



Elder Rights Advocacy

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ELDER RIGHTS ADVOCACY

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WHO ARE WE?

Older Personsø Action Centre Inc. established Residential Care Rights (RCR) in 1990 and auspiced the organisation for its first twelve years. In November 2002 RCR became a separately incorporated not for profit association. From February 2007 RCR commenced operating under the registered business name of Elder Rights Advocacy (ERA) to better reflect our consumer group.

While RCR Inc. is the funded entity eligible to receive grant monies, ERA as the trading organisation providing advocacy, will be the source of data and will be the organisationø referred to from this point forward in this document.

ERA is an independent agency funded by the Commonwealth Department of Health and Ageing (DOHA) to provide advocacy services for people receiving Commonwealth funded aged care services in Victoria. It is part of the National Aged Care Advocacy Program (NACAP).

We also assist carers and family members who represent their interests, as well as people who have been assessed as eligible for a Commonwealth funded aged care service.

Our service is managed through a volunteer Committee of Management, several of whom are older people with an interest and expertise in aged care. We employ six full time staff to provide information, advocacy and education across the state.

We provide a unique service to individuals through our model of advocacy that focuses on helping older people (or their representatives) to understand and exercise their rights, and to have those rights respected in the delivery of their care services.

In 2009-10 ERA reached 5,765 people with information, advocacy and education, distributed 16,918 information products, and had 220,860 hits on our website.

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WHAT IS NACAP?

The current National Aged Care Advocacy Program (NACAP) consists of nine 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 ó 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.

BACKGROUND

The National Aged Care Advocacy Program (NACAP) has been in place since 1990 following recommendations in the Ronaldø Report which identified the need for independent advocacy to assist older people receiving aged care services. The program is delivered through nine community based organisations: two in the Northern Territory and one in each of the other States and Territories.

The Program takes a holistic approach to consumer rights and inclusion through the provision of information and education about these matters to potential and current Commonwealth funded aged care service users, their families, service providers and the general community together with the provision of free, independent and confidential advocacy to potential and current service users.

NACAP advocacy focuses on the early resolution of issues with and for the consumer, where possible at their direction and with the least possible disruption to the important relationships in their lives.

NACAP STATISTICS

The NACAP program in 2009/10 received \$2.582m in funding spread across the nine community based advocacy organisations. This was an increase in funding of 2.1% from 2008/09. NACAP is currently funded on yearly contracts provided by DOHA, and managed as part of the Office for Aged Care Quality and Compliance.

In 2009/2010 NACAP agencies provided advocacy through 9,431 contacts. In addition, 37,713 people participated in education sessions about their rights and responsibilities within the aged care system.

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Client satisfaction with the advocacy and education provided under the program was high: ranging from 81 to 100% of those returning surveys for advocacy assistance and 74 to 100% of those returning surveys for the education sessions conducted in 2008/09.

All NACAP agencies except Elder Rights Advocacy (ERA) in Victoria receive advocacy funding from other sources, to provide HACC, disability or elder abuse prevention advocacy and information.

THE ADVOCACY FUNCTION

NACAP funded agencies protect the rights and well-being of frail and vulnerable older people and work towards their social inclusion. We assist them to exercise their legal capacity, to make and contribute to decisions about their lives and to participate in processes directed towards improving the quality of the care and support they receive.

NACAP agencies are in direct contact with many thousands of aged care service users each year and are the only agencies funded by the Commonwealth to act independently, confidentially and wholly for the benefit of the consumer. For this reason consumers provide information to NACAP agencies that they do not make available to anyone else.

NACAP agencies are thus well positioned to provide advice to government, to the broader community and in service quality assurance processes about the experiences and needs of frail and vulnerable older people whose interests are ordinarily not represented by other older persons' representative bodies.

In undertaking this work, NACAP also assists the government to meet its commitments and obligations under the various United Nations Human Rights Conventions and Instruments and specifically the recently ratified United Nations Convention on the Rights of People with Disabilities and the United Nations Principles for Older Persons.

NACAP also assists the government to fulfil their function under the Aged Care Act 1997 to encourage understanding of, and knowledge about, the rights of current and potential recipients of aged care services; to enable care recipients to exercise those rights; and to provide free, independent and confidential advocacy services to support the exercise of those rights.

NACAP agencies have long standing relationships with key industry providers and Government officials, the Complaints Investigation Scheme and the Aged Care Standards and Accreditation Agency. These relationships enable the agencies to provide both formal and informal consumer feedback to assist in service system development and improvement.

ADVOCACY — KEY TO PROTECTING RIGHTS AND INTERESTS

Frail and vulnerable older people do better in addressing issues that they might have with the aged care system if they have someone on their side to support them or to represent their interests. In many cases this role is carried out by a family member or friend but in circumstances where such support is not available, where the issue is complex and hard to

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resolve or where effective engagement requires specific knowledge and skills then it is important that an advocate is available to assist.

NACAP funded agencies have the knowledge and skills to support aged care consumers in their interactions with all the parts of the aged care system. Advocates assist consumers to understand their options, express their needs and wishes and assist services, government officials and other community members to understand how to effectively respond to this. Advocates assist in redressing the serious imbalance of power that exists between a single consumer and a large service, business enterprise or government agency. Advocate involvement in any issue or process generally leads to a more consumer focused or directed outcome.

In many cases advocate involvement allows an issue to be resolved close to the source without engagement in costly more adversarial processes. The resident is thus empowered and the relationship between older persons and the service or system remains cordial and collaborative.

Advocacy support can be particularly important for those aged care consumers who are indigenous, from a CALD background, who have dementia or cognitive impairment or who are experiencing abuse. Their particular circumstances create an additional layer of complexity in what is an already a complex regulatory and emotional environment.

To ensure that the rights of frail elderly people are acknowledged, respected and acted on it is important for advocacy support to be readily available to all frail elderly people when they engage with and seek to have their needs met or issues addressed in any part of the aged care system including:

Services providing residential care or community care and support

People receiving these personal care services either at home or in an aged care setting are extremely vulnerable because they rely heavily on the service provider for their ultimate survival and well-being. Without advocacy support many will be afraid to voice concerns or raise issues.

Government, Community or business providers of aged person's accommodation

Retirement villages are large and profitable businesses with ready access to legal and financial advice. Individual residents are thus at a significant disadvantage in circumstances when they disagree with their accommodation provider. Most retirement villages have exit arrangements weighted in favour of the village so changing villages is not usually a financially attractive option.

A retirement village resident appearing before the Fair Trading Tribunal will benefit from the assistance and support of an advocate who knows the process and how to effectively present in the Tribunal.

Tribunals considering guardianship or community care orders

For many people the possibility of losing the right to make their own decisions is terrifying. Tribunal processes can seem alien and be difficult to understand. When the consequences of Tribunal decisions are so great it is vital that the person concerned has the best possible opportunity to have their wishes and needs properly considered. An advocate can assist a

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person in these circumstances to present their views and wishes effectively and in a way that is useful to the Tribunal.

Service Quality Assurance processes

For example audits carried out by the Aged Care Standards and Accreditation Agency require the involvement of facility residents however without good independent support and preparation many residents are unable or unwilling to provide frank or relevant information. Advocates can assist residents to be knowledgeable and feel comfortable about engaging in audit processes. They can assist them to craft effective statements and they can assist in arranging privacy for their meeting with the auditor.

Advocacy agencies also support residents groups and/ or residents to communicate effectively with facilities and thus contribute to internal facility quality improvement processes.

Complaint's mechanisms, for example, the Complaints Investigation Scheme or the Fair Trading Tribunal

Complaints Investigation Scheme processes require evidence. A person who resides in an aged care facility does so because they have significant support needs. They are usually not then in a good position to collect evidence in support of their claims. By contrast aged care facilities, when advised of a complaint, are able to marshal many resources to assist their response. The availability of an independent advocate to support the resident make their complaint, provide their evidence and otherwise engage in the process goes some small way towards redressing this serious imbalance of power.

Advocacy agencies also contribute to the effectiveness of the Complaints Investigation Scheme by making referrals to it and assisting residents with appeals. The Scheme refers people to advocacy agencies where a more informal approach is required or because the issue concerned is out of scope for the Scheme. The Scheme selectively informs complainants about the availability of advocacy but no record is kept of referrals.

Hospitals, health care or legal systems

Each of these areas are complex systems requiring detailed knowledge and specialised skills to navigate through them when issues of concern arise. Advocates are experts in obtaining the necessary information and/or connecting consumers with the right people to assist them. They are also skilled at supporting people to understand and engage in stressful and demanding processes. Frail older people are at risk of their needs and interests being overlooked when these large systems are at work. The tendency is for decisions to be made for rather than with them. The involvement of an advocate changes this.

INNOVATION

Some NACAP agencies have also developed particular expertise or undertaken innovative projects that add value to or expand upon their core Program work for example:

- The Aged Rights Advocacy Service in SA received State department funding for a project undertaken in collaboration with the University of Adelaide to research how to improve the effectiveness of resident groups. The project was supported by the industry associations and produced in 2010 a set of guidelines for resident groups to use to

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improve the level and effectiveness of communication between residents and facilities, and to give residents greater opportunities to have a voice in their care.

- Advocacy Tasmania beginning with Commonwealth Project monies in 2006 developed in partnership with Alzheimer's Australia an innovative advocacy Program focused on linking to an advocate a person in the early stages of dementia who did not have positive other supports so as to enhance their ongoing independence and well-being as their health deteriorated. This Project had a positive formal evaluation and has grown to become a state wide HACC funded dementia advocacy service.
- ACT Disability Aged and Carer Advocacy Program carries out regular visits to aged care facilities on a rotation basis enabling it to connect and build trust with very vulnerable residents who might not otherwise access advocacy but whose issues can be quite significant.

These innovative projects fit well with the view we propose increased access to advocacy for clients accessing the aged care system. All NACAP programs could be resourced to provide such services to the client group, if a more extended role for access to advocates is implemented.

ERA COMMENTS ON THE DRAFT REPORT

Our comments in this submission will be related to matters we deal with through our advocacy work for aged care clients, rather than commenting on all areas such as policy and workforce issues in any detail.

OVERVIEW

Overall, we would see the proposed re-design of the aged care system with a simplified gateway assessment and entitlement to services as a positive move for consumers. We would also support the separation of the regulatory functions from the Department of Health and Ageing (DOHA). The establishment of the proposed AACRC agency is a means to avoid conflict of interest in the roles of policy, funding and regulation and should serve to enhance public confidence in the aged care system.

It is not clear however how some of the proposed measures such as increasing the funding contribution, and removing the high/low care distinctions to enable bonds or similar payments across the system will promote independence and wellness of older Australians or consumer direction of care as outlined in the framework. The recommendations appear to focus largely on capacity to pay, enhancing choice, and finally freeing up of market forces in aged care services as a means to ensure access to person-centred services. The market place model of aged care premised on choice is it seems, to be the means to achieve these principles.

We would contend that this sector is not, in the traditional sense only a marketplace rather we are providing end of life care for vulnerable older Australians, who have in many instances placed the majority of their financial assets on loan with the provider to secure a home and care. Currently this amounts to over \$10bl and will without any changes amount to approx. \$22bl by 2014. They deserve to have more protection through regulation as to who

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can gain the privilege of becoming an aged care provider, able to demonstrate their ability to provide sustainable, quality aged care for life.

We note this option has been linked to the notion of how the private rental accommodation market operates, however we would contend that the aged care sector is not a true market with residents' average age at entry approx. 85 years, and choice of options to home care severely restricted due to chronic health issues including dementia.

Residential aged care is thus not an area of total choice in the sense that market models envisage, and we believe that choice and general market protections alone are not sufficient for consumer protection. Market based options such as exiting the facility are not a feasible option for this group of consumers. There is a need to ensure the consumer voice is heard, and we propose that a strong rights based framework, as outlined in the Charter of Residents Rights and Obligations, supported by regulation, should be maintained. This is a means to ensure an entitlement for older people, particularly those entering residential care to have a secure home, be treated with dignity, and make decisions about their care at the end of their life.

FUNDING

We are concerned that the removal of supply side limits on services, including residential care has the potential to develop a two tier system of aged care, such as is prevalent in the Supported Residential Services (SRS) accommodation model in Victoria. This has resulted in a range of concerns about the treatment of older people and people with disabilities, which are well detailed in reports by the Office of the Public Advocate (Victoria). If we wish to continue providing a high level of quality care for all older Australians regardless of their assets or income, this proposal needs to be very carefully considered.

The entry of new providers in a true marketplace model is not necessarily appropriate in the residential sector, with older people needing security in what becomes their home, the aged care facility. We have observed in close detail the trauma that occurs when private providers become insolvent and residents are faced with relocation, many of them in their 80s and 90s and are also worried about their bond monies. Despite the protections of the bond guarantee scheme, the initial shock and distress are significant.

The concept of a national care co-contribution, with purchasing power transferred more directly to consumers, will also need to be developed carefully with consumer input, and protection for those who are financially disadvantaged or have low asset bases, and therefore have less purchasing power and choice of facility. Secondly, most older Australians who receive aged care services in their own home, do not generally think of their home as an asset particularly while they are still living in it. Their wish to continue living at home, with services to enable them to do so, are currently premised on what they can afford and qualify for with their income through a subsidised community service such as HACC or CACP and EACH programs. Changes such as those proposed will require ongoing information education and advice for this age group and their family who assist them with financial decisions.

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Protections and safeguards for the equity release scheme, will also need to be clearly defined and meet standards of financial probity, to build consumer and public trust in the system. The community experience with reverse mortgage schemes, even those accessed through banks has been somewhat problematic to date. This strategy will need to be carefully worked through, although the clearly offered choice between payment of a bond or a charge (or a combination of payments), may be welcomed as an option by some consumers.

Access to independent information products with financial planning advice should be considered, to ensure consumers and their family members are able to make informed choices about financial options. An organisation such as the National Investment Centre for Retirement Incomes (NICRI) could possibly be funded to produce such advice, as they are already funded as an independent financial information service by the Dept (DOHA).

We do have some concerns about providers having the scope to set the charges for care and accommodation based on market factors, with options to increase the daily charge for long term residents. This can place a considerable level of uncertainty and instability on residents as they plan their financial future, and may mean they face a potential move if their own savings or investments do not keep pace with increases, as currently happens with private rental accommodation.

The experience of consumers facing eviction due to providers misusing bonds and going into liquidation is one we have experienced several times in Victoria. The distress of residents and families facing yet another move, often with residents at 100 years of age is heartbreaking. Ensuring both the ongoing financial stability of providers, the quality of care they provide, and providing residents with the ability to plan for the costs of their care is therefore crucial to ensuring their wellbeing when they have placed their trust (and their money) with the organisation. In regard to the Australian Pensioners Bond scheme, it is not clear if interest would be gained through the bond, and how this would be distributed, however the concept is of interest and may well suit the needs of older people, once they are fully informed.

We would endorse the recommendation on improvements to quality assessment, and the adoption of outcome based standards, involving greater consumer focus and consultation on service delivery. We are pleased that the draft residential care Standards have been restructured to focus initially on "living in the home" and "the promotion of residents' rights and dignity".

CARE AND SUPPORT

The establishment of an Australian Seniors Gateway Agency is one that should benefit consumers, providing a clear entry point in what is an increasingly complex system of aged care options. The "building block" model (figure 3) appears to be a clear way to organise care services, and we propose that access to services, once clients are assessed as entitled to support, could be provided through a Medicare or HICS type card system, to avoid duplicating applications. The introduction of electronic health records would link well into such a system, and be welcomed by most older people as a means to avoid additional assessments by different agencies.

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The provision of clear consumer focused information will be vital to assist choice, as has been noted in the report. We would endorse the proposal for increased access to independent advocacy, particularly at this key entry point. This could be provided through enhancing the National aged care Advocacy Program (NACAP), to provide access to rights based advice and advocacy.

Linking the myriad community services on offer to The Gateway Agency will provide a more accessible framework for consumers, although the ability of providers to service geographical areas, and special needs groups such as CALD, or GLBTI clients needs to be maintained.

We would endorse the funding of providers to deliver appropriate end of life care in whatever setting older people are living, either their own home or residential care. This palliative option should be accompanied by education and information for service providers, consumers and their families through a program such as Respecting Patient Choices. This program has identified that such education is needed to ensure the person's rights and choices are respected.

We have been involved in several recent advocacy situations in residential care where family members have not understood the role of palliative care, and their religious and cultural beliefs have made them afraid that euthanasia was being proposed. In other situations, competent residents have refused hospitalisation and in doing so have faced opposition from nursing staff. At times such as this guardianship is often used as a threat to make people comply with health professionals or family, which is usually an entirely inappropriate use of such legislation.

CATERING FOR DIVERSITY (AND SPECIAL NEEDS GROUPS)

We agree with the need to properly cost the delivery of culturally appropriate services, including the use of interpreters at key points of assessment, care planning and medical decision making. This is vital to ensure older people from CALD backgrounds receive timely and safe care and can participate in decisions about their care and options. Access to and funding for interpreters should extend across the health system.

The report does not seem to have developed a strategic focus on the care and support of people living with dementia, who will be one of the major groups requiring care services into the future. The need for specialised education for aged care staff, both in the community sector and residential care remains high. In residential care the nature of the changing workforce, many comprised of recent immigrants provides an ongoing challenge to providers to ensure the needs of older Australians from a range of backgrounds-either Anglo or CALD are being met. We have been asked to provide education sessions to staff on rights based culturally appropriate care, in facilities comprising residents entirely from Anglo Australian backgrounds with a staff comprised of thirteen ethnic and cultural backgrounds, many fairly recent immigrants.

The needs of people with disabilities who are ageing will also provide new challenges, as will the need to ensure GLBTI seniors are not discriminated against in future service delivery. We have been involved in providing advocacy to many of these two groups of people, and would

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support the need for continuing education to change attitudes and practice, particularly by residential service providers both to prevent discrimination, and ensure the wellbeing and quality of life of the older person.

REGULATION

The proposal to separate the regulatory and quality functions from DOHA into the AACRC is a positive move, with the potential to deliver less conflicted decision making for complaints and regulation of the sector as detailed in the report. The perceived lack of natural justice for complainants to the Complaints Investigation Scheme has been of particular concern to many of our clients, and the restructuring and separation of this function from DOHA should be one way to address these concerns.

While we agree with the new structure, the proposal for appeals to be heard by the AAT is formal, onerous and not one which we believe consumers would find easy to access. In our experience consumers can even find the current appeal to the Commissioner's office somewhat daunting, although they can have some assistance to make such appeals and do so in a variety of ways, either verbally or written. We assist a number of complaints each year with written appeals.

We propose that the appeals process must be easily accessible, and take account of the already stressful nature of making a complaint about the care of oneself, or more usually a loved one in aged care. We would suggest that the Commonwealth Ombudsman's Office may be a better agency than the AAT to handle such appeals, if given the power to conduct a full merits appeal of the decision, not simply the process of decision making about the complaint. The role of the Ombudsman is one which in our experience, is less intimidating to consumers and the public and therefore better placed to enhance confidence in the process if merits appeals are allowed.

We agree that the results of quality assessments of the Community Care Common Standards should be available to the public, in line with published outcomes of residential care standards assessments and accreditation. The range of compliance options available to the regulator along with publication of non-compliance with regulation is important to ensure not only public confidence in the system, but to provide information to consumers to inform their choice.

In relation to financial disclosure we do have a concern about proposing changes to the prudential standards allowing on request disclosure of compliance with prudential standards and audit confirmation and accounts information (12.7). These statements are an important assurance of financial accountability, and should be able to be sighted by consumers as part of their decision making for what is both a life decision (to enter residential care), and a financial decision with their largest asset-their home. We do not agree with this change as proposed in the draft report, to make this information available on request. Disclosure requirements in other areas of financial decision making such as financial planning, mortgage broking, and superannuation place the onus on the provider of services to disclose. It is unclear why aged care providers, who are gaining access to increasingly large interest free loans from residents, should have less obligations.

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Amendments to reporting of missing residents (to DOHA) seem reasonable, and should ensure the most appropriate agency (the police), are actively engaged as early as possible to locate residents and ensure their safety.

POLICY RESEARCH AND EVALUATION

The proposals for a national clearinghouse are welcome, as a central clearinghouse function could ensure timely use of evidence based data and information (including data from the NACAP) is available to enhance improvements to the aged care system. We are not aware that data from the Complaints Investigation Scheme, the Accreditation Agency, or programs such as the NACAP program has been collected and used as an evidence base for improvements, or decision making at a policy level in the past.

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