

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY
THE DEPARTMENT OF AGEING, DISABILITY AND
HOME CARE**

Organisation: The Aged Care Rights Service (TARS)
Name: Ms Jillian McDonnell
Date received: 12/08/2010



including
Older Persons' Legal Service

SUBMISSION

NSW LEGISLATIVE COUNCIL INQUIRY

Into

**"Services provided for or funded by
the Department of Ageing, Disability and Home Care"**

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This submission is authorised by J. Taylor, CEO, TARS

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PART 1: INTRODUCTION

The Aged-care Rights Service

The Aged-care Rights Service (TARS) is funded under the National Aged Care Advocacy Program (NACAP) to provide advocacy services for residents of Commonwealth funded aged care homes and users of Commonwealth funded in-home aged care packages.

TARS is a community legal centre that specialises in aged care advocacy and legal issues for older people through the Older Persons' Legal Service (OPLS) as well as advocacy and casework to residents living in retirement villages under the Retirement Village Act 1999 (NSW).. TARS receives funding from the following Commonwealth and State government departments to provide these services:

- Commonwealth Department of Health and Ageing
- Department of Services, Technology and Administration / Fair Trading (NSW)
- Legal Aid NSW to run the Older Persons' Legal Service (OPLS)
- Human Services / Ageing Disability and Home Care (NSW)
- Commonwealth Attorney General's Department.

TARS began in the 1980s when a group of community workers known as The Aged Care Coalition worked together to identify a means of improving the quality of life for older people living in supported accommodation. As a result of the Coalition's work The Accommodation Rights Service was established in 1986 under the auspices of the Redfern Legal Centre, and with the support of the then Housing Commission and NSW Department of Community Services.

In May 1990 TARS was registered as an incorporated association under the Associations Incorporation Act 1984 (NSW). From 1 July 1997, after the Aged Care Act was legislated, The Accommodation Rights Service became known as The Aged-care Rights Service so that the name would better reflect the work being done with older people. TARS is overseen by a community based Management Committee. As well as the advocacy services TARS manages the Older Persons' Legal Service (OPLS) and a legal advice and case work service for residents of Retirement Villages under the NSW Retirement Villages Act of 1999. TARS employs 14 staff members made up of four in administration, six in advocacy/education and four legal staff.

In the reporting period from July 2008 – June 2009 TARS was contacted by 3575 people to provide information and advocacy on aged care issues, of these, 916 were advocacy cases.

Previous and current HACC/ADHC funding for TARS

ADHC funded the HACC Aged Access Pilot Project through TARS for two years from December 2002 to auspice an advocacy service for HACC clients and those eligible to receive HACC services. The HACC Aged Access Pilot Project was initially piloted in two regions of NSW: Sydney Inner West and the Illawarra. This Pilot Project did not continue after March 2004.

Terms used in this document

ADHC	Ageing Disability and Home Care
ATSI	Aboriginal & Torres Strait Islanders
CALD	Culturally and Linguistically Diverse
CIS	Aged Care Complaints Investigation Scheme
HACC	Home and Community Care
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
MRSA	Methicillin-resistant Staphylococcus aureus
NACAP	National Aged Care Advocacy Program
OPLS	Older Persons' Legal Service
RV	Retirement Village
TARS	The Aged-care Rights Service Inc
VRE	Vancomycin Resistant Enterococcus

Aged care advocacy

Advocacy, as provided by TARS under the Commonwealth Government's National Aged Care Advocacy Program (NACAP), is a partisan process where the client is supported by the advocate. NACAP guidelines state that advocacy provides clients with information and advice about their rights and responsibilities, as well as providing support for clients involved in decisions affecting their lives. TARS assists clients to resolve problems or complaints in relation to aged care services and also promotes the rights of older people receiving aged care services. This work is also done by means of information and education programs conducted in aged care homes and community organisations throughout New South Wales.

The role of NACAP services in mandating the rights of residents and care recipients contributes to the improvement of the overall conduct and management of aged care homes and service providers.

Aged care advocacy services are available for people receiving Commonwealth Government subsidised aged care services includes people who:

- have been assessed by an Aged Care Assessment Team (ACAT)
- receive an in-home aged care package (CACP, EACH or EACH D)
- live in an aged care home
- receive flexible care at home
- used to receive aged care services or
- are representing the interests of a person receiving aged care services.

What are the rights of people receiving aged care services?

We all have rights, no matter where we live or how much care, support or assistance we need.

If a person lives in an aged care home or receives aged care services in their own home, they have rights — including the right to:

- be in charge of their life, their money and their possessions
- privacy
- be treated with dignity and respect - taking into consideration cultural appropriateness

- good quality care that meets their needs
- be informed about their rights, care, accommodation and fees
- complain and take steps to sort out any problems
- advocacy support and legal advice if required.

How do TARS' aged care advocates work?

An aged care advocate is someone who stands beside a person and works solely on their behalf and at their direction. An advocate listens to their concerns, provides information and speaks on behalf of the person if that is what they want. Before taking any action, the advocate always seeks the person's permission.

Aged care advocates can:

- support people to speak out on their own behalf
- represent a person to service providers and other agencies
- refer a person to other agencies or organisations when needed - eg the Department of Health & Ageing, the Aged Care Complaints Investigation Scheme (CIS) and/or the NSW Aged Care Ombudsman about aged care complaints and concerns.

Advocacy assistance and support is provided in several ways:

- Telephone advice leading to self-advocacy
- Telephone advocacy directly to care management or senior staff on behalf of a resident or client
- Letter writing to care management on behalf of a resident or client
- Attending face to face meetings with care management with or on behalf of a resident or client. *Source: NACAP brochure*

Advocates at The Aged-care Rights Service (TARS) have significant contact with consumers of Commonwealth funded aged care services who have made or intend to make a complaint to, or have been referred by the CIS. TARS' advocacy work is carried out within the constraints of the Aged Care Act (1997), the Aged Care Principles (1997) and the Charter of Residents' Rights and Responsibilities specifically. This contact gives the organisation significant expertise in identifying the needs of older people receiving aged care services.

This submission reflects the work TARS' advocates do with our client group; and its relationship with the processes of the CIS as experienced by TARS' clients.

With regards to the CIS it should be noted:

"Generally the relationship between the CIS and advocacy groups, where it existed, (*including NSW*) was positive. The advocacy groups are handling a substantial case load. 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." *Source: Review of the Aged Care Complaints Investigation Scheme, October 2009, Page 68*

Brief statement: The Care Needs of Ageing Australians

TARS believes that the fundamental goal of all aged care services is to enhance representation to ageing Australians who depend on human service systems or require legal assistance. Older people, who lose independent living skills or lack financial resources are vulnerable to receiving sub standard care, having their rights as citizens extinguished and therefore their place in their own communities. It is the 'right' of ageing Australians to receive a high standard of care and services, tailored to meet individual needs and therefore ensure quality of life.

Research highlights that the Australian population is ageing at a rapid rate and aged care providers are currently under pressure to meet the care needs of older Australians now. In the next ten to fifteen years it is estimated that there will be long waiting lists for both residential homes and in-home care services.

Older Australians should to feel confident that appropriate and affordable services will be available when needed and that their care will not become a burden to a spouse, partner or families. In-home support is and will continue to be preferred to residential care.

Special needs groups amongst Older Australians in NSW

Through our advocacy and legal work with clients and ongoing contacts with Older Australians with special needs and their carers the following kinds of circumstances have been documented:

- Older (and younger people) with disabilities who have been refused care and have no other care options
- Older (and younger people) with special clinical needs including renal dialysis, MRSA, VRE, Alzheimer's Disease and Younger Onset Dementia with limited care options
- CALD groups: - older Australians from diverse language backgrounds and care needs and are often unaware of advocacy services. Some cultural groups don't have a word for "advocacy" in their first language and do not understand what aged care advocacy is
- ATSI groups – who may experience lack of access to aged care services, lack of cultural understanding and lack of ATSI sensitive staff
- LGBTI – privacy, invisibility, issues of non-disclosure for fear of victimisation, diverse life styles & their rights for in-home care, or refusal of aged care services
- Mental health – client care issues, staff awareness of mental health issues for their clients, and the lack of diagnosis of depression in older people particularly
- Older Homeless – inability to access community care and lack of financial means to access aged care
- Rural and remote older persons – distance can mean long delays for assistance and support in their own homes because of distant links to services. Difficulties attracting aged care workers. The additional expense of transporting supplies and long distance travel to reach

small numbers of people are daily challenges which have an impact on in-home services *endorsed by: Source - DPS eNews 23 July 2010*

- Isolated and single older people who have no family, carers or friends to visit, support them and assist them to advocate for their rights.

Many of these people have had no knowledge or understanding of the aged care services available to them and/or how to access them and/or make a complaint about them.

PART 2 :INQUIRY TERMS OF REFERENCE

This submission intends to focus on only one of the terms of reference for the inquiry.

Specific Term of Reference to be addressed:

“Adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services”

Brief statement: Role of ADHC

Source: NSW Government document - Towards 2030 : Planning for our changing population

The future focus of Towards 2030: Planning for our changing population does not overshadow the NSW Government's significant commitment to supporting older people today. Indeed, a special section of this document describes some of the ways in which we are delivering better services for older people, ensuring fairness and opportunity, growing prosperity, upholding rights, respect and responsibility and improving the environment for living.

Table 5: HACC Target Population Projections 2008/09, 2009/10 and 2010/11

2008/09		2009/10	2010/11
Age Group	Number (%)	Number (%)	Number (%)
65-74	103,808 (18.0%)	107,711 (18.3%)	111,282 (18.0%)
Total Population	577,751	587314	597256

Source: NSW HACC Triennial Plan 2008 - 2011

ADHC funded services

ADHC funds a range of organisations to provide in-home care services for the frail aged and people with a disability. These include:

- non-government disability organisations, such as those who run group homes, respite and day programs, case management
- organisations providing services under the Home and Community Care (HACC) program including in-home care for the frail aged and people with a disability, Meals on Wheels, Home Modification and Maintenance services, Community Transport and Case Management. *Source: ADHC website*

Effective complaints systems for ADHC

TARS has researched and read a number of the policy documents that ADHC has produced to enable organisations to put in place complaints procedures and grievance mechanisms: *See Appendix 1*

Differences between complaint handling, grievance mechanisms & ADHC funded advocacy services:

- **Complaint handling:** “DADHC is committed to handling complaints in a fair and open way. Every effort will be made by DADHC to resolve

the complaints it receives to the satisfaction of everyone involved.”
 “Anyone can make a complaint to DADHC. You do not have to be receiving services from DADHC or from a non-government organisation funded by DADHC to make a complaint and you may make a complaint on behalf of someone else.” Source <http://www.dadhc.nsw.gov.au/dadhc/Contact+DADHC/Complaints.htm>

- **Grievance Mechanisms:** TARS understanding is that grievance mechanisms refers to harassment free workplaces which includes clients’ homes where HACC staff provide their services.
- **ADHC funded advocacy services:** “ADHC funded advocacy services help people with a disability to participate in community life and to get their rights. Some people with a disability are able to speak up for themselves, others get help from their family and friends and some go to advocacy organisations that help people with a disability get their rights and have their voices heard. The Department of Ageing, Disability and Home Care (DADHC) supports advocacy and information organisations to provide free services to people with a disability, their families and carers”. Source ADHC website: *Disability Advocacy and Information Services Directory*

Current provision in NSW

Issue	TARS	Funded organisations	ADHC	Ombudsman
	Informal	Formal		External
Complaints	No funded advocacy service to assist frail aged clients	Requirement of funded organisations to have formal complaints procedures for clients	Feedback & Complaints Handling: Principles and Guidelines, May 2005	NSW Ombudsman
Funded Advocacy services	No funded advocacy service for frail aged clients	No funded advocacy service for frail aged clients	38 funded Disability advocacy organisations	
Grievance mechanisms	No funded advocacy service to assist frail aged clients	Requirement of funded organisations to have formal Staff & Client Grievance procedures	38 funded Disability advocacy organisations	

Other States and Territories of Australia:

Funded aged care advocacy services are available for all clients receiving HACC funded in-home aged care services in the following States:

- South Australia: Aged Rights Advocacy Service Inc – ARAS
- Queensland: Queensland Aged & Disability Advocacy Inc – QADA
- Western Australia: Advocare
- Tasmania: Advocacy Tasmania Inc.

What can ADHC clients complain about?

They can make a complaint by speaking or writing to one of the 38 funded Disability Advocacy funded services or directly to the NSW Ombudsman for frail aged clients if they believe that a service provider has acted unreasonably:

- in the way they provide or manage a service to someone
- by not providing a service to someone
- by withdrawing or changing a service to someone
- by providing a service to someone it is believed should not be getting it.

A complaint may be about the conduct of the service provider and/or the conduct of their employees.

A service provider may have acted unreasonably if their decision or conduct:

- does not conform to the relevant legislation or guidelines
- does not meet acceptable standards
- has a detrimental impact on a particular consumer or consumers of that service. *Source: Website NSW Ombudsman*

Who are the 'parties' to a complaint?

The parties to a complaint include:

the 'complainant' the person making the complaint (can be more than one person);

the 'respondent' the person or agency about whom the complaint is being made;

the 'advocate' the person supporting the complainant; possibly from an advocacy agency, a legal representative or an informal support.

"Importantly ADHC does not have the authority to directly investigate complaints about the organisations running the programs. ADHC recommends that clients discuss the complaint with the organisation first. If a client makes a complaint to ADHC about one of these organisations ADHC can refer the complaint to the organisation to look into, ask them how the complaint was resolved and make sure that the organisation has a complaint handling policy". *Source: DADHC Feedback & complaint handling: Principles & guidelines (V2.0) May 2005*

Clients with a Disability receiving ADHC funded services in NSW

There are a total of 38 advocacy services funded by ADHC for Disability clients but **NO** funded advocacy service for frail aged clients either mainstream or CALD of HACC funded programs. *Source: Disability Advocacy and Information Services Directory*

Aged care clients receiving ADHC funded services in NSW

If a frail aged client has asked ADHC to review how a complaint has been dealt with, and if s/he is still unhappy with the outcome of a complaint, then there are external agencies for advice or assistance at any point during the complaint handling process:

- NSW Ombudsman
- Independent Commission Against Crime
- Administrative Decisions Tribunal
- Anti Discrimination Board.

However this presumes that the person:

- Knows and is aware of the service provider's complaints process
- Has the capacity and confidence to make an initial complaint, then follow it up with the ADHC and then approach one of the above organisations.

From our experience and contact with clients it is unlikely that many frail aged clients would undertake this process. (see Appendix 2)

TARS Contact with ADHC clients, carers, family, or staff

Previously during the Pilot Project (conducted from December 2002 to March 2004) TARS received 140 requests for advocacy assistance. Currently for the year 2009 – 2010 anecdotally, because formal recording of HACC complaints are not recorded, it is estimated that advocates received approximately 100 calls. Other than referring the caller back to the organisation providing the HACC service the calls are referred to the NSW Ombudsman.

NSW Ombudsman data for 2008 - 2009

"Figure 9 — Complaints and notifications we received in 2008–2009 — by subject area:

Subject area	Formal	Informal	Total
Depts and authorities*	1,349	3,949	5,298
Local government	702	1,795	2,497
Correctional centres and Justice Health	750	3,062	3,812
Juvenile justice	70	255	325
FOI	186	407	593
Child & family services	449	868	1,317
Disability services	157	216	373
Other Comm services**	29	231	260
Employment-related			
child protection***	1,711	703	2,414
Police	2,948	2,832	5,780
Outside our jurisdiction*	391 6	636 7	027
Requests for information	3,298		3,298
Total	8,742	24,252	32,994

*We sometimes receive written complaints about public sector agencies that are within our jurisdiction but the conduct complained about, on assessment, is found to be outside our jurisdiction. We initially classify these as 'formal' complaints received about public sector agencies. Written complaints received about agencies outside our jurisdiction, and oral complaints about both agencies and issues outside our jurisdiction, are dealt with informally by referring the complainant elsewhere. They are classified as 'outside our jurisdiction' from the outset.

** This includes complaints about DoCS, DADHC and non-government agencies that are funded by one of those departments.

*** This includes notifications and complaints received."

Source 2008 – 2009 NSW Ombudsman's Report

PART 3: TARS' Recommendation:

To add value to, and supplement the role of the NSW Ombudsman and make it easier for older people in NSW – including retirement village residents & OPLS' clients to receive advocacy services and be assisted to make a complaint.

Through our work with older people across all our services we are aware that there are significant barriers for older people to making complaints including:

- Lack of confidence – in communicating with care management and to approach higher level organisations such as ADHC and/or the NSW Ombudsman
- Lack of skills - to communicate the issue, to understand the response or to negotiate a satisfactory outcome
- Lack of knowledge of complaints' procedures
- Believing they are unable to make things change
- Social issues: poverty, isolation, ethnicity, gender
- Dependency – on the service and/or on a carer
- Caregiver issues – as described above for clients
- Age and frailty
- Previous negative experiences – with the organisation and in life generally
- English Language difficulties
- Person specific issues like disability, mental health issues, dementia

And importantly and in particular:

- Fear of retribution or reprisals – “Many family members, and advocacy groups confirmed the vulnerability of numbers of care recipients and their relatives through the Review of the Aged Care Complaints Investigation Scheme. Reluctance to complain for fear of reprisal from a service was raised during the consultations and in the written submission many times. It was noted that while there may not be overt victimisation or retribution for making a complaint there can be hostility. This is particularly the case for families of care recipients with advanced health issues, mental health issues, Alzheimer's Disease or Dementia. Submissions to the review indicated that recipients and/or carers who receive community care packages are also reluctant to complain for fear of losing services that were initially difficult to access and the fact that there may be nothing to replace the service they need. The submissions also highlighted that care recipients and family members who live in rural and remote areas have the added fear that there may be no other care alternatives, and maintaining anonymity is more difficult in smaller places.” *Source: Review of the Aged Care Complaints Investigation Scheme, October 2009, Page 33.*

- "All parties to a complaint should have the opportunity to have his or her say, without fear of a negative reaction or victimisation. This means that a person should not be reprimanded in any way for making a complaint. Nor should usual service or communication with the complainant be altered in any way as a result of the complaint, unless this is an agreed outcome or has been specifically requested by the complainant. A person who takes or threatens to take detrimental action against another person because a complaint has been made may be found guilty of a criminal offence, as outlined in the Community Services (Complaints, Review and Monitoring) Act 1993 (s.47)." *Source: DADHC Feedback & complaint handling: Principles & guidelines (V2.0) May 2005*

Clearly these barriers would be representative of ADHC clients also.

TARS believes that that the opportunity to formalise the role of TARS' services in mandating the rights of aged care consumers of ADHC services would help to improve the overall conduct and management of ADHC aged care service providers and **supplement the role of the NSW Ombudsman.**

Three levels of complaint would then become:

- Informal – TARS – to act as first point of contact, try to give advice and resolve informally or subsequently assist to make a formal complaint or an external complaint
- Formal – Service Provider and/or ADHC
- External – Would only take the more serious or intractable issues to the NSW Ombudsman and have the capacity to refer lesser matters back to TARS making productivity gains for the NSW Ombudsman.

How would the aged care advocates work?

As in all our advocacy cases the aged care advocates would:

- support people to speak out on their own behalf
- represent a person to service providers and/or other agencies
- refer a person to other organisations when needed

Advocacy assistance and support would be provided in several ways:

- Telephone advice leading to self-advocacy
- Telephone advocacy directly to care management or senior staff on behalf of a client
- Letter writing to care management on behalf of a client
- Attending face to face meetings with care management with or on behalf of a client.

Part 4:In Conclusion

TARS is pleased to present this submission to the Inquiry.

If, as a result of the Inquiry, ADHC were to consider providing ADHC funded advocacy services for frail aged clients then TARS is well placed to provide this service. Our organisation has the staff, the expertise, the knowledge of the client group and the added services of the Older Persons' Legal service and legal advice and case work for retirement village residents, both of which were not available in 2002 – 2004.

Appendix 1 : Sources of Information

1. Community Services Complaints Appeals and Monitoring Act, CAMRA 1993
2. DADHC Feedback & complaint handling: Principles & guidelines (V2.0) May 2005
3. DADHC website
4. Disability Advocacy and Information Services Directory
5. Home Care Harassment Free Workplace Policy
6. NACAP brochure
7. NSW Government: Towards 2030 : Planning for our changing population
8. NSW HACC Triennial Plan 2008 – 2011
9. NSW Ombudsman: The Complaint Handler's Tool Kit 2004 and 2009
10. 2008 – 2009 NSW Ombudsman's Report
11. Review of the Aged Care Complaints Investigation Scheme, October 2009
12. Strategy to improve services for people from culturally diverse communities: DADHC CaALD Strategy 05-08, Dec 05
13. Website NSW Ombudsman
14. www.dadhc.nsw.gov.au/dadhc/Contact+DADHC/Complaints.htm
- 15.

Appendix 2: External Review Contacts

Appendix H: External Review Contacts

The NSW Ombudsman can deal with written and oral complaints about the conduct of a community service provider or an employee of such a service and inquire into major issues affecting clients and services. Further information about the NSW ombudsman can be found at www.ombo.nsw.gov.au or by calling 1800 451 524.

The National Disability Abuse & Neglect Hotline is an Australia-wide telephone hotline for reporting abuse and neglect of people with disabilities using government funded services. Allegations are referred to the appropriate authority for enquiry and/or investigation. The National Disability Abuse and Neglect Hotline is fully funded by the Australian Government through the Department of Family and Community Services. Further information about the National Disability Abuse and Neglect Hotline can be found at www.disabilityhotline.org or by calling 1800 880 052.

The Independent Commission Against Corruption (ICAC) accepts complaints about serious misconduct and allegations against public servants. Further information about ICAC can be found at <http://www.icac.nsw.gov.au> or by calling 02 8281 5999.

The Administrative Decisions Tribunal (ADT) reviews administrative decisions of New South Wales government agencies. The ADT is also responsible for conducting hearings into a range of other matters such as reviewing certain decisions regarding community and disability services. For example, funding of disability services or the refusal of a community service provider to implement a recommendation of the NSW Ombudsman. Further information can be found at <http://www.lawlink.nsw.gov.au/adt.nsf/pages/index> or by calling 1800 060 410.

The Anti Discrimination Board (ADB) investigates and conciliates complaints of discrimination, harassment and vilification. Further information can be found at <http://www.lawlink.nsw.gov.au/adb> or by calling 02 9268 5555 or 1800 670 812 (rural and regional NSW only).