

# **By the consumers' side**

JOINT SUBMISSION  
by the  
NATIONAL AGED CARE ADVOCACY PROGRAM  
(NACAP) MEMBERS

to the

PRODUCTIVITY COMMISSION INQUIRY  
into  
***CARING FOR OLDER AUSTRALIANS***

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NACAP contact person for further information:

Ken Hardaker, Chief Executive Officer  
Advocacy Tasmania Inc  
PO Box 426 Sandy Bay  
Tasmania 7006

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## **Overview and Summary of Issues in the NACAP Submission**

The National Aged Care Advocacy Program (NACAP) agencies welcome the opportunity to make this submission to the Productivity Commission's Inquiry into *Caring for Older Australians*.

The *Caring for Older Australians* Inquiry being conducted by the Productivity Commission for the Australian Government has given us as a society an opportunity to consider the rights of citizens in a publicly funded aged care system. The National Aged Care Advocacy Program has taken this opportunity of sharing 20 years of our experience and expertise in advocating for older people as consumers of the current aged care system. The key issues we highlight are: the human rights perspective and the imperative to reform the current systems. We fully support the development of a comprehensive, integrated national care system that can care for older Australians and enable them to age with dignity and respect with quality support services that meet their requirements.

The focus of our submission will be on advocacy for consumers of the aged care program provided in Australia. For over 20 years, all federal governments have recognised advocacy as a critical component of the aged care program.

### **What is NACAP?**

The current National Aged Care Advocacy Program (NACAP) consists of 9 services operating in every state and territory in Australia.

A key role for the advocacy services is supporting older Australians to negotiate the aged care system – from initial access, through assessment and planning, to the specification of actual service delivery; and with participation in quality improvement mechanisms.

The key aspects of our work and the principles that underpin it are outlined below:

- NACAP agencies protect older people's rights and wellbeing and work towards social inclusion;
- The advocacy program is the conduit for the consumer voice for frail and vulnerable older people being heard by government, the aged care system and the community;
- NACAP assists the government to meet its commitments and obligations under the UN Conventions, the Aged Care Act and the principles and service quality frameworks embedded within the aged care system.

In 2008/2009 NACAP agencies provided advocacy through 8,899 contacts. In addition, 35,000 people participated in education sessions about their rights and responsibilities within the aged care system.

### **Summary of issues raised in this NACAP submission**

We support the matters raised in the Productivity Commission's Issues Paper that highlighted the need for an integrated system of care that improves outcomes for older Australians.

#### **Human Rights**

The existing aged care system in Australia should be strengthened to uphold basic human rights applying to older persons. The Australian Government is a signatory to the UN Convention of the Rights of People with Disabilities and should recognise its formal obligations to develop the aged care system in ways that are compliant with human rights frameworks.

### **An integrated national care system**

Reforms need to consider both the aged and disability systems in Australia otherwise existing inefficiencies and inequities could be entrenched and transferred into the new system. We argue for the development of an integrated national care system, and point to the learnings from recent United Kingdom developmental work.

There are substantial inequities in the way in which the disability and aged care systems respond to the individuals with the same levels of needs. This submission argues that an individual in Australia should be able to access the quality of care they require regardless of age, disability and circumstances.

### **Aged Care as a market driven program**

Australia's aged care system is a market subject to supply and demand forces. Like all markets, the efficiency of our aged care system is constrained by over-regulation and by the inadequacies in the information available to those who may wish to invest in the aged care system – whether government or business or community sectors. While the restrictions are in place to provide some protection for the consumers, it is important in the redevelopment of a system of care to ensure efficiency and effectiveness in responding to caring for older Australians. This submission argues for a significant shift in these constraining factors. We argue for a care system comprised of more "buyers", and more "sellers" via a greater emphasis on individualised funding approaches.

### **Supported decision making for older consumers**

We further argue for a greater focus on the support structures required for older people and their families to participate as assertive, informed consumers. This shift – to a comprehensive, coherent infrastructure of supported decision-making – will be required even if the current 'supply' system of aged care continues unchanged. This shift will be especially important as we move towards a greater diversity of service providers.

### **Systemic and individual advocacy to support transition into a system of care for older Australians**

This submission focuses on the roles played by individual and systemic advocacy in supporting the effective flow of information and the provision of quality care. Our member advocacy organisations have accumulated decades of experience that reinforces our fundamental assertion that the advocacy process delivers the following outcomes for consumers:

- **Protection of consumer rights:** our holistic approach and advocacy supports the wellbeing of vulnerable older people;
- **Choice:** it assists the consumers of services to understand the choices available to them, to optimally participate in decisions about those choices and to effectively communicate their decisions to service providers; and
- **Service quality:** it assists service providers (and system-level decision-makers such as funding agencies) to better understand the needs of consumers.

**Individual advocacy** supports consumer decision making and communication and simultaneously enhances service provider information about consumer needs through the resolution of concerns and complaints that consumers have about the quality of care they are receiving

**Systemic advocacy** – based on the trends identified across individual advocacy contexts – supports continuous improvement processes at the service provider level. Systemic advocacy also contributes to service development and recognition by service providers and system-level decision-makers that service gaps exist.

## **RECOMMENDATIONS**

The National Aged Care Advocacy Program (NACAP) request that the Australian Government, in planning Australia's future aged care system, consider and address the following recommendations:

### **Recommendation 1: Human Rights**

- Ensure that all elements of the proposed service system are compliant with the essential human rights of older persons, as defined in existing legislative frameworks including Australia's obligations under the United Nations Convention on the Rights of People with Disabilities; the Charter of Resident's Rights and Responsibilities, the HACC Statement of Rights and Responsibilities, and the Charter of Rights and Responsibilities for Community Care, covering the aged care system.

### **Recommendation 2: Integrated and Comprehensive Care System**

- Recognition that to care for older Australians today and into the future requires a comprehensive, integrated national care system. This means that an individual in Australia should be able to access the quality of care they require regardless of location, age, disability and circumstances. A seamless 'person centred' system is required, catering for people as they 'age in place' and providing services to people who require support, care and advocacy to enable them to age and have continued quality of life.

### **Recommendation 3: Parallel Inquiries by the Productivity Commission**

- The Productivity Commission ensures that the Commission's concurrent inquiries into aged care and disability are developed in such a way that the option of a comprehensive, integrated care system is appropriately examined.

### **Recommendation 4: Individualised Funding**

- Develop a suite of service options based around the concept of individualised funding to consumers as a means of maximising consumer choice and decision-making control within a national care system, whilst maintaining quality and equity of service provision and ensuring accountability systems are sustainable.

### **Recommendation 5: Advocacy as an integral part of the reformed system**

- The further development of an infrastructural layer of independent, professional, well resourced and accessible advocacy organisations that meets older Australians' entitlement to advocacy. This would also recognise that advocacy is an important component of the change-management strategy required in reforming Australia's aged care system. Further it acknowledges that advocacy follows the consumer wherever their location is in accessing the support and care they require as they age in place.

## **INTRODUCTION**

### **The Inquiry – issues to be addressed by NACAP**

The scope of the Productivity Commission's Caring for Older Australians Inquiry is substantial, especially given the requirement specified in the Terms of Reference that the Commission should take into account the findings of a number of other recent major inquiries and reviews relating to the aged care system.

The NACAP submission will not attempt to address the full range of issues canvassed in the Terms of Reference. Instead we will focus most of our attention on the following two identified scoping issues:

*(2) Develop regulatory and funding options for residential and community aged care (including services currently delivered under the Home and Community Care program for older people)*

*(4) Recommend a path for transitioning from the current regulatory arrangements to a new system that ensures continuity of care and allows the sector time to adjust (IP, p32)*

This submission will be comprised of the following 4 key sections:

Section 1: Role of advocacy in caring for older Australians

Section 2: Transition to a comprehensive integrated care system

Section 3: Transition to a Rights based system of care

Section 4: Transition to a functioning market - building genuine choice for consumers.

### **Where advocacy fits in the National Aged Care Program**

#### **Advocacy in legislation relating to aged care**

Australian legislation protects the rights of consumers of aged care through the ***Aged Care Act 1997 (Part 5.5, Division 81 Section 1)***. Also: Chapter 4 Responsibilities of approved providers: Part 4.1 - Quality of Care Standards and Part 4.2 - User Rights) ***Aged Care Principles 1997*** which comprises 21 sets of Principles including Aged Care Standards and User Rights.

The Charter of Residents' Rights and Responsibilities became law in 1990. The Charter applies to people in residential care receiving low and high care services.

The Charter of Rights and Responsibilities for Community Care became law on 1 October 2009. The Charter applies to people in receipt of Australian Government funded packages legislated under the Aged Care Act 1997: Community Aged Care Packages (CACPs); Extended Aged Care at Home (EACH); and Extended Aged Care at Home Dementia (EACHD) packages.

*(1) Source: Department of Health and Ageing website, 2010 [www.health.gov.au](http://www.health.gov.au)*

The National Aged Care Advocacy Program (NACAP) is a national program funded by the Australian Government under the *Aged Care Act 1997* and the *Advocacy Grant*

*Principles 1997*. The NACAP aims to promote the rights of people receiving Australian Government funded aged care services. The Charter of Resident's Rights and Responsibilities Schedule 1 in the User Rights Principles, *Aged Care Act 1997* is fundamental to the work of the Advocacy Services.

(2) Source: Department of Health and Ageing website, 2010 [www.health.gov.au](http://www.health.gov.au)

Advocacy is a recognised part of the Home and Community Care (HACC) Program. It underpins the HACC Program through Principle 7: Advocacy, and is also provided for in the HACC Rights and Responsibilities. The HACC National Service Standards were introduced in 1991. Following the agreement of all State and Territory Ministers responsible for the HACC Program, the National Service Standards were gazetted on 17 May 1995.

(3) Source: [www.health.vic.gov.au/hacc/quality\\_frmwrk/prog\\_nat\\_comp\\_pol.htm](http://www.health.vic.gov.au/hacc/quality_frmwrk/prog_nat_comp_pol.htm)

### **Key features of advocacy as noted by NACAP**

Advocacy in the aged care program:

- is a process of speaking up for, or representing, a person or a cause;
- is partisan – it involves taking sides;
- involves the rights or entitlements of the consumer;
- happens where someone other than the consumer has the power to make a decision;
- involves empowering the consumer: seeks to readdress a consumer's feeling of powerlessness.

Advocacy is **not** complaints investigation or mediation.

(4) Source: *The Aged-care Rights Service (TARS), NSW, 2010* [www.tars.com.au](http://www.tars.com.au)

### **Funding of advocacy by the Australian Government**

Advocacy is a part of the public policy on aged care in Australia. A paper produced by NACAP in May 2010 provides the following information on the funding of advocacy.

In Australia the number of very frail vulnerable people in receipt of Commonwealth aged care services - 329,926 people in 2008-09 (5) is about half the number of Australians aged 5 to 64 with a severe or profound disability - 647,000 people in 2003 (6).

Government funding across Australia for advocacy and information for people with disability is approximately 18 times that provided for advocacy for people in receipt of Commonwealth aged care services (\$48.465m (7) compared to \$2.582m (8)).

### **About NACAP**

The current National Aged Care Advocacy Program (NACAP) was established under the Aged Care Act 1997 and the Aged Care Principles that flow from the Act. Prior to this it was known as the Residential Aged Care Advocacy Program which was funded from 1989.

The Australian Government funds independent community based organisations (Advocacy Services) through the NACAP to provide a free and confidential service promoting the rights of people receiving Australian Government subsidised aged care services.

The program aim is: *To contribute to improving the quality of life of consumers of aged care services and to the protection of their rights.*

NACAP funded services (see Attachment 1 for a full list of services) are available for people receiving Australian Government subsidised aged care services. This includes people who:

- live in an aged care home or hostel;
- receive a community aged care package (support at home);
- receive flexible care;
- have been assessed by an Aged Care Assessment Team (ACAT);
- previously received aged care services; or
- are representing the interests of a person receiving aged care services.

NACAP services are independent and confidential.

In advising clients and representing their interests, Advocacy Services aim to provide high quality consumer-focused practices that are delivered in a professional manner.

Advocacy Services can:

- provide clients with information and advice about their rights and responsibilities;
- support clients to be involved in decisions affecting their life;
- assist clients to resolve problems or complaints in relation to aged care services;
- promote the rights of older people to aged care providers.

Advocates work solely on behalf and at the direction of the client.

They listen to their concerns, give information and speak up for the client if requested to do so. Before taking action, they will seek the client's permission. Advocates can:

- support the client to speak out on their own behalf;
- speak for the client to aged care service providers and other agencies; and
- refer the client to other agencies where required.

In 2008/2009 NACAP agencies provided advocacy through 8,899 contacts.

In addition, 35,000 people participated in education sessions about their rights and responsibilities within the aged care system, resulting in self advocacy and advocacy through a third party.

Advocates possess a wealth of knowledge about clients' needs and service gaps that is fed to government as well as service providers to assist with future planning of services in the aged and disability sectors.

(For more information on NACAP please see Attachment 2)

(For consumer stories that highlight the work of advocacy services see Attachment 3)



## **SECTION 1 ROLE OF ADVOCACY IN CARING FOR OLDER AUSTRALIANS**

This section discusses the role of advocacy services and provides a rationale for why advocacy is required in the change process and should be embedded in the reforms of the aged care system.

The existence of independent, professional and accessible advocacy services for older persons is a key element of the care system's reform, and should be linked to growth in the aged care system. Currently, residents hold \$7.2 billion of their funds as bonds in the residential care system. In return, entitlement to independent advocacy should be part of their consumer protections.

NACAP member organisations are aware of the roles that they already play in supporting important change processes within their respective jurisdictions, such as feeding into future service planning and enhancements.

***We are confident that the development of a comprehensive national advocacy infrastructure for Australia's future aged care system will be an integral part of the change management strategies required and an essential component of the reformed system.***

### **1.1 Individual advocacy: supporting transitions in the consumer 'journey'**

#### **Advocacy in a 'person centred' care system**

For many people in the Advocacy field working in the aged care sector for over 20 years it has become apparent that a good care system for older Australians is one based on 'person centred' care that provides choice and service quality.

This central focus on the consumer will place the decision-making control in the hands of the consumer in their interaction with the aged care system through four key phases: initial access; engagement with service providers; receipt of services; and participation in service / system improvement.

Consumer advocates are constantly aware that consumers are typically subjected to substitute decision making rather than being engaged in taking their own decisions.

#### **Three key roles for advocacy services in the aged care system**

***(i) Supporting older Australians to negotiate the aged care consumer journey*** – from initial access; through assessment and planning; to the specification of actual service delivery; and participation in quality improvement mechanisms (particularly early and local resolution of complaints in aged care facilities) – is a key role for advocacy services.

Currently NACAP members devote considerable time to providing advocacy support to individuals with a concern about the aged care services they receive.

The *Review of the Aged Care Complaints Investigation Scheme* requested by the Minister for Ageing was conducted by Associate Professor Merrilyn Walton in October 2009 and highlighted the National Aged Care Advocacy Program (9). Particularly, ***“The role of advocacy groups in early resolution is important and can provide complainants with support during local resolution. The advocacy groups are staffed by experienced professionals who have years of experience in advocacy and aged care.”***

NACAP members note that the notion of an information, knowledge and power imbalance comes into play in relation to the consumer’s capacity to provide the evidence the Aged Care Complaints Investigation Scheme relies on to make its decisions. That is – the lone consumer versus the residential care facility with all its documentation and strong legal backing.

***(ii) Consumers moving between the aged care and health systems.*** A second aspect of this consumer journey involves decisions to move from one service provider to another service provider, or indeed from one service system to another (including the hospital / health system).

Irrespective of whether these decisions are made by the consumer or by another party, the transitions can frequently be challenging, even traumatic, for the older person and their family members.

An efficient aged care service system must find ways of managing these transitions, and the presence of independent advocates can maximise the decision-making capacity of consumers during these difficult processes. Currently NACAP support is not available to many of these consumers.

***(iii) Consumer purchased care.*** Third, the transition to individualised funding – from the consumer being a passive recipient of services to an active purchaser of services – will offer its own set of challenges.

NACAP members contend that this all-important system transition will require a comprehensive array of supports to consumers. These will include independent sources of advice and support on issues such as financial management, industrial relations, and equipment procurement. The need for such support has been identified by the aged care industry in recent comments about the proposed One Stop Shop services, calling for a ‘concierge’ model of support for consumers in making choices about care. (10) *Quote from Greg Mundy in The Senior newspaper, August 2010 edition*

Consumers making the transition to a more central decision-making role in their own care will need advocacy support, particularly in the early stages of deciding about the transition itself (i.e. whether to pursue / accept personalised funding) and the initial planning during the process of change.

## **1.2 Systemic advocacy: supporting transitions at service level**

Advocacy services have a proven record of assisting service providers to:

- better understand the consumer experience, and
- respond with changes to service models and management approaches.

The contribution made by NACAP members can be understood at two levels.

### **Service-level quality improvement**

Two basic mechanisms apply here.

First, advocates support consumers to communicate their needs and goals to service providers, assisting those service providers to understand the changes that may be required.

Second, all NACAP members engage in forms of systemic advocacy, where emerging patterns within the consumer experiences are noted and communicated to service providers (or to funding agencies where appropriate).

Advocacy services also regularly respond to service-initiated or system-initiated requests for input to review processes.

Some of the advocacy services are specifically funded for independent consumer engagement activities that feed directly into future service planning and development.

### **Quality Assurance and cross-sectoral accreditation issues**

At an accelerating rate, service providers are seeking external accreditation from quality assurance agencies. Some are doing this proactively, recognising that they will benefit from the range of processes associated with accreditation. Others are responding to pressure from funding agencies.

The ability of accrediting bodies to monitor the views of the consumers of services is sometimes hampered by the capacity limitations of those consumers. Advocacy organisations have a key role to play in supporting consumer involvement in quality audits and this role will become more important as more organisations pursue accreditation.

NACAP members are also well placed to act as informants in their own right within these audit processes, having an independent perspective on the operation of the service providing organisations. It should be noted that not all NACAP members accept that this is an appropriate role for their service.

NACAP can strengthen the 'consumer voice' in quality assurance processes through the educative work we currently do, e.g. with Residents Groups in Aged Care facilities.

NACAP can facilitate the input of consumers, residents, family members and carers within the accreditation and quality improvement processes in place for the various locations where older Australians live, i.e. residential aged care facilities, hospitals, hospices, retirement villages and where they receive community care (HACC, community aged care packages, extended care at home, palliative care) in their own homes.

## **Advocacy in the Home and Community Care Program**

As previously mentioned, advocacy is a recognised part of the Home and Community Care (HACC) Program.

The HACC National Service Standards were introduced in 1991 to provide agencies with a common reference point for internal quality controls by defining particular aspects of service quality and expected outcomes for consumers in seven key areas:

1. Access to Services
2. Information and Consultation
3. Efficient and Effective Management
4. Coordinated, Planned and Reliable Service Delivery
5. Privacy, Confidentiality and Access to Personal Information
6. Complaints and Disputes
7. Advocacy

States and Territories are now required to include the Standards in all service agreements. Monitoring and compliance with the HACC National Service Standards, including Standard 7 Advocacy, is a major part of service reviews.

(11) Source: [www.health.vic.gov.au/hacc/quality\\_frmwrk/nat\\_serv\\_stnds.htm](http://www.health.vic.gov.au/hacc/quality_frmwrk/nat_serv_stnds.htm)

## **Use of advocates in the complaint process for the Home and Community Care Program**

Advocacy can play a critical role in assisting consumers to pursue and seek resolution of complaints in the HACC Program. The HACC Statement of Rights and Responsibilities states that consumers have the right to involve an advocate of their choice when addressing issues with service providers and administering government departments.

The role of the advocate is not to mediate between consumer and agency or to arbitrate in a dispute, but to speak and act on behalf of the consumer. The role of mediation and arbitration, when a complaint cannot be resolved at the provider level, lies with the State or Territory Department with primary responsibility for HACC. Advocacy is about early intervention by assisting in achieving resolution through a positive negotiation process. The consumer is supported to be heard and therefore involved in the resolution process.

(12) Source: [www.health.vic.gov.au/hacc/quality\\_frmwrk/prog\\_nat\\_comp\\_pol.htm](http://www.health.vic.gov.au/hacc/quality_frmwrk/prog_nat_comp_pol.htm)

## **1.3 Supporting transition in the structure of Australia's aged care system**

One could ask "*Why is a comprehensive advocacy program required in the reform of the aged care system in caring for older Australians?*"

Above, we noted the role of advocacy organisations in supporting consumers through challenging changes to their care.

It is likely that any major transformation of Australia's aged care system – especially one that compels service provider organisations to respond to the direct purchasing choices

of consumers – will result in significant levels of dislocation. Some service providers will grow and develop new service models; others will fail and disappear.

Without support to older persons affected by these system changes, there will be pressure to maintain the status quo – the ‘devil we know’ – as a means of minimising the negative impact on consumers.

A comprehensive advocacy system, understood as a necessary entitlement for consumers in the emerging care system, will help to protect consumers during change – change that is essential if we are to develop a care system that combines important human rights with allocative efficiencies.

## **SECTION 2 TRANSITION TO A COMPREHENSIVE, INTEGRATED CARE SYSTEM**

### **2.1 Parallel inquiries**

NACAP notes that, parallel to this important inquiry, the Productivity Commission is conducting another vitally important investigation of *Disability Care and Support*. That inquiry has exceptionally broad terms of reference, including a requirement that the Commission consider design issues (for the envisaged disability care system) that take into account impacts on the aged care system. So too, the *Caring for Older Australians* inquiry acknowledges the link with the disability sector.

The Issues Paper formally poses the question of whether it is sensible to continue with separate aged care and disability service systems, or whether “*a broader conception of care and disability policy [would] be more appropriate, with the needs of the aged being one part of this continuum?*” (IP, p15)

### **2.2 Integrated Care System: Why and How?**

For NACAP, the answer to this vitally important question is that a single, integrated care system is both possible and desirable. The separation of the two service systems owes much more to history than it does to logic.

In both the Aged Care and the Disability systems, services are allocated on the basis of need, understood as some form of core activity limitation. The term ‘frail aged’ is often invoked in contexts where no specific condition is identified as contributing to an older person’s core activity limitations. Ultimately, though, it is the core elements of the ‘frailty’ – lessened core strength, stamina, balance, etc – that leave the individual less able to perform the activities of daily living and functioning.

An integrated service system would assist in the delivery of a continuum of care that addresses people’s individual needs supporting both their ageing and disability.

A comprehensive approach to care would keep the focus on the specific disabling impacts – the actual activities that are limited.

An integrated service system would out of necessity acknowledge the full continuum of disabling conditions. This would allow us to escape the artificial rationing device prevalent in the current disability system – the dominant focus on only those who are deemed to have a ‘severe or profound’ disability.

### **2.3 Social Inclusion**

NACAP members assert that if we are to develop a service system that takes seriously the stated social inclusion goals of the Australian Government (and indeed of most state and territory governments), then the full continuum of disablement must be addressed. The ability of many Australians to engage meaningfully as citizens is constrained by the impacts of conditions that are unlikely to be recognised as ‘severe or profound’ but

which nevertheless have a severe and profound impact in excluding them from activities and relationships that most of us take for granted.

Some of the NACAP members are regularly involved in providing support to clients who are negotiating the difficult transition from the disability service system to the aged care system. Some of our members also conduct advocacy services that are targeted at (younger) people with a disability. Advocacy work – across state and territory jurisdictional boundaries – confirms that:

- there are substantial inequities in the ways in which the disability and aged care systems respond to individuals with the same levels of need, and
- transitions between the two systems are handled poorly, frequently resulting in a reduction of services to individuals.

## **2.4 Toward a National Care System**

In considering the elements of a national, integrated care system, much can be learned from the important preparatory work undertaken by the UK Government in recent years, culminating in the *Building the National Care Service* report published last year (HM Government, 2009). (13) Note: it is currently unclear which elements of the proposed service structure will be progressed by the new UK government.

Faced with a similar array of system failures, the UK Government facilitated a wide-ranging national discussion (with over 68,000 British citizens participating in what was promoted as 'The Big Care Debate'), the result of which was a significant consensus about the need for a comprehensive, integrated service system.

This national conversation covered not only the service-delivery structure deemed to be necessary, but an equally ambitious investigation of the possible mechanisms for funding the proposed system (echoing one of the key goals of the current Productivity Commission Disability Care and Support inquiry).

The UK report proposes six key organising principles for a national care system:

Note: These principles are adapted from *Building the National Care Service*, 2009, p13

- **Accessibility:** offering clear and comprehensive information and, where necessary, support for individuals to take decisions;
- **Universality:** supporting all eligible persons with a comparable range of entitlements;
- **Affordability:** such that provision of services is based solely on need, not on ability to pay;
- **Choice and control:** respecting the right of individuals to take key decisions about their lives;
- **Support of families and communities:** recognising the roles that they play in enabling individuals to live their lives fully;
- **Partnership:** meaningfully involving the range of different organisations that contribute to the care and support system.

NACAP members endorse these principles as essential building blocks for Australia's care system. We also support the basic architecture proposed for the UK system – the so-called “six pillars” below: (14)

Note: This section draws on the discussion in *Building the National Care Service* on pp 14-16

Prevention and wellbeing	Eligibility Criteria	Information and advice	Personalised care and support	Joined-up assessment processes	Fair funding
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- **Prevention and wellbeing services to keep citizens independent** – enshrining a focus on preventative measures that include providing support when a care need first arises as a means of stopping problems from escalating.
- **Nationally consistent eligibility criteria** – offering genuine portability across jurisdictional boundaries and a level of certainty such that individuals / families can confidently engage in the same sort of long-term planning that we now encourage in other realms (e.g. superannuation).
- **Information and advice about care and support options** – including, where needed, the provision of independent, professional advocacy supports.
- **Personalised care and support, through a personal budget** – offering individuals the choice between an entitlement that they can use to pay for their needs or a direct payment to a service provider.
- **Joined-up assessment processes** – making it simpler and easier for individuals to access services.
- **Fair funding**, with collective, shared responsibility for paying for care and support – affordable and marked by genuine intergenerational equity.

An integrated care system would provide the potential for important cross-sectoral learnings. For example, we argue for a greater emphasis on the use of individualised funding packages as a mechanisms for increasing consumer choice and decision-making control. For all its manifold faults, Australia's disability service systems have made much more progress in exploring the use of individualised funding than has the aged care sector, and there is considerable scope for overdue cross-fertilisation.



## **SECTION 3    TRANSITION TO A RIGHTS-BASED SYSTEM: BUILDING AN AGED-CARE SYSTEM THAT SUPPORTS HUMAN FLOURISHING AND SOCIAL INCLUSION**

### **3.1    The rights of older Australians**

NACAP supports the National Aged Care Alliance in its view that older Australians are entitled to:

- Live active, contributory and fulfilling lives;
- Have their individual and collective needs fully and equitably considered when governments are making decisions about health, housing, transport and other community services;
- Make decisions for themselves, in conjunction with chosen family and friends where appropriate;
- Be treated with equity and fairness regardless of cultural background, geographic location, health, gender, sexuality and capacity, including their capacity to communicate their needs; and
- The removal of barriers and systemic limitations affecting the realisation of any of these principles.

(15) *National Aged Care Alliance, 2009, p4*

#### **United Nations Convention on the Rights of Persons with Disabilities**

Consistent with NACAP members' call for an integrated care system, we point to the understandings about rights issues that have emerged from the disability sector.

On 21 August 2009, Australia ratified the *United Nations Convention on the Rights of Persons with Disabilities*. That ratification obliges the Australian Government:

- (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognised in the present Convention;
- (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- (c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;

(16) *United Nations, 2007, p5*

in order to give effect to the stated principles within the Convention, which include:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;

- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility.

(17) United Nations, 2007, p4

### **United Nations Principles for Older Persons**

These principles refer to basic human rights underpinning our society. These include the right to:

- maintain independence;
- participate in society;
- access appropriate care and support services;
- achieve self-fulfilment; and
- live in dignity, safe from exploitation, abuse and neglect.

Consistent with NACAP members' call for an integrated care system, we point to the need to ensure all people accessing support in the aged or disability programs have their human rights protected, and have support to do so.

### **3.2 Legal Obligations**

It is important that we recognise that Australia's ratification of the United Nations Convention on the Rights of Persons with Disabilities brings with it more than just the moral obligation to pursue the above principles.

There is now a formal legal obligation that creates a solid platform for actions by individuals and groups who believe that their rights have been compromised or denied.

We stress again that Australia's aged care system, currently and prospectively, provides services to individuals who have disabilities.

Planning for the future of that care system must be continually guided by the question *'in what ways will these changes ensure compliance with the spirit and the letter of the UN Convention?'*

To fail to orient our care system to a rights framework would be to fail the first test of sustainability, as non-compliant programs and services will undoubtedly face legal challenges from an increasingly assertive consumer movement.

### **3.3 Deficiencies in the current system**

The existing aged care system fails older Australians on a number of levels.

Structurally, the focus has been – both in residential services as well as community care services – on decision-making processes that deny older Australians the right to make important choices about their care.

The provision of block-funding to service providers, rather than personalised budgets to consumers, has reduced the choices available to consumers, denying them fundamentally important forms of control over their own lives.

We assert that this is a form of de facto substitute decision-making, applied in contexts where independent and supported decision-making is possible and desirable for many older Australians.

### **3.4 Lack of options for consumer choice at the service level that limits social inclusion**

At a service level, too few options exist for the support of older Australians to continue or further develop:

- their interdependence with others;
- their social interaction; and
- their connection to communities.

Instead, the service models have concentrated on:

- a medical model of care primarily based around the nursing profession;
- personal care; and
- forms of home help / domestic assistance.

Within these models, the boundaries of older persons' lives are set as the boundaries of their residences.

The UN principle of "*full and effective participation and inclusion in society*" requires a very different approach.

Here, older Australians would be understood not just as individuals with rights and entitlements but as full citizens capable of fulfilling their civic responsibilities as part of their community and polity.

With appropriate support, older Australians will be granted a 'right' they regard as crucially important – the right to continue discharging their obligations; to *give* to their communities rather than merely *receiving* from those communities.

## **SECTION 4 TRANSITION TO A FUNCTIONING MARKET: BUILDING GENUINE CHOICE FOR CONSUMERS**

A mature and comprehensive aged care system for Australia will encourage a central focus on the consumer as the primary decision-maker.

This primacy of the consumer will emerge not just as a rights issue, but as a necessary foundation for the development of responsive, innovative and accountable services.

An aged care system driven by consumer choices will also attain a greater level of legitimacy – it will be supported by the wider Australian community as a significantly more transparent use of the public funds involved.

This central focus on the consumer will take the form of enhanced decision-making control by consumers in all aspects of the consumer 'experience'.

Four key phases are examined below:

- initial access;
- engagement with service providers;
- receipt of services;
- participation in service / system improvement.

### **4.1 Consumer decision-making in the access phase**

Older persons need access to information about:

- *service models,*
- *service providers,*
- *the rights and responsibilities* associated with services,
- *costs,* and
- *the systems that are in place to assure quality.*

As the number and range of service models and service providers increase, consumers will also need independent, trustworthy sources of information to assist them in comparing the actual performance of the care options they are considering.

Mature, efficient markets depend on consumers having access to reliable information about the choices they have on care options.

In the aged care system, not only are there very few choices available to consumers; consumers also face a struggle to obtain and interpret information about the services on offer and about their eligibility to participate in particular programs.

A consistent role for NACAP member organisations is that of assisting older persons and their families to negotiate and understand the often confusing or inadequate information resources currently available regarding the fragmented service system.

NACAP's advocacy work has found that many consumers simply cannot find the information they require about services.

## **4.2 Consumer decision-making in the engagement phase**

The engagement phase of the consumer journey involves direct contact with a chosen service provider (or, more likely, one chosen for them).

Here, the key processes are assessment and care planning. (In the aged care system, assessment is provided in a range of contexts, some directly involving the service provider, others performed by specialist units, e.g., Aged Care Assessment Team - ACAT).

### **Assessment**

The current system is based heavily on de facto substitute decision-making, rather than supported decision-making: the assessment process (and the organisation responsible for carrying out the assessment) are determined by policy, not by the consumer.

Few alternatives exist to allow consumers to engage a different assessment process / provider – not allowing for independence in the assessment process. While “*getting a second opinion*” might be recommended in our primary or acute health systems, no such option is available to most older persons in relation to their care needs.

### **Care Planning**

This is also the case with care planning.

Many service systems apply an ‘algorithm’ approach – a formulaic translation of assessed need into a standard package of services.

NACAP members devote far too much time to assisting older persons in their efforts to vary care plans that had failed to take into account the express wishes of the consumer or their real need in terms of services they are to receive. There are even cases where clients do not have a care plan in place or are aware of its existence.

We acknowledge that some service providers have made significant advances in this regard, but overall there is little understanding of the capacity of older persons to participate in, and markedly improve, these care planning processes.

## **4.3 Consumer decision-making in service delivery**

Again, many decisions about the minutiae of service delivery (which care worker, at what hours, providing exactly what services, etc) are determined by service-wide or system-wide policies – not by the consumer.

For consumers, these details are vitally important.

For consumers, being denied a say is even more important.

NACAP members recognise that there will always be efficiency arguments that can be made in relation to the specifics of service delivery – that, for example, the work of paid carers needs to be spread across the working day with the result that not all consumers can expect their service at a time of their choosing.

There have been many cases where the service model determined by the service provider allows little, if any, flexibility that would be more responsive to the consumer's needs.

However, it is often the case that consumer involvement in service planning (see 4.4 below) can generate imaginative responses to these efficiency imperatives.

#### **4.4 Consumer decision-making in service/system improvement processes**

Low level forms of consumer engagement in service and system quality improvement processes are now relatively common. Many organisations routinely involve consumers in reviews of service quality, often as part of external accreditation processes.

Less common, however, is the engagement of consumers in formal decision-making contexts that directly impact on services.

As the key stakeholders in all governance and management decisions relating to aged care services, consumers should have a central role.

NACAP members acknowledge that the development of genuinely representative structures, whether at local, regional, jurisdictional or national level, is a challenging and resource-intensive process. These tasks need to be tackled with skill and sensitivity if the resulting contributions to decision-making are to be seen as legitimate.

Without consumer and carer feedback mechanisms or 'learning loops' that centrally involve older persons and their significant 'others', the capacity of services to improve their service delivery is significantly limited.

Just as important, these feedback mechanisms are essential for service development processes, not just service improvement ones. That is, consumers are able to assist service providers (actual and prospective) to recognise 'gaps in the market' – new service modalities that could address unmet needs within sustainable business models.

#### **4.5 The role of personalised funding approaches**

##### **Block Funding**

The block-funding of service providers will continue to be a fundamentally important component of any future Australian aged care system.

Some service models can only be sustained on the basis of block-funding.

Indeed a continued focus on strategic block-funding will almost certainly be necessary to ensure that an adequate range of choice is available to consumers along with parameters to ensure adequate levels of service commensurate with the consumer's needs.

We should recognise, however, that block-funding is a form of substitute decision-making.

It is a mechanism whereby funding agencies:

- make an assessment of aggregate consumer needs,

- determine the service models they (the agencies) believe are most appropriate to meet those needs, and
- choose the service providers they believe are best placed to deliver the identified services.

That is, three kinds of decisions about need, service model, and service provider have been taken *on behalf* of the consumer, not *by* the consumer.

NACAP members acknowledge that there will be instances where, for reasons of incapacity, substitute decision-making is required.

However we assert and our evidence based practice in the aged care system demonstrates that: ***the vast majority of individuals are able to participate in at least some elements of decision-making processes, given appropriate support.***

A major focus of our work in the National Aged Care Advocacy Program is supporting individuals so that they can optimally participate in these decision-making processes.

While those support roles can be challenging, the real challenge arises from the reluctance of services/systems to acknowledge that consumers have the right to contribute to this decision-making.

### **Personalised Funding**

The Issues Paper poses the question in this form: "*Should subsidies that 'follow' approved clients be paid to providers or should care consumers be given the choice of receiving such payments first to promote a greater capacity to exercise choice?*" (IP, p20)

Our response is to argue that ***a major shift to individualised funding approaches will be necessary if we are to remedy:***

- (a) the paucity of choices available to consumers; and***
- (b) the systemic failure of block-funded service providers to offer genuine decision-making opportunities to consumers.***

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- (17) United Nations, 2007, *Convention on the Rights of Persons with Disabilities and Optional Protocol*, New York (<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>)



**Attachment 1: NACAP-funded services**

<p><b>New South Wales</b></p> <p>The Aged-care Rights Service (TARS)          Level 4, 418a Elizabeth Street          SURRY HILLS NSW 2010</p>	<p><b>Victoria</b></p> <p>Elder Rights Advocacy (ERA)          Level 4          140 Queen Street          MELBOURNE VIC 3000</p>
<p><b>Queensland</b></p> <p>Queensland Aged and Disability Advocacy          Inc.          121 Copperfield Street          GEEBUNG QLD 4034</p>	<p><b>South Australia</b></p> <p>Aged Rights Advocacy Service Inc.          45 Flinders Street          ADELAIDE SA 5000</p>
<p><b>Western Australia</b></p> <p>Advocare          Unit 1/190 Abernethy Road          BELMONT WA 6104</p>	<p><b>Tasmania</b></p> <p>Advocacy Tasmania Inc          Suite 6, Mayfair Plaza          236-244 Sandy Bay Road          SANDY BAY TAS 7005</p>
<p><b>Northern Territory</b></p> <p><b>Darwin</b></p> <p>Darwin Community Legal Service          Aged/Disability Rights          8 Manton Street          DARWIN NT 0801</p> <p><b>Alice Springs</b></p> <p>CatholicCare NT          6 Hartley Street          ALICE SPRINGS NT 0871</p>	<p><b>Australian Capital Territory</b></p> <p>ACT Disability, Aged and Carer Advocacy          Service (ADACAS)          Suite 207, Block C          Canberra Technology Park          Phillip Avenue          WATSON ACT 2602</p>

## **Attachment 2: The National Aged Care Advocacy Program (NACAP)**

### **Background**

For over 20 years, all federal governments have recognised advocacy as a critical component of the aged care program.

The current National Aged Care Advocacy Program (NACAP) consists of 9 services operating in every state and territory in Australia.

### **NACAP is important because:**

- NACAP agencies protect older people's rights and wellbeing and work towards their social inclusion
- Advocacy is the consumer voice for frail and vulnerable older people and people with disabilities with government, the aged care system and the community
- NACAP assists the government to meet its commitments and obligations under the United Nations Conventions, the Aged Care Act and the principles and service quality frameworks embedded within the aged care system.

### **How advocacy fits into the aged care system**

With the Commonwealth Government now taking full responsibility for the delivery of aged care services, we wish to share the expertise and knowledge we have developed over more than 20 years experience of providing advocacy to frail and vulnerable older people. The feedback from annual satisfaction surveys is that our work is meeting an important need but that *"not enough Australians know about us"*.

The NACAP funding has diminished in real terms over this 20 year period while the numbers of people receiving aged care services has dramatically expanded. At this critical time of government reform it is essential to expand the National Aged Care Advocacy Program to align it with the growth in the ageing population and of aged care programs and services over this period. It would also address unmet needs identified in each State and Territory. Such an expansion would assist the government to respond to key reports such as the Complaints Investigation Service (CIS) Review.

Ideally we are aiming for **advocacy following and being available to the older person** regardless of whether they use community care services or live in residential care. This would provide access to advocacy in the same way as it now occurs for people with disabilities and other vulnerable members of our community.

The Council of Australian Governments (COAG) has committed recently to seamless services for older people – aged care, hospitals, health, etc.

It is logical for the Aged Care Advocacy Program to be expanded nationally at this time of change to safeguard the rights and well-being of older people.

### **NACAP agencies are different**

***Our sole focus is older people as aged care consumers.***

**People come to us because of our independence.** For example, in a quality assurance process you can get an honest consumer opinion about the services – which means they will tell us as advocates what they will not tell an aged care service provider. Our advocacy efforts help service providers do their job better and the system to run better overall.

NACAP agencies have **a holistic approach to protecting the rights and wellbeing of vulnerable older people.**

We know we make an impact because the latest data from 2008 / 2009 shows we had 8,899 client contacts and that we reached 35,000 people who were part of education sessions for residents, families, staff and older people living in the community.

### **Funding Issues**

The number of very frail vulnerable people in receipt of Australian Government funded aged care services (329,926 people in 2008-09<sup>1</sup>) is about half the number of Australians aged 5 to 64 with a severe or profound disability (647,000 people in 2003<sup>2</sup>). However, government funding across Australia for advocacy and information for people with disability is approximately 18 times (\$48.465m<sup>3</sup> in 08-09) that provided for advocacy for people in receipt of aged care services (\$2.582m<sup>4</sup> in 2009-10).

Advocacy has dropped off the Commonwealth Department of Health and Ageing (DoHA) radar and the CIS Review has highlighted that it needs to be back on the agenda. NACAP is operating on year to year funding that is diminishing in real terms each year, restricting the reach of the program.

Most community services are now funded on three year cycles particularly those that have delivered consistent results over a long period of time. Despite their strong track record, NACAP agencies have not been provided with 3-year funding with provision for real growth.

### **NACAP Vision and Growth**

Our vision is for **advocacy following and being available to the older person regardless of where they are in the aged care system.** We aim to achieve this with a 5-year NACAP Strategic Plan that focuses on planned growth, addressing unmet needs, better geographic coverage, and improved access to advocacy.

By working strategically with government and with growth funding we can meet specific gaps and the significant unmet need for advocacy for vulnerable older people. In particular we can expand our advocacy for indigenous Australians and for the growing population of older Australians from culturally and linguistically diverse backgrounds. We can provide better geographic coverage in rural and regional Australia and very importantly we can provide more face to face advocacy. We can also resource residents in aged care facilities to be a stronger consumer voice. Together we can make a difference in the aged care system.

<sup>1</sup> Productivity Commission, Report on Government Services 2010, Table 13A.72

<sup>2</sup> ABS, Survey of Disability, Ageing and Carers 2003

<sup>3</sup> Productivity Commission, Report on Government Services 2010, Table 14A.8

<sup>4</sup> Review of the Aged Care Complaints Investigation Scheme, October 2009, Associate Professor Merrilyn Walton

## **Summary of the National Aged Care Advocacy Program (NACAP)**

### **NACAP**

- Established in 1990;
- Independent advocacy to assist older people receiving Commonwealth funded aged care services;
- 9 community based organisations (2 in Northern Territory);
- Free independent and confidential advocacy to consumers or potential consumers of aged care;
- \$2.582 million in 2009/2010.

### **Services**

- 2008/2009: 8,899 contacts and 35,000 people in education sessions;
- General information enquiries;
- Advocacy cases;
- Referrals to Complaints Investigation Scheme;
- Education sessions;
- Community consultation and engagement.

### **Benefits**

The NACAP promotes and protects the rights of older people using aged care services in order that they can make their own decisions about their own lives.

The NACAP provides independent support to ensure consumer rights in aged care and challenges aged care staff through education to improve the quality of care.

Specifically, the benefits of NACAP are:

- Early intervention and resolution of issues;
- Gives consumers a voice and empowered to make decisions;
- Informed and connected to alternative service provision;
- Increases communication between service provider and consumer;
- Cost effective resolution option.

### **Challenges**

- Funding.
- Education, e.g. only possible on a 3 to 5 year rotational basis for aged care facilities in NSW. In Queensland, most of the education, and particularly regional and outreach, is only possible with support from other funding sources and will no longer be possible into the future.
- Ageing population and the impact on Community Care services and Carers.

- Assisting and supporting increasing numbers of people with impaired capacity and mental health issues.

### **Consumer / Client satisfaction**

Consistently high across member organisations (e.g., Queensland received 97% client satisfaction for the last 12 months).

### **Interface with Complaints Investigation Scheme (CIS)**

- Referrals;
- Assistance to clients raising complaints;
- Follow up for appeals;
- Complaints Investigation Scheme request Advocates remain involved – meetings with facilities, ongoing communication;
- Complaints Investigation Scheme refers consumers to Advocates;
- Supporting consumers through Queensland's Aged Care Complaints Investigation Scheme conciliation processes

### **Opportunities**

Expanding projects that have been undertaken in particular States:

- effectiveness of residents groups (South Australia);
- people living with dementia: early intervention / early linking advocacy (Tasmania);
- value add for future aged care service planning through consumer engagement activities in Queensland.

### **Scope for Development of NACAP**

Areas for increased work / expansion of NACAP if funding was available include:

- Strengthening the consumer voice
- More advocacy in the area of community care rights and access to advocacy
- Proactive Advocacy in regard to assessments and care planning
- People with dementia through the early links approach used in Tasmania
- Data analysis to identify systemic trends
- Development of alternative education and information mediums to match changing client demographics.

### **Attachment 3:**

### **Consumer Stories from Elder Rights Advocacy (ERA) in Victoria that highlight the role of the advocacy program in the aged care system**

#### **Understanding Cultural Needs in Community Care**

Eva was a 79 year old woman from Germany with no family in Australia and with limited social supports. Eva was referred to ERA by Senior Rights Victoria as there were some issues regarding her Community Care Package.

The ERA advocate discussed the issues with Eva and found that Eva was extremely distressed and upset because the provider had cancelled her weekly social outing to a German Club. Eva had been attending the club for five years and had made many friends and she looked forward to catching up with them every week. She had also been looking forward to the Christmas party which was planned in a few weeks time.

The provider had cancelled the social outing (including attending the Christmas party), even though it was part of the original agreement, and had informed Eva of the decision without any prior consultation or discussion.

At Eva's request, the advocate spoke to the case manager and informed her of Eva's rights under the Aged Care Act in regard to the agreement.

Following this discussion, Eva's weekly outing to the German Club was reinstated. Eva was very happy when she heard the good news, and was able to attend the Christmas party with her friends.

#### **Stopping the Bullying**

Jan's husband, Michael, was an 85 year old high care resident with dementia.

Jan contacted ERA for help and informed the advocate that two other residents with dementia regularly bullied and struck her husband.

The advocate contacted the Director of Nursing (DON) at Jan's request to discuss the situation. The DON said that the two residents were waiting to be assessed by an Aged Psychiatric Assessment Team and acknowledged that staff were not acting proactively to minimise contact between Michael and the two residents.

The advocate emphasised Michael's right to safety, and the home's responsibility to implement appropriate behaviour management strategies to ensure that Michael was not at risk of further harm.

The DON agreed to develop new behaviour management plans for all three residents.

However, Michael was attacked on two further occasions by one of the residents.

The advocate attended a meeting with Jan, at which the DON acknowledged that not all staff were following the plans and that she would ask the Registered Nurse to provide training about the importance of all staff having a consistent approach.

Jan subsequently reported to the advocate that her husband had not been subject to further attacks and that she now had more confidence in the facility.