

# ADACAS

ACT DISABILITY, AGED & CARER ADVOCACY SERVICE Inc

Submission

to the

Productivity Commission  
Caring for Older Australians  
Draft Report

Public Hearing  
Tuesday 5 April 2011

## About ADACAS

ADACAS is a not-for-profit, community based organisation that provides advocacy to people with disabilities and frail older people. We assist individuals to speak out in relation to their needs and interests and represent them in circumstances where they are unable to speak for themselves. We are concerned to see that people with disabilities and frail older people are able to exercise their rights and assert their interests to the same extent as other members of the Australian community.

ADACAS receives a variety of funding to undertake advocacy including from the federal Department of Health and Ageing under the National Aged Care Advocacy Program (NACAP). This funding is for advocacy for people in receipt of Commonwealth Funded Aged Care Services including residents of aged care facilities. As part of this Program we work with individual residents and their families to resolve issues they have about the services they receive. We visit aged care facilities throughout the ACT on a regular basis and discuss with residents and their families their concerns about their living conditions, the care they are receiving and the systems and processes that they come into contact with. We assist residents and relatives to engage with the Complaints Investigation Scheme (CIS) and when the opportunity arises with the Aged Care Standards and Accreditation Agency Ltd (the Agency).

While ADADAS advocates largely work with individuals one by one we also undertake systemic advocacy on issues that affect large numbers of those individuals.

## This Submission

ADACAS contributed to the NACAP Members submission (Submission no. 167) to the Productivity Commission inquiry in July 2010. This paper supplements the NACAP submission and seeks to put before the reviewer ADACAS' response to the Productivity Commission's Draft Report – Caring for Older Australians.

## ADACAS comments on the Draft Report

ADACAS welcomes the Draft Report and generally supports many of the recommendations. However, we would like to comment on a number of issues.

### Advocacy is not a service

The Draft Report refers to advocacy agencies as advocacy services. We note that many NACAP advocacy agencies also refer to themselves as services. The ADACAS name, ACT Disability, Aged and Carer Advocacy Service, is historical and ADACAS advocacy principles state clearly that advocacy is not a service. It also does not generally provide advocacy for carers.

Advocacy is not a service. The repeated use of this language undermines the need for advocacy to be independent of service delivery to people with a disability or people who are ageing and is confusing both for them and to the clarity of that separation and independence. Advocacy is distinct from human service delivery, such as services that provide accommodation, accommodation support or community access. Advocates advocate against or to service providers. The consensus of opinion among disability advocacy agencies, in Australia and overseas, and some aged care advocacy agencies is that advocacy is not a service. Many agencies clearly articulate this as a basic principle of

advocacy. An example is the *Principles of Advocacy* by the Combined Advocacy Groups of Queensland.

### Focus on the person

ADACAS strongly supports the focus on individual persons and their rights. This is enunciated in the Draft Report in the following:

- The recommendation for increased flexibility of support services;
- The stress on meeting individual needs and for services to be person-centred;
- The emphasis on restorative care and rehabilitation;
- The right of people to make life choices, including choices with a higher level of risk (the principle of dignity of risk);
- The right of people to maintain their connectedness to others while in receipt of care, whether at home or in a facility;
- The right of people to exert influence over their environment.

### Separation of roles – policy and regulation

ADACAS strongly supports the recommendation to separate the policy role of Government from the regulatory activities. The current regime is flawed because of the lack of independence of some regulatory activities. This includes the lack of independence of the complaints handling process and an embedded culture in government of risk aversion.

### Interfaces

ADACAS confirms the ongoing issues of problems and confusion at the numerous interfaces encountered by people and service providers. In particular, we encounter people caught up in the interfaces between hospitals and aged care facilities and between hospitals and the person's home. In addition, significant issues exist in the interface between the hospitals and aged care facilities in relation to younger people with disabilities.

### Carers

ADACAS supports the need for carers of older people to be adequately supported. Carers should have access to advocacy and this should be provided by discrete carer advocacy agencies. Inherent conflicts of interest exist for aged care advocacy agencies if they provide advocacy for carers (see below).

## **Issues in need of clarification**

ADACAS is of the view that some clarification is needed with respect to some fundamental aspects of the proposed reforms. These include:

### Restorative care

ADACAS welcomes the emphasis on restorative care and that the person would 'receive a flexible range of care and support services that meet their individual needs and that emphasise, where possible, restorative care and rehabilitation'. However, we are concerned by the term 'where possible'. Clarification is needed on who determines 'where possible' and

how is this defined. This could easily be used to exclude a person from a service rather than include him/her. (page xx)

### Feasible and appropriate

ADACAS welcomes the ability of the person to choose whether to have care at home or in a facility and choose their approved provider. However, we are concerned by the term 'where feasible and appropriate'. Clarification is needed on who decides what is feasible and appropriate and how feasible and appropriate is decided. (page xx)

### Portability of funding

ADACAS welcomes the proposed funding system which may lead to greater control by older people. However, *clear portability of funding tied to the individual* would deliver better outcomes and accountability for people. Page xxxii states 'To reinforce the transfer of choice and control to older people, they would be responsible for paying their co-contribution for purchased services directly to the provider. For administrative efficiency, older people purchasing services would also 'sign over' to the provider their service subsidy from the government'. It is unclear whether 'signing over' their service subsidy from the government to the provider would deliver clear portability of funding tied to the individual.

### Assessment process

The assessment process needs to be underpinned by a statement of philosophy; is the process about thriving or merely surviving?

Assessments of older people are usually negative assessments in that they focus on what a person cannot do. This varies from assessments generally received by people with a disability and some older people living in the community. These assessments are holistic and focus on the 'characteristics' of the person and include what a person can do, who the natural supports are (family, friends, neighbours, church, club, etc.). The assessments also focus on what can be done to help a person to be an included member of the community; to thrive not just survive. Theoretically, this allows services provision to supplement existing natural supports.

### The Australian Age Care Regulation Commission (AACRC)

ADACAS welcomes the proposed establishment of the AACRC as an independent regulator. However, clarification is needed on how the proposal to have aged care data clearing house functions reside with the AACRC interact with the role of the Australian Institute of Health and Welfare. (page xlii)

### Consultation with older people and their carer

Whilst the need for consultation is mentioned in the report, including the establishment of an implementation taskforce, there is no mention of the need for resourcing of targeted consultations with older people, as well as their careers.

## **Who accesses the CIS?**

The most likely complainants to the CIS are family carers and care recipients who have ready access to a phone. It follows that the most vulnerable consumers, people in high level care without access to a phone, do not access the CIS. Two issues arise from this:

- The CIS is not accessible or relevant to a large number of people receiving services under the age care program, in particular people in high level care.
- It is not obvious that the CIS identifies whether or not the family carer has the permission of the care recipient to make the complaint to the CIS. Given that the care recipient is the most vulnerable person, we suggest that any proposed complaints scheme spells out what steps are taken to ensure that the care recipient is aware of the complaint and steps are taken, when appropriate, to protect the person from possible retribution.

## **Retribution**

ADACAS and other advocacy agencies have identified that the fear of retribution and experienced retribution are seriously inhibiting factors for carers and care recipients who wish to complaint about a service. This was recognised by Commissioner for Complaints and the Senate Community Affairs Committee Inquiry into Quality and Equity in Aged Care 2005. We refer to the ADACAS submission no. 167 and supplementary information provided, and the recommendations of the Inquiry.

Any proposed change in service provision and regulatory oversight needs to develop strategies to maximise the opportunities for care recipients and family carers to complain about service providers in a manner that minimises the fear of retribution. It is ADACAS' view that one demonstrated strategy is an adequately funded advocacy program that enables advocates to regularly visit all aged care facilities.

## **Younger people in aged care facilities**

The Draft Report has failed to address the issue of the more than 6000 younger people with disability living in aged care facilities. We recognise that the Productivity Commission is undertaking an inquiry into disability care and support and we recognise that the Productivity Commission Caring for Ageing Australians Report will make recommendations on the most appropriate funding, assessment and service delivery arrangements for people with disabilities who are ageing, and older people who incur a disability. However, ADACAS is of the view that the Draft Report should address this significantly disadvantaged group of people.

It is ADACAS' view that there needs to be a moratorium in place to stop additional younger people being placed in aged care facilities. ADACAS believes that younger people with a disability should be living in accommodation of their individual choice in the community, with adequate portable funding for supports in place.

## **A role for independent advocacy: but for whom?**

The only mention of advocacy in the proposed building block approach (figure 8.2, page 256) is in relation to carers. The Home and Community Care Program, (HACC) does provide funds to the Carers Association to provide advocacy for carers of older people.

The NACAP, funded by the Aged Care Program, has an individual and systemic advocacy role for consumers of the aged care program, which is primarily aimed at residents in aged care facilities or in receipt of the community based funding packages. Some of these

agencies also receive HACC funding to provide advocacy for older people living in the community, and their carers.

The Draft Report does not define 'consumer'. There is ongoing discussion within the NACAP, and between the NACAP and the Department of Health, about who the 'consumers' of the aged care program are. The Department generally regards both carers and residents as consumers of the aged care program, and of the NACAP. However this presents difficulties for some advocacy programs who understand that advocacy cannot be provided for an older person AND their carers, because there is an inherent conflict of interest.

ADACAS' advocacy principles provide for advocacy to be provided for the most vulnerable person in any given situation, which is invariably the older person. However, the ADACAS' advocacy process recognises the important role carers have in the lives of older people, and the agency has a commitment to maintaining and strengthening these connections where possible. ADACAS' advocacy is entirely client directed, and so the degree of involvement a carer may have in a specific advocacy matter is determined by the older person. In some cases there may be none. In other cases external bodies, eg Guardianship Tribunals, may have to be involved.

Recommendation 8.2 is welcomed. However, given the lack of clarity about who 'aged care consumers' are, it is unclear whether the Productivity Commission intends for the NACAP to be included in this recommendation, or whether it intends the resources to be given for carer advocacy only.

## **Funding of advocacy**

The NACAP is significantly underfunded for its current role. The implementation of these reforms will place additional strain on the Program. It has a vital role in providing an independent source of information to older people, and supporting them to make informed choices about their rights and care options. It could also have a role in assisting aged care consumers to understand these reforms, and how they would impact on services, and how these reforms will affect them.