



**Independence and advocacy: the key to  
gaining consumer trust in Australia's  
aged care complaints system**

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# 1. Introduction

## 1.1 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.

## 1.2 PIAC's work on healthcare rights

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> PIAC was central to the consultation process leading to the enactment of the *Health Care Complaints Act 1993* (NSW). PIAC also provided legal representation in the New South Wales Royal Commission into Deep Sleep Therapy (the Chelmsford Royal Commission) and was involved in related processes dealing with the specific issues at the Chelmsford Hospital, but also more broadly, about the handling of serious complaints about medical practice in NSW. In the past six months, PIAC has made submissions to several health complaint related inquiries, including a response to the *Consultation Paper on proposed arrangements for handling complaints and*

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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://piac.asn.au/publication/2008/03/080307-piac-sub2-charter-patient-rights>> at 31 March 2011.

*dealing with performance, health and conduct matters*,<sup>2</sup> a submission to the Senate Community Affairs Committee Inquiry into the National Registration Scheme for health practitioners<sup>3</sup>, and comment on the exposure draft of the Health Practitioner Regulation developed in response to the Senate Inquiry<sup>4</sup>.

Recently, PIAC made several submissions about aged care, including a response to the review and evaluation of the Aged Care Complaints Investigation Scheme.<sup>5</sup> PIAC also made a submission to the 2010 APC Issues Paper, *Caring for Older Australians*.<sup>6</sup>

PIAC wishes to declare that Merrilyn Walton, the author of *the Review of the Aged Care Complaints Investigation Scheme*, is a member of the PIAC Board of Directors.

## 2. Background – the loss of trust in aged care complaints

PIAC welcomes the opportunity to respond to the Productivity Commission's Draft Report, *Caring for Older Australians* (the Draft Report).

PIAC will confine its comments specifically to the matters raised in Chapter 12 of the Draft Report (Regulation — the future direction). More specifically, PIAC will respond in this submission to the parts of that chapter referring to complaints handling and appeals and access to independent consumer advocacy services.

PIAC is concerned that, to a fair degree, the aged care complaints system in Australia has lost the trust of Australian consumers.

PIAC sees this loss of trust resulting significantly, if not totally, from the lack of independence of the Aged Care Commissioner, in that decisions by the Commissioner about aged care complaints can be overturned by the Department of Health and Ageing. The Commissioner lacks the deliberative power that is exercised by health complaints commissions in the various states and territories. In NSW, the Health Care Complaints Commission does have deliberative power (sometimes exercised as co-regulators with registration boards) that the Aged Care Commissioner lacks.

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<sup>2</sup> Peter Dodd, *Maintaining a consumer focus in health complaints: the key to national best practice* (2008) Public Interest Advocacy Centre <<http://www.piac.asn.au/publication/2008/11/081121-piac-nat-complaints-sub>> at 31 March 2011.

<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 31 March 2011.

<sup>4</sup> Peter Dodd, *Putting healthcare rights to work* (2009) Public Interest Advocacy Centre <<http://www.piac.asn.au/publication/2009/07/090717-piac-national-reg-sub>> at 31 March 2011.

<sup>5</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 31 March 2011.

<sup>6</sup> Brenda Bailey, *Health Care Rights for Older Australians* (2010) Public interest Advocacy Centre <<http://www.piac.asn.au/publication/2010/08/health-care-rights-older-australians>> at 31 March 2011.

A major focus of Associate Professor Merrilyn Walton in her *Review of the Aged Care Complaints Investigation Scheme*<sup>7</sup> (the Walton Report) was that the lack of independence of the Aged Care Commissioner leads to a lack of trust in the complaints process, by consumers and all those concerned with the safety and quality of aged care in Australia.

Commenting on the submissions received, the Walton Report noted:

Providers felt that the CIS had found them at fault before the investigations commenced, and the consumers thought that the CIS was on the side of the providers. These attitudes indicate a lack of trust in the processes.<sup>8</sup>

The Walton Report states:

Complaint management is one of the most difficult areas in public administration precisely because one has to instil trust from stakeholders who are often in a vulnerable position. Any sign of poor practices or communications can easily damage trust. Mistrust in the outcome of a complaints investigation can be a powerful motivation for further examination through external review of the decisions. Creating a professional and trustworthy complaints scheme requires dedication and focus.<sup>9</sup>

In her report, Associate Professor Walton continued to emphasise the importance of trust in the independence of complaints bodies:

Complaint management directly impacts on the personal experience between a citizen and the bureaucracy; making trust in the 'neutrality' or 'impartiality' of the complaint body essential. The current system in which complaints are part of the bureaucracy responsible for aged care services makes it harder for a complainant to accept the final outcome if it is not favourable to their case. This adds to disquiet in the administration of the complaint scheme, as evidenced by the submissions from consumers and providers who shared their concerns about the impartiality or unreliability of decisions.<sup>10</sup>

In an interview with the ABC, Associate Professor Walton described the following statement about the current system of aged care complaints as a 'fair summary':

You say essentially that it's a system that's not meeting anyone's expectations. It's not trusted by those who complain nor by those who are complained against. Both sides perceived bias in the system. The appeal mechanisms are restrictive and inadequate. And the scheme is run by

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<sup>7</sup> Merrilyn Walton, *Review of the Aged Care Complaints Investigation Scheme* (2009).

<sup>8</sup> Ibid, 22.

<sup>9</sup> Ibid, 40.

<sup>10</sup> Ibid, 81.

staff who are overworked, inadequately trained and don't have enough access to expert clinical advice.<sup>11</sup>

PIAC strongly urges that the Productivity Commission recommend to the Federal Government a model for health care complaints that is independent and therefore able to create a system that is trusted by both consumers and providers.

PIAC develops the argument for an independent complaints body further in this submission. PIAC also emphasises the need for effective advocacy services to complement the work of an independent complaints body. Finally the submission discusses the need for the protection of complainants and whistleblowers from intimidation and retribution as another essential element in building trust in Australia's aged care complaints system. These comments are in response to the Issues raised in Chapter 12 of the Draft Report.

### **3. Issues discussed in Chapter 12 of the Draft Report**

#### **3.1 Need for independence**

PIAC supports for the recommendations in the Walton Report about the need for an independent authority to deal with the assessment and investigation of aged care complaints. We note this view is also expressed in the Draft Report.

PIAC strongly supports for the concept that the authority that assesses, investigates and manages aged care complaints should be directly responsible to the Minister for Aged Care. The authority should be autonomous in its decision making, in the same way that the NSW Health Care Complaints Commission cannot be overruled in its key assessment and investigation functions.

PIAC submits that section 81 of the *Health Care Complaints Act 1993* (NSW) appropriately sets out the responsibilities of an independent complaints body.

That section states:

The Commission is subject to the control and direction of the Minister, except in respect of the following:

- the assessment of a complaint
- the investigation of a complaint
- the prosecution of disciplinary action against a person
- the terms of any recommendation of the Commission
- the contents of a report of the Commission, including the annual report.

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<sup>11</sup> ABC Radio, 'Aged care complaints system found wanting', *The National Interest*, 16 April 2010 <<http://www.agedcarecrisis.com/news/3909-aged-care-complaints-system-found-wanting>> at 30 March 2011.

Giving an aged care complaints body clear deliberative powers does not preclude other means of accountability.

There are several ways to strengthen accountability in this situation:

- oversight of administrative actions by the Ombudsman;
- effective internal and external review mechanisms;
- parliamentary oversight through the parliamentary committee system. (The HCCC in NSW has its activities reviewed by the Committee on the Health Care Complaints Commission, a joint statutory committee, established in 1994)

### **3.2 The proposal to set up an Australian Aged Care Regulation Commission**

PIAC gives qualified support for the recommendations by the Productivity Commission for an Australian Aged Care Regulation Commission (AACRC), including a Commissioner responsible for Complaints and Reviews.

PIAC is primarily concerned with achieving the outcome of an effective independent complaints body in aged care. Whatever the final structure, the body undertaking the complaints function must be staffed by experienced and appropriately trained persons who are dedicated to the particular tasks of assessment, investigation and resolution of aged care complaints, and have no other conflicting task or function.

### **3.3 Reviews of decisions**

PIAC supports for the proposal that there should be, in any internal review structure, firewalls or 'Chinese walls' between the original assessment and investigation decisions and those who undertake internal review. This could mean that in the structure proposed by the Productivity Commissioner, the Chairperson of the AACRC could delegate reviews of decisions by the Complaints Commissioner to a separate dedicated review body or section of the AACRC.

If there is a rigorous internal review system, with institutional separation between the original decision makers and those determining the appeal, then PIAC suggests this would obviate the need for a review body between the complaints body and the Administrative Appeals Tribunal (AAT).

### **3.4 Use of alternative dispute resolution Strategies**

PIAC supports the use of alternative dispute resolution (ADR) as part of the management of aged care complaints. PIAC supports the model where complaints that suggest there is a significant risk to the health or welfare of care recipient(s) are investigated, and others are attempted to be resolved by a form of ADR. This process should always have the caveat that if significant and serious risk of harm issues come to light in the ADR process, that they can be easily and quickly referred back to be investigated.

Language like 'your complaint has been dismissed and referred for resolution' should never be used. To have trust in ADR strategies, complainants must feel that their complaints/concerns are being treated seriously and, whatever the ADR process used, that they have some ownership of

the processes. PIAC believes the inclusion of independent advocates in the system will go a long way to achieving this aim (see comments below).

PIAC notes that both the Walton Review and the Commission's Discussion Paper support the increased use of ADR in the resolution of aged care complaints.

### **3.5 Advocacy and advice services**

If ADR strategies are going to be an integral part of Australia's aged care complaint processes, there must be funding and adequate resourcing of independent consumer advocacy services. PIAC recommends that these services be modelled on the New Zealand Health and Disability Advocacy Service.

Crucial to PIAC's view on these matters is the contention that consumers and providers are not on an equal footing in the resolution of complaints. Aged care providers have the resources of either government or private enterprise (and sometimes of the community sector) to answer and deal with complaints. They hold the overwhelming majority of any written documentation relevant to any given complaint. Consumers have to seek access to this information. Large private sector providers of aged care often have large and well-funded complaints and risk management departments, with dedicated officers skilled in complaints handling. Consumers just cannot match these resources.

Consumers and/or their family and friends are unlikely to have the skills or temperament to match the skills and relative dispassionate approach of complaints managers, general managers and health professionals when trying to resolve a complaint without advocacy or assistance. They are often angry and frustrated with a provider before they make a complaint. Relatives and friends, after the death of a family member or friend, are also likely to be going through different stages of the grieving process, at the very same time as the complaints resolution process is taking place.

This means, that, particularly after a critical incident, consumers or their family and friends are not in the right frame of mind to negotiate a successful and appropriate resolution that responds to their concerns; at least, not without the assistance of dedicated advocates.

As stated above, PIAC believes that with regard to supported resolution (and approved provider resolution), complainants should have the assistance of independent advocates in the resolution process.

The model for achieving these aims should be the New Zealand (NZ) Health and Disability Advocacy Service. This service was established in 1996, under the NZ Health and Disability Commissioner's legislation, as a result of the Cartwright Inquiry<sup>12</sup> recommendation that there was a need for advocates to be on the side of the consumer to ensure their healthcare rights were upheld.

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<sup>12</sup> Silvia Cartwright, an Auckland District Court Judge, was appointed by the NZ Minister of Health, Michael Bassett, in June 1987 to conduct an Inquiry into allegations concerning the treatment of cervical cancer at National Women's Hospital, and other related matters. The *Report of the Committee of Inquiry* is found at <<http://www.nsu.govt.nz/current-nsu-programmes/3233.asp>> at 22 March 2011.



The Advocacy Service is a free service available to any person in NZ who has a concern or a complaint about a health or disability service. The Advocacy Service also deals with complaints referred by the Health and Disability Commissioner. The NZ model is very similar to the proposed supported resolution model, except that, in NZ, the independent advocates play an active role, on behalf of the complainant, in initiating and guiding the resolution process.

Significantly, the NZ service operates independently of the Health and Disability Commissioner, practitioners/providers, government agencies and organisations' funding services. Advocates also have a key education role, in that they provide education sessions for both consumers and providers, to promote awareness and understanding of the rights of consumers, and responsibilities of providers as outlined in the Code of Health and Disability Services Consumers' Rights. 'Health and disability advocates use what is called 'empowerment advocacy' to assist or act on behalf of a consumer. This requires them to direct the process to assist the consumer to resolve his or her complaint rather than directing the content of the complaint.'<sup>13</sup>

PIAC notes that services, such as the Aged Care Rights Service (TARS) in NSW, have been previously funded to provide advocacy services for complainants to assist them with the resolution of their complaints and concerns about aged care services. PIAC would be very concerned if there were no specifically funded advocacy services available to assist complainants with supported resolution under the scheme.

PIAC also supports the continued role of community legal centres like the NSW Aged Care Rights Service in providing legal advice to people in aged care facilities and their families and carers. PIAC, however, does not believe that advocates who assist a consumer to resolve their complaints have to be lawyers or come from legal backgrounds. The roles of a legal service providing advice on elder law and accommodation law and an advocacy service that assists and promotes complaint resolution, should be complementary.

### **3.6 Protection of complainants and whistleblowers**

One of the major reasons that consumers and/or their carers and families are reluctant to complain, or even ask questions of the provider, is a perceived (and on some occasions real) fear that a complaint will lead to adverse outcomes for the patient or person in an aged care facility. Employees of aged care facilities are also clearly reluctant to report abuse or a deterioration in standards, because they fear they will lose their employment as a consequence.

In aged care, complainants and families alike feel particularly vulnerable. Many people in aged care facilities have dementia, which makes them vulnerable because they may not remember incidents or be able to relate in a coherent way, their recollections about their treatment and care. They are also seen as unreliable or incapable witnesses to report what has happened to them (or others), and often simply not believed when they report abuse.

Families and carers put their trust in aged care facilities and their staff. They fear that if they complain, their frail and elderly family member may not receive appropriate care.

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<sup>13</sup> Health and Disability Advocacy (NZ) *Models of Advocacy* <<http://advocacy.hdc.org.nz/resources/models-of-advocacy>> at 21 March 2011

This problem can be addressed at several levels.

Firstly, there should be engendered a culture of open disclosure that is encouraged and nurtured at all times by the Minister and the Department. Failure to disclose or co-operate with investigations and failure to fully cooperate in strategies to resolve consumer concerns through ADR should not be in any way rewarded, and should be positively discouraged, by sanctions if necessary.

Secondly there should be legislative sanctions against intimidation of complainants, in any form.

Section 98 of the *Health Care Complaints Act 1993* (NSW) provides:

(1) A person who, by threat, intimidation or inducement, persuades or attempts to persuade another person:

- (a) not to make a complaint to the Commission or a professional council or not to continue with a complaint made to the Commission or a professional council, or
- (b) not to have discussions with, or take part in proceedings before, the Commission or a professional council concerning a complaint or a matter that could become the subject of a complaint,

is guilty of an offence.

(2) A person who refuses to employ or dismisses another person, subjects another person to any detriment, or harasses another person, because the other person:

- (a) intends to make a complaint, has made a complaint, or has had a complaint made on his or her behalf or otherwise concerning him or her, to the Commission or a professional council, or
- (b) intends to take part, is taking part, or has taken part in any discussions with, or proceedings before, the Commission or a professional council concerning a complaint or a matter which could become the subject of a complaint,

is guilty of an offence.

PIAC submits that similar offences should be created in Commonwealth aged care legislation.

Finally, there must be laws and policies in place that demonstrate to consumers that all those participating in the regulation of aged care are serious about eliminating elder abuse and maintaining best practice standards of care in aged care facilities. The independence of an aged care complaints body with determinative powers is important in gaining the public's trust in this regard. Therefore, there also must be strong legislative protection for whistleblowers who report elder abuse by fellow employees in aged care facilities or report low standards of care in aged care facilities where they work.

There also must be policies and practices that allow for anonymous complaints about serious breaches of standards and elder abuse to be investigated to the maximum extent possible without breaching procedural fairness principles.