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## National Disability Advocacy Framework

# QDN

QUEENSLANDERS WITH DISABILITY NETWORK  
*NOTHING ABOUT US WITHOUT US*

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## About Queenslanders with Disability Network (QDN)

QDN is an organisation of, for, and with people with disability and the organisation's motto is "nothing about us without us." QDN operates a state-wide network of members who provide information, feedback and views from a consumer perspective to inform systemic policy feedback to Government and peak bodies. QDN also provides information and referral support to people with disability.

QDN has over 700 members across Queensland. All of QDN's voting members are people with disability.

## About this Submission

QDN's submission responds to the questions listed in the National Disability Advocacy Framework Consultation paper. Additionally, the submission raises issues and proposes solutions/options raised by QDN members and supporters as part of this consultation, in relation to locating funding for individual advocacy under the National Disability Insurance Scheme.

## Value Statement on People with Disability

QDN's work in providing feedback and input into systemic policy issues is based upon the organisation's core values and the place of people with disability in an inclusive, Australian society.

QDN believes that:

- All people with disability have a right to a place in the community and have contributions to make to community. This is as empowered, free citizens who are as valued, present, participating and welcomed as members of any dynamic and diverse society.
- The place of people with disability in the community is not just about people with disability having a house in the community. Core to this is that they are welcomed in the community as ordinary citizens where they are genuinely given opportunities to contribute and actively participate. People with disability need to be in communities where their individuality, their talents, and their lived experiences of disability are recognised and acknowledged.
- Culturally and historically, people with disability are not afforded the same value, opportunities or access to community life.
- Any inclusion in community for people with disability is conditional and vulnerable to withdrawal.
- Many people with disability in Queensland are excluded from the most basic experiences of ordinary lives.

- Current exclusionary practices are unacceptable and must be challenged.
- These issues affect not only people with disability but the whole community.
- The responsibility is shared. It lies within government (federal, state and local) and the community at large, to ensure that people with disability have a place and are resourced to belong in community.

## **Overview of National Disability Advocacy Framework (NDAF) Consultation**

The purpose of the discussion paper is to review the National Disability Advocacy Framework, which is the structure governments' work within to provide advocacy and advocacy support to people with disability in Australia. The NDAF is guided by principles set out in the Convention on the Rights of Persons with Disabilities (CRPD), the National Disability Strategy, the National Disability Agreement and Commonwealth, State and Territory Disability Services legislation. The Framework is being reviewed due to significant changes to the disability landscape, particularly the commencement of the National Disability Insurance Scheme in 2013. The review sets out to examine whether the vision, principles, outcomes and outputs that are currently in the NDAF are still relevant and appropriate to the NDIS environment.

The discussion paper that has been released includes the April, 2015 decision by the Council of Australian Governments' (COAG) Disability Reform Council that the NDIS would fund:

- Decision supports
- Safeguard supports
- Capacity-building for participants, including support to approach and interact with disability supports and access mainstream services

The Council agreed systemic advocacy would be funded outside of the NDIS, in line with the 2011 Productivity Commission Inquiry report recommendation. These decisions impact on how advocacy will be provided under the NDIS.

The feedback from the consultation will assist the Department of Social Services and Commonwealth, State and Territory Governments to develop a new framework. The new NDAF will be presented to the Disability Reform Council for endorsement in December 2015 and released in early 2016.

## **QDN Consultation and this submission**

A consultation was undertaken by QDN with its members and key disability sector allies. QDN sought and received feedback from our members on the review of NDAF through engagement with our 700 strong Queensland wide member network, a teleconference with

QDN's Regional Facilitators and Group Convenors and discussions with key disability and advocacy sector organisations.

## Key Feedback

QDN congratulates the Commonwealth Government on its timely review of the Framework in light of the significant change occurring across the disability sector and welcomes the opportunity to make this response.

QDN endorses the current Framework as robust and accurate and encourages the Commonwealth Government to continue to use the current Framework as the premise for any future advocacy development.

QDN stresses that any proposed new National Advocacy Framework needs to continue to be linked to the United Nations Convention of the Rights of Persons with Disabilities (CRPD) – and the six principles of the National Disability Strategy, namely:

1. Inclusive and accessible communities
2. Rights protection, justice and legislation
3. Economic security
4. Personal and community support
5. Learning and skills
6. Health and wellbeing<sup>1</sup>

In light of the NDIS's impact upon the contemporary disability policy environment, advocacy principles should incorporate NDIS principles of choice and control and social and economic participation. This approach acknowledges that people need real choice under the NDIS and the ability to control various aspects of their supports and funding.

QDN believes there should be a 'no wrong door' universal access principle to advocacy for people with disability and that advocacy should be available to all people with disability who need it, regardless of where they access supports across service systems (ie either inside or outside the NDIS). Additionally, as much as possible, advocacy should be funded and delivered independently from other services and supports.

While QDN sees real voluntary and paid employment opportunities being key to social and economic participation of people with disability, QDN members have concerns about employment outcomes being linked to the definition of advocacy. This view has been clearly articulated during consultations with members and other sector stakeholders. While it may be relevant for an advocate to assist a person to negotiate with their employment service, or represent a person with disability to ensure they are given fair wages and

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<sup>1</sup> Accessed via: [https://www.coag.gov.au/sites/default/files/national\\_disability\\_strategy\\_2010-2020.pdf](https://www.coag.gov.au/sites/default/files/national_disability_strategy_2010-2020.pdf) 10.7.15.

conditions and protected from unfair dismissal, seeking employment in and of itself is not advocacy.

In relation to the Disability Reform Council's decision around individual advocacy and the NDIS, QDN members and our supporter networks have identified a need advocacy to sit outside of the NDIS to ensure its independence and to remove any potential conflicts of interest. There is also a competing need for NDIS participants to be able to purchase advocacy supports alongside other supports offered by the NDIS, particularly for people with impaired capacity.

Additionally, QDN has concerns about people living in rural and remote communities and the availability of advocacy services, especially in the Queensland context. Adopting a model whereby individuals will 'purchase advocacy' as part of their NDIS package may create a situation for many people in rural and remote areas where service providers are also the only source from which to 'purchase advocacy'. This creates a fundamental conflict of interest that does not align with the definition or role of advocacy.

Outside of this scenario there is potentially an opportunity for the unmet need for advocacy in many parts of the disability community to be addressed through individuals accessing advocacy services as part of their personal NDIS plans.

In reviewing the NDAF, QDN believes it is also important to make links to the recent Information, Linkages and Capacity (ILC) (formerly Tier 2) Framework and Quality and Safeguarding Review consultations. In both its submissions around these consultations QDN stressed the importance of strong individual and systems advocacy as key mechanisms to inform process and quality improvements in regard to the progressive implementation of the NDIS across the nation.

Ensuring that the individual and collective voice of people with disability is heard, listened to and acted upon in a productive and proactive way is vital. Making the voice of people with disability heard ensures service providers and mainstream services are continually challenged to improve through constructive and independent feedback.

Advocacy at all levels is fundamental in order to ensure people with disability have a strong, thoughtful and informed voice to develop more inclusive communities, constructively influencing government and ensure people with disability are given a voice in decisions that affect their lives.<sup>2</sup>

Individual and systems advocacy was also identified as fundamental safeguarding strategies in QDN's submission on the draft Quality and Safeguarding Framework.

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<sup>2</sup> QDN Submission to the Information, Linkages and Capacity Framework (Tier 2), April 2015.

QDN's submission highlighted that:

- Individual advocacy was important for all people but particularly those with limited voice and that this individual advocacy should be funded separately to the NDIS as this is consistent with the 2011 Productivity Commission recommendation.
- Things should not have to “go bad before we start doing advocacy” and advocacy could be included in planning as a safeguarding process.<sup>3</sup>

Advocacy is required to support people with disability accessing government and community mainstream services and other systems such as fair trade practices, discrimination, health, education, and housing - not just the NDIS.

## Funding Individual Advocacy under the National Disability Insurance Scheme

Overall, QDN commends the Disability Reform Council's decision to fund:

- Decision supports
- Safeguard supports
- Capacity-building for participants, including support to approach and interact with disability supports and access mainstream services

However, as raised above, QDN members and allies have expressed issues in relation to funding individual advocacy under the NDIS, including:

- **Conflict of Interest:** The National Disability Insurance Agency (NDIA) is currently responsible for developing individual plans and the subsequent funding aligned with a plan. In a model where individual advocacy is funded under the NDIS and actioned via the NDIA, a conflict of interest may arise when an advocacy organisation also funded through the NDIA supports a person to complain about their plan and/or their funding.

The NDIA may subsequently perceive the advocacy organisation as “problematic” when considering further funding.

Likewise, the advocacy organisation will be aware of the need to retain a relationship with the NDIA, as the organisation's funder, whilst acting in the best interests of the person.

- **Independence of advocacy:** A fundamental principle of advocacy is that advocacy is independent and free from conflict of interest. Locating individual advocacy within the NDIS, as illustrated above, will diminish the independence of advocacy both in practice and perception.

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<sup>3</sup> QDN Submission to the Quality and Safeguarding Framework, April, 2015.

- **Weakening the capacity to inform systems advocacy:** currently issues and outcomes from individual advocacy can be useful in informing systems advocacy efforts. This capacity may diminish when responsibilities for each aspect sits under different government agencies.  
QDN member feedback reinforced that the presence of individual advocacy acts as a social safeguard alongside systemic advocacy, providing protection for both individuals and the collective.
- **Need for individual advocacy for issues outside the NDIS:** Many vulnerable people will continue to need robust advocacy and may either, be ineligible for the NDIS, or require advocacy for issues that sit outside the NDIS.  
It is important to realise that people will continue to require individual advocacy for a broad range of issues that fall outside the scope of the NDIS, including: abuse, neglect, discrimination and other fundamental needs.  
It is therefore vital to have access to robust advocacy for people with disability, regardless of whether they are eligible for, and have readily available access to, services and support under the NDIS.
- **To be effective, advocacy needs to be pro-active not reactive:** In the context of funding advocacy as a component of the person's supports, the planning process is not a time effective process to attain individual advocacy, particularly in instances of an urgent need for advocacy.  
For example, if the purpose of the advocacy is to assist a person to maintain their tenancy, they may not be able to wait the required time for their plan to be approved. Therefore, some individual advocacy needs to be block funded to have capacity to respond to a person's unplanned, emergent needs.
- **Capacity building for self-advocacy:** While QDN agrees with this notion there is real concern that the majority of people who initially access advocacy support are highly vulnerable and do not have others who can freely advocate on their behalf, nor do they have the capacity to advocate for themselves and require formal individual advocacy carried out by someone on their behalf.  
Some people may develop capacity to self-advocate over time, however many may not. Where capacity of the individual allows, QDN supports skill and capacity development to support people in becoming their own advocates and decision makers as citizens.  
Again, this is something that best sits outside the service system.

## Safeguards that need to be in place

QDN believes that if individual advocacy is funded under the NDIS, clear processes need to be in place to ensure its overall independence, transparency and effectiveness.



This may include:

- **A clear separation of advocacy and service provision:** QDN fully supports the funding of individual advocacy independently from service provision and sees this as key to the provision of effective advocacy support.
- **Processes and practices that are open to outside scrutiny:** all organisations should operate in open and accountable ways, and if instances occur where the one organisation is funded to deliver disability services and advocacy it is especially important that the organisation is able to demonstrate these to outside parties. This may include: how they keep service provision business and advocacy business separate, their complaints/disputes resolution processes, processes that safeguard against retribution, for example, a person's service isn't in jeopardy if they raise a complaint or have an advocacy issue, policies that clearly state how conflicts of interest will be managed and high level Advisory Groups established to provide strategic oversight of advocacy work. The Group's members should be external to the organisation and have expertise in advocacy or community visitor-like functions.
- **Measurement of advocacy effectiveness:** clear processes to assess the effectiveness and robustness of the advocacy provided, including its outcomes and outputs as defined in the funding service agreement.

## Current National Disability Advocacy Framework in an NDIS context

QDN believes that the principles, outcomes and outputs in the current NDAF continue to provide a strong and robust framework to deliver advocacy in a NDIS environment.

However, QDN also believes that the definition of advocacy in the Discussion Paper does not fully reflect the principles in the current framework, nor the contemporary definition of disability advocacy in the international, national and state/territory context.

## Defining Advocacy

QDN fully supports and endorses the key concepts and principles that underpin the definition of social advocacy, as reflected in the current framework. These have been endorsed by advocacy organisations throughout Australia and define advocacy as speaking out, acting or writing with a minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, to protect and defend their welfare and rights by:

- Taking positive, ethical action;
- Being on the side of someone who is vulnerable;

- Understanding the position and vulnerability of the person;
- Remaining loyal and accountable over time;
- Being independent with minimal conflicts of interest;
- Focusing on the fundamental needs, welfare and interests of the person; and
- Doing advocacy with vigour and a sense of purpose.<sup>4 5</sup>

QDN believes that wherever individual advocacy is situated, inside or outside of the NDIS, it is fundamental that these agreed core concepts and principles continue to underpin both individual and systemic advocacy into the future.

QDN believes the definition highlighted in the discussion paper does not reflect the current national and international policy framework and the social advocacy principles generally agreed upon by advocacy organisations in Australia, as highlighted above. The Discussion Paper focuses on self-advocacy, when the reality for many vulnerable people is they may not have the capacity to advocate for themselves and may be reliant on informal advocacy (provided by family and other networks) and formal individual advocacy (provided by advocacy services). The discussion paper defines advocacy as the following:

Advocacy means supporting people with disability:

- To stand up for their rights and choices
- Take part in their community
- Find employment and training
- Feel valued and respected
- Achieve their goals
- Have their say

QDN supports dot points 1, 4, 5 and 6 with the understanding that advocates work from the truly perceived best interests of the person and this may sometimes conflict with the wishes of the person. QDN offers the following alternatives to dot points 2 and 3:

- Participate as citizens within their community; and
- Actively participate in meaningful activity, either in a voluntary or paid capacity

The first suggested dot point highlights the human rights concept of citizenship and the second attempts to move away from the outcome language of employment service provision.

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<sup>4</sup> Systems Advocacy Policy (last reviewed August, 2013), Brisbane: AMPARO Advocacy Inc.

<sup>5</sup> This advocacy definition is based on the work of Dr Wolf Wolfensberger and was discussed at a National Advocacy workshop in Sydney in June 1994.

## Retaining the existing National Disability Advocacy Framework

### QDN's vision for advocacy

QDN strongly endorses the principles of the current Framework. The current Framework is robust and has a strong international and national policy base drawn from the CRPD and the National Disability Strategy.

The current Framework enables the provision of advocacy to people with disability that is independently on the side of people with disability and free from conflict of interest. It is important that the principles of the Framework remain strong for everyone with a disability regardless of where they access supports across service systems, either inside or outside of the NDIS.

In light of the NDIS, QDN believes it is relevant to highlight the various points at which advocacy may have particular relevance for people, for example, at the pre-planning and planning stages, so that people can have access to strong advocacy to maximise their opportunity to have real choice and control that facilitates economic and social participation.

QDN cautions against the inclusion of additional aspects such as employment as this merges advocacy with service provision and dilutes the function of advocacy creating confusion with activities that are not advocacy.

### Principles

QDN strongly endorses the current principles of advocacy as they still align well with the framework in seeking to promote and protect the rights of people with disability.

These principles will still be effective in the NDIS environment as they support the notions of autonomy of the person and individual control.

### Outcomes

QDN strongly endorses the outcomes articulated in the current Framework as they uphold the outcomes of advocacy for all people with disability both inside and outside of the NDIS.

QDN believes the outcomes of the Framework are still relevant. However, the final outcome; *“People with disabilities are actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them”* may be seen as systemic and may need further alignment to fit into the context of individual advocacy.

Amending this to *“The individual advocacy stories and issues of people with disability go on to further inform the development, delivery and evaluation of disability and broader*

*government policies, programs and services that impact them.”* Would create a more robust outcome.

## **Outputs**

QDN endorses the outputs of the current Framework going forward.

Additional consideration could be given to include the role and function of supported decision making that many advocates undertake with people in the absence of family, networks of support or formal decision-makers.

Similarly QDN believes the outputs of the Framework are still relevant.

However, again the final outcome, below, would need aligning as it is more systemic.

*“Systemic advocacy that positively contributes to legislation, policy and practice that will support the agreed outcomes”* could be strengthened by amending it to read, *“The learnings from individual advocacy positively contribute to legislation, policy and practice that will support the agreed outcomes.”*

## **National Disability Advocacy Framework in the current and future disability environment**

Regardless of what point of the NDIS or other disability system a person fits within, there is a need for robust and vigorous advocacy as an ongoing requirement for people with disability. This need is even more significant for vulnerable people residing in closed systems or experiencing homelessness, with increased risk of violence, abuse and neglect.

QDN echoes previous acknowledgements of the importance of advocacy that were made in the Quality and Safeguards Framework and Information, Linkages and Capacity Building Framework (ILC) consultations. Feedback from members around both consultations reinforce that advocacy needs to be independent, have minimal conflict of interest and be available to all people with disability.

Additional supports and safeguards are necessary for people who may not be able to manage their supports and articulate their advocacy requirements.

## **CONCLUSION**

QDN acknowledges the positive steps that the Commonwealth has taken in reviewing the current National Disability Advocacy Framework. As the transition to the NDIS fundamentally alters the disability environment it is important to ensure advocacy is appropriately funded and recognised as a vital pathway for individuals and communities.

Advocacy is vital to ensuring fundamental needs and rights are represented and met within services and the broader community to support full social and economic participation by people with disability as well as real choice and control in regard to their services and supports.

In summary, QDN believes the NDAF is still relevant in the context of the NDIS and the benefits for people with disability in preserving the current advocacy framework include:

- It provides a clear framework for customers in terms of how advocacy works as a safeguard that contributes to their social and economic participation
- It provides an ethical framework to guide workers and advocacy organisations
- It provides a nationally consistent approach that complements quality and safeguards and services and support provided under the Information, Linkages and Capacity Building component (Tier 2 ) of the NDIS.

Queenslanders with Disability Network – 23 July 2015.