



## **Health Care Rights for Older Australians**

**30 July 2010**

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# Introduction

## The Public Interest Advocacy Centre

The Public Interest Advocacy Centre (PIAC) is an independent, non-profit law and policy organisation that works for a fair, just and democratic society, empowering citizens, consumers and communities by taking strategic action on public interest issues.

PIAC identifies public interest issues and, where possible and appropriate, works co-operatively with other organisations to advocate for individuals and groups affected. PIAC seeks to:

- expose and redress unjust or unsafe practices, deficient laws or policies;
- promote accountable, transparent and responsive government;
- encourage, influence and inform public debate on issues affecting legal and democratic rights; and
- promote the development of law that reflects the public interest;
- develop and assist community organisations with a public interest focus to pursue the interests of the communities they represent;
- develop models to respond to unmet legal need; and
- maintain an effective and sustainable organisation.

Established in July 1982 as an initiative of the (then) Law Foundation of New South Wales, with support from the NSW Legal Aid Commission, PIAC was the first, and remains the only broadly based public interest legal centre in Australia. Financial support for PIAC comes primarily from the NSW Public Purpose Fund and the Commonwealth and State Community Legal Services Program. PIAC also receives funding from the Industry and Investment NSW for its work on energy and water, and from Allens Arthur Robinson for its Indigenous Justice Program. PIAC also generates income from project and case grants, seminars, consultancy fees, donations and recovery of costs in legal actions.

## PIAC's work on health consumer rights

PIAC has approached this submission from the perspective of protecting the rights of older people to access high care residential beds as an essential part of the health care system. PIAC has undertaken a considerable amount of work on patient and health care rights over its 27 years of operation. Much of this work has focussed on patient safety, complaints and investigation processes and the development of an Australian Health Consumers' Charter.<sup>1</sup> For example, PIAC was central to the consultation process leading to the enactment of the *Health Care Complaints Act 1993* (NSW).

Recently PIAC made submissions to several health complaint related inquiries, including a response to the review and evaluation of the Aged Care Complaints Investigation Scheme.<sup>2</sup> Other recent work includes Commenting a submission to the Senate Community Affairs Committee Inquiry into the National

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<sup>1</sup> See, for example, Carol Berry and Robin Banks, *A tool for healthcare improvement: Comment on the Draft National Patient Charter of Rights* (2008) Public Interest Advocacy Centre <<http://www.piac.asn.au/publication/2008/03/080307-piac-sub2-charter-patient-rights>> at 5 August 2010.

<sup>2</sup> Brenda Bailey, Consumer Protection: a submission to the review of the Aged Care Complaints Investigation Scheme (2010) Public Interest Advocacy Centre< <http://www.piac.asn.au/publication/2009/09/090831-piac-aged-care-cis-sub>> at 5 August 2010.

Registration Scheme for health practitioners<sup>3</sup> and comment on the exposure draft of the Health Practitioner Regulation.

## Context of the review

PIAC submits to the Commission that the approach taken in the Issues Paper to review all ageing residential<sup>4</sup> services for older people could lead to a ‘one-size-fits-all’ reform that puts at risk the most vulnerable in the ageing population. The issues discussed in this submission aim to identify the regulation and funding factors that should be considered by the Commission when analysing the impact of proposed reforms on older people’s access to high level care.

The circumstances and needs of older people when seeking care differ and therefore care options, regulation and funding arrangements should reflect the level and type of needs as well as the capacity of the individual to take part in the decision making process. For example, older people requiring high care beds are often accessing this health service in a time of crisis and are in a particularly vulnerable situation. This service type requires additional consideration when reviewing its funding base and governing legislation. In contrast, older people down-sizing from a family home to a retirement village are making a lifestyle choice, are likely to be less pressured and to have the capacity to make decisions with limited assistance.

## Regulation

The objectives of the *Aged Care Act 1997* (Cth)<sup>5</sup> remain relevant and any reforms should continue to meet all of the objectives. Objectives should not be weighted against one another due to pressure from the industry to increase profit by reducing costs, for example, by reducing the requirements of industry to account for public funds (accountability and transparency objectives).

Current regulations are not duplicated but form part of a structure to ensure equitable distribution of services and protection of older people. For example,<sup>6</sup> the Aged Care Assessment Teams (ACAT), assess the needs of individuals, providing a gateway to residential services. The teams ensure that the level of care is appropriate for the individual, guaranteeing that subsidies are paid according to service delivered and that older people are placed appropriately. This arrangement does not duplicate the regulations controlling the number and location of bed licenses across the community as suggested in the Issues Paper.<sup>7</sup> There may be arguments about the formula used to determine the number and type of subsidised services, but a system for equitable distribution of subsidies is essential. The allocation of subsidies ensures a level of equity, quality of care and delivery of services in geographic areas in which it would otherwise be unviable.

Elder abuse is an issue that should be considered when reviewing regulations that affect the assets and well being of the frail and vulnerable. Research into elder abuse, particularly financial abuse (which accounts for 38 percent of all abuse) reports that older people subject to abuse will draw more heavily on community services, and be a greater cost to the community. A common scenario for older people in abusive situations is to hand over their assets in exchange for housing and care. Following the exchange, the support is

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<sup>3</sup> Peter Dodd, *Enhancing the rights-based approach to health care complaints in NSW* (2008) Public Interest Advocacy Centre <<http://www.piac.asn.au/publication/2008/12/081212-piac-hccc-sub>> at 5 August 2010.

<sup>4</sup> Productivity Commission, *Caring for Older Australians - Issues Paper* (2010) 2.

<sup>5</sup> Ibid [15].

<sup>6</sup> Ibid [23].

<sup>7</sup> Ibid [21].

withdrawn and the older person is reliant on community services. ACAT teams provide an important role recognising and preventing some forms of elder abuse.<sup>8</sup>

PIAC notes the Commission's reference<sup>9</sup> to the number of reviews about aged care services in the past six years. The report on the *Review of the Aged Complaints Investigation Scheme* by Professor Merrilyn Walton (the Walton report), released in April 2010, coincided with the release of the current inquiry and is therefore not listed. PIAC recommends that this report feature in the Commission's review of regulations governing the sector.<sup>10</sup>

The number of agencies that accept health care and aged care service complaints can be very confusing for the consumer. The Walton report acknowledges the various health complaint bodies that a consumer may approach. This is not necessarily a duplication, each having clear demarcation of areas of responsibility. However, this situation requires the consumer to be able to analyse the complaint to identify responsibility and then find the appropriate body to make the complaint to. How that complaint can be made also differs between agencies. Consumers would find it more convenient to go to a central point for all complaints – aged care and health related. This matter was considered in the Walton report. Walton recommends that services develop a memorandum of understanding between the Aged Care Complaint Investigation Scheme, State complaint services and professional registration boards. Although the idea is not developed in the report, such a process could be used to allow each service to take the initial inquiry and refer it to the relevant complaint service for action and contact with the consumer. In this way, it would not matter to which point the consumer entered the complaint.<sup>11</sup>

The Government has not made a commitment or responded fully to the Walton report. PIAC encourages the Inquiry to support the recommendations, particularly the key recommendation to establish and a complaint service separate from the funding provider.

## Funding

It is commonly accepted by economists that the health sector is a classic example of market failure. High care residential services are no exception to the failure to meet the classical description of a perfect market. Information held by the consumer is at the extreme end of information asymmetry, as it is not possible for an older person in crisis to try and test a service, and to change that service if it fails to meet acceptable standards. The consumer must rely on others to know what services are available, and measure its effectiveness by trusting that advice. Imposing market theory on products that require regular and routine purchases may work, but this is not the case for residential care. If options are provided at all, the decision can determine the quality of life and well being for the rest of his or her life. When consumers do not have options or have limited capacity to exercise choice, protections must be in place.

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<sup>8</sup> Professor Peteris Darzines, *Financial Abuse of elders: a review of the evidence* (2009), Monash University, Medicine, Nursing and Health Sciences; House of Representatives Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, *Older People and the Law* (2007), and Russel G Smith, 'Fraud and Financial Abuse of Older Persons' (1999) 132 *Trends and Issues in Crime and Criminal Justice*.

<sup>9</sup> Productivity Commission, above n 4 [2].

<sup>10</sup> Merrilyn Walton, Review of the Aged Complaints Investigation Scheme (2009) <[http://www.health.gov.au/internet/main/publishing.nsf/Content/6E29D85E65EF32FACA25770300036CB1/\\$File/ReviewCIS21009.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/6E29D85E65EF32FACA25770300036CB1/$File/ReviewCIS21009.pdf)> at 27 July 2010.

<sup>11</sup> *Ibid* [16].

The issues paper refers to industry claims about financial hardship but does not provide any specific details about the current capital costs and income generated by residential care services.<sup>12</sup> Without an analysis of the businesses providing the services, it is impossible to assess the economic status of the industry or to make recommendations about funding reforms.

In 1997 there was a brief period when bonds were introduced. They were withdrawn within six months of commencement.<sup>13</sup> The completion of the assets test compounded the stress of older people and their carers who were usually in crisis, having managed a progressive illness for many years or experienced a sudden trauma. Starting the process to access funds such as a \$212,958 bond (current average bond) simply added to the trauma. The question also remains as to who bears the cost if funds are not available when an older person is moving from a hospital bed. How will this transition be managed if the hospital cannot negotiate a bed for the right price?

PIAC recommends that the Commission analyse the viability of service providers as part of its review and prior to making recommendations about funding reforms. Questions to consider include:

- How much is currently being kept in bonds by the 82 percent of service providers that hold them?
- Is this pool increasing over time?
- What is the average level of profit services of particular size can expect? and
- How does a residential care service contribute to the overall interests of a particular business? For example, do businesses benefit from residential care investments even though it has a lower return than other enterprises because it has an assured income with regular cash payments and no bad debts?

## **Exercising choice**

Generally an older person will enter into a high care facility because an event places him or her in hospital and he or she is unable to return home, or because a progressive disease such as dementia has made it too dangerous for him or her to remain at home or because of health needs are too demanding for a family carer. This is not a circumstance where the individual or their family carers exercise a choice in the type of care or of a service provider. Pressure on carers, the hospital system and sometimes a lack of information about available services will combine to limit options. Addressing this situation would require the health system to have the capacity to provide non-acute care in hospitals for extended periods, a high vacancy rate in residential places, greater funding for non-residential options and case workers that can work with carers to explore alternatives.

Some suppliers of residential services have as part of their business retirement villages, hostels and low and high care beds in residential services, as well as home and community care programs. The industry often refers to this as ‘tiered care’, suggesting that once in the care of the provider, clients’ changing needs are met. Services providers may endeavour but cannot guarantee delivery of tiered care in this way to an individual.

An older person may be encouraged to choose a provider because of this ‘tiered care’ possibility, in the mistaken belief that it can be guaranteed. Even when the services are co-located, an older person in a retirement village (which is not aged care but a housing option), may one day need a high care bed, but

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<sup>12</sup> Productivity Commission, above, n 4 [23].

<sup>13</sup> Matthew Franklin, ‘Aged-care bonds rejected in fear’, *The Australian* (Sydney), 13 February 2007.

there is no guarantee that the same provider will be able to provide a service when needed, or that the particular type of aged care service would be appropriate. For example, an older person may need a dementia specific unit. Tiered care is misleading, because even if it can be provided, the appropriateness of encouraging consumers to tie themselves to the one provider and not explore choices as their needs change, limits competition.

Currently it is very difficult for older people and their carers with capacity to exercise options even if they do exist. On entering a facility (except for high care and a limited number of subsidised places) it becomes very difficult to exercise choice as capital (the bond payment) is lost immediately on entering a facility. The percentage returned on leaving a facility (such as a retirement village or residential service) is unlikely to be enough to start again with another provider of the same standard. Allowing providers to draw down larger amounts from the bond or to take funds beyond the current five years will make the option of choosing a different provider even more difficult.

## Conclusion

The Productivity Commission will put older people at risk if it applies a competitive economic model across the aged care sector. The following describes how the market place fails the health consumer:

The concept of the rational, informed consumer lying behind the conventional market demand function seems far removed from the parties in health care who face uncertainty and lack of information and who may be too ill or too scared to act rationally. The potential risks that are faced in health care generate a strong demand for insurance, with a resultant sharing of health care costs.<sup>14</sup>

Aged care services, like all other health services should be provided on the basis that the community supports a universal health service. Like other health services, this requires decisions about how to allocate limited resources

Asking whether choice is important for consumers of high level aged care becomes irrelevant when an older person is in hospital with a broken a hip and is assessed as requiring a high care bed. They will be sent to the first available. The option of staying in their area, of finding a case-worker to organise community care, of moving closer to family is not impossible but is unlikely to occur when the hospital service is pressured to clear the bed.

In this submission PIAC questions the assumption that the number of subsidised places and eligibility for those places is a duplication of process and regulation. As the government subsidises places it has the responsibility to ensure that the geographic spread of places is equitable, that standards will be met and that there are appropriate levels of care. For the individual who must be 'eligible', this provides protection ensuring that he or she is not coerced into taking a place that is not necessary and that he or she is referred to the appropriate level of care.

However, this is not an argument for not improving access and information for decision makers. Consumers should have better access to information about accreditation results, statistics about complaints and basic details about costs and services provided.

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<sup>14</sup> Gavin Mooney, *Economics and Australian health Policy* (1999) 9.

Financial reports should be included in the information available to the consumer as part of the responsibility for those receiving government funds to be accountable and transparent. There also needs to be scrutiny of services that hold the funds of individuals, particularly since those in high care services cannot provide the scrutiny themselves. Regulation is important to provide checks and balances to reduce the risk of fraud by service providers.

Currently taxpayers subsidise essential health care in the community and in hospitals. High level care should not be treated any differently because of the age of the person needing health care or the location of that health care. While models of care that are more humane and accessible should be explored, the principle of providing universal health care for everyone in the community should remain.

PIAC is concerned that the Issues Paper lists predominantly the concerns that industry experiences in meeting regulation and funding guidelines. This inquiry requires greater balance to properly assess the need for regulation and the high costs to individuals and the community if the service fails the consumer. Funding and regulation also fail the community if the market provides only for those in locations of sufficient number who can afford the entry cost of health care.

## **Recommendations**

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*PIAC recommends that the issues identified in this submission be considered by the Commission when analysing the impact of proposed reforms on older people's access to high level care, in particular, the needs and circumstances an older person and their family at the time of selecting and entering high level residential care.*

*PIAC recommends that the objectives of the Aged Care Act 1997 (Cth) are not diminished and that industry receiving subsidies continues to be accountable for government funds in a transparent and timely way.*

*PIAC recommends that regulations be in place to assist in the equitable distribution of government subsidised services and ensure individuals receive an appropriate level of care.*

*PIAC recommends that in considering regulatory requirements the Commission considers the risk of fraud in the aged care industry and elder abuse and ensures regulation is in place to reduce this risk.*

*PIAC recommends that the report on the Review of the Aged Complaints Investigation Scheme by Professor Merrilyn Walton feature in the Commission's review of regulations governing the sector.*

*PIAC recommends that the Commission examine evidence about the income generated by individual residential care services and in particular, the way aged care services are used to assist in the overall financial viability of an organisation.*

*PIAC recommends that if the Commission recommends bonds for high care beds, it establish whether payment is conditional on accessing a bed. If this is the case, the Commission should also establish how the failures evident in the last introduction of bonds in 1997 will be avoided and how the hospital system will manage if older people cannot be moved to a residential service.*

*PIAC recommends that service providers be restricted in how they can advertise and promote 'tiered care', to ensure that consumers are aware of the limitations on providers' ability to ensure other services.*

*PIAC recommends that aged care services should be a component of a universal health service, in the same way as other essential health services. The delivery of health care should not be limited because of a person's age or type of residence.*

*PIAC recommends that adequate information be available to consumers to enable an informed choice about providers, including access to accreditation results, statistics about complaints and basic details about costs and services provided.*