decision making and consultation. As stated in the *United Nations Declaration of Human Rights,*[16] the *United Nations International Covenant on Civil and Political Rights,*[17] and the *United Nations Convention on the Rights of Persons with a Disability,*[18] all people have the right to make decisions about their own lives, including people with disability. This is also included in the draft NDAF through the Principles for Presumption of Rights and Capacity, in particular:

- *All adults have an equal right to make decisions that affect their lives, and to have those decisions respected;* and
- *Adults with disability are presumed to have capacity to make and take part in decisions affecting all aspects of their lives.*[19]

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[12] (Australian Government, 2022)
[13] (Australian Government, 2012)
[14] (Commonwealth of Australia (Department of Social Services), 2021)
[15] (National Disability Services, 2019)
[16] (United Nations, 2015)
[17] (United Nations & United Nations Human Rights: Office of the High Commissioner, 1966)
[18] (United Nations Treaty Collection, 2006)
[19] (Australian Government, 2022)

One of the decisions which a person with disability may make is to have an unpaid carer or other informal support involved in their care, advocacy, and to support their decision making to whatever extent the person with disability desires and requires. In these cases, carers can play an important role in supporting people with disability, a role which must be recognised within the NDAF. To achieve this, Carers Australia and the National Carer Network recommend the inclusion of the following Outcome:

- *Where people with disability have decided to make use of an informal advocate, such as an unpaid family or friend carer, this decision is respected through recognition and inclusion of the nominated person/s.*

The draft NDAF also does not make mention of differing levels of support which people with disability may choose to access. This may range from no advocacy support at all being chosen; to the person with disability wanting to have their voice shared and heard, but not requiring support around decision making; right through to choosing to have an informal advocate and/or formal advocate substantially involved in advocacy and supported decision making across many different areas. i.e. health, medical treatments, other supports, social, goals, housing, etc. This distinction, as well as recognition of the role of informal supports (including carers) within each unique case-by-case scenario, is an important one to make. This is recommended to be included within the draft NDAF, inclusive of routine identification, recognition and inclusion of informal supports (including carers) in areas as specified by the person with disability.

Even in cases where the person with disability may have Guardianship, Administrator or other legal orders relevant to their decision-making capacity, it is recommended that supported decision making be a standard of practice wherever possible, with the support of the informal carer and inclusion of the person with disability (even in cases where there is a public guardian appointed).

Further, it is also recommended that all advocacy services be trauma informed, due to the high likelihood that people with disability may have experienced trauma through experiencing the issues they are seeking advocacy for or advocating on. This may also be applicable to any carers and/or the family and friends of the person with disability.

### Recommendations:

6. Recognise and define 'informal advocacy' in the NDAF, expressly including unpaid carers within the definition., for example '*informal advocacy and advocates are informal supports (including carers) which the person with disability may choose to have act as advocate with or on their behalf.'*
7. Recognise and define additional forms of advocacy within a glossary in the NDAF, inclusive of the terms: self advocacy, family advocacy, group advocacy, citizen advocacy, legal advocacy, parent advocacy and peer advocacy.
8. Include and define the role of carer(s) and other informal supports, supported decision making in advocacy and the role that carers can play as advocate to the advocate within a glossary and throughout the NDAF.
9. Codify respecting the decision of people with disability to include their informal supports as informal advocates through subsequent inclusion and recognition of the chosen person, with the inclusion of the following Outcome in the draft NDAF:

   *Where a person with disability has chosen to receive support from an informal advocate, such as a family or friend carer, this choice is respected through recognition and inclusion of the nominated person/s.*
10. Clarify terminology and best practice processes for variations in desired levels of advocacy by people with disability, inclusive of routine identification, recognition and inclusion of informal supports (including carers) in areas as decided by the person with disability.
11. Codify that all advocacy services must be trauma informed for the person with disability, their carer(s) and/or their families and friends.

## Timeliness

A significant concern for people with disability and their informal supports is when advocacy cannot be accessed in a timely manner, particularly if advocacy is for a time sensitive issue or case, which may often be the time when an informal advocate such as an informal carer may become or continue to be heavily involved. This lack of timeliness is not necessarily within the control of any individual service provider, being heavily impacted by workforce shortages, funding restrictions and other industry-wide concerns.

The draft NDAF aims for national consistency, yet allows states and territories to determine their own funding models, stating *'How each advocacy program is developed, funded and managed is the decision and subsequent responsibility of the funding government'.* [20] While this responsibility sits with the funding government, the consequent short-term funding contracts (1-2 years rather than 3-5 years) and group-specific funding models seen in some areas are resulting in contractual uncertainty and concerning gaps in advocacy. Moreover, where state- or territory-funded advocacy services are not permitted to support clients with issues with systems or services delivered by federal government funders and agencies, further gaps, complexities, confusion, and double-handling arises. People with disability, their carer(s), or the formal advocate representing them are also then required to repeat the issue to a federally funded advocate for actioning at a national level.

In addition, the contractual uncertainty resulting from the short-term contracts can result in reduced staff retention, a particular concern where staff shortages are already being experienced as per the current job market in Australia. Thin markets and poor rates of access due to unsuitable services are a well-identified issue, particularly impacting people with disability and carers living in regional or remote locations.

### Recommendations:

To address the issue of timeliness within the draft NDAF, Carers Australia and the National Carers Network recommend the following amendments and initiative:

12. Amend the NDAF to include timeliness and address systemic funding and implementation issues which affect the timely provision of advocacy services.
13. Amend and include within the 'Responsibilities, Reform and Policy Directions' section in the draft NDAF to:

    > *The development, funding and management of each advocacy program is the decision and subsequent responsibility of the funding government. These are to be established in consultation with relevant stakeholders (including but not limited to people with disability, informal supports (including carers), peak bodies, service providers and community organisations). As part of this responsibility the funding government is mandated to collect data and maintain an issues register, and actively seek solutions to verified issues in consultation with the above relevant stakeholders.*

14. Amend the draft NDAF Objective to:

    > *'People with disability access timely and effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation and inclusion'.*

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[20] (Australian Government, 2022)

15. Amend Outcome 4 to:

    *'Regardless of where they live, people with disability can access timely, quality, appropriate and independent advocacy support'.*

16. Develop and implement national guidelines for jurisdictionally funded advocacy programs, inclusive of minimum contract lengths, as well as consideration of initiatives to address unique workforce and other shortages within each region e.g. where there is a shortage of independent advocates, consider delivering cost-subsidised, accredited training programs for this profession, including prior recognition of informal advocacy experiences.

## Empowerment and Education

An important aspect of advocacy for upholding the rights of people with disability is ensuring the person with disability is supported to self advocate, or upskill to be able to effectively self advocate solo if desired. While some mention has been made within the draft NDAF of self advocacy and disability advocates needing to '*foster independence through educating individual in self advocacy',*[21] Carers Australia and the National Carers Network view this as an overarching responsibility of all stakeholders, inclusive of government, community organisations and disability advocates. As such, Carers Australia recommends the inclusion of an Outcome to achieve this:

- *People with disability will be supported, empowered and educated to advocate on their own behalf.*

Further, this is recommended to be extended to educating informal supports in advocacy as well, especially where the person with disability has chosen to have their informal supports involved in this area of their lives. This could be achieved through the addition of the following Outcome:

- *Carers and other informal supports of people with disability will be supported, empowered and educated to advocate.*

Moreover, it is also recommended that self advocacy for people with disability include renumeration for contributing their expertise and lived experience on committees, working groups, etc. A model of how this could be achieved is the Western Australian Carer Representation Program operated by Carers WA, which enables people in a caring role to provide a voice for carers by using their lived experience to improve services and increase awareness of the carer's point of view, placing carers on committees, working groups, etc and renumerating them for their time.[22]

### Recommendations:

17. Self advocacy and advocacy education be included in the draft NDAF for both people with disability and their informal supports, as an overarching responsibility of government, community organisations and disability advocates, and through inclusion of the Outcomes:

    *People with disability will be supported, empowered and educated to advocate on their own behalf.*
    *Carers and other informal supports of people with disability will be supported, empowered and educated to advocate.*

18. Self advocacy for people with disability also to include renumeration for contribution of their expertise and lived experience on committees, working groups, etc. i.e. based on the Carers WA 'Carer Representation Program Model'.

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[21] (Australian Government, 2022)
[22] (Carers WA, 2022)

## Clarity and Accessibility

The Objective stated within the draft NDAF requires governments to commit to striving for advocacy that people with disability can access. Key to this accessibility is that information regarding these advocacy services be accessible by people with all levels of digital, written and verbal literacy; culture; religion; and ability. Also important is that the advocacy services provided are reflective of these elements as well, requiring advocates available who understand and can advocate appropriately with respect to the person's culture, religion and other important influences.

To action this, Carers Australia and the National Carers Network recommend the following changes and initiatives be considered to improve the accessibility of advocacy services and information available on advocacy services:

- Information available about advocacy services on government websites be reviewed for accessibility for people with disability (and their informal supports, including carers), with regard to all levels of digital, written and verbal literacy; culture; religion; and ability.
- An accessible and clear guide and online directory to available advocacy services be developed.
- Amending language in Responsibilities, Points 1, 3 and 6 within the draft NDAF

Carers Australia and the National Carers Network are concerned as to the lack of clarity on how the Outcomes within the draft NDAF are to be achieved or measured, or who is responsible for achieving them/aspects of them. While cognisant that the draft NDAF is intended to be aligned to a work plan, it was anticipated some detail of these variables would be outlined within the draft document. Consequently, it is critical that the next version includes further detail about implementation and accountability, including clarity about what further is intended to be developed in consultation with people with disability and other stakeholders (including informal supports), then outlined within the work plan.

### Recommendations:

19. Clarity be provided on the Outcomes in the draft NDAF through alignment to a table, with clear specification on details including how they are to be achieved or measured and who is responsible for achieving them/aspects of them. In absence of this information, clarity to be provided in this table on what further will be developed in the workplan and in consultation with which stakeholders.
20. Review information regarding advocacy services on government websites to ensure accessibility by people with all levels of digital, written and verbal literacy; culture; religion; and ability.
21. Develop an accessible and clear guide and online directory to available advocacy services.
22. The draft NDAF include that advocacy services be accessible to people with all levels of digital, written and verbal literacy; culture; religion; and ability.

    Responsibilities, Point 3 amended to: *'Building awareness across the disability sector and the community about the rights of people with disability, the rights of carers and role of informal advocates, what disability advocacy is and the diversity of disability advocacy, the importance of disability advocacy and how to access disability advocacy.'*

    - Responsibilities, Point 6 amended to: *'Improving coordination and communication between disability organisations, people with disability and informal advocates such as carers (where applicable), disability services, the National Disability Insurance Agency, mainstream services, community-based services and governments to develop the overall capacity of the disability sector, including promoting linkages between individual and systemic advocacy.'*
    - Responsibilities, Point 1 amended to: *'Ensuring policy and reform that affect people with disability are designed and implemented including people with disability at the centre of the design, as well*

> *as other stakeholders affected such as informal supports (including carers). This includes implemented person-centred approaches and co-design principles.'*

## Conclusion

Should any further information be required or the Department have any queries regarding the comments included within this submission, please contact Carers Australia and the Carers Network at policy@carersaustralia.com.au.

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