



Review of the National Disability Advocacy Framework

**Submission by the
*Young People In Nursing Homes National Alliance***

August 2015

The Young People In Nursing Homes National Alliance

The Alliance is Australia's first national peak organisation representing young disabled Australians with high and complex health and other support needs living in residential aged care facilities or at risk of placement there (YPINH). The Alliance supports these young people to have choice about where they live and how they are supported and draws its membership from all stakeholder groups including YPINH, family members and friends, service providers, disability, health and aged care representatives, members of various national and state peak bodies, government representatives and advocacy groups.

Since its inception in 2002, the Alliance has argued for a lifetime care approach to development of supports and services for disabled Australians; and for collaborative arrangements between programs and portfolio areas including health, disability, aged care and housing to provide the integrated service pathways YPINH and others with disability require.

Introduction

The Alliance is pleased to contribute to this consultation on the National Disability Advocacy Framework (NDAF). The NDAF is a critical component of the overall reform program currently in play nationally in Australia. At this significant point in time, the importance of ensuring that the NDAF can deliver reform outcomes cannot be overstated.

Over recent decades, advocacy has played a fundamental role in confirming community recognition of Australians with disability as citizens. Advocacy practice has also influenced reforms and political priorities that aim to redress the marginalisation Australians with disability experience through a lack of supports or lack of access to employment, education, accessible infrastructure and healthcare.

As well as affecting the ways in which people with disability are supported, the Alliance recognises that the introduction of the National Disability Insurance Scheme (NDIS) will have a profound impact on the supply and delivery of funding for disability services. The NDIS will certainly offer improvements in the provision of these disability services for many people. But significant barriers remain for people with disability keen to participate in mainstream areas of Australian life.

The NDIS' provision of individual support will be limited to the estimated 460,000 people classed as having a severe or profound disability. Yet there are many more people living with mild to moderate disability who will be ineligible for the NDIS individualised funding packages, but still require responses from the broader human services system and other areas of the community, including the corporate sector.

The NDAF must continue to provide advocacy support to this larger group facing barriers that, despite the NDIS' Independence, Linkages and Capacity building component, the scheme may be unable to directly resolve.

For this reason, and because we are in a rapidly changing policy landscape, the NDAF's role over the next 3-5 years must be framed as a transition vehicle operating alongside the NDIS.

Such a frame will enable the NDIS' future architecture to emerge without creating gaps by withdrawing advocacy support too soon; or setting something in stone that is not flexible and lacks capacity for change. It will also guarantee that advocacy support will be available, not only for those eligible for the NDIS' support, but also for Australians with disability ineligible for the scheme's individualised packages while the NDIS is being implemented nationally. Embracing a transition function in this way will ensure that advocacy can be proactively redefined to suit these new arrangements.

Because provision of disability services alone will not resolve poor access and/or poor responses by mainstream programs to people with disability, the sustained provision of skilled advocacy is essential into the future. The Alliance is acutely aware of the limitations of a single program response to people with a need for support from multiple service areas, something the Younger People In Residential Aged Care initiative (YPIRAC) demonstrated only too well over its 5 years of operation.¹

In formulating the NDAF framework, clarity is thus required about what the transitional ambitions of the NDAF are, as well as the continuity of service that it will engineer. In addition, it is essential that it articulate how the framework will continue to address the individual and systemic barriers faced by people with disability inside and outside both disability services and the NDIS.

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;

¹ The YPIRAC initiative was a single, disability program response to a multi program issue. Implemented by State and Territory Disability Services programs, YPIRAC delivered some benefits to some people during its 5 years of operation, but did not generate systemic benefit to health, aged care or disability programs. For example, of 6,500 eligible participants in the program, only 1,432 received funded input. Of these, an estimated 250 people achieved the first YPIRAC objective (a move out of residential aged care to more appropriate accommodation); 244 people achieved the second YPIRAC objective (diversion from residential aged care); and 456 people achieved the third YPIRAC objective (receiving enhanced services within residential aged care). See AIHW, *Policy Bulletin 103, Younger People in Residential Aged Care*, Canberra, April 2012.

- 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 out the Alliance after not being able 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.

The Alliance takes a solution focussed approach to these requests for assistance and works collaboratively with the young people and family members concerned, as well as with relevant health, aged care, housing and disability programs and their representatives to develop the funding and integrated service responses required. At their request, we also take a mentoring role with NDAP and other disability advocacy organisations trying to negotiate cross sector solutions for their clients.

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. 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.

Defining Advocacy

Over the last 30 plus years, organisations have undertaken a range of activities that have fallen under the broadest definition of advocacy, such as self-advocacy, citizen advocacy, representational advocacy, peer support and systemic advocacy campaigning. Over time and in an underdeveloped funding and service system, these activities have largely suited the interests of people with disability. For these reasons, the definition of advocacy in play has been loose, changeable and contested. It has also led to advocacy being largely self-defined and self evaluated by advocacy practitioners.

While the historically strong rights foundation NDAP agencies' base their work on is highly appropriate, we do, however, note the lack of consistent or defined practice; the lack of standards; and the lack of practical systems for linking individual advocacy

to systemic advocacy. Deciding on a vision for advocacy requires articulation of both practice standards and the expectations of advocates who choose to work in this area. The move to the NDIS also requires greater rigour in the definition and practice of advocacy.

For these reasons, one of the core objectives in the development of this NDAF must be to settle on a clear working definition of advocacy.

Bearing in mind the need for advocacy services to continue in a transitional capacity as the NDIS moves to full scheme; as well as the need for funded advocacy services to support disabled Australians ineligible for the NDIS post full scheme, the Alliance believes advocacy should be taken to mean activities that aim to influence decisions within systems and/or institutions.

Within the terms of the proposed Advocacy Framework then, advocacy for Australians with disability may thus involve provision of information; assistance and support to make informed decisions; and negotiation to achieved desired results. In this sense, advocacy services should be solution focussed, be collaborative in approach and assume a 'whatever it takes' methodology to resolving the issue at hand.

The Alliance thus believes the definition of advocacy in the *Review of the National Disability Advocacy Framework Discussion Paper* is completely inadequate to the transitional task advocacy will be required to fulfill as the NDIS moves to full scheme.

In the Alliance's view, the definition of advocacy in the NDAF discussion paper is not only confused, but is a poor conception of what advocacy is actually about. Its description of the value and distinct roles of advocacy is insufficient and fails to reflect the interaction between the individual and the policy and social aspects of advocacy practice.

The discussion paper's definition of advocacy that focusses on employment, community participation and goal attainment, also allows too much overlap with disability service provision and forbids a distinct identity for advocacy practice within the Framework. In other words, advocacy should not be conceived as a service or be confused with disability services. Advocacy practice has a distinctly different purpose and a very different character.

The practice of what is loosely defined as advocacy has also been picked up by organisations that are not traditional advocacy organisations. Some diagnostic peak bodies with service provision responsibilities have, for example, established advocacy functions that challenge the notion that advocacy should be separate from service provision. In some instances, this advocacy has been effective in promoting the rights and opportunities of members and has enabled individuals with disability to participate in wider policy debates and campaigns. However, where generalist disability service providers have established internal advocacy units, these units have

proven to be service provision by another name, delivering useful brand promotion for the provider concerned, rather than real advocacy for service users.

In the Alliance's experience, the skills and capacities of NDAP agencies have traditionally been patchy and personality driven. To address this, the NDAF must include a segment on defining and improving advocacy practice.

The Alliance is aware that some groups are proposing vocational TAFE training qualifications, such as a Certificate 3 or 4 in advocacy, similar in nature to the extant Certificates 3 and 4 in Disability. Programs such as the latter have done little to improve the practice competencies of workers in the disability sector. More effective models for improving advocacy – and support worker – practice are required in the dynamic environment of the NDIS rollout.

The Alliance does not therefore support the development of certificates 3 and 4 programs in advocacy. Instead, the NDAF should be encouraging mentoring and 'apprenticeship' approaches, industry based training and supporting mainstream programs to offer professional development initiatives to enable those working in advocacy settings to improve their working knowledge of other sectors.

The NDAF must also enable advocacy practice to link activity at the micro (individual), meso (service sector) and macro (government and policy) levels.² Isolating each or all of these levels puts unreasonable constraints on advocates and ignores valuable integrated, multi level solutions.

Finally, a flaw in the current NDAP arrangement is the over reliance on 'casework' advocacy. This constraint has significantly held back the maturation of advocacy practice for people with disability in Australia and must be corrected in the NDAF.

Specialist advocacy

As mentioned earlier, significant number of people the Alliance works with have not been able to get advocacy support from NDAP agencies. This has been because the NDAP agency concerned has either lacked

- Confidence in their own capacity to deliver the responses required;
- The requisite knowledge of non disability programs needed to negotiate agreed outcomes;
- Active contact networks of individuals in non disability programs who could assist with negotiation of integrated responses; and/or

² For a more comprehensive description of these terms as factors in change agency, see Figure 2, "Outcomes at different levels", in YPINH National Alliance and University of Sydney CRPD, *Cross Sector Service Coordination for People with High and Complex Needs: Harnessing existing evidence and knowledge*, Policy Bulletin 2, Sydney, 2014.

- Capacity to take new referrals because the funded agency is already over subscribed, has a long waiting list or has closed the waiting list till further notice.

Our work in this area has thus revealed that many NDAP agencies do not presently have the skills or the working knowledge required to work across and with health and aged care programs with the YPINH group. Our work has also revealed how the lack of this expertise marginalises these young people as a result.

Yet some of the most effective advocacy the Alliance has seen has been from specialist agencies. Whether it is a diagnostic organisation, or one focused in a particular mainstream sector (such as education or employment), the deep working knowledge of the environments experienced by their members is extremely valuable for the success of the advocacy practices these specialist agencies undertake.

Having said that NDAP capacity is variable, the Alliance is aware that some NDAP agencies are highly skilled and have engaged with YPINH issues. As well as working with people with dual disability, some agencies have great capacity working in the forensic, mental health and justice systems.

In a post NDIS world, however, advocacy practice will be a more complex and nuanced endeavour. A more generalist system for advocacy – a franchise type system similar in design to the Disability Employment Services Contract (DES) – will simply not work in the advocacy area. The purchasing arrangements for advocacy need to be completely unlike those for purchasing disability services.

The Alliance thus believes that the NDAF must allow specialisation in the practice of advocacy; and that both specialist and generalist disability advocacy agencies must be funded under the NDAF.

The Alliance believes strongly that the next 3-year NDAP contracts should be block funded, focused on transition and enable specialist agencies to receive advocacy funding. The Department of Social Services (DSS) should be the funding body for the NDAP for this time and DSS should use this period to build the capacity of other portfolio areas to take on greater funding responsibilities in the area of citizen services for people with disability.

While we are only at the half way point of the implementation of the National Disability Strategy and have yet to fully embrace the Strategy's priority areas as a nation, the days of disability programs leading or funding all things disability must be actively brought to an end. This NDAF framework has huge potential to support this change dynamic and must be strongly supported with this in mind.

The Alliance also believes that NDAP's capacity to fund agencies as diagnostic specialists (e.g. for acquired brain injury), must be available in every jurisdiction. We furthermore believe that in addition to enabling diagnostic specific advocacy, NDAP's

funding of agencies with specialist expertise in mainstream program areas should match the National Disability Strategy's six priority areas (inclusive and accessible communities; rights protection; economic security; personal and community support; learning and skills; and health and well being).

Finally, it is easy to simply say that advocacy is necessary. The purpose, methods and outcomes of advocacy practice must, however, be explicit and the NDAF must articulate exactly what the advocacy sector is there to deliver and how it will fit in the new NDIS environment.

Advocacy in an NDIS world

It is likely that as the NDIS rolls out, new functions and types of organisations will emerge to respond to the NDIS reform and the development of the Independence, Linkages and Capacity Building (ILC) framework. Community Living Organisations or CLOs (named Disability Support Organisations by the Productivity Commission and the National Disability Insurance Agency (NDIA), as well as Plan Management Providers (PMP) and Local Area Coordinators (LAC), will all develop, take over and/or redefine many of the non-representative functions currently undertaken by advocacy organisations.

Over the next 3-5 years and as we transition to full scheme, it is important that the NDAF be cognisant of these developments, synthesizing the advocacy role from these other disability sector functions. Far from being in competition with the NDIS, these organisational functions and categories must be clearly defined so that organisations currently engaged in broad advocacy practices can make decisions about remaining in the advocacy space and maintaining a distinct representational advocacy role; or opting to fulfill other roles in the future. Such important decisions need to be supported as part of a phased transition process, rather than delivered through pseudo commercial tender processes.

As these new classes of organisations develop, they will lap at the edges (or indeed wash through) what is now the practice and scope of NDAP agencies. The prominence of the functions performed by this broader group of organisations is also likely to be re-ordered as we move into the NDIS environment. In as much as advocacy practice will remain essential to the suite of supports required by people with disability, advocacy practice will also need to redefine its scope and become more specialised around formal representation.

To mark this separation of roles and functions and create the best environment for the development of a new NDAF culture of working with mainstream programs, the NDAF needs to separate advocacy funding from disability services funding. So that distinct cultures and practice expectations can be established; and to provide the mandate for outward looking advocacy, the Alliance recommends that the NDAF framework articulate advocacy as a *citizen service*, not a disability service; and remove the word disability from the Framework's name.

As mentioned earlier, it is vital that there be no overlap between advocacy and service provision and that they are distinct in every way (i.e. funding source, accountability, identity). Under this model, it would be possible for mainstream community agencies doing other forms of advocacy to build their capacity in supporting people with disability who could access these other specialised advocacy areas.

Because of the multi disciplinary, multi program work advocacy practice must embrace in a post NDIS world, the Alliance also strongly recommends that advocacy practice have multi program funding input that recognises both the need for integrated services responses; and the mutual benefit this work will deliver to all programs involved.

Finally, to confirm its departure from disability and to convey the significant mandate that attends multi disciplinary, citizen service advocacy practice, the Alliance suggests that advocacy organisations and the NDAF itself come under the auspice of state and federal Attorneys General Departments. This portfolio area is the most appropriate for funding and governing the type of representational advocacy for citizens that we believe the NDAF needs to transition towards; and is an appropriate location for the multi program funding contributions that future advocacy organisations, like the CLOs, will draw on to deliver their practice.

From this new location, the practice of advocacy can be delivered not as a disability service, but as a specialised citizen service for individuals needing representation and other supports to engage with the various arms of government including mainstream programs; providers of services; and other bodies that interact with people with disability. Devolved in this way, the character of advocacy will have more in common with other forms of advocacy in the community (financial counsellors, tenants' advocates, welfare advocates etc.) than it would with specialist disability services.

In this context of moving advocacy funding beyond disability programs, the ongoing dilemma about the States' and Territories' continued roles in funding disability advocacy under the National Disability Agreement (NDA) is redundant. The NDAF needs to set a new course and open new conversations about the role and purpose of advocacy practice beyond the NDA. As it currently stands, the location of NDAP within the NDA is stifling the evolution of modern and responsive services in the broad area of advocacy practice and community participation.

In as much as the reform in and around the NDIS is designing and delivering a new architecture for the planning and provision of disability services, advocacy in its current form is thus residual to this reform. Advocacy practice must therefore change and evolve to deliver a broader suite of functions in a post NDIS world.

Advocacy thus remains a critical function in the transition to the NDIS and the scheme's individualisation of supports. For this reason, advocacy practice must be

properly resourced and actively supported by the multiple programs Australians with disability will look to for funding and other supports.

The reform context

In recent decades, advocacy has been fundamental to greater recognition of the place of people with disability in the Australian community.

The Alliance recognises that the introduction of the NDIS will have a profound impact on the supply and delivery of funding for disability services, as well as the way that people with disability are supported. The focus of the NDIS on the economic and social participation of scheme participants, has changed the way advocacy will be viewed and enacted, both in transition to the scheme and in a post NDIS environment.

As this submission has reiterated, advocacy practice in the post NDIS world will have moved from the historical starting point of arguing for improved *disability* services responses, to one of engagement with improved human services system responses. These broader responses will include engagement with programs in health, aged care, housing, disability, employment, education, justice, transport et al. Advocates with knowledge of program responsibilities under the National Disability Strategy and National Disability Agreement and who are skilled in negotiating multi program, integrated service responses, will be required for this brave new world.

This shift demonstrates the nature of the transitional role of the NDAF – shifting the main focus from the limited world of specialist disability services to the wider community that people with disability will increasingly engage with. There will, of course, be a need for advocacy to play a safeguarding role in disability services, as it will need to do with all service areas. But the emergence of the NDIS and ILC framework will necessitate dramatic policy and practice shifts in advocacy practice “across the board”.

Transition to full scheme

Until such time as the full NDIS architecture – including the vitally important ILC component – is in place to encompass individualised funding mechanisms, DSO/CLO's, plan management organisations and LAC arrangements, advocacy must be comprehensively funded.

Comprehensive funding of advocacy in this transition period will ensure that the transition process serves the interests of people with disability; that unintended gaps do not open up; and that the opportunities promised by the rollout of the NDIS are available to individuals and community organisations alike.

To achieve this, the NDAF must continue to fund a suite of organisations to deliver individual advocacy services as part of the transition to full scheme and to

- Develop integrated service responses with other human services programs including those in health, education, aged care, justice, employment and housing et al.
- Develop additional skills required to work with and across multiple program boundaries.
- Assist organisations to transition themselves to a representational advocacy role within the Attorneys General Departments of the Commonwealth and the States and Territories.

Community Living Organisations (CLO)³

CLOs have a valuable role to play in delivering advocacy practices that promote the citizenship of Australians with disability, both for those eligible for the NDIS as well as those ineligible for the scheme's funded supports. CLOs can successfully undertake this role because they carry a mandate to work with individuals across all three tiers of the NDIS; and to work at the community and multi program levels.

The movement of individuals across all three tiers of the scheme will be a feature of a well functioning NDIS. Because they will be in a position to work with the NDIS and governments on disability awareness; create and manage the cross sector pathways needed for Tier 2; and negotiate sometimes complex arrangements for people in Tier 3, CLOs are essential to the successful operation of all proposed tiers of the NDIS.

CLOs are thus ideally placed to develop and deliver advocacy practices that work across programs, engage with individuals inside and outside the NDIS and deliver solid community connection.

At a broad remove, CLO's will have a mandate to

- Deliver community connections and engagement;
- Ensure coordination and cohesion of NDIS packages with other service and program areas including health, housing, education, justice, transport, aged care et al.;
- Mediate long term support delivery via a role with provider management.

Wider community roles should also include:

³ The naming of these front line agencies continues to change. In the Alliance's 2010 submission to the Productivity Commission's (PC) Inquiry into Disability Care and Support, they were named Lifetime Support Agencies. In its final Inquiry Report, the PC used the term Disability Support Organisations to refer to these agencies as financial intermediaries. The NDIS legislation refers to plan management providers (PMP) that undertake this task. In order to clarify a specific role and purpose, the Alliance now refers to these front line agencies as Community Living Organisations (CLO) that have a mandate to work with scheme participants and others to access formal and informal supports and engage proactively with their local communities. This submission uses this latter term to refer to these front line agencies and their purpose.

- Development of improved awareness and training in the needs of individuals with disability with providers in health, aged care, disability, education et al;
- Tertiary consultancy;
- Provision of information to individuals, providers and the community;
- Collaboration on service development and innovation in service design in response to the needs of individuals;
- Collaboration with other program areas to deliver integrated supports and services individuals may need;
- Community development opportunities that reinforce the citizenship of Australians with disability;
- Peer support for individuals with disability;
- Provider management for providers in aged care, health, housing, NDIS and other disability agencies, education, justice, employment et al.;
- Research and evaluation of activities undertaken to inform the nuanced rollout of the NDIS nationally.

At a more individual level, these frontline agencies should undertake

- Information provision and individual resourcing, assistance with goal setting;
- Service planning, coordination and lifetime care management;
- Jointly manage assessments with NDIS staff;
- Carer support and advising on community networks;
- Provider management vis-à-vis care plans;
- Secondary consultancy for providers;
- Information and advocacy;
- Financial intermediary services;
- Service procurement.

All of these activities and responsibilities embrace roles currently undertaken under the existing practice of advocacy. This includes through multi program engagement, collaboration with providers, delivery of integrated responses to individuals and proactive connection with communities.

Existing NDAP agencies must be supported to investigate and consider transitioning to become a CLO. Funding and other supports must be in place to allow NDAP agencies the opportunity to both consider this new role and responsibility; and determine whether they wish to move into this space or not.

Because mainstream programs such as health, aged care, housing, employment, education and justice will benefit from the advocacy practice NDAP agencies and

CLOs will undertake in the future, these programs must also contribute to funding and resourcing these agencies over time. Doing so will facilitate capacity building for inclusion in these programs and assist the NDIS as it moves to negotiate cross program integrated responses for participants.

Recommendations

- Maintain existing advocacy services for all Australians with disability as part of the transition to full scheme for all NDIS participants, but include capacity to better define advocacy in the context of the NDIS rollout and the development of the ILC sector.
- Encourage the development of comprehensive community based organisations that can deliver advocacy and specialist expertise at the micro, meso and macro levels in the community and not limit advocacy activity within NDAP to any one level and certainly not just to casework.
- Mandate the development of practice guidelines for representational advocacy, to ensure that clear expectations can be established and to provide for the establishment of a comprehensive cross-sector practice framework.
- Include provision for DSS to undertake cross-government capacity building in the life of the next NDAP contract so that the Attorneys Generals departments can assume responsibility for representational advocacy as a citizen service; and ensure that other mainstream portfolios are well placed to provide funding and partnered roles for CLOs as they develop.
- Establish a cross-portfolio advisory council to provide advice and guidance to mainstream programs, the NDIS and the NDAP agencies in their next contract, particularly with regard to NDIS developments concerning the National Disability Strategy.
- As a matter of priority, articulate an NDAF process that will transition funding for advocacy as a 'service type' from the National Disability Agreement to enable segmentation of responsibility for this area across comparable mainstream portfolio agreements.

References

AIHW, *Policy Bulletin 103, Younger People in Residential Aged Care*, Canberra, April 2012.

YPINH National Alliance and University of Sydney CRPD, *Cross Sector Service Coordination for People with High and Complex Needs: Harnessing existing evidence and knowledge*, Policy Bulletin 2, Sydney, 2014.