Arafmi
Mental Health Carers | Australia

Mental Health Carers
ARAFMI NSW
Carer Information Line: 1800 655 198
Website: www.arafmi.org
Admin: (02) 9332 0777

Submission to the Review of the National Disability Advocacy Framework

About of Organisations

This is a joint submission on behalf of Mental Health Carers Arafmi Australia and MHC ARAFMI NSW Inc.

Mental Health Carers Arafmi Australia (MHCAA)

MHCAA is the name of the national group of mental health carers services across Australia. Member organisations have been providing information and support to carers across Australia for over 30 years. Initially founded through the grassroots efforts of mental health carers, MHCAA seeks to explore and strengthen the mental health caring role, develop knowledge, improve skills and offer support to reduce isolation and enhance the caring journey.

Our vision is that people with a mental illness, and their families and carers, will be understood, respected and provided with a level of treatment and support which provides them with the opportunity to be included in their community.

MHC (Mental Health Carers) ARAFMI NSW Inc.

MHC ARAFMI NSW Inc. is a community-based, non-government organisation that provides support, education and advocacy for the carers, family and friends of those experiencing mental illness across NSW. MHC ARAFMI NSW Inc. encourages an active membership from carers among all of the diverse communities of NSW and its activities and goals are informed by their experiences.

Introduction

We would like to take the opportunity to thank the Commonwealth Department of Social Services for the chance to have input into the National Disability Advocacy Framework (the Framework). The Framework is a step forward in guiding the future directions for disability advocacy in Australia. However, we are concerned about the lack of inclusion of families and carers within the framework. This is outlined further in the below document.

Responses to the questions

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

Families and carers of people with a psychosocial disability need to be included in the framework.

Carers should be included as part of the National Disability Advocacy Framework. They have the right to advocacy in their own right, and to be advocates of their loved ones with a disability (where appropriate). This is outlined in more detail below.

Part A: Carers as advocates for their loved ones

At times, some people with disability may wish to be supported when they make decisions, or to have someone advocate on their behalf. In respect to the NDIS, the contribution of mental health carers is crucial to attaining positive outcomes for participants with psychosocial disability. This is because carer involvement is often important to ensuring that:

- The assessment of the person with psychosocial disability is accurate and captures the impact of their disability on their everyday functioning.
- The support plan is applicable to the participant's needs and takes account of the role of the carer and the whole family.
- The support plan also supports the sustainability of the caring relationship. [1]

The NDIS, acknowledges the important role of carers. For example, the NDIS Operational Guideline – General Conduct – Supporting Participants' Decision-Making NDIS states the "NDIA is to support the person in the decision-making process and this may involve a range of approaches, including:

- Acknowledging and facilitating the role of the person's 'natural' supports already available to reinforce the person's capacity to determine their own best interests and make decisions for themselves.
- NDIA officers should be sensitive to the role of family, carers and other support people in the person's life and should not impose decision-making services in preference to existing networks.
- Acknowledging and respecting the role of advocacy in representing the interests of people with disability.
- Maintaining a 'person-centred' approach at all times."[2]

Therefore, family members as potential advocates for their loved ones needs to be included in the framework, in order to reflect NDIS documentation and best practice when engaging with families.

B: Advocacy for Carers in their own right

The state-wide Carer Consultation conducted by ARAFEMI in 2007 revealed "that many carers felt they were not able to advocate successfully at all times. They identified that the impact of caregiving, the dual nature of dealing with the behaviours/symptoms of mental illness and trying to access services was at times overwhelming and exhausting - they felt unable to advocate and be heard."[3]

"Systemic gaps in advocacy for carers, paucity of available individualized advocacy supports and service boundaries on access to carer supports (service/ region specific) were further seen as limiting carers ability to have their needs heard. In summary, there was a strong desire and need for available, independent, individualised support and casework advocacy to assist mental health carers with complex advocacy issues. Further support was needed to:

- advise, support or 'walk alongside' carers when needed.
- provide voice to the concerns and issues experienced by carers and families.
- provide specific advice in relation to rights & advocacy."

There are times when I want to and can go and fight the system … and there are others when I want someone with expert assistance to come and help me- Carer Quote, Carer Consultation.

NIDS currently allows carers to bring an advocate to the planning meeting to help them and the person they care for discuss their support needs. Therefore, this should be reflected in the framework. However, as stated above systemic gaps in advocacy for carers, paucity of available individualized advocacy supports and service boundaries on access to carer supports (service/ region specific) limits carers' ability to have their needs heard. Support within the framework, and funding for, advocates for families of people with a psychosocial disability is required in order for our vision for advocacy in the NDIS to be upheld.

---

[1] Carers Australia. (2015). Retrieved 30th July 2015 form http://www.carersaustralia.com.au/ndis-and-carers/carers-in-the-ndis/

[2] NDIS. (2013). NDIS Operational Guideline – General Conduct – Supporting Participants' Decision-Making NDIS

[3] Arafemi Vic. (2007). Executive Summary Carer Advocacy Project.

C: Definitions of Carers and Improving Service Delivery

While the Framework appears to document methods of improving the capacity for living skills for disabled people, it does not mention any persons with psychosocial disability or mental health issues. There needs to be a clearer definition of what a disabled person is, in other words, does this also include people with psychosocial disability or mental health issues or this relating to physical disabilities only.

The document shows Government agreeing to support people with a disability in administration of advocacy services, with the view of improving service delivery, but does not seem to adequately tackle the issue of funding for these services. As is, the document states that 'responsibility for funding advocacy services will be reviewed' (National Disability Services: 2015)[4].

Lastly, the document does not define or include carers. We define a mental health carer as someone who provides unpaid care and support to a family member or friend with a mental illness or mental health condition. A carer may or may not live with the person they support. In some cases and on some occasions a person with a mental illness may not be cognisant of that illness and/or may not recognise the role of a person who provides a significant level of support to them. For this reason, a carer does not necessarily need to be identified by the individual with a mental illness to be their carer.[5]

D: Capacity Building

Throughout the entire document, there does not seem to be a mention of capacity building for carers and families. This is evident in the following principles as found within the *National Disability Advocacy Framework 2015*:

Principles

> 10. d - Disability advocacy promotes leadership and capacity building by people with disability;
>
> 10. f - Disability advocacy strengthens the capacity of people with disability to speak for themselves by actively supporting and encouraging self-advocacy;
>
> 10. i - Disability advocacy will foster effective strategic alliances to develop capacity to identify and respond to the needs of people with disability.
>
> Although principle 10.i seems to make reference to fostering strategic alliances which may indicate the role of carers and families.
>
> REFORM AND POLICY DIRECTIONS
>
> 15 c (v) - Increasing workforce capacity;
>
> 15 c (f) - Improving coordination and communication between the disability advocacy, mainstream sector and governments to develop the overall capacity of the sector, including promoting linkages between individual and systemic advocacy.

It is recommended that carers are included in the principles and this is outlined further in the answer to question 2 below.

---

[4] National Disability Services. (2015). NDS Submission on the National Disability Advocacy Framework

[5] Arafmi Mental Health Carers Australia. (2014). Involving Carers and Family Members in the NDIS. p.1

2. Are the principles of the Framework appropriate for guiding the 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?

Families and carers of people with a psychosocial disability need to be included in the principles of the framework as outlined below.

The parties to this Framework accept and adopt the following National Disability Advocacy Principles as guiding the provision of advocacy for people with disability in Australia:

(a) Disability advocacy operates under relevant Commonwealth, State and Territory legislation and the principles of the United Nations Convention on the Rights of Persons with Disabilities and other relevant United Nations Rights Treaties, to protect and promote the legal and human rights of people with disability;

(b) Disability advocacy promotes the interests and wellbeing of people with disability and their families and promotes their full and valued inclusion as contributing and participating members of the community;

(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;

(d) Disability advocacy promotes leadership and capacity building by people with disability and their families;

(e) Disability advocacy ensures that views represented meet the individual preferences, goals and needs of people with disability and their families;

(f) Disability advocacy strengthens the capacity of people with disability and their families to speak for themselves by actively supporting and encouraging self-advocacy;

(g) Disability advocacy recognises and respects the diversity of people with disability and their families;

(h) Disability advocacy ensures that the rights of people with disability and their families to privacy, dignity and confidentiality are recognised and upheld;

(i) Disability advocacy will foster effective strategic alliances to develop capacity to identify and respond to the needs of people with disability and their families.

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

We recommend rewording the outcomes of the framework to include families:

Advocacy provided under this Framework will contribute to the following outcomes:

a) people with disability and their families are accorded the rights and freedoms described in the United Nations Convention on the Rights of People with Disabilities and other relevant United Nations Rights Treaties;
b) people with disability and their families achieve economic participation and social inclusion;
c) people with disability and their families enjoy choice, wellbeing and are supported to pursue their life goals;
d) people with disability and their families are able to make decisions that affect their lives, or where necessary are supported in making those decisions;
e) people with disability and their families receive independent advocacy support that is free from conflict of interest;
f) people with disability and their families experiencing multiple disadvantage have their needs met;
g) people with disability and their families are actively involved in all aspects of the development, delivery and evaluation of disability and broader government policies, programs and services that impact them.

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

We recommend rewording the outcomes of the framework to include families:

The Framework will contribute to the following outputs in support of the agreed outcomes:

a) Individual advocacy that is tailored to meet the individual needs of people with disability and their families including a focus on the needs of people with disability experiencing multiple disadvantage;
b) Disability advocacy that is informed by an evidence base and is provided in an accountable and transparent manner;
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;
d) Disability advocacy that promotes community education and awareness of disability issues and rights;
e) Systemic advocacy that positively contributes to legislation, policy and practice that will support the agreed outcomes.

Further information

For further information please contact:

Jane Henty, Executive Officer,

Mental Health Carers Arafmi Australia,

arafminational@mindaustralia.org.au

03 9455 7967

Jonathan Harms, CEO

Mental Health Carers Arafmi NSW Inc.

jonathan.harms@arafmi.org

02 9332 0777