



Australian  
Human Rights  
Commission

# Respect and choice

A HUMAN RIGHTS APPROACH FOR  
AGEING AND HEALTH • 2012



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## **Executive Summary**

Australia is experiencing a demographic shift with life expectancy 25 years longer than it was a century ago. We are seeing an increase in the size of the older population in Australia as a result. This lengthened life expectancy is to be celebrated. But it comes with challenges, with a substantial impact on Australia's health system and the aged care sector.

In April 2012, the federal government released its aged care reform agenda. This was in response to the Productivity Commission's inquiry into aged care services in Australia. This position paper outlines a human rights approach for the implementation of the aged care reforms.

A human rights approach is the implementation of a set of essential principles that provides a baseline for human rights protection. It is an approach that can result in improvements in service delivery standards. The approach can provide a framework to guide decision-making, encourage the collection of disaggregated data to inform policy decisions and promote age sensitive programmes.

The approach adopted in this paper reflects that developed by the United Nations Committee on Economic Social and Cultural Rights in General Comment No. 14 'The right of everyone to the enjoyment of the highest attainable standard of physical and mental health'.<sup>1</sup>

By adopting a human rights approach we are able to better understand how health services can be delivered in a manner that is non-discriminatory and promotes equality; ensures that services are available, accessible, appropriate and of good quality; and have adequate monitoring mechanisms and ensure government accountability.

The paper briefly discusses these elements and then applies them to selected components of the aged care reforms. The selected components include consumer directed care, advance care planning, special needs groups, accessible services and human rights training for health workers.

The aged care reform package can be strengthened by incorporating a human rights approach to the delivery of services for older Australians. The aim would be to promote people-centred decision-making and real change in organisational culture. The specific areas of the reform package that can easily accommodate a human rights approach include:

- The incorporation of indicators to monitor the implementation of consumer directed care. These indicators will be essential to determine the accessibility and quality of these services and to ensure the rights of older recipients of these services are protected and their decisions respected.
- The implementation of advance care training programs that extend beyond general practitioners to include health workers in the acute care sector and in the aged care sector. This would facilitate a process of effective

communication between the acute care sector and the aged care sector and promote respect for the end-of-life decisions of older Australians.

- The development of a national program for improvement of health literacy to promote the participation of older Australians in consumer directed care.
- The development of disaggregated indicators, at least on the grounds of sex, race, ethnicity, sexuality, socio-economic status, place of abode and urban/rural/remote location. These indicators will provide detailed information on the human rights issues of availability, accessibility and acceptability of aged care services to the whole of the older Australian population as well as to the special needs groups.
- Improvement of the effectiveness of the *Broadband for Seniors Initiative* to ensure that older Australians are confident internet users and can effectively engage with the Telehealth program.
- The development of indicators related to the charters of rights contained in the *User Principles 1997 (Cth)*. These indicators should be included in the set of national quality indicators that will monitor the quality of aged care services.
- Human rights training for health workers to ensure they are culturally competent, respect difference and diversity in the older Australian population and understand and respect human rights.

We are at the very beginning of the implementation of the aged care reforms. It is a time that offers us a significant opportunity. One that can ensure the human rights of all older Australians in receipt of aged care services are protected and their choices respected.

## 1 Introduction

Australia, like many countries, is experiencing a demographic shift. Australians are living 25 years longer than they did a century ago.<sup>2</sup> The number of Australians aged 85 and over is projected to increase from 0.4 million in 2010 to 1.8 million by 2050.<sup>3</sup> In 2007 people aged 65 years and over made up 13 per cent of Australia's population. This proportion is projected to increase to between 23 per cent and 25 per cent in 2056.<sup>4</sup> This will have a substantial impact on Australia's health system generally and the aged care home based, flexible and residential care system specifically.

The aged care sector has recognised for some time that Australia's aged care health system would be unable to respond appropriately to the changing demographic and that reform to the system was required. To that end, in 2010 the federal government requested the Productivity Commission to conduct a comprehensive inquiry into aged care and to provide a set of recommendations for reform of the system. The Productivity Commission released its report in August 2011 and following national consultations the federal government released the aged care reform package *Living Longer. Living Better.* in April 2012. The reforms are to be implemented over a period of 10 years with a review of implementation in 5 years.

The provision of quality aged care and support in the appropriate environment is a fundamental human right.<sup>5</sup> This paper proposes a human rights approach as the lens through which implementation of the federal government's aged care reform package can be monitored and reviewed.

A human rights approach is the application of a set of essential principles to policies and programs that provides a baseline for human rights protection.<sup>6</sup> The approach is a systematic way of integrating the norms, principles, standards and goals of national and international human rights law into all decision making processes, law and policy development and project implementation. It requires that the content and process of all our actions are informed by human rights principles such as participation, accountability, equality and empowerment.

Central to human rights is the protection of the most vulnerable. For those who have had a lifetime of disadvantage, their ability to claim their rights can be severely compromised. A human rights approach will assist to enable these older members of our society to claim their rights. **Annexure A** provides an example of a set of questions that would be asked if a human rights approach was to be implemented.

The aged care sector has long been concerned with equitable access to services and participation. However, the sector policy tends to speak in terms of priorities and goals rather than in terms of rights.<sup>7</sup> The application of a human rights approach will assure a strengthened focus on a people-centred approach to aged care and the requirement for meaningful participation by older Australians. The approach will assist with ensuring that older recipients of home and residential care can help to set their own agenda and have their decisions respected.

The requirement for accountability is not new to the health sector. Financial accountability (tracking and reporting on allocation, disbursement and utilisation of funds) and performance accountability (demonstrating and accounting for

performance in the light of agreed indicators) are well known. Although human rights accountability is also concerned with these two categories, its focus is the degree to which the government is complying with human rights obligations.

When the human rights approach is properly applied to the provision of health programs to older people it can help to transform the design and delivery of services. As noted by the United Kingdom Joint Committee on Human Rights,

It is an approach that promotes 'people-centred' decision-making, and at the same time provides guidance on how to balance competing rights in the presence of restricted resources; it can promote real change in organisational culture and improve the quality of service provision.<sup>8</sup>

## **1.1 Access to care and support for older Australians**

The increase in life expectancy is a cause for celebration. As the World Health Organisation has said 'Population ageing is one of humanity's greatest triumphs'.<sup>9</sup>

While older Australians are living longer and healthier lives, it is inevitable that as we get older we will be increasingly likely to require health service provision of some sort, be it support to ensure access to social activities, assistance with daily living, assistance with medications, monitoring for illness, or more intensive assistance such as that provided in a residential care facility.<sup>10</sup>

The increase in the number of older Australians will result in an increased demand for aged care services. The increased demand will require increased federal government and private spending on aged care.<sup>11</sup>

Funding for aged care services principally comes from the Australian government. State and Territory governments and individuals receiving care also contribute.<sup>12</sup> Overall federal government expenditure for ageing and aged care during 2010–11 totalled \$11.024 billion.<sup>13</sup> This amount included aged care support and assistance provided both under and outside the *Aged Care Act 1997* (Cth) (the Aged Care Act). The largest amount of expenditure outside the Aged Care Act was \$1.291 billion for the Home and Community Care program.<sup>14</sup>

The Intergenerational Report 2010 recorded that Australian government aged care services spending was estimated to be 0.8 per cent of GDP in 2009–10 increasing to 1.1 per cent when State and Territory government and individual contributions are included.<sup>15</sup>

As the population ages, more people will fall into the older age groups that are the most frequent users of the public health system. From 2009–10 to 2049–50 Australian Government spending on aged care is expected to rise from 0.8 per cent of GDP to 1.8 per cent,<sup>16</sup> and real health spending on those aged over 65 years is expected to increase around seven-fold.<sup>17</sup> Over the same period, real health spending on those over 85 years is expected to increase around twelve-fold.<sup>18</sup>

Although many of us will require some sort of assistance as we grow older, this does not mean that all of us will spend our last years in a residential aged care facility.

Research shows that while 15 per cent of those 80 years and over live in care accommodation, only one per cent of people aged 60 to 79 years does so.<sup>19</sup> Early last year a Galaxy Poll found that more than 90 per cent of Australians want to stay in their own homes, even after the negative effects of ageing begin to set in.<sup>20</sup> These data confirm the reality of older people's lives but are contrary to media portrayal.

Media reporting of older people and health service provision gives the false impression that most are in residential care facilities. In fact, 94 per cent of Australians aged 65 and over live in private dwellings or self-care accommodation and 77 per cent of people over 85 years live at home. Source: Australian Institute of Health and Welfare, 'Ageing and Aged care', *Australia's Welfare*, Australia's Welfare series no. 10, Catalogue No AUS 142 (2011). At: <http://www.aihw.gov.au/publication-detail/?id=10737420537> (viewed 18 July 2012)

**Only one per cent of people aged 60 to 79 years live in care accommodation. In the 80 and over age group, the number increases to 15 per cent.** Source: Australian Bureau of Statistics, 'Latest Findings', 4914.0.55.001 – Age Matters, June 2011. At: <http://www.abs.gov.au/ausstats/abs@.nsf/7d12b0f6763c78caca257061001cc588/ea6bbe44feac7fe2ca2572a400109d19!OpenDocument> (viewed 21 June 2012 )

One of the most common reasons for entering residential aged care is dementia.<sup>21</sup> The Australian Institute of Health and Welfare found that in 2008–09, 53 per cent of the permanent residents living in Australian Government subsidised aged care facilities had been diagnosed with dementia and approximately 79 per cent of all residents with dementia were aged 80 years or older.<sup>22</sup> At the same time over 60 per cent of people with dementia live in the community, with many of them receiving no support from funded programs.<sup>23</sup>

In 2011, there was an estimated 266,574 people with dementia in Australia.<sup>24</sup> The Australian population is projected to increase by 40 per cent in the next 40 years and the prevalence of dementia, in the absence of a medical breakthrough, is predicted to grow by up to 300 per cent with approximately 730,000 Australians estimated to have dementia by 2050.<sup>25</sup>

## **1.2 Government action to reform Australia's aged care system**

In August 2011, the federal government and the State/Territory governments finalised the new National Health Reform Agreement.<sup>26</sup> From 1 July 2012, the Commonwealth Government assumed funding and program responsibility for people aged 65 years and older in the general population, and for Aboriginal and Torres Strait Islander Peoples who are aged 50 years and older (excluding Western Australia and Victoria).

In view of the ageing of Australia's population, the projected increase in demand for aged care services and the then planned national health reforms, in 2010 the federal

government requested the Productivity Commission to conduct a public inquiry into aged care. The Productivity Commission was asked to develop detailed options for the redesign of Australia's aged care system.<sup>27</sup>

The Productivity Commission found that Australia's aged care system had strengths but also many weaknesses. Older people and their carers found the system to be difficult to navigate, provided limited choice and services, and services that were of variable quality.<sup>28</sup> The final report, tabled in Parliament in August 2011, proposed a detailed reform package to address the weaknesses in the system. The report encompassed the issues of access to services, availability and quality of services, health care workforce and funding.

On 20 April 2012, the federal government released the *Living Longer. Living Better.* aged care reform package, which provides \$3.7 billion over five years.<sup>29</sup> The package represents the commencement of a 10 year reform program to create a flexible and seamless system that provides older Australians with more choice, control and easier access to a full range of services, where they want them and when they need them.<sup>30</sup> The federal government's aged care reform package has been widely welcomed although with some qualifications.

Mechanisms contained within the package provide the opportunity for monitoring and review of the 10 year implementation process. It is in monitoring the implementation of the reforms where a human rights lens will be appropriate and helpful and will promote respect for the human rights of recipients of aged care services.

### **1.3 Why Australia requires a human rights approach to care and support**

#### *International legal and policy frameworks*

Australia has ratified a wide range of international human rights instruments that contain important provisions relevant to health service provision for older people. These include, the Constitution of the World Health Organisation, the International Convention on the Elimination of All Forms of Racial Discrimination, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination against Women, and the Convention on the Rights of Persons with Disabilities.<sup>31</sup>

These instruments provide a framework for legislation and policy at the national level related to the protection of the human rights of older persons and the promotion and protection of their health.

Australia has also endorsed a wide range of non-binding international instruments relevant to the provision of health services to older people. Adopted at the Second World Assembly on Ageing in April 2002, the Madrid International Plan of Action on Ageing and the Political Declaration detail a new agenda for addressing the issue of ageing in the 21st-century. It focuses on three priority areas: older persons and development; advancing health and well-being into old age; and ensuring enabling



and supportive environments. The recommendations take a strong and positive position on the promotion of the participation of older persons as citizens with full rights, and to assure that persons everywhere are able to age with security and dignity. The Australian Government has also committed itself to meeting various health-related goals and targets through its membership of the World Health Organisation and through its participation in international conferences such as the Millennium Summit of the General Assembly and the Second World Assembly on Ageing.<sup>32</sup>

Central to the international human rights treaties that Australia has ratified and non-binding international instruments that Australia has endorsed is a range of interrelated human rights principles. These principles underpin the realisation of all human rights of recipients of aged care services, including non-discrimination and equality, participation, monitoring and accountability mechanisms and remedies.

#### *National legal and policy frameworks*

The Australian Human Rights Commission works to find practical and long-term solutions to the human rights issues facing people in Australia, as well as to build greater understanding and respect for human rights in our community. The Commission priorities (2011–14) are to:

- tackle violence, harassment and bullying, and
- build community understanding and respect for rights.

Through the application of an explicit human rights approach to care and support for older Australians, the issues of violence, harassment and bullying of older Australians can best be addressed while building community and health worker understanding and respect for human rights.

The Age Discrimination Act 2004 (Cth) prohibits age discrimination in many areas of public life including the provision of goods, services and facilities. It is through this Act that Australia implements the international commitment to eliminate age discrimination embodied in the various international human rights treaties to which Australia is a party and in the various international non-binding instruments and declarations such as the Madrid International Plan of Action on Ageing and the Political Declaration.

The aim of the legislation is to act as a catalyst for attitudinal change and to provide individuals with an avenue to make complaints of discrimination. The primary purposes of the Act are to raise awareness that people of all ages have the same fundamental rights to equality before the law regardless of age and to eliminate unlawful age discrimination within our community. The Act also contains the specific objective of responding to 'demographic change by removing barriers to older people participating in society ... and changing negative stereotypes about older people'.<sup>33</sup>

As part of Australia's Human Rights Framework, the Joint Parliamentary Committee on Human Rights was established by the Human Rights (Parliamentary Scrutiny) Act 2011 (Cth). The Act came into effect on 4 January 2012 and the Committee commenced operation on 13 March 2012. The Committee will examine Bills for Acts

and legislation that come before either House of Parliament for compatibility with human rights. Any amendments to the Aged Care Act, including those arising from the current aged care reforms, will be examined for their compatibility with the seven core United Nations human rights treaties Australia has ratified.<sup>34</sup>

The Aged Care Act governs residential care and Commonwealth community care packages. The main areas of regulatory control include: funding services; allocating aged care places to approved providers; assessing client eligibility; determining quality care and accommodation standards; ensuring compliance; and handling complaints.<sup>35</sup> The Home and Community Care Act 1985 (Cth) governs the provision of basic maintenance and support services to older people who live at home.<sup>36</sup>

Section 63-2 of the Aged Care Act requires the Minister for Mental Health and Ageing to present to Parliament a report on the operation of the Act for each year. The report includes detailed information on funding, aged care programs, the Aged Care Complaints Scheme (Complaints Scheme) and the Aged Care Standards and Accreditation Agency (Standards and Accreditation Agency).<sup>37</sup>

The Aged Care Commissioner is a statutory appointment independent from the Department of Health and Ageing Complaints Scheme and Accreditation Agency. The Commissioner's functions are set out in subsection 95A-1 of the Aged Care Act and Part 7 of the Complaints Principles 2011.

The Commissioner is able to review certain decisions made by the Complaints Scheme and to examine complaints about the Complaints Scheme processes for handling matters under the Complaints Principles 2011. The Commissioner may also examine complaints about the conduct of the Accreditation Agency and the conduct of persons carrying out audits under the Accreditation Grant Principles 1999 or assessment contacts under the Accreditation Grant Principles 2011. The Act also gives the Commissioner the power to examine particular matters on the Commissioner's own initiative.<sup>38</sup>

In addition to international and national legal and policy frameworks there is an active and informed aged care civil society that includes community groups, consumer organisations such as Council on the Ageing (COTA) Australia and National Seniors Australia, providers (non-profit and for profit), informal alliances and health worker organisations.<sup>39</sup> This diverse group of individuals, organisations and alliances is essential to effective aged care advocacy and for monitoring of the implementation and review of the aged care reform package.

## **2 A human rights approach and the aged care reforms**

### **2.1 Added value**

A relatively wide range of human rights approaches has been developed for different areas.<sup>40</sup> Which approach is likely to be most effective varies according to the circumstances, such as the particular sector being addressed and the social and political context. These approaches are united by a common purpose and core principles, and all share in common the essential principles that provide a baseline for human rights protection.<sup>41</sup>

The human rights approach adopted in this paper reflects that developed by the Committee on Economic, Social and Cultural Rights in General Comment No. 14 'The right of everyone to the enjoyment of the highest attainable standard of physical and mental health' (the right to health)<sup>42</sup> and subsequently refined by the Special Rapporteur on the right to health (Paul Hunt 2002–08).<sup>43</sup>

International evidence points to the positive impact that a human rights approach can have on the quality of health service delivery. The United Kingdom Audit Commission, for example, found that a human rights approach had resulted in improvements in service delivery standards in mental health, general healthcare, and disability and carer services.<sup>44</sup>

The approach can provide a framework to guide decision-making, encourage the collection of age-disaggregated data to inform policy decisions, promote age-sensitive programmes, help governments allocate resources fairly, lead to the training of healthcare personnel, employees, the judiciary and others involved in older people's issues, and guide the private sector on how it can protect older people's human rights.<sup>45</sup> Application of the approach can help to improve the quality of health care and lead to improved outcomes.<sup>46</sup> It is an approach that can shift the focus from one based on welfare, charity or paternalism to one based on human rights and the requirement for meaningful participation to ensure that service users can help to set their own agenda.

There is also value for aged care providers and peak bodies. The human rights approach offers a framework that will better enable providers and community organisations to understand society's expectations and deliver more sustainable services that are respectful of the inherent dignity of individuals.

The elements of the human rights approach applied in this paper include those identified in General Comment No. 14. The elements are:

- non-discrimination and equality
- available, accessible and appropriate health service provision which is of good quality
- progressive realisation
- participation
- monitoring and accountability.

The following sections provide a brief explanation of these elements.<sup>47</sup>

## **2.2 Non-discrimination**

Stigmatisation and discrimination are two major impediments to the enjoyment of human rights by older persons. Stigma is often based on myths, misconceptions and fears about older people and ageing. These myths, misconceptions and fears include beliefs that everyone loses decision-making capacity, gets dementia, becomes dependent and a burden, and ends up in residential care.

Older people are not an homogeneous group. Older women and men age differently and the discrimination that they experience is often multi-dimensional, based not only on age but on other factors, such as gender, ethnic origin, where they live, disability, poverty, sexuality or literacy levels.

Policy related to the delivery of aged care needs to be developed within an ageing-well framework and in a manner that respects difference and diversity. Careful consideration of health resource allocations is required to ensure that the development and implementation of an ageing-well policy promotes equality rather than perpetuating inequalities.

## **2.3 Availability, accessibility, acceptability and quality**

The human rights approach when applied to home and residential aged care includes four interrelated and essential components: Availability, Accessibility, Acceptability and Quality (AAAQ).

### *Availability*

A sufficient quantity of home and residential care must be progressively made available. Accordingly, indicators are required to measure progressive improvement in the availability of home and residential care. Availability includes not only services but also appropriately trained health workers and preventive and reablement programs.<sup>48</sup> Availability also extends to the underlying determinants of health such as safe housing and adequate nutrition and therefore incorporates issues identified by the Advisory Panel on the Economic Potential of Seniors (the Advisory Panel) such as home modification and maintenance, and transport to shops and social activities.

### *Accessibility*

Health and aged care services are to be accessible to everyone without discrimination. They are to be economically and physically accessible. While health and aged care services may be available at the local level, they may not be accessible to those who cannot afford to pay. Building codes must be complied with to ensure that people with disabilities can access the health service.

Accessibility also includes the right to seek, receive and impart information. This component of accessibility is particularly important for participation in advanced care planning, consumer directed care and personal decision-making.

### *Acceptability*

Health and aged care services are to be respectful of difference and diversity, culturally appropriate and gender sensitive. All home and residential care workers and hospital workers will need to be trained to be aware of, and able to respond to, different cultural sensitivities and diversity. To assist in this process, the inclusion of human rights training in the curricula of all people working in health and aged care services including doctors, nurses, allied health professionals and personal care workers would be appropriate.

### *Quality*

As well as being culturally appropriate and gender sensitive, home and residential aged care services are to be medically appropriate and of good quality. This includes skilled medical, nursing, allied health and personal care personnel, adequate equipment, application of safety and building codes, and adequate food.

Quality also extends to the manner in which people are treated. Recipients of home and residential aged care services are to be treated with respect and dignity. Quality therefore includes older people, carers and all health workers being aware of and understanding the two charters of rights and responsibilities scheduled to the *User Rights Principles 1997* (Cth) made under section 96-1(1) of the Aged Care Act.

## **2.4 General and immediate obligations**

The human rights approach incorporates general obligations to respect, protect and fulfil the human rights of all older people in the country.

The obligation to **respect** requires the federal government to ensure access to health services by older people extends to all groups including special needs groups, minority groups and prisoners. The obligation to **protect** requires the federal government to take steps to ensure the highest possible standards in all aged care service provision including that offered by private providers. The obligation to **fulfil**, which includes the obligation to promote,<sup>49</sup> requires the adoption of the necessary measures to ensure the provision of aged care services, including prevention programs, rehabilitation programs and palliative care.

Immediate obligations include the development of a national aged care strategy. The reforms make reference to the need for the aged care sector to be incorporated or better linked with the general health sector.<sup>50</sup> This aim would be assisted by the development of a national ageing-well framework or strategy that incorporates aged care within the framework. The opportunity to develop a single national ageing-well framework has been provided by the national health reform agenda and the aged care reforms. It is also a recommendation of the Advisory Panel on the Economic Potential of Seniors:

[D]evelop a national framework to recognise the life course approach to Active Ageing, based on World Health Organisation (WHO) Active Ageing principles and including wellness, age-friendly environment, availability and accessibility of effective health care, and active participation in all aspects of community life.<sup>51</sup>

The World Health Organisation's (WHO) 'active ageing' principles recognise older people's human rights and the United Nations Principles of independence, participation, dignity, care and self-fulfilment.<sup>52</sup>

The development of an 'ageing-well' or 'active ageing' strategy could provide the single platform for the development of disaggregated indicators, data collection, monitoring and reporting on data, and advocacy.

The Republic of Ireland 2007 Programme for Government included a commitment to develop a national strategy on ageing. The Government then conducted a comprehensive and wide-ranging consultation with older people in Ireland between June 2009 and June 2010. 'Older and Bolder', an alliance of eight non-government organisations, has called for a national ageing well strategy that contains a blend of values, policies, laws and services that will maximise the independence of older Irish people. The alliance has called for an ageing well strategy that addresses: equality for older people; respect and dignity for people of all ages; fairer health care; effective home and community care; clarity about rights and entitlements; secure pension; effective transport; meaningful involvement of older people; joined up planning and delivery of services and supports; a road map for implementation. (Source: Older and Bolder: Support Equality for Older People. At: <http://www.olderandbolder.ie/content/positive-ageing> (viewed 13 May 2012).

## **2.5 Progressive realisation**

Both policy makers and peak bodies recognise that the fundamental changes to the current system proposed by the federal government reform package will need to be implemented gradually and transparently.<sup>53</sup>

Progressive realisation as an element of a human rights approach does not make the impractical demand of immediate implementation. Rather, the human rights approach requires that effective measures be taken to progressively work towards the implementation of the reforms.

Essential to this is the development of a comprehensive plan that includes indicators to measure the implementation of reforms. Aged care professionals and policy makers regularly use a very large number of health indicators, for example, access and equity measures, quality and sustainability measures, efficiency and cost effectiveness measures.<sup>54</sup>

A human rights approach to indicators requires additional features such as an emphasis placed on disaggregation. The goal is to disaggregate in relation to as many of the internationally prohibited grounds of discrimination as possible, including sex, race, ethnicity, sexuality, rural/urban/remote locality and socio-economic

status.<sup>55</sup> These indicators should be supplemented by additional indicators that monitor essential features of a human rights approach such as participation, access to health information and the presence of accessible and effective monitoring and accountability mechanisms.<sup>56</sup>

The monitoring of indicators by government and civil society can ensure that, in the presence of resource constraint, and the need for prioritisation, the implementation of individual components of the reforms takes place as planned and, if postponed, is not postponed indefinitely.

## **2.6 Participation**

Active and informed participation of people and groups in health related decision-making is an essential component of a human rights approach to community and residential aged care.

The right to active and informed participation relies in part on other human rights. These other human rights include the right to seek, receive and impart health-related information, the right to express views freely and the right to basic health education.

Participation is a complex area. While methods for undertaking participation are context dependent, steps must be taken by the government to develop institutional mechanisms to enable participation to take place. Because participation is an essential element of a human rights approach, indicators are needed to measure the degree to which aged care health policies and programs are participatory.<sup>57</sup>

## **2.7 Monitoring and accountability**

Accountability is concerned with providing a system to enable government and the community to look at what it has done well, to identify where mistakes have been made and to implement change. It includes remedies for when violations of the human rights of older people occur.

Remedies are key to ensuring that human rights have meaning and include restitution, compensation, rehabilitation, satisfaction and a guarantee of non-repetition.<sup>58</sup> The remedies of satisfaction and a guarantee of non-repetition are particularly important for aged care policy. These remedies are aimed at structural change and include legislation, policy change, and human rights training for health workers.

As the non-government sector also has a responsibility to monitor public and private delivery of services, accountability provides the mechanism to encourage ongoing dialogue between government, civil society organisations and the private sector through monitoring the implementation of programs and the delivery of services.

### 3 The Aged Care reforms and human rights

The purpose of this section is to discuss selected elements of the reforms within a human rights approach. Making linkages between the reforms and elements of the human rights approach is timely as the federal government works with the aged care sector and older Australians to refine and give greater detail to the implementation of the reform agenda.

The adoption of an explicit human rights approach to the reforms will promote 'people-centred' decision-making and respect for the inherent dignity of older people. At the same time it will provide guidance on how to balance competing rights in the presence of restricted resources.

#### 3.1 Consumer directed care

The federal government aged care reform package includes funding to embed ongoing consumer directed care pilot programs into mainstream aged care program delivery. This initiative, launched in 2010 and extended in 2011,<sup>59</sup> aims to give older people greater control of their lives by allowing them 'to the extent that they are capable and wish to do so and relative to their assessed care need level',<sup>60</sup> greater say in, and more control over, the design and the delivery of the community care services they receive.

Evaluation of the pilot programs found that there were benefits to recipients and their carers in terms of increased satisfaction and the care provided.<sup>61</sup> The Productivity Commission also noted the strong empirical evidence that greater choice improves wellbeing and independence and provides better continuity of care.<sup>62</sup> Older Australians indicated to the Productivity Commission that they did not wish to be passive recipients of the aged care system. Rather, they wished to be independent, choose where they live, decide which services they want and which provider to deliver those services.<sup>63</sup> These views were confirmed during the conversations held on ageing across Australia. Older Australians and their carers expressed strong views that they should have a greater say in their care.<sup>64</sup>

The federal government's reforms aim to mainstream consumer directed care programs from 1 July 2012 with the program principles embedded into all new home care packages from 1 July 2013. Ongoing monitoring of the mainstreaming of consumer directed care will be essential to determine the accessibility and quality of these services and to ensure the rights of older recipients of these services are protected and their decisions respected.

Human rights challenge for this area:

- The development of indicators to monitor the accessibility and quality of consumer directed care
- The development of indicators to monitor respect for the decisions of older Australians.



### **3.2 Advance care planning**

Advance care planning was identified by the Productivity Commission's *Caring for Older Australians* report as a core issue for aged care and was also frequently raised in the national conversations on ageing.<sup>65</sup>

Advance care planning aims to keep the individual involved in health related decision-making and ensure that a plan has been made in advance that indicates to the family, carers, health professionals and others, how a person would like to be cared for should they be critically ill and/or not have decision-making capacity. Palliative Care Australia notes that advance care planning supports patients in communicating their wishes about their end of life.<sup>66</sup>

The Productivity Commission recommended a community awareness campaign to promote knowledge and understanding of the importance of this process amongst all Australians including older Australians and their families. Additionally, health professionals and care workers should also be better informed and trained to be able to discuss and put in place advance care directives.<sup>67</sup> Importantly, the Productivity Commission noted that there needed to be effective communication between health care sectors (hospital to residential care facility and vice versa) if patients' preferences and end-of-life care wishes were to be known and respected.<sup>68</sup>

The aged care reform package includes funding to increase general practitioners' knowledge and awareness of State/Territory advance care planning legislation, documents and related resources.<sup>69</sup> Understanding of advance care planning is essential to ensure older Australian's end-of-life wishes are respected. This is particularly important in view of the lack of confidence that many older Australians have that their end of life plans will be respected by their families and importantly, health professionals.<sup>70</sup> Therefore, the federal government should consider extending advance care training programs beyond general practitioners and include health workers in the acute care sector and in the aged care sector. This would also facilitate a process of effective communication between the acute care sector and the aged care sector and promote respect for the end-of-life decisions of older Australians.

Human rights challenge for this area:

- Extending advance care planning training to include health workers in the acute and aged care sectors.

### **3.3 Supported decision-making**

Central to the successful implementation of consumer directed care and advance care planning is the consideration that is given to the freedom and right of a person to actively participate in decision-making about their health care and personal matters and to have those decisions respected. Important examples of health care and personal matters include living arrangements, health care, palliative care and end-of-life care. In turn, active participation relies on a person's capacity to participate.

Recognition of capacity is fundamental to human personhood and the freedom to make decisions regarding one's own health. Yet the determination of capacity differs across Australian jurisdictions.<sup>71</sup>

Most older people will continue to have full capacity to decide where they want to live and if requiring care, how they want this care delivered. However, there are some older people who do not have decision-making capacity or who, because of frailty, are assumed not to have decision-making capacity. The former could be due to a cognitive impairment such as dementia. The latter is more likely than not, due to age stereotyping. A frail older person has no capacity to make decisions.

Bev and Arthur had been married for 60 years. She had been assaulted by their son. Bev was subsequently admitted to hospital with an infection. The hospital staff discussed the woman's discharge with the son, not the 91 year old husband. The son wanted his mother admitted to an aged care facility. His father (the husband) wanted his wife to return home – as did she. Due to the conflicting wishes of the son and his parents about his mother's care and accommodation, the hospital made an application to the state administrative tribunal for the appointment of a guardian. The administrative tribunal appointed the son as the guardian and she was placed in an aged care facility with no discussion with the husband. The husband and the wife were distressed as they missed each other. Both were lonely and the husband walked every day to see his wife. Neither were offered any support by the hospital network nor had any counselling for grief. Source: COTA Victoria, *Hospital Initiated Guardianship Applications*.

A 74 year old man who had been living in the same community for 55 years and living with one of his five children for 10 years was admitted to hospital after a fall. There was conflict between the five children, one of which was estranged from the family. Four of the children were supportive of their father returning home with a family roster of support. The estranged child wanted the father admitted to an aged care facility. The father became increasingly angry due to sitting in his hospital room awaiting discharge to his home. Due to the conflict a hospital social worker, who had only discussed the issue with the estranged child, lodged an application for guardianship. Noted on the application by the social worker was a notice that indicated that the older person should not attend the hearing due to 'blindness' and 'aggressive behaviour'. Attached to the application was a neuropsychologist's report stating that the father had dementia. Not attached to the application was a recent Aged Care Assessment Record stating that the older person had no dementia and was continent. The older person was told they had to stay in hospital until the application was determined, thus increasing his anger and frustration. When the four children attempted to remove their father from the hospital, they were told the police would be called. Eventually with the support of a senior rights organisation, the father attended the administrative tribunal hearing. The decision of the tribunal was that the hospital and the family come up with a plan to support the older person at home. Source: COTA Victoria, *Hospital Initiated Guardianship Applications*.

In the situation where there is a cognitive impairment such as dementia, Article 12 of the Convention on the Rights of Persons with Disabilities emphasises that a person's decision-making capacity may not be taken away simply by reason of their disability.<sup>72</sup> The Convention requires an approach that moves away from a paternalistic view of an older person with a disability, to an approach that centres on respecting the will and choices of a person and ensuring that they are supported in decision-making.<sup>73</sup>

Supported decision-making is based on a broad definition of capacity that recognises the wishes of the individual and the trusting relationships they have with people in their network. While exact definitions vary, it is a formalised system that makes clear who is to provide the decision-making support.<sup>74</sup> It is often contrasted with substituted decision making, where the decision is made on behalf of a person who has impaired decision-making capacity.<sup>75</sup> It is worth noting that for older people without a support network, the extension of the existing Community Visitors Scheme to recipients of home care services is an important reform as it has the potential to assist with the creation of trusted social networks for older people.<sup>76</sup>

Closely related to supported decision-making is assisted decision-making. The older person has full capacity to make a decision but requires some form of assistance, for example, collection of information or talking through options. It is autonomous decision-making by a person where others are providing assistance with communication and retrieving information.<sup>77</sup>

The idea of supported or assisted decision-making does not only relate to cognitive disability but also to protection for vulnerable people. For example, a physically frail older person may be subject to age stereotyping and/or intimidation and abuse even if they have capacity. To avoid this situation, the federal government could consider the development of an adult protection system that focuses on making communities safer rather than relying on removal of the decision-making rights of the older abused person.<sup>78</sup>

With the ageing profile and the potential for the increasing use of guardianship applications and substituted decision-making, the federal government should give consideration to the development of a national system to protect the decision-making rights of older persons through assisted or supported decision-making, with substitute decision-making for situations of severe or profound impairment when there is risk.<sup>79</sup>

#### Human rights challenges for this area

- Development of a national system to implement assisted and supported decision-making
- Development of an adult protection system focusing on safer communities.

### **3.4 Health literacy**

Related to decision-making in consumer directed care and advance care planning is health literacy. The level of a person's health literacy will affect not only the decisions they make in consumer directed care, but also the decisions they make about end-of-life care and how they wish to be medically treated. The National Seniors Productive Ageing Centre report *Improving Health Literacy in Seniors with Chronic Illness* notes that there are rival definitions of health literacy.<sup>80</sup> These different definitions lead to different approaches such as top down where the lack of health literacy is seen as a clinical risk. In this case, the older person is a passive recipient of health care and not an active participant. In contrast, the adoption of an empowering definition will provide the older person and their carer with the capacity to engage as an independent agent and play an active part in defining their needs. The intent behind the expansion of consumer directed care and advance care planning indicates the aged care reform package points to the adoption of an empowering definition.

Statistics show that rates of health literacy vary with age and show a similar pattern for men and women. In 2006, the rate of adequate or better health literacy increased from around one-third of both men and women aged 15–19 years to around half of all people aged 20–49 years, before declining in older age groups. The decline in older groups may be due to the effects of age on peoples mental processing skills, the length of time since leaving formal education, and the lower levels of formal education received by older generations.<sup>81</sup> Whatever the cause, the decline indicates that there is a need for a formal program to promote health literacy.

The internet has the potential to assist with improving the health literacy of older Australians. However, research shows that older people are less likely to have an internet connection<sup>82</sup> and are less likely to enjoy going on-line.<sup>83</sup> While the federal government is providing a degree of access to the internet by older Australians through its *Broadband for Seniors Initiative*, more work is required to improve the effectiveness of the program and ensure that older Australians are confident on-line.<sup>84</sup>

#### Human rights challenges for this area

- Development and implementation of health literacy programs for older Australians and their carers
- Improvement in the reach and effectiveness of the *Broadband for Seniors Initiative* to promote older Australians' confident engagement with the Telehealth program.

### 3.5 **Acceptability of services**

Human rights require that aged care health services are respectful of difference and diversity. Health workers, for example, should be sensitive to issues of ethnicity and culture.<sup>85</sup> This is not only a matter of human rights but it also makes sense. Thoraya Ahmed Obaid, Executive Director of the United Nations Population Fund has observed that ‘cultural sensitivity ... leads to higher levels of programme acceptance and ownership by the community, and programme sustainability’.<sup>86</sup>

A number of special groups are defined in the Aged Care Act and the *Allocation Principles 1997 (Cth)*.<sup>87</sup>

#### **Special needs groups recognised in the aged care system**

The Aged Care Act, section 11-3 specified the following special needs groups:

- people from Aboriginal and Torres Strait Islander communities
- people from non-English speaking backgrounds
- people who live in rural or remote areas
- people who are financially or socially disadvantaged
- people of a kind (if any) specified in the *Allocation Principles 1997 (Cth)*.

The *Allocation Principles 1997 (Cth)*, part 2A specifies the following groups as special needs groups:

- people who are veterans
- people who are homeless or at risk of becoming homeless
- people who are care-leavers.

*Sources: Aged Care Act 1997 (Cth) and Allocation Principles 1997 (Cth).*

The aged care reform package includes a total of \$192 million over five years to better support people with special needs.<sup>88</sup> The reforms focus on ensuring culturally appropriate aged care services for Aboriginal and Torres Strait Islander peoples and older people from culturally and linguistically diverse communities, more aged care support for veterans, and more assistance for older people who are homeless or at risk of homelessness.<sup>89</sup>

#### *Aboriginal and Torres Strait Islander peoples*

The estimated resident population of Aboriginal and Torres Strait Islander peoples at 30 June 1991 was 351,000 people.<sup>90</sup> In 2006, there were 517,000 people, representing 2.5 per cent of the total Australian population.<sup>91</sup> Between 1991 and 2006 the population increased by 2.6 per cent per year on average, compared with 1.2 per cent for the total Australian population.<sup>92</sup>

The population of Aboriginal and Torres Strait Islander peoples is projected to increase to between 713,300 and 721,100 people in 2021. This is an average growth

rate of 2.2 per cent per year, compared with between 1.2 per cent and 1.7 per cent per year for the total Australian population over the same period.<sup>93</sup> The number of older Aboriginal and Torres Strait Islander people (55 years and over) is projected to more than double over the period, from 40,000 in 2006 to between 82,000 and 86,600 in 2021.<sup>94</sup>

Culturally appropriate care is essential for aged care services delivered to all older Aboriginal and Torres Strait Islander peoples and is particularly crucial for Aboriginal and Torres Strait Islander people with dementia. Though there are no national studies on the prevalence of dementia in Aboriginal communities, small studies suggest that the rate is much higher than that in the general population and that the onset is earlier.<sup>95</sup> Access Economics noted a small study in the Kimberley region of Western Australia which sampled 400 members of the community aged 45 years and over finding a prevalence rate of 12.4 per cent (compared with 2.6 per cent in the Australian population generally).<sup>96</sup> The study revealed that not only was there a much higher prevalence rate, but the onset was also much earlier than for other Australians. The impact of this disease on the individual, the family and Aboriginal communities is potentially devastating.

Aged care services for Aboriginal and Torres Strait Islander peoples are delivered through mainstream services, for example the Home and Community Care program (HACC) and also through the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. The HACC program has a special advisory body, the National Aboriginal and Torres Strait Islander HACC Forum that provides input to policy and planning on Indigenous matters.<sup>97</sup>

The *Social Justice Report 2005* recommended that a human rights approach be adopted to address the health of Aboriginal and Torres Strait Islander peoples.<sup>98</sup> This includes older Aboriginal and Torres Strait Islander people. Since that time the 'Close the Gap' campaign has been designed and implemented.<sup>99</sup> The federal government should ensure that the provision of aged care services to older Aboriginal and Torres Strait Islander people is coordinated with this campaign.

### *Culturally and Linguistically Diverse older people*

At 30 June 2010, data on the estimated resident population of Australia (22.3 million people) revealed that 27 per cent of the population was born overseas (6.0 million people). Over the past 60 years the overseas-born population has increased from about 1.3 million to 6 million.<sup>100</sup>

One in five older Australians comes from a non-English speaking country, and the size of this group is growing faster than other segments of the older population. Although people from non-English speaking countries made up only 15 per cent of the very old population (85 and over) they represented 21 per cent of those aged 75–84 years and 23 per cent of those aged 65–74 years.<sup>101</sup>

Over the coming decades, immigrants from non-English-speaking European countries, who arrived in Australia during the peak of post-war immigration up to 1971, will become a more significant part of the very old (85 and over), and Asian

immigrants from countries such as Vietnam, Malaysia and the Philippines will become a more significant part of the younger old, with implications for provision of health and aged services.<sup>102</sup>

While older people born overseas in non-English speaking countries are generally healthier than the rest of the older population, they can face barriers in accessing appropriate health and aged care services,<sup>103</sup> such as accessing information and services that are sensitive to their backgrounds, circumstances and language. Indeed, older members of culturally and linguistically diverse backgrounds (CALD) frequently revert back to their first language as a result of the ageing process.<sup>104</sup> In the case of older people with dementia from CALD communities, culturally appropriate aged care services with first language support are particularly crucial as the language most recently acquired is lost first.<sup>105</sup>

To address the situation of access to services and to information, the aged care reform package includes funding to improve the accessibility of information materials as well as the skills and knowledge of aged care providers and their staff to meet the care needs of their clients. To assist with the implementation of aged care services that address the needs of older CALD Australians, the federal government has recently announced plans for the development of a specific CALD aged care services strategy to be developed before the end of 2012.<sup>106</sup>

### *Older Veterans*

Statistics show that an estimated 394,516 Australians received some form of assistance from the Department of Veterans Affairs (DVA) at 30 June 2007 of which 78 per cent were aged 65 years and over.<sup>107</sup> It is also estimated that DVA clients make up at least 17 per cent of permanent residents of aged care services<sup>108</sup> and 16 per cent of the packaged care (community aged care package, extended aged care at home, extended aged care at home – dementia) population.<sup>109</sup>

In 2007, approximately 143,000 DVA clients had some experience of mental health concerns. The most common conditions are generalised anxiety disorder, depression, alcohol dependence and post-traumatic disorder.<sup>110</sup> While the Veterans and Veterans' Families Counselling Service provides counselling and group programs,<sup>111</sup> there is currently no additional funding provided for veterans with mental health problems that are in receipt of home care packages.<sup>112</sup> The aged care reform package redresses this through the provision of additional funds to introduce these services to veterans in receipt of home care packages and to provide better services to veterans in residential aged care.<sup>113</sup>

### *Lesbian, gay, bisexual, transgender and intersex people*

The reforms will also work to improve the provision of aged care services for older lesbian, gay, bisexual, transgender and intersex (LGBTI)<sup>114</sup> Australians through their inclusion as a special needs group under the Aged Care Act. This will assist members of the LGBTI community to access acceptable and appropriate care suitable to their needs.<sup>115</sup>

Sexual orientation, sex and/or gender identity have important implications for the provision of aged care services as many LGBTI people have experienced unlawful discrimination over the course of their lives. It is thus imperative to ensure that this discrimination does not continue into the provision of aged care services.

Additionally, there are no comprehensive projections of the number and distribution of older LGBTI people.<sup>116</sup> Nevertheless, it is anticipated that consistent with the ageing Australian population, there will be a large increase in the demand for aged care services by older LGBTI people.

### *Women*

Ageing is gendered, with women tending to live longer than men.<sup>117</sup> In 2010, just over 50 per cent of people aged 65–74 years in Australia were women. In the same year, women comprised 65 per cent of those 85 years and older.<sup>118</sup> Women 65 years and over require more assistance than men for activities such as property maintenance, housework and transport.<sup>119</sup> In 2004–05, home and community care services were provided to over 744,000 people, 75 per cent of whom were 65 years and over. Two thirds of these clients were women.<sup>120</sup>

Additionally, there are clear gender differences amongst informal carers.<sup>121</sup> Women make up over 69 per cent of primary carers of older people. Older men, particularly those aged 75 years and over, are more likely to be cared for by an older female carer and women in this age group are more likely to be cared for by a female carer.<sup>122</sup>

The Australian Institute of Health and Welfare has noted that this sex composition of the older population has implications for aged care policy. The survival of women to more advanced ages means they will have higher levels of severe disability and are less likely to have a spouse carer.<sup>123</sup> In 2010, women comprised 56.5 per cent of the 2.16 million recipients of the Age Pension,<sup>124</sup> making it less likely for older women to afford private aged care services. The gendered nature of ageing also has implications for the human rights of women.

Women are not listed as a special needs group in the Aged Care Act. However, due to the multidimensional nature of the discrimination experienced by many women throughout their lives together with the gendered nature of ageing,<sup>125</sup> it is essential to ensure the accessibility (including economic accessibility) and acceptability of aged care services delivered to older women.

The federal government and aged care providers need to ensure that the human rights of older women in receipt of aged care services are protected and respected. Monitoring of the accessibility and acceptability of aged care services to older women will assist this process. Monitoring will require the development of data indicators, disaggregated at least by age, sex, race, place of abode and geographical location, in order to better assess the situation of older women as recipients of aged care services and as carers.



### *Other special needs groups*

Homeless people and those at risk of homelessness, care leavers,<sup>126</sup> and people who are financially or socially disadvantaged have also been acknowledged as special needs groups. It is important that this is the case. Due to their diverse circumstances, frequently resulting in discrimination on multiple grounds, these groups are particularly susceptible to having their human rights violated.

In addition to and also overlapping with these groups is a section of the older population with substance misuse problems.<sup>127</sup> As the number of older Australians increases, so too will the number of older Australians with substance misuse problems. As with alcohol misuse, there is Australian evidence of misuse of prescribed drugs such as pain relief drugs, particularly among older Australians.<sup>128</sup>

Acceptable aged care services tailored to the specific needs of this group will require a health workforce with the competence to recognise and manage substance misuse. The federal government could consider planning for the demand that will arise with the ageing of this population group to ensure non-discrimination in access to aged care services.

The human rights of special needs groups can be better respected and protected through the inclusion of disaggregated indicators in the national quality indicators. The indicators should measure access to services and be disaggregated, at least, on the grounds of age, sex, race, ethnicity, sexuality, place of abode, and socio-economic status.

#### Human rights challenges for this area

- Development of disaggregated indicators to better assess the situation of all older people with special needs. These indicators will need to be disaggregated, at least on the grounds of age, sex, sexuality, race, ethnicity, place of abode, socio-economic status
- Ensuring that amendments to the Aged Care Act are compatible with the human rights contained in the seven core treaties to which Australia is a party

### **3.6 Quality of services**

A human rights approach to quality of aged care services requires, at a minimum, that the services be culturally appropriate. It also requires that medical, nursing and other care be evidence-based and delivered by skilled medical, nursing, allied health personnel, and health workers such as direct care assistants and care aids. It should be delivered in a safe environment, and delivered in a manner that respects the dignity of the person in receipt of the care.

The federal government and aged care providers are also concerned with these issues. However, defining, measuring and ensuring the quality of care and support is not a straightforward issue.<sup>129</sup>

The Aged Care Act provides for an accreditation-based quality assurance system. Aged care homes must be accredited in order to receive Australian Government subsidies. This process is undertaken by the Standards and Accreditation Agency (see page 10), an independent company limited by guarantee under the *Commonwealth Authorities and Companies Act 1997* (Cth). Every three years, government approved aged care providers undergo an accreditation process generally lasting 2–3 days and conducted by 2–3 assessors. The agency also undertakes unannounced visits.

The accreditation process assesses the performance of homes against the 44 expected outcomes of the four accreditation standards: management systems, staffing and organisational development; health and personal care; resident lifestyle; and physical environment and safe systems.

It is clearly a comprehensive system. However, there are criticisms that the focus has been on the process of meeting the minimum standards rather than on the outcomes.<sup>130</sup> There is also anecdotal evidence that although the *Charter of Resident Rights and Responsibilities* and the *Charter of Rights and Responsibilities for Community Care* contained in the schedules to the *User Rights Principles 1997* (Cth) initially informed the standards against which an aged care service is accredited, they are rarely raised in accreditation reviews.<sup>131</sup>

Complaints also expose opportunities to improve the quality of care. The rights of aged care recipients under the charters are considered when the Complaints Scheme is looking at whether service providers have met their responsibilities in providing care. (See page 39)

The rights in the charters include:

- the right to full and effective use of personal, civil, legal and consumer rights
- the right to full information on health and treatment
- the right to be treated with dignity and respect
- the right to live without exploitation, abuse or neglect
- the right to live without discrimination
- the right to be involved in decision-making, and to have decisions respected
- the right to not feel obliged to be grateful to those providing care and accommodation.

These two charters are critical components of a human rights approach. Their implementation would provide the opportunity for emphasis to be placed on people-centred decision-making, participation and respect for the decisions of recipients of aged care services. The federal government could consider tasking an external organisation or alliance, such as the National Aged Care Alliance, with community, provider and health worker education on the two charters of rights and responsibilities.

The aged care reform package includes placing a greater emphasis on the development of a consistent approach to monitoring quality across the continuum of aged care.<sup>132</sup> National quality indicators will be developed to support a new quality ratings system that will be made available through the *My Aged Care* website. Additionally, a new agency will be created. From 1 July 2014, the Aged Care Quality Agency will be established, replacing the Aged Care Standards and Accreditation Agency, to accredit and monitor both residential and home care providers. The Agency will be the sole agency that providers deal with in relation to quality assurance of aged care services.<sup>133</sup>

To promote respect for the human rights of recipients of aged care services, the federal government should consider the inclusion of a set of disaggregated indicators related to the knowledge and application of the rights contained in the *Charter of Resident Rights and Responsibilities* and the *Charter of Rights and Responsibilities for Community Care* contained in the schedules to the *User Rights Principles 1997* (Cth).

#### Human rights challenges for this area

- Development of programs to ensure increased knowledge by aged care recipients, their carers and aged care sector workers of the *Charter of Resident Rights and Responsibilities* and the *Charter of Rights and Responsibilities for Community Care*
- Development of process and outcome indicators for the inclusion of the two charters in accreditation processes.

### **3.7 Access to services**

The human rights requirement of access to health facilities and services includes physical, geographic and economic accessibility. The spread of health professionals across Australia is uneven. Despite initiatives to improve access to medical doctors and allied health professionals in rural and remote areas, access to these health professionals remains relatively low compared to urban areas.<sup>134</sup> And while there are greater numbers of medical doctors and allied health professionals in urban areas, older people in their homes or in urban residential care can often find it difficult to easily access these health professionals.<sup>135</sup>

In addition, one of the results of older Australians choosing to remain at home as they age is that the older people who do enter residential care are likely to be frail and have complex conditions. Therefore, access to specialist health teams that include general practitioners and geriatricians will be increasingly important if the quality of care is to be achieved.<sup>136</sup>

To promote greater access to health professionals, the federal government has proposed several reforms including the delivery of medical and allied health consultations via Telehealth. The program is designed to be supported by the National Broadband Network.<sup>137</sup> It is a method that allows older people in their homes or in residential care to access general practitioners, specialists, pharmacies and allied health professionals, amongst others. Of course, the successful implementation of Telehealth relies on the willingness and ability of older Australians to safely access the internet.

Research shows that older people are less likely to have an internet connection,<sup>138</sup> are less likely to enjoy going on line,<sup>139</sup> and are likely to be the most vulnerable to internet fraud.<sup>140</sup> These factors negatively impact on the potential for success of the Telehealth program and point to the need for targeted and effective strategies to ensure that older Australians become confident internet users. While the federal government is providing a degree of access to the internet by older Australians through its *Broadband for Seniors Initiative*, research has shown that more work is required to improve the effectiveness of the program.<sup>141</sup>

The human rights approach to access also includes economic access, with a focus on the need for equity. The human rights approach does not specify a particular funding formula. Whatever system is decided upon it needs to be equitable and financially accessible to all and ensure that economic accessibility is able to be monitored. As Ian Yates of COTA Australia has observed:

How user charges are raised is not a straightforward issue. It goes to intergenerational equity as well as horizontal equity among the current aged population. There is room to weigh up the options as reform progresses, but we need them to be equitable, affordable, transparent and provide a sustainable funding base for care alongside majority Government funding.<sup>142</sup>

#### Human rights challenge for this area

- Development of disaggregated indicators that show access to aged care health professionals across urban, rural and remote regions.

### **3.8 Accountability and the Aged Care Sector**

The principal focus of human rights accountability is the degree to which the human rights of older Australians are respected. Accountability requires mechanisms that provide the opportunity for government and the community to identify what has been done well, to identify mistakes and to implement change. The provision of remedies for violation of human rights is important as it is the remedies that help make human rights real.

The remedies of satisfaction and guarantees of non-repetition are of particular importance for the health sector. These remedies include the steps required to make sustained changes to the aged care health system. For example, legislation, changes to policy and programs, and human rights training for health workers.<sup>143</sup>

Within the current aged care sector there are several accountability mechanisms. These mechanisms are:

#### *The Aged Care Standards and Accreditation Agency*

The Standards and Accreditation Agency manages the accreditation of aged care homes in accordance with the *Accreditation Grant Principles 2011*.<sup>144</sup> The accreditation process is linked with the quality of services as it provides the opportunity to identify what has been done well and to implement change where mistakes have been made. Homes found to have not met the Accreditation Standards are placed on a timetable for improvement, providing them with an opportunity to meet the Accreditation Standards.<sup>145</sup> Information about a home's accreditation status, including copies of the most recent accreditation and review audit reports, is published on the Accreditation Agency's website at [www.accreditation.org.au](http://www.accreditation.org.au).

#### *The Aged Care Complaints Scheme (Complaints Scheme)*

The Complaints Scheme commenced operation on 1 May 2007 and is a free service that allows aged care clients, carers, health workers and others to submit anonymous, confidential or open complaints about the quality of care and services being delivered in federal government subsidised residential and home care settings.<sup>146</sup> The Complaints Scheme received 8,468 in-scope contacts in 2010–11 (total of 13,606) of which 4,013 complaints related to Australian Government subsidised residential and community aged care.<sup>147</sup>

When dealing with complaints about Commonwealth subsidised aged care providers, the Complaints Scheme assesses whether approved providers are meeting their responsibilities under all of the principles covered by the Aged Care Act, including the *Quality of Care Principles 1997* (Cth) and the *User Rights Principles 1997* (Cth).<sup>148</sup> It is during this process that the Complaints Scheme gives consideration to whether the approved provider has breached any of the rights set out in the *Charter of Resident Rights and Responsibilities* and the *Charter of Rights and Responsibilities for Community Care* referred to earlier.

Following a review in 2009, reforms to the system are being implemented over four years from 2010–11 to 2013–14 to strengthen complaints handling. From 1 July 2012 the complaints scheme will be broadened to include federal funded home and community care services. The reforms include increasing options to resolve complaints, for example, early resolution and conciliation and better access to seek review of a Scheme decision.<sup>149</sup>

#### *The Office of the Aged Care Commissioner*

As discussed earlier in this paper (page 10), the Aged Care Commissioner is a statutory appointment independent of the Department of Health and Ageing. The

functions of the Commissioner include examination of the Complaints Scheme decisions and processes either in response to a complaint or on their own initiative. Currently, the Aged Care Commissioner may only make recommendations regarding the findings of these examinations. In relation to complaints about the Complaints Scheme's decisions, the Commissioner may recommend no further action or that the Complaints Scheme undertake a new resolution process. The Commissioner may identify particular matters which should be included in the reconsideration process. Following an investigation of a complaint about the Scheme's processes, the Commissioner may recommend ways to improve the Scheme's complaints handling processes in the future. The Commissioner can also examine the conduct of the Standards and Accreditation Agency audits and assessors, again either on their own initiative or in response to a complaint.<sup>150</sup> Following the investigation of complaints against the Standards and Accreditation Agency, the Commissioner may make recommendations to the Agency. At present the Commissioner's functions do not extend to home and community care services.

During the Productivity Commission Inquiry and subsequent national consultations held by the federal government, concern was expressed by older Australians and their carers regarding the lack of independence of the Complaints Scheme and the powers of the Office of the Aged Care Commissioner.<sup>151</sup>

In response, the federal government aged care reforms include changes to the Aged Care Standards and Accreditation Agency, a revamped Complaints Scheme which enables a greater range of resolution options,<sup>152</sup> and increased powers for the Aged Care Commissioner.<sup>153</sup> These increased powers include the ability to:

- direct the Complaints Scheme to undertake a new complaints resolution process
- require the Complaints Scheme to provide the Aged Care Commissioner with a copy of draft decisions following resolution processes
- require the Complaints Scheme to take into account any further comments made by the Aged Care Commissioner
- make a special report to the Minister for Mental Health and Ageing if the Aged Care Commissioner is dissatisfied with the response of the Complaints Scheme.<sup>154</sup>

While the details to all of the changes have not been finalised, there will be improvement in the current accountability system and the potential to bring the system into closer alignment with the requirements of human rights. The federal government should consider early consultation with the Australian Human Rights Commission during the drafting of the amendments to the Aged Care Act. This early involvement would ensure that all planned amendments to the Aged Care Act result in greater consistency with the human rights obligations contained in the seven core treaties to which Australia is a party.

#### *National Aged Care Advocacy program*

The advocacy support services funded under the National Aged Care Advocacy program provide independent advocacy for, and information to, older Australian recipients or potential recipients of aged care. The services also provide an important

educative role for aged care recipients and government approved providers on the rights and responsibilities of aged care recipients including the *Charter of Residents' Rights and Responsibilities* and the *Charter of Rights and Responsibilities for Community Care* contained in Schedules 1 and 2 of the *User Rights Principles 1997 (Cth)*.<sup>155</sup>

As advocacy and educative services, they have a particularly important role to play as a social accountability mechanism. Through their advocacy and educative roles, there is the potential for the community based organisations, aged care clients and their carers to be involved in monitoring the implementation of the reforms. This participatory monitoring should be encouraged, not only because of the principle of participation but also because of the particular vulnerability of Australia's older population.

As part of the right to seek, receive and impart information, social accountability mechanisms such as the advocacy support services, working with aged care recipients and their carers together with civil society organisations, could undertake this monitoring role. There are many places where this external monitoring is taking place, either cooperatively with government or independently.

Participation and Practice of Rights Project, The Belfast Mental Health Rights Group is a group of people who use mental health services as well as carers of those who use these services. Drawn from all over Belfast, they share concerns about the rights of patients and carers who use mental health services. Since 2006 they have been working to make small but important changes in local mental health services. The group uses international human rights standards on mental health to gather evidence, monitor government's activity, and campaign to improve local mental health services. When the group came together, they identified a long list of issues which they felt were problems with mental health services for them and for others in their community. The list was then shortened to reflect specific issues which the group wanted to see change on and which were also reflected in international and national standards. The issues were turned into indicators capable of being measured to show whether things are getting better or worse over time. The group then carried out a survey of those with experience of mental health services within the last six months to set a baseline picture of the extent of the problem. From this benchmarks were set that were specific targets about what improvements should be made over the next year to ensure that the government was meeting its international human rights obligations. Source: Participation and Practice of Rights Project, Belfast, Northern Ireland. At <http://www.pprproject.org/right-to-health> (viewed 18 July 2012).

#### Human rights challenge for this area

- The development of indicators to measure the effectiveness of aged care accountability mechanisms

## 4 Health Workers – an essential building block

The World Health Organisation identifies ‘six essential building blocks’ which together make up a health system.<sup>156</sup> Health workers, including aged care health workers, are one of the building blocks, each of which ‘allow a definition of desirable attributes – what a health system should have the capacity to do in terms of, for example, health [workers]’.<sup>157</sup>

A well-performing **health workforce** is one which works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances. ... There are sufficient numbers and mix of staff, fairly distributed; they are competent, responsive and productive.<sup>158</sup>

The human rights dimensions of the health workforce building block include the development of a human resources aged care plan that encompasses strategies to ensure:

- the recruitment of health workers in the aged care sector, palliative care, prevention and rehabilitation
- the recruitment of a mix of health workers, such as Aboriginal and Torres Strait Islander health workers and health workers from CALD communities
- a gender balance in health workers
- the numbers of health workers is equitably distributed among remote, rural and urban areas
- human rights training, including respect for cultural diversity, and the importance of treating clients and others with courtesy
- opportunities for further professional training
- competitive salaries and workplace conditions.<sup>159</sup>

There is a decline in the number of qualified nurses in aged care, and a shortage of 20,000 nurses right now.<sup>160</sup> In 2010, it was estimated that there were just over 300,000 aged care workers in Australia. The Department of Health and Ageing anticipates that by 2050 more than 500,000 additional workers will be required to meet the needs of the ageing population.<sup>161</sup>

The federal government aged care reforms respond to the aged care sector workforce crisis and have been welcomed.

Through the adoption of a human rights approach, the federal government would not only address issues specific to health workers such as a career path and competitive remuneration but also address the training required to ensure that health workers are culturally competent, respect difference and diversity in the older Australian population, and understand and respect human rights.

There would also be added value for aged care providers. Protecting the human rights of employees leads to increased productivity, as workers who are treated fairly and with dignity and respect are more likely to be productive. Research has found that organisations that avoid human rights violations can reduce employee turnover and achieve a higher standard of service delivery.<sup>162</sup>



In addition to adopting a human rights approach to the aged care sector, the federal government and aged care providers could also give consideration to the potential of the aged care sector to provide an avenue for employment of older workers and in the process promote cross-sector planning and programs. By recognising prior skills or re-skilling, opportunities can be provided to older people willing to continue in employment. Implementing this strategy would also be added value for aged care providers as research shows that older aged care workers are loyal, adaptable, dependable and able to connect with clients.<sup>163</sup>

#### Human rights challenges for this area

- Incorporation of human rights training into the curricula of health professionals
- Coordination and collaboration across government sectors, such as aged care and employment.

## 5 Conclusion

The adoption of a human rights approach to the aged care sector and the reforms will promote people-centred decision-making and real change in organisational culture.

The aged care reform package is capable of recognising and strengthening the human rights of older Australians. Essential elements of the approach can be easily incorporated into the plans for implementation of the reforms through consideration of the following:

- The incorporation of indicators to monitor the implementation of consumer directed care. These indicators will be essential to determine the accessibility and quality of these services and to ensure the rights of older recipients of these services are protected and their decisions respected.
- The implementation of advance care training programs that extend beyond general practitioners to include health workers in the acute care sector and in the aged care sector. This would facilitate a process of effective communication between the acute care sector and the aged care sector and promote respect for the end-of-life decisions of older Australians.
- The development of a national program for improvement of health literacy to promote the participation of older Australians in consumer directed care.
- The development of disaggregated indicators, at least on the grounds of sex, race, ethnicity, sexuality, socio-economic status, place of abode and urban/rural/remote location. These indicators will provide detailed information on the human rights issues of availability, accessibility and acceptability of

aged care services to the whole of the older Australian population as well as to the special needs groups.

- Improvement of the effectiveness of the *Broadband for Seniors Initiative* to ensure that older Australians are confident internet users and can effectively engage with the Telehealth program.
- The development of indicators related to the charters of rights contained in the *User Principles 1997 (Cth)*. These indicators should be included in the set of national quality indicators that will monitor the quality of aged care services.
- Human rights training for health workers to ensure they are culturally competent, respect difference and diversity in the older Australian population and understand and respect human rights.

We are at the very beginning of the implementation of the aged care reforms. It is a time that offers an opportunity not to be missed, that of ensuring the human rights of older Australians in receipt of aged care services are protected and their choices respected.

## Appendix A – A human rights approach guideline questionnaire

Human rights elements	Example questions
Non-discrimination and equality	<p>Do the aged care reforms enhance access to and provision of aged care services</p> <ul style="list-style-type: none"> <li>• without discrimination on any prohibited grounds?</li> <li>• by promoting equality for older people who are at greatest risk, including those with special needs and other marginalised older people such as prisoners?</li> </ul> <p>The prohibited grounds of discrimination are: race, colour and ethnicity, sex and gender, sexual orientation, health status, physical or mental disability, language, religion, political or other opinion, national or social origin, property, birth, civil, political, social or other status.</p> <p>The development of disaggregated monitoring indicators will be required to measure non-discrimination and equality.</p>
Availability	<p>Do the aged care reforms enhance or jeopardise the availability, throughout the country, of</p> <ul style="list-style-type: none"> <li>• a sufficient number of aged care services?</li> <li>• trained health professionals receiving domestically competitive salaries?</li> </ul>
Accessibility	<p>Do the aged care reforms enhance or jeopardise the accessibility of aged care services throughout the country</p> <ul style="list-style-type: none"> <li>• without discrimination on any prohibited grounds?</li> <li>• in terms of physical distance from services?</li> <li>• for people with physical, sensory or mental disabilities?</li> </ul>
Acceptability	<p>Do the aged care reforms enhance or jeopardise the acceptability of aged care services, specifically by respecting</p> <ul style="list-style-type: none"> <li>• the decisions of older people regarding their health care</li> </ul>

	<p>and their advance care plans?</p> <ul style="list-style-type: none"> <li>• the confidentiality of personal health information?</li> <li>• the cultures and special needs of individuals, minority groups and communities?</li> </ul>
Quality	<p>Do the aged care reforms enhance or jeopardise the quality of</p> <ul style="list-style-type: none"> <li>• skilled health professionals trained to meet the needs of aged care recipients?</li> <li>• programs for prevention and reablement and also palliative care?</li> <li>• the standard of care delivered in home and residential care settings?</li> </ul>
Progressive realisation	<p>Do the aged care reforms make deliberate steps to ensure progressive realisation of accessible, acceptable and quality aged care services for all older Australians by</p> <ul style="list-style-type: none"> <li>• recognising human rights as a crucial concern in policy-making?</li> <li>• the incorporation of disaggregated indicators and benchmarks to monitor implementation of the policy?</li> </ul>
Informative	<p>Do the aged care reforms enhance or jeopardise the availability and accessibility of health information, including information on aged care services, and issues and problems relevant to the older community, by</p> <ul style="list-style-type: none"> <li>• respecting the right to seek, receive and impart health-related information?</li> <li>• providing health information accessible to all, including in all relevant languages and alternative formats, such as in large print, Braille or audio recording?</li> <li>• collecting and distributing data on the provision and standard of aged care services?</li> </ul>
Participatory	<p>If the aged care reforms have any potential impact on the availability, accessibility, acceptability or quality of aged care</p>

	<p>services, did the federal government consult with a wide range of organisations and groups of people, including those older people and their carers who are most likely to be affected, in designing (and/or implementing) the policy by</p> <ul style="list-style-type: none"> <li>• informing all stakeholders that aged care reforms were being developed (and/or implemented)?</li> <li>• providing all stakeholders with information explaining the implementation plan and the forums for receiving their views?</li> <li>• respecting the rights of everyone to seek, impart and receive aged care services information?</li> <li>• providing opportunities to be heard and to influence decision-making?</li> <li>• engaging in transparent policy implementation processes that are accessible to all relevant individuals, groups, organisations?</li> </ul> <p>Do the aged care reforms enhance or jeopardise the participation of older people in decision-making related to aged care services and facilities by</p> <ul style="list-style-type: none"> <li>• improving access to information on proposals and decisions that may affect aged care services?</li> <li>• providing mechanisms to receive feedback on the impacts of the reform package?</li> <li>• providing for transparent monitoring?</li> <li>• providing information on the effects of the reform package to others, including non-governmental organisations and peak bodies, to ensure external monitoring?</li> <li>• providing opportunities for all stakeholders to participate in regular reviews of the reform package to ensure that adjustments, modifications or complete changes in the reforms are carried out where the evidence of the impacts justifies such action?</li> </ul>
Accountable	<p>Do the aged care reforms enhance or jeopardise the availability and accessibility of mechanisms of accountability for the progressive realisation of available, accessible, acceptable aged care services, which are of good quality by</p>

	<p>providing</p> <ul style="list-style-type: none"><li>• for transparent monitoring of the implementation of the reforms?</li><li>• quasi-judicial or administrative review of the implementation of the aged care reforms and/or the impact of the reforms?</li><li>• remedies if the implementation of the aged care reforms violate the human rights of recipients of aged care services?</li></ul>
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<sup>1</sup> Committee on Economic, Social and Cultural Rights, *General Comment No. 14: The right to the highest attainable standard of health*, UN Doc E/C.12/2000/4 (2000). At <http://www2.ohchr.org/english/bodies/cescr/comments.htm> (viewed 3 May 2012).

<sup>2</sup> Australian Bureau of Statistics, *Australian Social Trends*, Catalogue No 4102.0 (2011). At <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features10Mar+2011> (viewed 14 May 2012).

<sup>3</sup> Commonwealth of Australia, *Australia to 2050: Future Challenges*, The Treasury (2010), p 56. At <http://archive.treasury.gov.au/igr/igr2010/default.asp> (viewed 24 July 2012).

<sup>4</sup> Australian Bureau of Statistics, 'Population Projections, Australia, 2006 to 2101' (Media Release, 4 September 2008). At <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3222.0> (viewed 14 May 2012).

<sup>5</sup> *International Covenant on Economic, Social and Cultural Rights*, 1976, art 12. At <http://www2.ohchr.org/english/law/cescr.htm> (viewed 3 July 2012); Committee on Economic, Social and Cultural Rights, *General Comment No. 14: The right to the highest attainable standard of health*, UN Doc E/C.12/2000/4 (2000), paras 1 and 12. At <http://www2.ohchr.org/english/bodies/cescr/comments.htm> (viewed 4 July 2012); Committee on Economic, Social and Cultural Rights, *General Comment No. 6: The economic, social and cultural rights of older persons*, UN Doc E/1996/22 (1995), paras 10, 34 and 35. At <http://www2.ohchr.org/english/bodies/cescr/comments.htm> (viewed 21 June 2012).

<sup>6</sup> Equality and Human Rights Commission, *Close to Home: An Inquiry into Older People and Human Rights in Home Care* (2011), p 20. At <http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-into-home-care-of-older-people/close-to-home-report/> (viewed 24 July 2012).

<sup>7</sup> National Aged Care Alliance, *Leading the Way: Our Vision for Support and Care of Older Australians* (2009). At <http://www.naca.asn.au/publications.html> (viewed 28 June 2012).

<sup>8</sup> Joint Committee on Human Rights, *The Human Rights of Older People in Health Care, Eighth Report* (2008). At <http://www.publications.parliament.uk/pa/jt200607/jtselect/jtrights/156/15602.htm> (viewed 24 July 2012).

<sup>9</sup> World Health Organisation, *Active Ageing: A Policy Framework*, WHO/NMH/NPH/02.8 (2002), p 6. At <http://www.who.int/ageing/publications/active/en/> (viewed 21 June 2012).

<sup>10</sup> Australian Medical Association, *AMA Position Statement: Funding of Residential Aged Care – 2011* (2011), p 1. At <http://ama.com.au/node/7322> (viewed 24 July 2012).

<sup>11</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p 2. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 3 July 2012).

<sup>12</sup> Commonwealth of Australia, *Australia to 2050: Future Challenges*, The Treasury (2010), p 56. At <http://archive.treasury.gov.au/igr/igr2010/default.asp> (viewed 24 July 2012). The major aged care services funded by the Australian government are residential services, classified as high care (formerly nursing home care) or low care services (formerly hostel care); and community care

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services, which include Home and Community Care program services, the Community Aged Care Package program, the Extended Aged Care at Home program and Veterans' Home Care.

<sup>13</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011). At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012).

<sup>14</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011). At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012).

<sup>15</sup> Commonwealth of Australia, *Australia to 2050: Future Challenges*, The Treasury (2010), p 56. At <http://archive.treasury.gov.au/igr/igr2010/default.asp> (viewed 24 July 2012).

<sup>16</sup> Commonwealth of Australia, *Australia to 2050: Future Challenges*, The Treasury (2010), p 57. At <http://archive.treasury.gov.au/igr/igr2010/default.asp> (viewed 24 July 2012).

<sup>17</sup> Commonwealth of Australia, *Australia to 2050: Future Challenges*, The Treasury (2010), p 51. At <http://archive.treasury.gov.au/igr/igr2010/default.asp> (viewed 24 July 2012).

<sup>18</sup> Commonwealth of Australia, *Australia to 2050: Future Challenges*, The Treasury (2010), p 51. At <http://archive.treasury.gov.au/igr/igr2010/default.asp> (viewed 24 July 2012).

<sup>19</sup> Australian Bureau of Statistics, *Age Matters: Latest Findings*, Catalogue No 4914.0.55.001 (2011). At <http://www.abs.gov.au/ausstats/abs@.nsf/7d12b0f6763c78caca257061001cc588/ea6bbe44feac7fe2ca2572a400109d19!OpenDocument> (viewed 24 July 2012).

<sup>20</sup> S Lunn, 'Older Australians keen to age at home', *The Australian*, 25 February 2011. At <http://www.theaustralian.com.au/news/nation/older-australians-keen-to-age-at-home/story-e6frg6nf-1226011617585> (viewed 24 July 2012).

<sup>21</sup> National Aged Care Alliance, *Aged Care Reform Information Sheet: Dementia and Aged Care Reform* (2011). At [http://www.naca.asn.au/Age\\_Well.html](http://www.naca.asn.au/Age_Well.html) (viewed 24 July 2012).

<sup>22</sup> Australian Institute of Health and Welfare, *Dementia among aged care residents: first information from the Aged Care Funding Instrument*, Aged care statistics series No. 32, Catalogue No. AGE 63 (2011). At <http://www.aihw.gov.au/publication-detail/?id=10737419025> (viewed 24 July 2012).

<sup>23</sup> National Aged Care Alliance, *Aged Care Reform Information Sheet: Dementia and Aged Care Reform* (2011). At [http://www.naca.asn.au/Age\\_Well.html](http://www.naca.asn.au/Age_Well.html) (viewed 24 July 2012).

<sup>24</sup> Deloitte Access Economics, *Dementia Across Australia 2011–2050*, Report prepared for Alzheimer's Australia (2011), p 15. At <http://www.fightdementia.org.au/research-publications/access-economics-reports.aspx> (viewed 18 July 2012).

<sup>25</sup> T Drabsch, *Preparing for the Impact of Dementia*, NSW Parliamentary Library Research Services, Briefing Paper No. 4/06 (2006), p 7. At <http://www.parliament.nsw.gov.au/prod/parlment/publications.nsf/key/Preparingfortheimpactofdementia> (viewed 18 July 2012).

<sup>26</sup> Council of Australian Governments, *National Health Reform Agreement* (2011). At [http://www.coag.gov.au/docs/national\\_health\\_reform\\_agreement.pdf](http://www.coag.gov.au/docs/national_health_reform_agreement.pdf) (viewed 13 May 2012).

<sup>27</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p xix. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 3 May 2012).

<sup>28</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p xxii. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 3 May 2012).

<sup>29</sup> Commonwealth of Australia, *Living Longer. Living Better: Aged Care Reform Package*, Department of Health and Ageing (2012). At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 3 May 2012).

<sup>30</sup> Commonwealth of Australia, *Living Longer. Living Better: Aged Care Reform Package*, Department of Health and Ageing (2012). At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 3 May 2012).

<sup>31</sup> World Health Organisation, *Constitution of the World Health Organisation* (1946), Preamble. At <http://www.who.int/governance/eb/constitution/en/> (viewed 4 July 2012); *International Convention on the Elimination of All Forms of Racial Discrimination*, opened for signature 21 December 1965, 660 UNTS 195 (entered into force 4 January 1969); *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January

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1976); *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976); *Convention on the Elimination of All Forms of Discrimination against Women*, opened for signature 18 December 1979, 1249 UNTS 13 (entered into force 3 August 1981); *Convention on the Rights of Persons with Disabilities*, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008). See also the *United Nations Declaration on the Rights of Indigenous Peoples*, GA Resolution 61/295, UN Doc A/61/L.67 (2007).

<sup>32</sup> Second World Assembly on Ageing 2002, *Political Declaration and Madrid International Plan of Action on Ageing* (2002). At <http://social.un.org/index/Ageing/Resources/MadridInternationalPlanofActiononAgeing.aspx> (viewed 4 July 2012).

<sup>33</sup> *Age Discrimination Act 2004* (Cth), s 3(e).

<sup>34</sup> *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976); *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976); *International Convention on the Elimination of All Forms of Racial Discrimination*, opened for signature 21 December 1965, 660 UNTS 195 (entered into force 4 January 1969); *Convention on the Elimination of All Forms of Discrimination against Women*, opened for signature 18 December 1979, 1249 UNTS 13 (entered into force 3 August 1981); *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, opened for signature 10 December 1984, 1465 UNTS 85 (entered into force 26 June 1987); *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990); *Convention on the Rights of Persons with Disabilities*, opened for signature 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008).

<sup>35</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p 15. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 3 May 2012).

<sup>36</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p 16. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 3 May 2012).

<sup>37</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011). At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012).

<sup>38</sup> The Office of the Age Commissioner, *The Office of the Age Commissioner: Introduction*. At <http://www.agedcarecommissioner.net.au/introduction.php> (viewed 4 July 2012).

<sup>39</sup> These organisations include: National Seniors Australia, Leading Age Services Australia, Australian Medical Association and the National Aged Care Alliance. The latter is an informal coalition of leading consumer, provider and professional associations and unions involved in the provision of care and support for older people and is comprised of the following: Aged and Community Services Australia, Aged Care Association Australia, Alzheimer's Australia, Anglicare Australia, Association of Independent Retirees Limited, Attendant Care Industry Association, Australian Association of Gerontology, Australian General Practice Network, Australian Healthcare and Hospitals Association, Australian Nursing Federation, Australian Physiotherapy Association, Australian and New Zealand Society for Geriatric Medicine, Baptist Care Australia, Carers' Australia, Catholic Health Australia, COTA Australia, Diversional Therapy Association of Australia, Health Services Union, Legacy Australia, Lutheran Aged Care Australia, Macular Degeneration Foundation, National Presbyterian Aged Care Network, National Stroke Foundation, Occupational Therapy Australia, Palliative Care Australia, Pharmacy Guild of Australia, Returned & Services League of Australia, Royal College of Nursing Australia, United Voice and UnitingCare Australia.

<sup>40</sup> Australian Human Rights Commission, *Social Justice Report 2005*, Aboriginal and Torres Strait Islander Social Justice Unit (2005). At [http://www.humanrights.gov.au/social\\_justice/sj\\_report/sjreport05/index.html](http://www.humanrights.gov.au/social_justice/sj_report/sjreport05/index.html) (viewed 17 May 2012); Australian Human Rights Commission, *Aboriginal and Torres Strait Islander Peoples Engagement Toolkit 2012*, Social Justice Unit (2012). At <http://www.humanrights.gov.au/about/rap.html> (viewed 4 July 2012); Victorian Equal Opportunity and Human Rights Commission, *From Principle to Practice: Implementing the Human Rights Based Approach in Community Organisations* (2008). At [http://www.humanrightscommission.vic.gov.au/index.php?option=com\\_k2&view=item&id=1268:from-principle-to-practice-implementing-the-human-rights-based-approach-in-community-organisations-sep-](http://www.humanrightscommission.vic.gov.au/index.php?option=com_k2&view=item&id=1268:from-principle-to-practice-implementing-the-human-rights-based-approach-in-community-organisations-sep-)



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<sup>41</sup> Equality and Human Rights Commission, *Close to Home: An Inquiry into Older People and Human Rights in Home Care* (2011), p 20. At <http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-into-home-care-of-older-people/close-to-home-report/> (viewed 24 July 2012).

<sup>42</sup> Committee on Economic, Social and Cultural Rights, *General Comment No. 14: The right to the highest attainable standard of health*, UN Doc E/C.12/2000/4 (2000). At <http://www2.ohchr.org/english/bodies/cescr/comments.htm> (viewed 3 May 2012).

<sup>43</sup> A Grover, *Thematic study on the realization of the right to health of older persons*, Report by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health to the General Assembly of the Human Rights Council Eighteenth session, UN Doc A/HRC/18/37 (2011). At <http://www.ohchr.org/EN/Issues/Health/Pages/AnnualReports.aspx> (viewed 3 May 2012).

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- <sup>126</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011). At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012). A care leaver is a person who was in institutional care or other form of out-of-home care, including foster care, as a child or youth (or both) at some time during the 20th century. This includes the Forgotten Australians and former child migrants.
- <sup>127</sup> For the purposes of this paper, 'substance misuse' includes prescription medications, over the counter medications, illicit drugs, alcohol and tobacco.
- <sup>128</sup> A Roxburgh, R Bruno, B Larance and L Burns, 'Prescription of Opioid Analgesics and Related Harms in Australia' (2011) 195(5) *Medical Journal of Australia* 280, 283. At <https://www.mja.com.au/journal/2011/195/5/prescription-opioid-analgesics-and-related-harms-australia> (viewed 21 June 2012).
- <sup>129</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p 188. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 3 May 2012).
- <sup>130</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p 128. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 28 June 2012).
- <sup>131</sup> C Rigby, *Our Rights Our Future: Towards a Rights-Based Framework for Older People* (Speech delivered at the NSW COTA Forum, Sydney, 21 March 2012).
- <sup>132</sup> Commonwealth of Australia, *Living Longer. Living Better: Aged Care Reform Package*, Department of Health and Ageing (2012), p 86. At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 8 May 2012).
- <sup>133</sup> Commonwealth of Australia, *Living Longer. Living Better: Aged Care Reform Package*, Department of Health and Ageing (2012), p 86. At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 8 May 2012).

<sup>134</sup> Commonwealth of Australia, *Australia's Health Workforce*, Productivity Commission Report (2005), pp xxvi–xxvii. At <http://www.pc.gov.au/projects/study/health-workforce/docs/finalreport> (viewed 20 May 2012).

<sup>135</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p 177. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 28 June 2012).

<sup>136</sup> Commonwealth of Australia, *Caring for Older Australians*, Report No. 53, Productivity Commission (2011), p 185. At <http://www.pc.gov.au/projects/inquiry/aged-care/report> (viewed 28 June 2012).

<sup>137</sup> Minister for Health and Minister for Broadband, Communications and the Digital Economy, 'Invitation to Apply for NBN-Enabled Telehealth Programs' (Media Release, 4 April 2012). At <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/mr-yr12-tp-tp033.htm> (viewed 24 July 2012).

<sup>138</sup> Australian Bureau of Statistics, *Patterns of Internet Access in Australia 2006*, Catalogue No. 8146.0.55.001 (2007). At <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/8146.0.55.0012006?OpenDocument> (viewed 24 July 2012).

<sup>139</sup> Commonwealth of Australia, *Australia in the Digital Economy: Report 1 Trust and Confidence*, Australian Communications and Media Authority (2009), p 11. At [http://www.acma.gov.au/WEB/STANDARD/pc=PC\\_311655](http://www.acma.gov.au/WEB/STANDARD/pc=PC_311655) (viewed 24 July 2012).

<sup>140</sup> S Ross and RG Smith, 'Risk Factors for Advance Fee Fraud Victimization' (2011) *Trends & issues in crime and criminal justice*, No. 420. At <http://www.aic.gov.au/publications/current%20series/tandi/401-420/tandi420.aspx> (viewed 24 July 2012).

<sup>141</sup> See generally, Australian Human Rights Commission, *Inquiry into Cybersafety for Senior Australians: Submission to the Joint Select Committee on Cybersafety* (2012). At [http://www.humanrights.gov.au/legal/submissions/2012/20120101\\_cybersafetySenior.html](http://www.humanrights.gov.au/legal/submissions/2012/20120101_cybersafetySenior.html) (viewed 20 May 2012).

<sup>142</sup> I Yates, *National Press Club Address – The Aged Care Time Bomb is Ticking* (April 2012), p 4. At [http://www.naca.asn.au/Age\\_Well.html](http://www.naca.asn.au/Age_Well.html) (viewed 24 July 2012).

<sup>143</sup> H Potts, *Accountability and the Right to the Highest Attainable Standard of Health*, Human Rights Centre (2008), p 29. At [http://www.essex.ac.uk/human\\_rights\\_centre/research/rth/projects.aspx](http://www.essex.ac.uk/human_rights_centre/research/rth/projects.aspx) (viewed 18 May 2012).

<sup>144</sup> *Accreditation Grant Principles (2011)* made under subsection 96-1(1) of the *Aged Care Act 1997* (Cth).

<sup>145</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011), p 78. At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012).

<sup>146</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011), p 88. At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012).

<sup>147</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011), p 89. At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012).

<sup>148</sup> Department of Health and Ageing, *Aged Care Legislation*. At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-legislat-aca1997-prindex.htm-copy2> (viewed 25 July 2012).

<sup>149</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011), p 88. At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012).

<sup>150</sup> Commonwealth of Australia, *2010–11 Report on the Operation of the Aged Care Act 1997*, Department of Health and Ageing (2011), p 97. At <http://www.health.gov.au/internet/main/publishing.nsf/content/ageing-reports-acarep.htm> (viewed 13 May 2012).

<sup>151</sup> Commonwealth of Australia, *Living Longer. Living Better: Aged Care Reform Package*, Department of Health and Ageing (2012), p 4. At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 8 May 2012).

<sup>152</sup> Commonwealth of Australia, *Living Longer. Living Better: Aged Care Reform Package*, Department of Health and Ageing (2012), p 4. At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 8 May 2012).

<sup>153</sup> Commonwealth of Australia, *Living Longer. Living Better: Aged Care Reform Package*, Department of Health and Ageing (2012), p 87. At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 8 May 2012).

<sup>154</sup> Commonwealth of Australia, *Australian Government Response: Productivity Commission's Caring for Older Australians Report*, Department of Health and Ageing (2012), p 34. At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 24 July 2012).

<sup>155</sup> *User Rights Principles 1997* (Cth).

<sup>156</sup> World Health Organisation, *Everybody's Business: Strengthening Health Systems to Improve Health Outcomes: WHO's Framework for Action* (2007), p v. At <http://www.who.int/healthsystems/strategy/en/> (viewed 17 May 2012). The six health system building blocks are: health services; health workforce; health information system; medical products, vaccines and technologies; health financing; leadership, governance, stewardship.

<sup>157</sup> World Health Organisation, *Everybody's Business: Strengthening Health Systems to Improve Health Outcomes: WHO's Framework for Action* (2007), p v. At <http://www.who.int/healthsystems/strategy/en/> (viewed 17 May 2012).

<sup>158</sup> World Health Organisation, *Everybody's Business: Strengthening Health Systems to Improve Health Outcomes: WHO's Framework for Action* (2007), p 3. At <http://www.who.int/healthsystems/strategy/en/> (viewed 17 May 2012).

<sup>159</sup> P Hunt and G Backman, 'Health Systems and the Right to the Highest Attainable Standard of Health' (2008) 10(1) *Health and Human Rights* 81. At <http://www.hhrjournal.org/index.php/hhr/issue/view/1> (viewed 4 July 2012).

<sup>160</sup> Lee Thomas, *National Press Club Address – The Aged Care Time Bomb is Ticking* (April 2012), p 8. At [http://www.naca.asn.au/Age\\_Well.html](http://www.naca.asn.au/Age_Well.html) (viewed 24 July 2012).

<sup>161</sup> Commonwealth of Australia, *Living Longer. Living Better: Aged Care Reform Package*, Department of Health and Ageing (2012). At <http://www.health.gov.au/internet/main/publishing.nsf/Content/aged-aged-care-review-measures-techdoc> (viewed 16 July 2012). These workers include health and other professionals, personal carers, community care workers, registered nurses, enrolled nurses, allied health professionals and support staff such as cooks, gardeners, cleaners and drivers.

<sup>162</sup> L Amis, P Brew and C Ersmarker, 'Human Rights: It Is Your Business. The Case for Corporate Engagement' (2005) *International Business Leaders Forum*, pp 4–8. At [http://www.iblf.org/programmes/Business-standards/Human\\_rights\\_2011/Human\\_rights\\_decade.aspx](http://www.iblf.org/programmes/Business-standards/Human_rights_2011/Human_rights_decade.aspx) (viewed 16 July 2012).

<sup>163</sup> BUPA Viewpoint, *Championing the Older Worker* (April 2012). At <http://www.bupaagedcare.com.au/our-approach/Bupa's-viewpoint> (viewed 31 July 2012).