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### **Submission – Review of the National Disability Advocacy Framework Discussion Paper**

The Illawarra Forum is the peak body working for community services and organisations in the Illawarra and the Shoalhaven. We support community organisations, promote expertise and innovation in community development, foster industry development and advocate for social justice.

For more than twenty years, the Illawarra Forum has taken a leadership role in the local community services sector, which is a major employment sector in the region, and currently consists of more than 300 organisations in the Illawarra and Shoalhaven areas of New South Wales.

The Illawarra Forum works closely with numerous organisations which provide support to vulnerable people across the region including:

- Home and community care services;
- People with disability;
- Individuals and families with multiple layers of social and financial disadvantage;
- Victims of domestic violence and sexual assault ;
- Youth work programs;
- Social housing and homelessness services;
- Community health services, including mental health and drug/alcohol services;
- Community legal centre services; and
- Community development and community capacity building programs.

The Illawarra Forum consulted with members and service providers to develop this response. We note that during our consultation, members expressed concern that for such a complex issue, the discussion paper lacked detail, leading to ambiguity and possible inconsistency for implementation.

#### **1. Do you believe the current Framework encompasses your vision of advocacy in the NDIS environment? If not, what changes are required?**

The Illawarra Forum would encourage more aspirational changes to the framework, for example a clear principle with a focus on changing community attitudes and building inclusive communities through awareness raising and education.

The use of the term 'disadvantage' in the discussion paper has also been questioned. Whilst we are pleased to note that multiple disadvantage has been considered in the Framework,

we are concerned that lifestyle characteristics such as sexual orientation or geographic location are referred to as 'disadvantages'. We believe it is misguided to state that someone has multiple disadvantages simply because they have a disability and they are considered part of a special needs group. The Illawarra Forum recommends that the term 'barriers' be used to change from a deficit model of a person with disability and instead focus on addressing each of the barriers that people face.

We concur that advocacy needs to be funded separately from the NDIS. The new landscape of disability funding and service provision makes it all the more imperative that people with disability receive independent advocacy support that is free from conflict of interest. People with disability must have access to free individual advocacy to address issues relating to supports provided under the NDIS and/or to be present at individual planning processes.

Advocacy must also be available for people with disability who will not be eligible for NDIS (outside of Stream 4: Individual Capacity Building under the Information, Linkages and Capacity Building Framework), as advocacy is not just about interaction with the NDIS but should also be about accessing mainstream supports such as Centrelink, Housing NSW, GP's, etc.

Further detail is required regarding the requirements for advocacy services to be informed by an evidence base, and services provided in an accountable and transparent manner as outlined in Output (b) *'Disability advocacy that is informed by an evidence base and is provided in an accountable and transparent manner.'*

The success of advocacy service delivery currently depends primarily on the passion and commitment of the advocate, meaning that quality of advocacy services is inconsistent across NSW. The Illawarra Forum would like to see clear guidelines and an accountability framework developed so that quality is less dependent on an individual worker or organisation.

There is also inconsistency in the availability of advocacy services across NSW, as demonstrated by this story which was shared by an Aboriginal Ability Linker.

A young Aboriginal man who has a mental illness was referred to the Ability Links program to support his move back to the region to be closer to family. The young man was allocated a 2 bedroom unit through Housing NSW but was required to accept the property quickly which entailed completing a large amount of documentation.

The young man was unable to complete the documentation on his own and was at risk of losing the unit because of his inability to complete it on time. The Aboriginal Ability Linker was unable to find a local advocate and assisted the young man to complete the paperwork himself as he had established trust and rapport with the young man.

This action is outside the remit of the Ability Links program, however, through his actions, the paperwork was completed with informed consent.

The Ability Linker then assisted the young man to undertake a full property inspection and to take photos of the unit before taking up residence. Support was also provided to access the furniture and appliances necessary to furnish the home through a local charity.

Advocacy and case management are not the intent of the Ability Links program. Whilst the Ability Linker concedes that this is not his role, he identified that he is required to undertake a significant amount of case management/advocacy (up to 90% of his role) due to the lack of culturally appropriate advocacy service. He states that it highlights a gap in advocacy and case management services for the Aboriginal community who may not access mainstream service for this support.

The Illawarra Forum supports the descriptions of different types of advocacy in the Framework but recommend the inclusion of Medical advocates. Many people with disability require an advocate to attend medical appointments with them to ensure that they understand information that is provided to them, and that they give informed consent for any procedures. The following example cited at our consultation demonstrates this necessity:

A case manager was attending a medical appointment with a young woman who has an intellectual disability. The GP explained that he would provide a general anaesthetic to the young woman in order to undertake a Pap smear. He then stated that he would also take the opportunity to insert an IUD.

The young lady was ready to consent to the procedure, however, after taking some time to discuss it with the case manager, it became clear that the young woman had not understood what the doctor was intending to do.

If the case manager had not been present to advocate for this lady she would have provided her consent for something that she did not understand.

Systemic advocacy is also defined in the Framework glossary. The Illawarra Forum recommends that systemic advocacy be retained in the National Disability Advocacy system and should be funded unconditionally to allow for free and honest feedback to influence long term change. Providers should not be constrained by contractual obligations when undertaking systemic advocacy i.e. through 'gag' clauses.

It was generally thought that the paper lacks sufficient detail about meeting the needs of individuals who are part of special needs groups. It is critical that advocacy services meet the needs of particular groups, for example they must be delivered in a culturally appropriate manner by providers that are accessible to each group. Women, children, people from culturally and linguistically diverse (CALD) backgrounds, people from Aboriginal or Torres Strait Islander (ATSI) communities and people who identify as lesbian, gay, bisexual, transgender, intersex or queer (LGBTIQ) should all have access to advocacy services delivered in a manner which creates trust and addresses issues of safety. Likewise people living in rural and remote communities must have access to advocates within their region. As the National Disability Advocacy Program (NDAP) has at its core advocacy that is provided free from conflict of interest, the Illawarra Forum is interested in who will fund this National system, how will it be implemented, monitored and evaluated?

**2. Are the *principles* of the Framework appropriate for guiding delivery of advocacy for people with disability in a changing disability environment, including in the context of the NDIS? If not, what changes are required?**

The Illawarra Forum is generally supportive of the principles guiding the Framework, particularly the key principle for advocacy to operate under relevant legislation and the UN Convention on the Rights of Persons with Disabilities and other UN Treaties. The principles should also recognise the barriers for people with disability in living a good life and in turn aim to tip the balance against these barriers.

We recommend that Principle g) '*Disability advocacy recognises and respects the diversity of people with disability*' should go further than recognising and respecting the diversity of people with disability. It should instead outline that people with disability should have a range of options for accessing advocacy that is culturally appropriate and delivered in safe environments, for example for women, people from ATSI communities, CALD backgrounds and those that identify as LGBTIQ.

Principle c) '*Disability advocacy seeks to influence positive systemic changes in legislation, policy and service practice and works towards promoting inclusive communities and awareness of disability issues.*' should include a provision to remove barriers faced by people with disability to full participation in community life.

**3. Are the *outcomes* of the Framework still relevant or should different ones be included? If so, what should be included?**

The Illawarra Forum would like to see some further development of the Outcomes contained within the Framework. We recommend the following amendments:

Outcome d) '*People with disability are able to make decisions that affect their lives, or where necessary are supported in making those decisions.*' should read: '*people with disability **make** decisions that affect their lives, or where necessary are supported in making those decisions.*' This uses more person centred language instead of 'being able to' which has a more patronising approach.

Outcome e) '*People with disability receive independent advocacy support that is free from conflict of interest*' should read: '*people with disability **have access** to independent advocacy support that is free from conflict of interest.*' Again this is more person centred and positive language.

Outcome f) '*People with disability experiencing multiple disadvantage have their needs met.*' should read '*People with disability that have to overcome multiple barriers should be supported to overcome them*'

We also recommend two new Outcomes for inclusion in the Framework. These Outcomes reflect areas covered in the Principles and are as follows:

(g) People with disability live in inclusive communities

(h) People with disability have choice and access to a range of advocacy services that is reflective of the diversity of the population.

#### **4. Are the *outputs* of the Framework still relevant or should different outputs be included?**

Outputs should be clear and measurable. Information is required into how these outputs will be measured and how success of advocacy services will be measured against these outputs. Further work needs to be undertaken to ensure that the outputs create a framework for monitoring and evaluation.

We recommend that Output (a) *'Individual advocacy that is tailored to meet the individual needs of people with disability including a focus on the needs of people with disability experiencing multiple disadvantage'* be amended to read: *'Individual advocacy that is tailored to meet the individual needs of people with disability including a focus on the needs of people with disability experiencing multiple barriers.'*

Output (b) *'Disability advocacy that is informed by an evidence base and is provided in an accountable and transparent manner'* should be more clearly defined in terms of what evidence base is to be used, to whom will advocacy services be accountable, and how will this ensure nationally consistency in the delivery of advocacy services.

Output (c) *'Disability advocacy that is planned and delivered in a coordinated manner and supports communication between disability advocacy support, disability services, mainstream services and governments'* has no mention of people with disability being an integral partner in this process.

Furthermore, it was felt that output (c) lacked clarity. At our consultation, there were multiple interpretations as to what this output meant. Thus the output needs to be reworded and defined clearly, to avoid misinterpretation. It must be clearer about if it is communication regarding the needs of individuals with disability or about systemic advocacy. Is it the role of advocacy services to be improving communication between these agencies or is it the role to improve the lives of people with disability?

#### **Does the Framework identify what is needed in the current and future disability environment? If not, what changes are required?**

The Framework does not clearly identify what is needed currently or in the future. There is far more detail required particularly regarding the Outputs. The Illawarra Forum recommends that people with disability and carer groups be consulted to further develop the Framework. While we have gathered representatives from our membership to develop this submission, nothing can replace feedback from people with lived experience.

To truly reflect Principle (b) *'Disability advocacy promotes the interests and wellbeing of people with disability and promotes their full and valued inclusion as contributing and*

*participating members of the community'*, people with disability must be consulted in the review of the Framework.

Thank you for the opportunity to comment on the Review of the National Disability Advocacy Framework discussion paper. We would be happy to discuss our comments or recommendations in more detail if required.



**Nicky Sloan**

**CEO**

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