



*Review of the draft
National Disability Advocacy Framework*

Submission to the Department of Social Services

***Young People In Nursing Homes National Alliance
July 2022***

Introduction

The Alliance is pleased to contribute this brief response to the Review of the draft National Disability Advocacy Framework (NDAF).

Since its inception, the Alliance has provided a range of individual advocacy services to younger people living and at risk of placement in residential aged care (RAC).

Characterised by individuals with complex disability and health issues that can include physical, neurological, cognitive and psychosocial impairments, these individuals commonly require negotiation with programs provided by different government agencies and service sectors to create the integrated service responses they need.

As well as working with the disability services system, we work with and across such non disability or mainstream service systems as health, mental health, aged care, housing and justice to achieve the outcomes these younger people and their families desire.

People living in an institutional setting such as residential aged care routinely have little say in decisions about their daily living and many do not identify as decision makers. Individual advocacy and the provision of supported decision making assistance is critically important in supporting younger people in these settings to articulate their choices regarding their current and future living arrangements, and have these acted upon.

The Alliance has drawn on its extensive provision of individual advocacy services to younger people and their families to deliver the systemic advocacy needed to resolve the Younger People In Residential Aged Care (YPIRAC) issue and to contribute to other policy development.

In 2020 and as a result of this extended systemic advocacy, the federal government endorsed a YPIRAC Strategy that contains dedicated targets that will see no younger people entering residential aged care by 2022; and no younger person living involuntarily in residential aged care by 2025.

The advocacy role of the YPINH National Alliance

Although the Alliance is primarily engaged in policy and service development work, we routinely undertake individual advocacy. We receive requests from the following people:

- Young people facing nursing home placement;
- Those living in residential settings (both aged care and disability);
- Health networks attempting to discharge young people with complex health and functional disability support needs to community settings;
- Family members trying to obtain needed supports and services for loved ones;
- Jurisdictional representatives from state and territory disability services programs trying to achieve cross program outcomes for clients;
- National Disability Advocacy Program (NDAP) agencies struggling with the complexity of the issues presented by YPINH;

- Disability service providers trying to manage the complex health needs of service users and
- Nursing home managers seeking additional funding and resources to support the young people in their care.

In many cases people seek the Alliance out after being unable to access advocacy through NDAP agencies. In some cases, NDAP agencies have turned people away because of closed or indeterminable waiting lists; or because they are not part of the agency's 'target group'. In other cases, people have worked with NDAP advocates who have not resolved their issues.

In all instances, the Alliance takes on this work largely unfunded. Because of our mission and the importance of demonstrating cross sector approaches, we provide this support willingly. In recent years the number of people seeking support has been increasing, thereby stretching our capacity.

The individuals we have supported have directly influenced the Alliance's substantial body of work in this area, including our focus on cross sector service methodologies and our multi system advocacy practice. We have included their experiences in our research and collaborative policy development. This body of work has in turn informed the positions outlined in this response.

Disability sector reform

In making this submission, we endorse the points made by Disability Advocacy Network Australia (DANA) in their submission to this review.

Like DANA, the Alliance firmly believes that the advocacy sector must be integrally engaged in the continuing disability social reform in Australia that includes the evolving National Disability Insurance Scheme (NDIS) and the Australian Disability Strategy. Having this close engagement enables Australians with disability, through their advocates, to have their interests and citizenship recognised across government programs and service sectors, including the NDIS and the disability services market.

As a small but significant funding program, the National Disability Advocacy Program (NDAP) for which this draft Framework provides both the context and the platform, needs to position itself overtly as part of this reform agenda and not allow disability advocacy be viewed simply as a casework program that supplements the NDIS and other government programs. Both the NDAF and the NDAP program it references have critically important roles to play in this reform, with NDAP agencies well placed to take a leading national role in the reform activities the draft Framework alludes to.

To take advantage of the skills, experience and proximity to the lived experience of people with disability, the Framework must recognise this and, as well as their role in supporting individuals, mandate the NDAP agencies to engage in local networks and participate more actively in systemic advocacy. Improved funding must also be allocated to both the Framework and the NDAP to enable both entities to deliver these expanded but critically important roles.

A key area of the disability reform that must be revisited is what the Productivity Commission and others have called 'Tier 2' of the NDIS, which includes community sector organisations from a range of sectors. The new Minister for the NDIS and Government Services has recently indicated that work on Tier 2 is needed and will be prioritised in this current term of government. The draft Framework needs a much clearer statement of intent regarding this stated priority area. This statement should also include a description of how NDAP agencies can, with improved funding and greater capacity, contribute significantly to achieving this intention.

With the NDIS now at full scheme and the need for more collaborative engagement with communities and other service systems now on the agenda (in addition to moves to reduce the level of disputation about NDIS decisions), the Alliance believes that the role of advocacy and its practice must evolve. Advocates and advocacy organisations will need to meet the different expectations that Australians with disability have to not only access disability and non disability services, but to be part of change, policy and practice in all sectors of the Australian community.

Under the section on *Responsibilities, Reform and Policy Directions*, the Framework describes one of its key outcomes as

*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.¹*

To have capacity to work with and across multiple service systems as this outcome describes, advocates will need to have a working knowledge of the operation of disability and non disability systems; and have good networks within and across those systems.

These networks have a direct bearing on the ability of advocates and their clients to achieve good outcomes. Building and maintaining them requires dedicated time and investment. The draft Framework needs to recognise the importance of system networks to achieving its stated aims and provide the resources required to deliver the outcomes it has identified.

Because this work underpins the effectiveness of the NDAP as a whole, discrete funding must be made available so that NDAP organisations and the advocates they employ can action this investment successfully.

As well as understanding the capacities and challenges different service systems confront, and building systems networks to draw on, advocates will also need to be strongly solution focussed with an emphasis on collaboration and negotiation with all actors to achieve the outcomes the draft Framework describes.

¹ Department of Social Services. *Draft National Disability Advocacy Framework*, Canberra 2022: 5. Emphasis added.

Multi system advocacy

To achieve the reform the Framework has identified, advocacy practice must change and evolve. New and different skill sets will be needed if advocacy practice is to be effective in delivering service system access and the enhanced agency Australians with disability are looking for.

In the section titled *Responsibilities, Reform and Policy Directions*, the Framework identifies the need to develop the disability sector's capacity through "...improved coordination and communication..." between disability advocacy organisations and mainstream services amongst others.²

Again, to support this important reform, advocates will need to not only be skilled in coordinating arrangements within and across different programs. To deliver multi system advocacy, they must also be able to work at the policy (macro) level, service (meso) level and individual (micro) levels.

This concept of multi system advocacy is a practice the Alliance has developed through its extensive work with individuals needing integrated multi system responses; and with the service systems involved.

When taking a multi system advocacy approach, working at the **macro or policy level** is a functional approach employed by an advocacy organisation that values collaboration and reform as a means of developing solutions. Working from this perspective means the organisation also embraces a capacity to 'think outside the square' when working with others to deliver these solutions.

At this level, policy imperatives are influenced directly by the work systems advocates undertake; *and* by the systems advocates' capacity to identify systemic gaps and failures, as well as areas in which the service system and the policy that underwrites it is working effectively. In their capacity to offer feedback to policy makers, systems advocates can offer a 'temperature taking' capability that provides insight into areas where current policy directives are either not scaleable and/or not workable.

At the **service or meso level**, systems advocates consciously and deliberately seek to influence the ways in which service programs work and interact with each other, with individuals and families and with governments and communities at large. It's at this point that the 'whatever it takes', solution focussed approach that effective systems advocates bring to problem solving comes into its own, the result being innovative approaches to service arrangements that deliver the mutual benefit required.

At the **micro level**, the systems advocate's interaction with individuals and families ensures that the consumer voice is incorporated in service planning; and helps to interpret the language of different service systems into a coherent support response. Their work at this level recognises both the value and the imperatives of informal care, as well as the impact of formal service provision on families and individuals.

² Op. Cit: 6.

Working with the eligibility, assessment and service delivery processes of different programs is an important part of the systems advocate's role at this important level.

At the **organisational level**, multi system advocacy is expressed by a corporate commitment to cross program collaboration. It is not simply a matter of inserting a single advocate into a program, with KPIs to negotiate with different program areas on behalf of individuals.

Multi system advocacy: key competencies

The following list of competencies is drawn from the Alliance's individual and systemic advocacy work and highlights the key qualities multi system advocates must possess.

1. A solution-focussed approach to problem resolution

Requires an ability to work with individuals, families, services and systems to design and implement collaborative practices that deliver agreed solutions and outcomes at the micro, macro and meso levels of engagement. Negotiation of transparent agreed outcomes is essential to enable stakeholders to feel they have ultimately delivered on agreements.

2. Understanding risk management

An ability to identify and address existing and future risks to individuals and systems is an imperative of the systems advocate's role and requires a working knowledge and understanding of the different programs the systems advocate is collaborating with.

3. Capacity to work with volatile situations and change

Demonstrated skills and experience with innovation and problem solving is needed to enable systems advocates to respond to volatile situations and be effective change agents. This capacity demands a good working knowledge of policy and practice in relevant sectors. It also requires a mandate from participating organisations and stakeholders that supports innovation and unconventional approaches and responses.

4. Strategic relationship management

An ability to identify, establish and maintain strategic working relationships with cross sector stakeholders, individuals and families is at the heart of the systems advocate's effectiveness.

5. Working positively with families

Families are a vital 'partner in care' of their loved ones. Effective systems advocates have an understanding and ability to work from a family sensitive practice perspective. Their work here helps maintain the importance of the family/carer role; helps services and systems understand the crucial role families/carers play in the support of loved ones; and supports families in their interactions with often obtuse system and service expectations.

6. Taking a systems view

Their capacity to take a meta-service or "helicopter" view of service systems, is something effective systems advocates use to:

- Identify and capitalise on system, program and service opportunities;
- Identify and analyse issues around gaps in services and systems and develop collaborative responses;

- Keep abreast of policy and practice change including variations in funding and/or program operations or rules changes;
- Develop and maintain working relationships with influencers in multiple services, programs and sectors.

7. Strong working knowledge of systems

Knowledge of the 'workings' of the multiple systems in which systems advocates will operate and where individuals with disability are often 'stranded' or 'locked out' is an imperative of the systems advocate's role. Understanding the different languages various programs employ, having knowledge of eligibility and application processes in different systems and development of relationships with key decision makers in the programs systems advocates work with, is a critical part of this work.

Conclusion

The Alliance believes that, as a key part of the wider disability reform project, the National Disability Advocacy Framework and the National Disability Advocacy Program it supports, must be elevated within government and not subsumed into the operations of disability funding and service delivery.

Instead, the Framework must prioritise a multi systems advocacy approach as fundamental to enabling Australians with disability, through their advocates, to have their interests and citizenship recognised across government programs and service sectors, including the NDIS and the disability services market.

We have focused on the ongoing professional role of advocates and their practice in this brief submission and would like to see greater investment in the development of the advocacy workforce as part of the general elevation of disability advocacy.

We are happy to discuss issues raised in this submission and the development of the Framework more broadly.

Further contact:

Dr Bronwyn Morkham
National Director
E: bronwyn@ypinh.org.au
M: 0437 178 078