



ARAFMI ILLAWARRA
Caring for Carers

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14 July 2017

The Commissioners
Productivity Commission

Dear Commissioners

**Mental Health Carers ARAFMI Illawarra Submission to the Productivity
Commission on NDIS Costs**

Thank you for inviting submissions from the Australian community and stakeholders for the very significant costs issues regarding the NDIS and the NDIA.

Mental Health Carers ARAFMI Illawarra (Association of the Relatives and Family of Mentally Ill People Illawarra) has a long history as a charity/NGO of some 30 years in providing programmes and support for carers of people with mental illnesses, mental disorders such as bi-polar, borderline personality disorders, schizophrenia and other mental illnesses in the Illawarra.

Our submission refers to these illnesses and disorders as 'psychosocial disabilities.'

A history of ARAFMI and its current programmes and support services are **attached**.

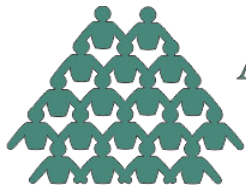
Our submission, based on years of experience, focusses on informal carers (i.e. unpaid carers who are family members or other carers such as friends) and their needs in the NDIS scheme.

Underpinning all of our submission and recommendations is the need to make legislative changes to ensure clarity as to what are reasonable and necessary supports for both participants **and** carers who seek funding.

The NDIS/NDIA schemes cannot avoid the crucial role of carers in supporting loved ones who apply for packages.

ARAFMI Illawarra is of the view that the main needs of carers in the context of psychosocial disabilities are:

1. Emotional supports: either formal (e.g. psychologist, GP, social work, other counselling, social support groups as provided by RAFMI) or informal (family, friends).
2. Respite care or respite relief.
3. Advocacy.



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The Need for Emotional Supports:

ARAFMI's experience is that the spectrum of emotional stresses for a carer in the psychosocial disability context are not always clearly articulated. Whilst there may be a widely held perception that a carer may regularly encounter situations of low to moderate stress in caring for a loved one (with a psychosocial disability) there are also some cases with more extreme circumstances of stress.

These include witnessing, and coping with traumatic events, including suicide attempts, self-harm and domestic violence. These are limited in number but call for extensive support and counselling.

Emotional impacts for carers can be constant, daily, grinding, stressful and often perceived as never-ending. If they are not adequately supported then, to put it bluntly, both the carer(s) will 'go under,' leaving the participant/loved one very vulnerable. The costs implications and blowout include further hospitalization and dependency on costly government services. Social interaction initiatives provided by NGOS such as ARAFMI are crucial for carers but NGOS are also well-placed to provide similar support for joint participants and carers.

Recommendation 1: We recommend that participant assessment for a NDIS/NDIA package must include the need for properly funded formal or informal emotional supports as noted above for carers. Legislative changes must reflect compulsory assessment for this funding and clarity as to when such funding is reasonable and necessary. **(Request 4.1)**

Respite Care-or Respite Relief? :

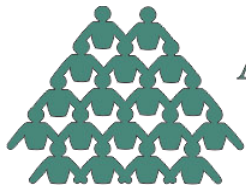
Much has been written and stated regarding the significance for respite care for carers. ARAFMI suggests the better terminology is 'respite relief' since it is the carer who needs time away from the constant and often demanding nature of that role. We support a model of cost-effective, in-home respite relief (as opposed to respite care placement for participants) given obvious benefits of remaining at home with a relief worker.

Recommendation 2: We recommend that properly funded in-home respite relief must be included as a significant consideration during assessment for participant packages. **(Requests 7.1 and 7.2-Respite Care).**

Advocacy:

Advocacy for carers encompasses a broad range of services and supports.

These include:



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1. Legal advice and representation.
2. Assistance to a participant making his/her way through the complicated, time-consuming and sometimes very stressful NDIS/NDIA application process.
3. Intermediary support which assists the participant and carer liaise on an on-going basis with Local Area Co-Ordinators and/or NDIA assessment teams.
4. Advocacy by NGOS (such as ARAFMI) which are well placed with skills and relevant community and more formal contacts, including the health and other NGO sectors. The Illawarra has a high CALD population. ARAFMI has close contacts with CALD and ATSI Illawarra agencies, including NGOS, and would provide an **appropriate advocacy model** for participants and carers as recommended below. Where conflicts of interest (between participant and carer) arises we are well versed in referrals to other agencies.

Recommendation 3: We recommend mental health NGOs are well placed to advocate on behalf of participants and carers in assisting them not only to navigate through the NDIS/NDIA application process and ensuring the needs of both are maintained. NDIS funding should be provided to relevant NGOs to assist them in providing advocacy as stated in 2-4 above. Appropriate NGOs throughout Australia should be appointed and adequately funded to provide these advocacy services. (**Request 6.1-dealing with thin markets and better market innovation with responsiveness to demand, 7.2-Support Co-Ordination and 8.1-Intermediaries**).

Other Comments:

‘Permanence’:

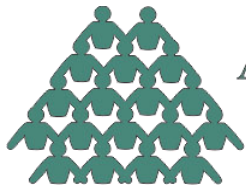
ARAFMI is very concerned regarding the criteria for likelihood of permanence of a disability.

Firstly, there is a need for clarification of the definition of ‘permanence’.

Secondly, we consider the concept of permanence of a disability ignores now well recognized patterns of psychosocial disabilities.

Certainly, some people will have significant and permanent psychosocial disabilities.

However, others may have a short to medium term significant psychosocial disabilities. People can recover but may need reasonable and necessary supports for the duration of a significant level of disability, perhaps for months or years but not necessarily permanently. And episodic.



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Recommendation 4: We recommend the criteria of 'permanence' be supplemented by a further realistic criteria of 'longer term' disability.

Recommendation 5: We recommend out of hours support. Carer NGOs and support services need extra funding to be able to facilitate support programs out of hours for working carers to attend and extra funding to deliver services and programs.

Recommendation 6: We recommend NGOS and support services be provided with extra funding to be able to facilitate support programmes out of hours for working carers to be able to attend.

Case Study: Kate (not correct identity)

Kate is caring for her sister who has schizophrenia and Aspergers. Kate spends on average of approximately \$500-700 per fortnight to supplement her sister's rent, bills, medications and medical dr/specialist visits. This has put Kate significantly behind her peers who have been able to buy houses, study, advance their careers and start a family. She just can't afford to do the normal everyday activities that her friends are doing and provide the level of care that her sister requires to stay alive and safe (not even thriving). Being a sole carer so young has taken her life choices away from her. Siblings are more likely to have a longer role in caring for a family member than parents due to age. Kate suffers with her own anxiety and depression due to her caring role and finds it hard to access help herself. Kate hasn't the resources or funds to:

- A) Go away for a break with friends
- B) Access regular counselling
- C) Access education and training (employment).

Thank you for considering our submission.

Michael Sergent-Member of Management Committee
On behalf of Mental Health Carers ARAFMI Illawarra Management Committee