



“Caring for Older Australians from a Rights Approach”

Submission from:

The Aged-care Rights Service (TARS)
CEO, Janna Taylor
L4 418A Elizabeth St
Surry Hills NSW 2010
tars@tars.com.au
www.tars.com.au

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

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SUMMARY

Advocates at The Aged-care Rights Service (TARS) have significant contact with consumers of aged care services who have made or intend to make a complaint to the Aged Care Complaints Investigation Scheme. TARS' work is carried out within the constraints of the Aged Care Act (1997), Aged Care Principles (1997) and the Charters of Residents' Rights and Responsibilities and Clients' Rights and Responsibilities in Community Care specifically. This contact gives the organisation significant expertise in identifying the needs of older people receiving aged care services.

The following submission reflects the work TARS' advocates do with our client group; it addresses the processes of the CIS as experienced by TARS' clients and uses anecdotal evidence as part of its argument.

TARS endorses and supports the Joint Submission to the Productivity Commission submitted by the National Aged Care Advocacy Program members entitled "BY THE CONSUMERS' SIDE".

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 aged care services.

TARS is a community legal centre that specialises in aged care and legal issues for older people. TARS receives funding from the following Commonwealth and State departments to provide services to older people in New South Wales and residents of aged care homes and retirement villages:

- 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 came into being, 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. There are 14 staff employed by TARS consisting of administrative, advocacy/education and legal staff.

In the reporting period from July 2008 – June 2009 TARS was contacted by 3575¹ people to provide information and advocacy on aged care issues, of these, 916 were advocacy cases.

Aged care advocacy

Advocacy, as provided by TARS under the 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 is done by means of information and education programs conducted in aged care homes throughout New South Wales.

Aged care advocacy services are available for people receiving Commonwealth Government subsidised aged care services. This 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
- used to receive aged care services or
- are representing the interests of a person receiving aged care services.

¹ Note that these figures constitute the work of the aged care advocacy program only, and not the work conducted by TARS in Retirement Villages or by TARS' Older Persons' Legal Service

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
- 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.

How do aged care advocates work?

An 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 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/client
- Letter writing to care management on behalf of a resident/client
- Attending face to face meetings with care management with or on behalf of a resident/client. *Source: NACAP brochure*

Terms used in this document

ACAT	Aged Care Assessment Team
ACH	Aged Care Home
ATSI	Aboriginal & Torres Strait Islanders
CACP	Community Aged Care Package
CALD	Culturally and Linguistically Diverse
The Charter	The Charter of Residents' Rights and Responsibilities and/or The Charter of Clients' Rights & Responsibilities in Community Care
CIS	Aged Care Complaints Investigation Scheme
DoHA	Department of Health and Ageing
DoN	Director of Nursing
EACH	Extended Aged Care at Home package
EACHD	Extended Aged Care at Home Dementia package
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 Enterococci

Brief statement: The Care Needs of Ageing Australians

TARS believes that the fundamental goal of aged care 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 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 and in-home services.

Older Australians need 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.

For the purpose of this submission, productivity needs to be defined in a wider sense; not just unit cost of delivery but in the social welfare of aged people. The consequent benefits of enhanced care, improved health and well-being or the avoidance of health related issues coming out of the absence of bad treatment may not be measurable but also do need to be considered as flowing from the wider understanding or definition of "productivity" as it concerns older people and their non productive needs.

TERMS OF REFERENCE

Examine the social, clinical and institutional aspects of aged care in Australia, building on the substantial base of existing reviews into this sector

Our Comments:

TARS endorses the Recommendations of the “Review of the Aged Care Complaints Investigation Scheme, October 2009” This is the most current review discussing the role of the CIS and the place of advocacy services, including TARS in NSW, in the aged care sector. The role of NACAP services in mandating the rights of residents and care recipients improves the overall conduct of the business of aged care homes and service providers.

In particular:

Fear of making complaints resulting in retribution or reprisals

Many family members, residents and advocacy groups confirm the importance of the Complaints Investigation Scheme in light of the vulnerability of numbers of care recipients and their relatives. 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. *Reference: Review of the Aged Care Complaints Investigation Scheme, October 2009, Page 33.*

Through our work with clients TARS endorses and supports:

- The Objects of the Aged Care Act 2-1 in particular:
 - high quality care that meets the needs of individuals
 - diversity, flexibility and responsiveness in aged care – particularly for the increasing numbers of residents who have Alzheimer’s Disease or dementia
 - Rights of clients receiving in-home care through CACP, EACH & EACHD packages
 - Increased age of entry and increasing incidence of dementia, with related diminished capacity
- The Charter of Residents’ Rights and Responsibilities in aged care homes and the Charter of Rights and Responsibilities for Community Care in particular:
 - Retribution and fear of retribution and how this impacts on residents’ rights

- Increasing ages of and increased incidences of Alzheimers' Disease and Dementia-related diminished capacity and control over their lives
- The role of the Office of Aged Care Quality & Compliance to provide a focus on the quality improvement of care and services and to ensure the financial security of aged care residents and care recipients in Australian Government subsidised aged care services .

Address the interests of special needs groups

Our Comments:

Through our work with clients with specific needs the following situations have been dealt with as part of our service:

- Younger people with disabilities who have been refused CACP & EACH packages and have no other living and care options
- Younger people with special clinical needs including renal dialysis, MRSA, VRE and Younger Onset Dementia with limited care options
- CALD groups: - older Australians who have 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 experience lack of access to aged care services, lack of cultural understanding and lack of ATSI sensitive staff in aged care homes
- LGBTI – privacy, invisibility, issues of non-disclosure for fear of victimisation, diverse life styles & their rights in both aged care homes and in-home care, or refusal of aged care services
- Mental health – client care issues, staff awareness of mental health issues for their residents, and the lack of diagnosis of depression in residents particularly on entry into aged care
- Older Homeless – inability to access community care and lack of financial means to access residential 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. Residential aged care can mean moving away from family, friends and a supportive community for appropriate residential care because there are no local 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
Source - DPS eNews 23 July 2010
- Isolated and single residents in aged care who have no family, carers or friends to visit, support them and assist them to advocate for their rights.

Develop regulatory and funding options for residential and community aged care (including the Home and Community Care program)

Our Comments:

Through our work with clients TARS puts forward the following issues for consideration:

ACCOMMODATION BONDS in aged care homes:

Why are bonds required? – Are they a barrier for people? Do they act as a sluice gate for entry into an ACF? What are the normative issues to be considered when thinking about the philosophical basis for the existence of bonds?

- Is there transparency by aged care providers in the expenditure of the income raised by bonds. Should there be more regulatory requirements regarding bond amounts to be set at upper limits?
- Should residents have the choice of a bond or accommodation charge for both low care and high care accommodation payments? The resident decides which payment suits their financial situation. For example; will they use share dividends or rent from their home? Will they sell the house? Assistance with these decisions could be sought from Centrelink Financial Information Services. Would this take away the often perceived pressure put on the ACAT to assess a resident as high care to avoid a bond payment and give more options for the resident?

COMMUNITY PACKAGES:

- TARS' clients frequently complain about under resourced community packages tailored to individual needs therefore early entry to residential aged care can have devastating effects financially, socially, emotionally and personally.

REGULATIONS:

Through our legal work with clients the legal staff of OPLS puts forward the following issues for consideration:

- A review should be conducted of Guardianship and Power of Attorney roles because of the confusion created by the different definitions of Power of Attorney and Guardianship documents adopted by different state legislation. Clarity as to the role of a Guardian and the role of an Attorney across Australia could be achieved through the introduction of Commonwealth legislation
- The introduction of civil and criminal remedies in all states and territories against attorneys who abuse their position under an enduring power of attorney appointment. This could be achieved by amending the Power of Attorney legislation to provide for criminal sanctions and civil remedies against attorneys who breach their obligations to residents. The obligations of the attorney should be set out in the legislation. This legislation could be modeled on the Powers of Attorney Act 1998 (Qld)
- In addition to criminal sanctions there should be clear civil remedies, against misuse of an attorney's powers contained in the Act itself, available to be commenced by "interested parties" but which can only benefit the older person if successful. This point is made on the basis that the civil remedy has the lower burden of proof and the usual, for

example tort or contract, civil remedies are too nebulous for older persons

- In New South Wales the NSW Trustee and Guardian should improve its communication with residents in aged care about their finances. This can be done through development of basic correspondence setting out funds held and funds going in and out of clients' account each month. Also the NSW Trustee could have officers visit residents in aged care homes to discuss major financial transactions with them face to face such as the sale of a home for payment of nursing home bond / fees or due to other circumstances.

Examine the future workforce requirements of the aged care sector

Our Comments:

Through our work with clients TARS endorses and supports:

- Resident to Staff ratios to be specified and legislated similarly to ratios on child care staff as set out in a pre-election promise by the Labor Government. This would mean linking staffing numbers directly to ACFI funding ie the more subsidies that are claimed the more staff that have to be employed to meet specific residents' care needs
- Improved staff employment and selection processes including compulsory Police Checks and demonstrated previous experience working in aged care
- Improvements in rural and remote employment pay and conditions because of the difficulties in attracting aged care workers due to low wages, the additional expense of transport and depreciation on private vehicles because of the long distances travelling to reach small numbers of people
- Increasing the number of qualified nurses working in aged care
- Improving the skills of all aged care staff – through mentored experience, qualifications including higher levels of training for all care staff – to a minimum of Certificate III or Certificate IV
- Staffs' ability to communicate in the native language of aged care residents for the benefit of residents from CALD backgrounds
- Recommended levels of English language skills – including speaking listening and writing skills
- Education and training on:
 - Regular and compulsory Rights and Advocacy Education for all residents and staff in aged care homes by impartial non-provider services ie NACAP funded organisations
- Compulsory education and training on positive attitudes and skills in relating to and working with older people receiving aged care services including people of CALD or ATSI backgrounds. This training will help to eliminate the abuse of older people in aged care homes and receiving in-home care– including active or passive neglect, frail older people receiving home care services who may be suffering abuse, domestic violence, or older people who refuse an ACAT assessment for services that are genuinely needed
- Compulsory education for all aged care staff on retribution and fear of retribution and its impact on residents, clients, carers and other staff

members This recommendation endorses the role of NACAP Advocacy services in mandating the rights of residents and care recipients thus improving the overall conduct of the business of aged care homes and service providers. The elimination of these attitudes improves the well being of the residents which improves the productivity of the delivery of the service and the corporate governance of the aged care home.

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

Our Comments:

Through our work with clients TARS endorses and supports the principle that residents' rights are upheld, maintained and reinforced in any new regulatory system through:

- NACAP and its role in informing, educating, supporting and advocating for older people and their carers in accessing aged care services
- Increased funding to expand the provision of NACAP services. For example TARS has six Advocacy and Education Officers whose role is to cover the whole of the state of NSW which has in excess of 900 aged care homes
- The Review of the Aged Care Complaints Investigation Scheme and in particular the recommendations for its restructuring to provide an Aged Care Complaints Commission – *Reference: Review of the Aged Care Complaints Investigation Scheme, October 2009, Recommendation 4 Page 12.*

Examine whether the regulation of retirement specific living options should be aligned more closely with the rest of the aged care sector

Our Comments:

Through our legal work with clients the legal staff of OPLS puts forward the following issues for consideration:

TARS endorses and supports:

- The alignment of retirement specific living and aged care options by realigning the Retirement Village Acts in each of the states and territories with the Commonwealth Aged Care Act and other relevant legislations
- The putting in place of special provisions between the different states and territories RV Acts and the Commonwealth Aged Care Act in terms of finances as people move from RV to ACH because they continue to pay RV charges as well as interest on the bond as they are unable to realise funds by selling the RV unit to pay off the bond.

Assess the fiscal implications of any change in aged care roles and responsibilities.

Our Comments:

Through our work with clients TARS endorses and supports:

- Community transport, similar to the transport provided through the HACC program, being made available for aged care residents to use to improve their access to community resources including for medical appointments, dental appointments, shopping and social outings
- Social, educational, informative community and interactive programs and activities for aged care residents who are cognitively aware and have physical abilities providing quality and meaningful activities. Whilst many residents enjoy Bingo, watching television and/or videos and movies as well as craft sessions and old time singalongs, many other residents are denied meaningful activities relevant to their capabilities
- A review of the burden of responsibility of costs onto residents including telephone & internet access in their rooms, transport to and from the home, podiatry, physiotherapy, hairdressing, dental care. All adding extra expenses to residents
- Support for carers who are also ageing, may have dementia and receive no aged care services themselves
- Social supports and assistance for frail older people receiving home care services who may be suffering abuse, domestic violence, or who refuse an ACAT assessment for their care needs
- Residents rights to access to personal computers, current and future innovative technologies and the maintenance of people's personal interests being accommodated in aged care homes
- Social inclusion: TARS' clients frequently complain about social exclusion, their inability to participate in community activities, boredom and that their options to 'stay connected' are severely inhibited in residential care
- Flexibility of care accommodation giving aged care residents private time with their partners, being able to stay together overnight within the home and at the time of end of life when the dying person and their family wish to be together at any hour of the day or night and not restricted to standard visiting hours.

TARS RECOMMENDATIONS:

1. That the advocacy services of NACAP are maintained and expanded in each state and territory and are available for all Australians interested in and already receiving aged care services across community care, residential care and flexible care.
2. That NACAP services are recognised and approved for increased funding to continue to provide advocacy services across the community in order to improve and increase productivity by facilitating positive relationships and promoting and serving the rights of older people receiving Commonwealth funded aged care services.
3. That uniform Commonwealth legislation should be prepared for Guardians and Attorneys replacing the diverse State and Territory Power of Attorney and Guardianship Acts and this legislation sets out an attorney's obligation under an enduring power of attorney appointment and set out criminal and civil remedies which apply when an attorney breaches any one of the obligations imposed under the appointment.
- 4 That there is a realignment of the Retirement Village Acts in each of the states and territories with the Commonwealth Aged Care Act and other relevant legislations.