

---

## 4 A framework for assessing aged care

### Key points

- A wellbeing framework for assessing policy options is required to guide the development of future aged care policy.
- There are strong rationales for government involvement in aged care, including the pursuit of equity of access to care and correcting market failures (information gaps and the protection of vulnerable consumers).
- The ultimate objective of policy is to improve the wellbeing of the community overall. As such, the benefits from reform must outweigh the costs to the community.
- To guide future policy change, the system of aged care and support should aim to:
  - promote the independence and wellness of older Australians and their continuing contribution to society
  - ensure that all older Australians needing care and support have access to person-centred services that can change as their needs change
  - be consumer-directed, allowing older Australians to have choice and control over their lives and to die well
  - treat older Australians receiving care and support with dignity and respect
  - be easy to navigate, with older Australians knowing what care and support is available and how to access those services
  - assist informal carers to perform their caring role
  - be affordable for those requiring care and for society more generally
  - provide incentives to ensure the efficient use of resources devoted to caring for older Australians and broadly equitable contributions between generations.
- Based on a wellbeing framework and the governments stated objectives, the system for care and support for older Australians should be assessed against the criteria of equity, efficiency, effectiveness (choice, quality, appropriateness) and sustainability.

While many participants to this inquiry acknowledged that reforms over the last decade or so had improved access to care and the range and quality of care, they were also of the view that, in light of future challenges, ‘fundamental’ reform was required. For example, the Victorian Government said:

The scale of forecast requirements for aged care services demands fundamental changes in both the underpinning economics of the sector and how the system itself is planned and developed to stimulate the necessary capital investment. ... Services need

---

to be planned, allocated, funded and managed around optimising the experience for the client. This will require fundamental changes to many aspects of the service system to put older Australians at the centre and make them active participants in both decisions about and delivery of services. (sub. 420, p. 5)

The National Aged Care Alliance (NACA) maintained that:

... it is now time for action to substantially change the system and take ... reforms to the next level. (sub. 88, p. 3)

And Anglicare Australia said:

There is a need for systemic change which gives stronger influence and participation in aged care service delivery to service users. (sub. 461, p. 1)

This chapter looks firstly at participants' visions for future care and support for older Australians (section 4.1). It then looks at the reasons why governments are involved in aged care and the steps to securing good policy (section 4.2). Section 4.3 provides a framework for informing aged care policy. Section 4.4 sets out criteria for assessing the performance of the aged care system.

## **4.1 A new vision for care and support**

A number of participants presented their visions of what they thought a future system of care and support for older Australians should look like. In the main, the impetus for change was based on the view that the current system was not sufficiently person-centred, nor consumer directed, as 'choice' for older Australians receiving care was limited. Also, the system was considered poorly placed to respond to future challenges — including the increasing number of older people with diverse needs and the rising expectations about how care should be delivered. A number of participants' 'visions' are presented in box 4.1.

The vision and principles put forward in *Leading the Way: Our Vision for Support and Care of Older Australians*, developed by the National Aged Care Alliance (NACA 2009) (a coalition of consumer, provider, professional associations and unions involved in the provision of care and support for older people) received wide support. NACA's vision is that:

Every older Australian is able to live with dignity and independence in a place of their choosing with a choice of appropriate and affordable support and care services as and when they need them. (sub. 88, p. 4)

---

### Box 4.1 Participants' visions for future aged care and support

The National Aged Care Alliance's (NACA's) underpinning principles for older Australians requiring support and care are that they:

- will have access to services in their own communities and homes that:
  - are readily available, affordable and client-directed
  - promote wellness and wellbeing, and assist them to realise their aspirations
  - provide genuine choice to meet the aspirations, needs and preferences of a diverse older population
- are underpinned by a commitment to quality improvement, evaluation and ongoing research
- be the principal decision makers about when they may need assistance and the nature of the assistance
- have access to affordable, effective, and safe health and medical care
- have easy access to reliable and relevant information about the availability, quality and cost of aged care services. (sub. 88, p. 5)

#### Medibank:

Medibank has a vision for how aged care and supports which assist people to live independently will be delivered in the future. This vision encompasses a future where a seamless continuum of supports incorporating preventative activity, healthcare, community based services, aged care and other supports are delivered in the right setting at the right time. (sub. 250, p. 3)

#### Aged and Community Services Australia (ACSA):

Aged care services will support older people to have a good old age — to live satisfying, self-directed lives to the maximum extent of their capacity. This aim should be the driving force for any changes to the aged care system. To achieve this aim the aged care service system of the future must deliver older people more **choice** of, and better **access** to, financially **sustainable** aged care services. (sub. 181, p. 17)

#### Uniting Care Australia:

Imagine ... an Australian community where older people are valued and included in community life, enabled to maintain health & independence, are able to contribute their talents and wisdom, pursue their interests, nurture relationships, maintain their culture and spirituality and be in control of their future. Imagine if those who need support can receive it in a way that supports the above, and is provided with dignity and respect. (sub. 406, p. 8)

The Older People's Reference Group (sub. 25) said any reforms to the aged care system should embody the following principles and values: autonomy and choice; social inclusion and community participation, quality, equity and affordability; the crucial role of carers; information and access.

---

The underpinning principles of NACA’s vision include access, affordability, promotion of wellness and wellbeing, choice and access to health services and information.

The Victorian Government’s vision for the future system spoke about having ‘fun and enjoying life’, being able to make choices, take risks and feel safe:

Older Australians can: make their own choices and decisions; are valued and respected; can take risks; connect with family, friends and others; are involved in the community; feel safe and comfortable; are active; get their health and care needs met; have fun and enjoy life. (sub. 420, p. 6)

The New South Wales Government considered that a reformed system should promote ‘wellbeing’, prevention and early intervention and give stronger recognition to the role of carers:

Any reform of the aged care system should be aimed at achieving better linkages and smoother transitions between services as and when needed by older people. It will also need to: promote well-being, including independence, through a person-centred, enabling approach; increasingly emphasise prevention and early intervention; give stronger recognition to the role and importance of carers; and provide holistic and seamless continuity of care across health and aged care service sectors. (sub. 329, p. 3)

While the visions presented by participants varied, they also had common themes, including the importance of focussing on wellbeing and promoting wellness, independence and choice. System oriented themes included the provision of easily understood information, a more continuous person-centred range of services and smoother transitions between aged care, and health and housing services. Carer support was also an important theme.

## **4.2 Caring for older Australians — what role for government?**

An important first step in considering a new system of care and support for older Australians, and the policy changes it would require, is to revisit the rationales for government involvement in aged care.

Governments are currently involved in almost every aspect of caring for and supporting older Australians. They organise and subsidise care and support services, support aged care infrastructure and provide assistance to carers of older people. Governments regulate the supply and distribution of funded care places and the prices that aged care providers can charge their clients. The Australian Government also regulates the quality of aged care through quality assurance and consumer

---

protection arrangements, including the accreditation of aged care homes, building certification requirements, a Complaints Investigation Scheme (CIS), an Aged Care Commissioner and prudential regulation covering accommodation bonds (chapter 10 and 15).

The pursuit of equity is a key reason for government involvement in aged care. It seeks to ensure that all older Australians have access to affordable support and care at a standard that is in line with community expectations. National Seniors Australia (NSA) quoted the Special Secretary of Human Rights for Brazil as saying:

A country that does not look after its older people does not have a soul. (sub. 411, p. 8)

Addressing failures of the aged care market is a further reason for government involvement. There are a number of areas where the market for aged care lacks features of an ideal market:

- People or families seeking aged care services may not have the information or expertise to accurately judge the quality of aged care (particularly clinical quality). They may use unreliable indicators to assess quality (such as the appearance of the facilities), where what may matter more is the experience, attitude and attention of staff and the time they take in providing care services. People may make choices based on inadequate information about preventative or early intervention measures.
- Often decisions about aged care are made at short notice during times of emotional or acute medical crisis. This can limit the scope for individuals and their families to be fully informed about their options and can also mean that there are a limited number of options available. As such, providers may have less incentive to compete on quality (especially if it is difficult to move between providers).
- Aged care is not a service people normally want to buy; rather they do so because of need, and often in response to circumstances beyond their control. In the absence of government support, a proportion of older Australians may not be able to access services which are important to their health and wellbeing because they cannot afford them.
- The level of demand for aged care services varies across locations and the cost of providing care differs with scale and with location. As such, if left to the market, services may not be provided in some areas, such as rural, remote or low income locations or to groups who have special needs.
- Elderly and frail people may be vulnerable to exploitation and need protection. For example, they may not be able to judge quality for themselves due to cognitive impairment or be able to communicate their wishes to their representatives, or have family or friends who are able to look after their

---

interests. Poor quality aged care can mean reduced quality of life, physical or mental harm or even premature death for older people and can also impose substantial costs of others.

Government intervention may also be required to correct failures arising from existing government policies. By way of example, the current supply constraints on the number of bed licences and community care packages reduces incentives for providers to compete on price and quality. Where public subsidies are provided to defray the costs of providing aged care services, further government intervention to promote accountability, ensure quality outcomes and contain expenditure (lessen fiscal risk) is warranted.

### **But ‘when’ should policies be implemented or reformed?**

An in-principle rationale for government intervention does not of itself justify a policy response. Because interventions have costs, it is necessary to demonstrate that the benefits to the community from a new policy, program or regulation outweigh the costs of the intervention. There are a number of key steps in ensuring good policy outcomes. As a general rule, policies should:

- address problems that are large enough to justify government action and are amenable to such action
- have clear objectives, to underpin the development of targeted policies and to reduce the risk of unintended consequences
- reflect assessment of the likely effectiveness of different policy options, including the likely costs and benefits for the community as a whole (taking into account economic, social and environmental impacts)
- enable consumers, industry and the community to give their views about policy development and the performance of existing policies — supported by transparent decision making (and public availability of data) — to facilitate effective design, implementation, monitoring and modification of policy over time.

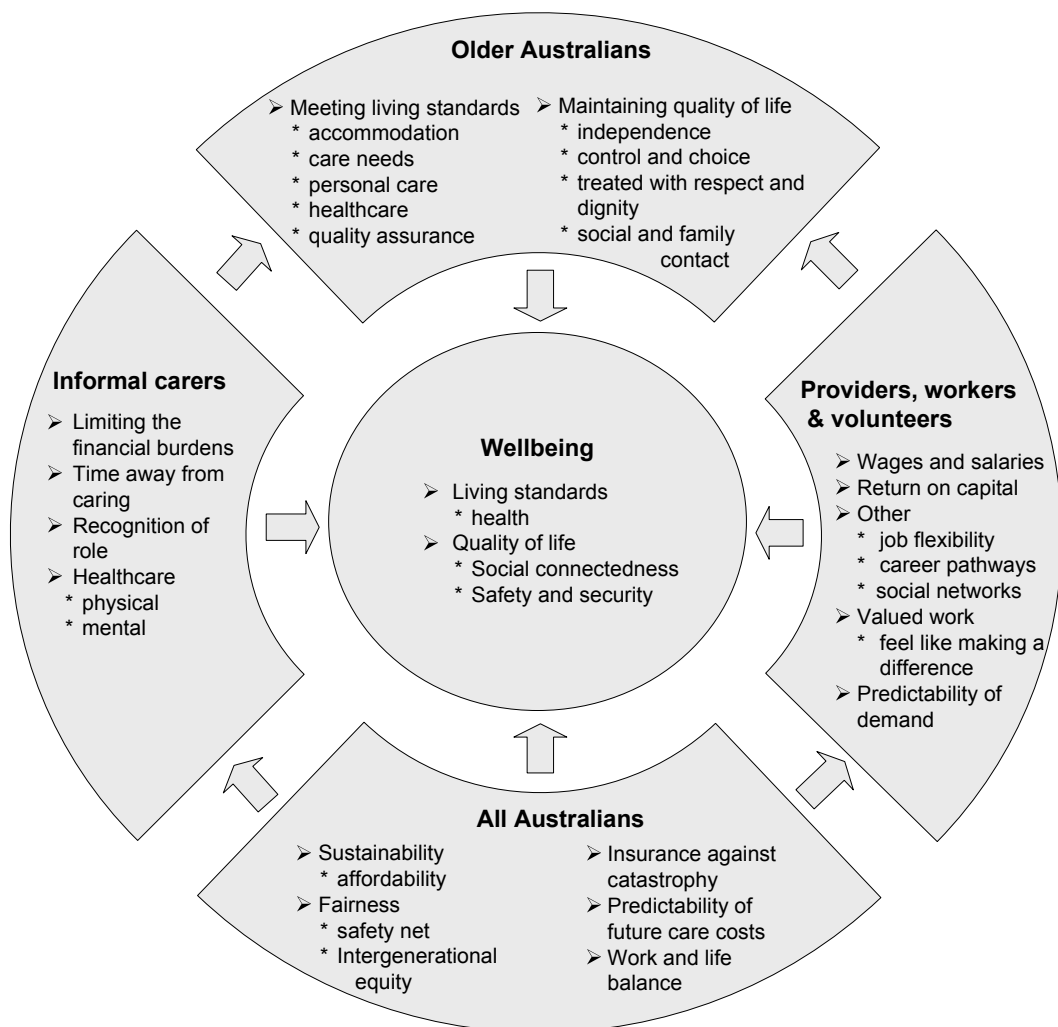
## **4.3 ‘Wellbeing’ of the community — the key objective**

The ultimate objective of any government policy should be to enhance the ‘wellbeing’ of the community overall. The Australian Bureau of Statistics (ABS) suggests that wellbeing relates to ‘the desire for optimal health, for better living conditions and improved quality of life’ (2001, p. 3).

Wellbeing, or quality of life, is a multi-dimensional concept incorporating physical and emotional needs, connectedness to others, the ability to exert influence over one's environment and safety from harm (figure 4.1). The World Health Organization (WHO) defines quality of life as:

... an individual's perception of his or her position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way a person's physical health, psychological state, level of dependence, social relationships, personal beliefs and relationship to salient features in the environment. (1994, p. 43)

**Figure 4.1 Factors influencing wellbeing in the context of aged care**



The domains of wellbeing are 'person-centric', reflecting the view that at a community level wellbeing is a collective of individual wellbeing. At the broadest level, the social, material and natural environments surrounding individuals become part of the wellbeing equation (ABS 2001). The Benevolent Society put to the

---

Commission a broad wellbeing framework comprising several domains under three broad categories — physical, mental/emotional and social (sub. 252).

Measuring wellbeing, however, is not easy because it involves making value judgements about what aspects of life are important to an individual's wellbeing (knowing that people value outcomes differently) and what matters to society. As the Australian Treasury said:

... each person will have their own interpretation of what is specifically important with respect to their own wellbeing, the wellbeing of others, and the weight that they place on each dimension of wellbeing. (Treasury 2004, p. 2)

One approach to measuring wellbeing is to use an individual's assessment of how happy or satisfied they are with particular aspects of their lives. While the results can be aggregated to get a community view about life satisfaction, the scope to use such measures to guide policy is debateable.

The Australian Unity Wellbeing Index, a measure of subjective wellbeing and of national and personal satisfaction with life, finds that some of the happiest Australians are those aged 65 years and over with an annual household income of more than \$60 000. Although older Australians have lower satisfaction with their health (which declines as aged related ailments set in), positive personal relationships with others are found to offset this (Australian Unity Wellbeing Index, sub. DR626)

In the context of aged care policy, while the focus is on supporting the highest possible quality of life for older Australians unable to care for themselves, the wellbeing of family members, friends and neighbours providing care to older people (they provide most of the care), and people providing formal care (owners of services, workers and volunteers) is also important and should be considered. The impact of policies on the broader community, including current and future taxpayers who can be asked to pay for care subsidies, should also be taken into account (figure 4.1).

## **The wellbeing of older Australians needing care**

The focus of the United Nations Principles for Older Persons is:

To add life to the years that have been added to life. (United Nations 1991)

The WHO also states that the goal of long term care should be about maintaining the best quality of life:

... to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of

---

independence, autonomy, participation, personal fulfilment, and human dignity. Appropriate long-term care therefore includes respect for that individual's values, preferences, and needs; it may be home-based or institutional. (2000, p. 1)

Participants also suggested that enhancing wellbeing or 'quality of life' should be the goal of providing care and support for older Australians. National Seniors Australia (NSA) said:

... quality of life should be a fundamental goal of the aged care system. At present, however, the aged care system is more heavily focused on technical constraints, such as risk management, economic imperatives, and rigid timetabling. (sub. 411, p. 9)

Anglicare Australia said:

In caring for older people services have to take into account the needs of the whole person, physical, emotional, psychological, social and spiritual. (sub. 461, p. 16)

Access to services that provide the required level of support for maintaining health, personal hygiene, physical safety and pain management forms the first level of support and care that promotes the wellbeing of older Australians. ('Health', in this context refers to physical, mental and social wellbeing, as defined by the WHO.)

The Commission repeatedly heard from older Australians that they wanted to be confident that appropriate and affordable care would be available if or when it was required. NSA said:

The ability to access aged care services, from home assistance through to residential care, is an *essential* service to protect older Australians when they become more vulnerable. (sub. 411, p. 4)

To achieve this, services should be person-centred. They should be available and accessible when and where they are needed, tailored to the person's own needs, changed as required, and not be limited as a result of inability to pay. This points to the importance of continuous and seamless care and effective interactions with the health care system.

Participants also noted the importance of having a system that is easy for older Australians and their families to navigate. For example, the Victorian Government claimed:

Into the future, services and support should be organised and delivered in ways that ensure that older people can easily find the *right types* of aged care services in the *right settings* when they need them. ... We need to make it as simple as possible for older Australians to receive the supports they need as their requirements change over time, recognising that in many instances, the relationships they have with both their communities and their current service providers are critical to positive health outcomes and need to be maintained. (sub. 420, p. 5)

---

*The aged care system should seek to ensure that all older Australians needing care and support have timely access to appropriate person-centred services that can change as their needs change.*

*The aged care system needs to be easy to navigate. Australians need to know what to expect from the system in terms of accessing care and support and their responsibilities (including what they are required to contribute).*

### **Older people requiring care are not all the same**

While the process of ageing is continuous from birth to death, it varies considerably from one person to another. As the Department of Health and Ageing (DoHA) said:

Ageing affects every person throughout their lifespan at different rates and in different ways as unique individuals. It is inescapable, normal and not necessarily an indication of frailty. (sub. 482, p. 7)

Some of the factors influencing the way that people age include genetics, gender (women, on average, live longer than men, but tend to experience more disabling diseases as they grow older), ethnic and cultural backgrounds, health/disease experience throughout life, lifestyle choices and general life experiences and exposures (WHO 1999).

A life course perspective on ageing shows that individual diversity increases with age (figure 4.2). That is, the range of function of two 80 year-olds is likely to be less similar than those of two 10 year-olds.

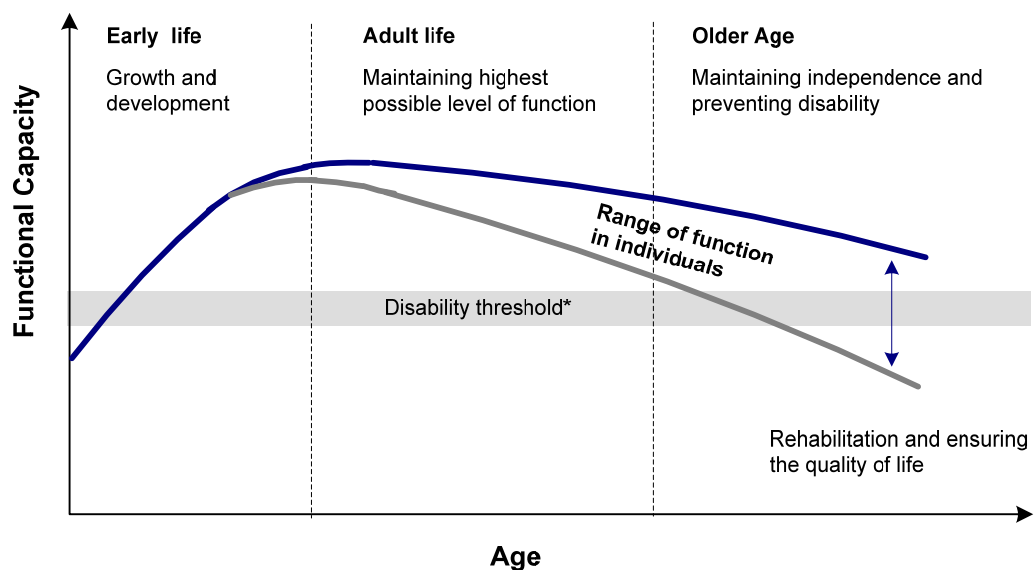
Because people age in unique ways, the needs of older people will vary markedly, depending on functional capacity, physical and mental health, culture and language and the built environment in which they live. Support and care should, therefore be flexible enough to recognise diverse needs and be able to adapt the services provided accordingly. This points to the importance of a person-centred (rather than program-centred) approach to providing care and support. As Banksia Villages said:

Ageing is an incremental, highly variable and unique process that requires a response that is incremental, flexible and accessible. (sub. 467, p. 1)

NSA argued that an aged care system:

... should not just 'facilitate access to care' or 'guarantee an acceptable or even a minimum standard of care', rather it should customise care and meet individual care needs as identified in a personal care assessment. (sub. 411, p. 7)

Figure 4.2 Maintaining functional capacity over the life course<sup>a</sup>



<sup>a</sup> Changes in the environment can lower the disability threshold, thus decreasing the number of people with a disability in a given community. Functional capacity (such as ventilatory capacity, muscular strength, and cardiovascular output) increases in childhood and peaks in early adulthood, eventually followed by a decline. The rate of decline, however, is largely determined by factors related to adult lifestyle — such as smoking, alcohol consumption, levels of physical activity and diet — as well as external and environmental factors. The gradient of decline may become so steep as to result in premature disability. However, the acceleration in decline can be influenced and may be reversible at any age through individual and public policy measures.

Source: Kalache and Kickbursch 1997, in WHO (2002).

Anglicare Australia also said:

Older people do not want to be made to fit into programs. Not surprisingly, they would like the care designed to suit their needs. By necessity then, older Australians and the families need to be partners in the design and management of the care they receive. In terms of people's wellbeing, this is where the notion of choice is most useful. (sub. 461, p. 3)

Sensitivity to specific cultural requirements is also important for wellbeing. As a participant to the Ministerial Advisory Council of Senior Victorians said:

(We are) the same as other sections of the community — we are still diverse — only older. Give us choices! (Written input, 2008, p. 13)

Culturally appropriate care is particularly important for people with dementia because the language most recently acquired is lost first (Access Economics 2009b). Indeed, some people in their final years find comfort in revisiting earlier customs, languages and other meaningful symbols of their life. Even small differences, such as food preferences and recognising special days and/or events, can make a difference to someone's wellbeing. In this context, Pratt said:

---

One of the more visible differences among cultures is the type of food preferred. Being able to eat the foods we like plays an important part in how we define the quality of our lives. Yet, until recently, most nursing facilities paid little attention to satisfying the seemingly exotic culinary wishes of their residents, ignoring their importance. (2010, p. 39)

### *The importance of independence and being a contributor to society*

A very strong message coming from older Australians participating in this inquiry was that they wanted ‘support’ in older age to be able to manage their own lives and to remain independent (to the extent that is possible). The then Minister for Ageing stated:

I have the opportunity to speak with older Australians on a regular basis and their resounding message is that they want to live with maximum independence and maximum dignity. They want to remain active in their communities and close to their families, friends and neighbours. (DoHA 2009e, p. iii)

Recent focus group research also showed that older people living in Victoria had a strong desire to remain independent as they age (Victorian Government, sub. 420).

Beresford, commenting on the concept of ‘care’ in a policy sense, said:

Many see care as inextricably associated with dependence, control and inequality. Few of us want to see ourselves as, or be seen as, dependent.

... what’s needed next is a truly public debate about what frameworks are likely to help all of us secure the personal and social support that improvements in our societies mean more and more of us are likely to need. (2008, p. 15)

The WHO describes active ageing as ‘the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age’ (2002, p. 12). An important dimension to active ageing for a person is maintaining their functional capacity over their lifetime. While the degree of functional capacity progressively widens between individuals over their lifetime, active ageing is about ensuring individuals are at the highest level of function possible for their age (figure 4.2). For older individuals this means maintaining independence and preventing disability for as long as possible (Oxley 2009).

An aged care system with a focus on promoting wellness, active ageing and enhancing the independence of people in later life might not only enhance the wellbeing of older people, but could also be effective in reducing demand for more expensive and ongoing services (box 4.2). There is emerging evidence that timely intervention, restorative home support, education and assistive technologies can improve quality of life and the functional status of older people, and reduce costs because of a reduction in the ongoing use of home care services (Ryburn et al. 2009). Support to help older people maintain independence can involve making

---

available assistive devices (hand rails, safety bells, etc), changing the physical environment, providing restorative care, rehabilitation services and support for families and carers. For example, helping someone maintain independence could mean facilitating a move into more congregate living arrangements where they will require less assistance to perform functions related to daily living.

**Box 4.2 Participants support healthy ageing and maintaining independence**

**Alzheimer’s Australia, WA:**

‘Aging well’ is a life span approach to the aging process, with the objective of contributing to the health and wellbeing of all members of the Australian community. Health and the capacity to remain independent are important aspects of older people’s lives, are intrinsically linked and thus government policy and spending on one aspect is likely to impact on outcomes of the other. (sub. 345, p. 4)

**Aged Care Assessment Service Victoria:**

A goal should be to revise the system with the main aim to restore/retain the independence of older people in a timely manner rather than responding to their advanced decline with less capacity to reverse the functional deterioration. (sub. 214, p. 2)

**Business Council of Australia:**

Just as policy attention is turning to greater efforts at prevention for the population at large, so too should it turn to promotion of healthy living for ageing Australians. Preventing or managing chronic disease and limiting disability are vital elements in managing the demand for care and health services and for improving the quality of life of both the ageing and their carers. This necessarily requires consideration of all the elements of wellness as well as access to ongoing physical and mental activity; social connection; cultural activities and transport for all services. (sub. 274, p. 10)

**Australian General Practice Network:**

A greater focus on restoring functionality amongst individuals receiving HACC services should be supported through more flexible funding arrangements and performance indicators and reporting requirements linked to reduction of dependence amongst service recipients. (sub. 295, p. 19)

**Community Care (Northern Beaches):**

International and national research and service pilots have demonstrated the capacity of community-based allied health interventions/independence models with service provision (e.g. Re-ablement Project in the UK, TARGET Project in New Zealand, Home Independence Pilot in Western Australia, Active Service Model Pilots in Victoria, and the IMPACT/Better Practice in HACC Project in NSW) in the promotion of wellbeing, and prevention of unnecessary functional decline for older people living in the community. While potentially more resource intensive in the early stages, these models have proven the long term financial savings, in addition to positive health and wellbeing outcomes for older people. (sub. 142, pp. 2–3)

---

Being a contributor to society for as long as possible can also influence people's sense of worth and hence their wellbeing. The Council on the Ageing (COTA) Australia argued that older people want recognition of the fact that they continue to play a valuable role.

The often unstated assumption is that life has a point or period when it is at its best. After that we are 'over the hill' or 'on the downhill slope', with the 'best years behind us' or another of many more similarly negative colloquialisms. Older people are increasingly laying claim to a different paradigm of ageing, which gives explicit recognition to the fact that even if experiencing physical and health challenges they continue to have roles that have value and meaning. Most older people still have goals to achieve, contributions to make, a life to live. (COTA Australia, sub. 337, p. 8)

Pratt also argued that:

We all have a need to be needed, perhaps our greatest need. Our self-worth is diminished if we feel that we are not contributing something useful to those around us. One of the ways in which the system can ... allow its consumers to contribute is by promoting their highest achievable level of functioning and by showing society in general, and people as individuals, that they have value. (2010, p. 40)

The psychology literature suggests that 'meaning' and 'engagement' are important dimensions of wellbeing (Vella-Broderick et al. 2009). The notion of 'meaning' captures the idea that people seek to find purpose in their lives, while 'engagement' is about the degree to which people immerse themselves in specific activities. The evidence suggests a link between 'meaning' and 'engagement' and positive physical and mental health outcomes.

*The aged care system should promote independence, wellness and the continuing contribution of older people to society.*

### ***Being able to exercise choice is important to wellbeing***

How older Australians' needs are met can also have a significant influence on their wellbeing. People generally value the opportunity to make choices about things that are important to them. At a time in life when people may feel that they have little personal control over many aspects of their daily lives (for example, because they require assistance with meals and showering), it is particularly important that they can exercise choice and maintain control over those aspects of their life where they can. Sen argues that freedom to exercise choice 'makes our lives richer':

Expanding the freedoms that we have reason to value not only makes our lives richer and more unfettered, but also allows us to be fuller social persons, exercising our own

---

volitions and interacting with — and influencing — the world in which we live. (1999, pp. 14–5)

Having choice empowers people and can allow better matching of preferences. When people can choose freely, they will generally choose in a way that maximises their wellbeing. NACA said:

Older Australians deserve and are entitled to a care and support system that ensures them the same freedoms and choices as all other Australians. (sub. 88, p. 10)

Just Better Care also said:

We need to change the way we provide services, from one of ‘giving’ services to one of ‘empowering’ individuals to unlock productivity potentials. It is what our ageing Australians demand, and it is also good for the country as a whole. ... Empowered service users will be healthier, happier and more capable and willing to be independent, therefore having less need for services. (sub. 281, pp. 3–4)

There is strong empirical evidence to suggest a wide range of positive wellbeing outcomes, including higher life satisfaction, more independent living and better continuity of care from providing greater choice in the context of health care (Barnett et al. 2008).

Choices will, however, inevitably involve individuals making some trade-offs, for example, trading off the risk of physical injury for being able to engage in activities such as gardening or making a cup of tea. As one participant said ‘people are the experts of their own lives so who can be better placed to make decisions about their care?’. Choice can be constrained by limited service options, access to information and capacity to pay. And, individuals with cognitive impairment may not have the ability to make choices that are in their best interest.

There is also some evidence that people do not always value choice when there are too many options (Schwartz 2004). Choice can impose costs if people worry about making the wrong choice or they find the range of options confusing. There is a balance between choice that empowers and choice that can detract from wellbeing. Because people have different preferences regarding risk, wellbeing is likely to be improved if there is a better match between people’s risk preferences and the risk borne (Treasury 2004).

How care is provided can also be important for wellbeing as assistance with daily living activities often involves intimate tasks. Anglicare Australia said:

Older people may receive the best practice medical and clinical care yet have little life satisfaction. (sub. 461, p. 16)

---

Another participant, Jean Wortley, in relation to the care provided to her frail and ageing parents said:

Care in itself means much more than clean floors, bed making and fixing meals for people. It means building relationships that allow a frail, helpless and often frightened older person to know who to expect will be coming through their door. (My parents were initially very anxious about allowing strangers in to handle their possessions, take over their kitchens and ultimately handle their bodies, shower them, dress them etc.) These are intimate tasks that of necessity challenge people's privacy, control over their shrinking world and trust in others. (sub. 470, pp. 1–2)

While quality of care is often assessed on an objective basis, an important dimension of quality is subjective — how people feel about who is delivering the service and how the service is delivered. The Commission was told on a number of occasions of people having a succession of strangers coming into their homes to provide care and people not wanting to receive higher levels of care because it meant they could not retain their current carer. Beresford argued that:

Care is increasingly organised as a set of mechanical tasks. The range of these tasks has tended over time to be restricted and sometimes divorced from their human associations. The skill and experience required to undertake these often intimate and potentially invasive tasks in a sensitive, respectful and positive manner tend to be overlooked. (2008, p. 3)

For older people receiving care, the respectful nature of the engagement is particularly important as it contributes to their self esteem. It is also important for the family and friends of older people that their loved ones are treated with respect and dignity. Aged Care Crisis spoke about the 'loss of human rights that so often occurs at the end of life — when it is far too easy for individuals to lose their social identity and the rights of citizenship' once they enter residential care (sub. 433, p. 2).

### *Dying well*

A number of participants also spoke about the importance of 'dying well' for positive wellbeing outcomes. Palliative Care Australia argued that issues of death and dying should be included in the objectives for aged care:

With 50,000 older Australians approaching death and dying each year in residential aged care facilities alone, the wellbeing of older Australians would be further advanced through explicit recognition of the issues of death and dying and the inclusion of an additional key goal of the aged care reforms — to assist all older Australians to die well. (sub. DR731, p. 2)

---

Others spoke about the importance of advance planning for people to have a good death. Hal Kendig, for example, said:

A ‘good death’ is part of a good life and this requires advance planning for individuals as well as a care and health system focused on comfort and dignity to the end of life. (sub. 431, p. 4)

Palliative and end-of-life care is ‘core’ business of any aged care system. This points to the importance of access to good palliative and end-of-life care for elderly Australians. According to Palliative Care Australia:

... all Australians should be able to expect to die with their preventable pain and other symptoms well managed, with the people they wish to be present and, whenever, possible, in the place of their choice. (sub. 77, p. 2)

A survey conducted by the British Medical Journal of people approaching death asked ‘what is a good death’ and came up with 12 principles. The principles include, amongst other things, being able to retain reasonable control of what happens, to have control of pain and other symptoms, to have access to information and expertise and to be able to issue advance directives so that one’s wishes are respected (box 4.3 provides the full list of principles).

#### **Box 4.3 Dying well — what is a good death?**

British Medical Journal surveys of people who are approaching death (and their relatives) resulted in a supplement — ‘What is a good death?’. The views of people were summarised as ‘principles of a good death’ in the following 12 points:

- to have an idea of when death is coming and what can be expected
- to be able to retain reasonable control of what happens
- to be afforded dignity and privacy
- to have control of pain and other symptoms
- to have reasonable choice and control over where death occurs
- to have access to necessary information and expertise
- to have access to any spiritual or emotional support required
- to have access to ‘hospice style’ quality care in any location
- to have control over who is present and who shares the end
- to be able to issue advance directives to ensure one's wishes are respected
- to have time to say goodbye and to arrange important things
- to be able to leave when it is time, and not to have life prolonged pointlessly.

Source: Jones and Willis (2003).

---

*The aged care system should be consumer-directed. It should promote choice and be sufficiently flexible to allow people to live their lives the way they wish and to die well. Older Australians receiving care and support (including palliative and end-of-life care) should be treated with dignity and respect.*

### *The importance of social connections*

Maintaining family and social connections matters for older people, just as it matters for people of all ages. The Benevolent Society said:

Social dimensions feature strongly in older people's perceptions of their wellbeing. Social networks, activity and access to confidants can help protect people from the negative impact of stressful life events and are associated with higher quality of life and life satisfaction and better physical, mental and emotional health.

Conversely, social isolation and loneliness in old age are linked to a decline in physical and mental wellbeing. Life events such as bereavement and loss of mobility may trigger social isolation, especially among people who are more at risk. (2010, p. 3)

Many participants also noted the importance of social inclusion to the wellbeing of older people (box 4.4). The Australian Government has a social inclusion agenda in relation to older Australians.

There are differing views in the literature about the extent to which particular types of relationships matter in terms of a person's wellbeing (for example, how significant and lasting the welfare effects are of a happy marriage). But, there is general agreement that 'connectedness to others' is a key dimension of wellbeing.

Inadequate social support is associated with an increase in mortality, morbidity and psychological distress. A Japanese study, for example, found that older people who reported a lack of social contact were 1.5 times more likely to die within the next three years than those with higher social support (Sugiswawa et al. 1994).

Older people are also more likely than people at other stages in life to be losing friends and family members (because of death) and so can be particularly vulnerable to loneliness and social isolation, especially those with reduced mobility.

The location of services and their accessibility can be very important for maintaining independence and social connections. Carers NSW said:

Transport is also crucial to improve the social inclusion of older people, and to enable them to retain more independence for longer. (sub. 211, p. 7)

---

#### **Box 4.4 Social connections and wellbeing — participants' views**

The Victorian Government:

Older people still want to be connected, contributing, and cared for. (sub. 420, p. 10)

NSW Government:

The NSW Government is also keen to see social exclusion addressed as an issue affecting the wellbeing of individuals and their capacity to remain healthy and independent as they age. The provision of flexible access to community and support services is critical to helping people maintain social networks and retain independence, particularly if their functional capacity is declining. (sub. 329, p. 9)

National Rural Health Alliance:

... older people are particularly vulnerable to social isolation which can impact heavily on their health. Community support from someone to drop in for a cup of tea or help with transport to a Senior Citizens craft session can be extremely important for people living in small communities. (sub. 277, p. 9)

The Benevolent Society:

In older age social exclusion can result in poor quality of life, avoidable illness and disability, higher rates of hospitalisation, premature institutionalisation and premature death. ... Most older people want to live as independently as possible, continuing to do the things they enjoy and staying connected to their community. (sub. 252, p. 14)

Diversional Therapy Australia:

Not only is it proven that life enriched with meaningful activity, social connections and laughter is an effective preventative medicine, it is also a vital part of being human. (sub. 175, p. 1)

The Benevolent Society also said:

There are also systemic barriers to social connectedness. They include lack of suitable transport and aspects of the built environment such as inappropriate housing, public spaces without seating, poor footpaths and inaccessible public buildings. These can reduce people's ability to take part in social activities outside the house, or can force them to have to move elsewhere away from their social networks. (2010, p. 3)

Broader issues relating to age-friendly neighbourhoods are discussed in chapter 12.

### **The wellbeing of carers**

#### *Informal carers*

Many people wish to care for their partners, parents and friends whenever they are able to do so. Older people themselves can also be the providers of care, such as to their partners or to dependent children. The experience of caring for a partner,

---

relative or friend can be a positive experience and give a sense of purpose that is important for the self-esteem of carers (chapter 13).

However, the positive effects on wellbeing from caring can be eroded if carers:

- are unable to look after their own physical and emotional needs, including finding time to engage in leisure activities or maintain social connections (activities that can be important for the health and self-esteem of carers). The demands of caring can be stressful and isolating and this can affect the health and wellbeing of caregivers. There is a substantial body of evidence that shows the personal costs of caring on carers. Informal carers have poorer physical and mental and emotional health and less social support than non carers (chapter 13; ABS 2008a; Access Economics 2009b; McKenzie et al. 2009). A number of participants to this inquiry spoke about the effect caring has on carers' lives (box 4.5). The Australian Unity Wellbeing Index (sub. DR626) found that informal carers have the lowest level of wellbeing of any group.
- experience financial stress. If a caring role means someone is not able to participate in paid work or to participate less, a carer's income is likely to be lower than would otherwise have been the case
- feel they are struggling to provide the quality of care they want for their loved ones, or that the care they are providing is not appreciated by other family members or the community more generally.

Many participants acknowledged the important role of carers in supporting older people. The New South Wales Government, for example, said:

The important role of carers and volunteers in supporting older people and the health and aged care sectors as a whole must continue to be acknowledged, sustained and facilitated. (sub. 329, p. 7)

The Australian Institute of Health and Welfare (AIHW) describe carers as the 'enablers of community care' noting that:

... for many older people with disability, the level of assistance provided by formal services is not sufficient to enable them to remain at home. But the presence of a carer who provides ongoing assistance (which is supplemented by community care services) can tip the balance in favour of home-based care. (2009a, p. 212)

---

### **Box 4.5 The impact of caring on the wellbeing of carers**

Alzheimer's Australia:

... caring for a person with dementia has a negative impact on the health and wellbeing of family carers. Social impacts may include loss of work, friends and acquaintances and social activities. Health impacts can include depression, anxiety, stress, physical health impacts and sleep disruption. Additional stresses can occur if the family carer is older and in failing health themselves. (sub. 79, p. 12)

Eva Gross:

Carers burn out, become physically and psychologically unwell, have to take days off work, drop out of work etc because of the demands of care, adding costs to the health and welfare systems and impacting on productivity. (sub. 435, p. 7)

Carers Australia:

Long-term caring can take its toll, socially, emotionally, physically and economically. Older carers are caring at a time when their own health may be deteriorating and they are at risk of the normal range of health issues that arise for older Australians. (p. 247, p. 8)

Jennifer Proberts:

Ask any carer and you will be told they have put their life on hold because they do what they do because of the love they have for the person they are looking after. Many families break up with this constant extra pressure on emotional, physical and mental wellbeing. Obviously as time goes on the work load and pressure increases which results in the carer suffering burn out or breakdown. (sub. 66, p. 1)

The wellbeing of informal carers can be enhanced by arrangements that allow them time away from caring to engage in activities for themselves, assistance with the financial burden of caring, access to counselling and training, and by having a role that is recognised and valued. Without support and assistance, carers can burn out which can then mean greater reliance on more formal forms of care. Providing support for people who care for older Australians can also be an important aspect of improving the quality of care. As Hal Kendig put it:

In many cases, support for frail older people is best achieved by sharing responsibilities for care and providing respite and other services that can lessen stress. Research has shown that caregiver stress is one of the main predictors of entry to residential care. It is important to recognise, however, that the interests of frail older people and their caregivers can diverge, and it is important to listen to and respond to both parties. (sub. 431, p. 4)

*People who provide care and support for older Australians should be provided with support to assist them to continue performing this role.*

---

### *Formal carers and providers*

Opportunities for career progression, job flexibility, workplace safety, social engagement, and the personal sense of value people get from their work are important contributors to the wellbeing of workers. Some of these non-monetary aspects of working may be more important in aged care than in other industries (chapter 14).

While an aged care system needs to offer competitive remuneration to attract labour, workers may be willing to trade off some financial returns for more flexible work arrangements, potential career progression, and enhanced self esteem (although the financial recognition of the contribution also contributes to self esteem). The funding and regulatory arrangements of the aged care system can enable or constrain the scope for employers to offer such outcomes.

The high level of involvement of not-for-profit providers in aged care reflects the interest in a wider range of outcomes in this industry. While the original involvement of faith-based and local community organisations in the provision of aged care services may have been motivated by the desire to alleviate the poverty suffered by some older Australians, many such organisations have evolved to provide services to a much broader share of the aged population. This has been accompanied by increased professionalisation of much of the management and staffing. Volunteers also play an important role in service delivery and seek to enhance the wellbeing of those they assist as well as gain a sense of satisfaction themselves.

### **The wellbeing of the broader community**

As ageing is an inevitable process, there are few Australians who will not engage with the system over time. In general, wellbeing of the broader community is enhanced by knowing that care services will be there when required, that there is a safety net and that nobody will be faced with catastrophic costs of care.

Care and support should not only be affordable to those requiring care, but also affordable to society (taxpayers) who contribute to the costs of care. To ensure that care services will be available over time requires that the system be fiscally sustainable.

Sustainability can be thought of broadly as the ability of the system of care over time to provide services of an appropriate standard in a way that meets community expectations in relation to their accessibility, affordability and quality. With a smoothly growing population, a pay-as-you-go system can be affordable as there

---

are always more younger people to support the aged care needs of the older generation. However, the post-world war II baby boom, combined with an increase in life expectancy, means that the dependency ratio is predicted to rise substantially over the next 40 years (chapter 6).

There are some concerns that the intergenerational inequities that are arising, in part, from greater costs of aged care, may create tensions between generations. For example, the then Governor of the Reserve Bank of Australia, Ian Macfarlane, said at the *2003 Economic and Social Outlook Conference* that:

If we are not careful, there is a potential for conflict between generations. The young may resent the tax burden imposed on them to pay for pensions and health expenditure on the old. This will particularly be the case if they see the old as owning most of the community's assets. Housing is the most obvious example, where people of my generation have benefited from 30 years of asset price inflation, while new entrants to the workforce struggle to buy their first home. (Macfarlane 2003, p. 19)

Getting the best 'value' out of the resources devoted to providing care and support to older Australians is also important for taxpayers and for the community more generally because it is about maximising overall welfare and living standards. This requires that resources are used where they give the greatest benefit (allocative efficiency), and that services are produced using the lowest level of resources required to meet a specific quantity and quality standard (technical efficiency). It also requires that investments are made where the stream of future benefits more than outweighs the costs, including the opportunity cost. Another dimension is how aged care services interact with other services that are critical to the health of older Australian, including health, housing and transport services.

When considering efficiency in the context of aged care, it is important to design appropriate incentives within the system to:

- ensure services are provided as needed, but with the older person's choice of provider being made on a value-for-money basis
- reduce the unit cost of producing services of any given quality
- be innovative and flexible in the face of changing expectations and economic and social circumstances.

The role of consumers in facilitating competition and promoting well-functioning markets has long been recognised. In seeking to get the 'best' value (the good or service and price/quality combination most appropriate for them), consumers not only advance their own self-interest, but also provide signals to suppliers about the product characteristics they require. People who have the information and capacity

---

to make informed choices will choose the services that best suit their needs (and retain control over their lives).

Competition between suppliers, who respond to these signals, can variously lead to lower costs, improved product quality and choice, greater innovation and higher productivity.

Markets, by their nature, cannot offer certainty and providers who cannot attract enough clients will fail. This can pose risks for the clients of these providers, especially in the case of aged care. There are also risks that providers will not enter a market where demand is limited, such as in rural and remote areas or where there are relatively few clients with particular needs, or a capacity to pay. Insufficient demand can be managed by financial support to marginal providers, but such support can also erode incentives for efficiency. In such cases, the provision of public subsidies which reflect the higher costs of service provision can be combined with competitive tendering arrangements.

There are also quality risks where consumers have difficulty assessing the quality and safety of a service. This risk is compounded where there are high costs associated with changing a service provider. As discussed in section 4.2, these risks can justify government intervention. However, any intervention must be carefully designed to not raise costs without a commensurate reduction in risks. These costs are not just financial in nature. Regulation that erodes choice and control, reduces recognition of the value of carers, or reduces the flexibility the industry can offer its workers, can also impose costs. A recent United Kingdom report titled *'Nothing Ventured, Nothing Gained': Risk guidance for people with dementia*, explored balancing the positive benefits of taking risks against the negative effects of attempting to avoid risk and said:

Risk enablement goes beyond the *physical* components of risk, such as the risk of falling over or of getting lost, to consider the *psychosocial* aspects of risk, such as the effects on wellbeing or self-identity if a person is unable to do something that is important to them, for example, making a cup of tea. (DOH 2010a, p. 9)

Imperfect markets may well deliver better outcomes for the community than would be achieved through additional government intervention. In many situations, individual consumers are best placed to decide what is in their best interest, and importantly, be able to take responsibility for their decisions, even when they do (sometimes) make less than 'optimal' decisions.

The funding and regulatory arrangements for the delivery of aged care services to older Australians must find the right balance between market forces and government intervention to manage risks while encouraging the efficient provision of services. The funding formula needs to be affordable and considered fair within

---

and across generations. There is no one right balance — it depends on the overall preferences of the community, its appetite for control and for risk, and the importance attached to equity.

*Care and support needs to be affordable for those requiring care and for society more generally.*

*Funding arrangements for care and support should encourage broadly even contributions between groups over time (that is, promote intergenerational equity) and provide incentives to ensure Australians are getting the most out of the resources devoted to the care and support of the elderly.*

RECOMMENDATION 4.1

***To guide future policy change, the aged care system should aim to:***

- ***promote the independence and wellness of older Australians and their continuing contribution to society***
- ***ensure that all older Australians needing care and support have access to person-centred services that can change as their needs change***
- ***be consumer-directed, allowing older Australians to have choice and control over their lives and to die well***
- ***treat older Australians receiving care and support with dignity and respect***
- ***be easy to navigate, with older Australians knowing what care and support is available and how to access those services***
- ***assist informal carers to perform their caring role***
- ***be affordable for those requiring care and for society more generally***
- ***provide incentives to ensure the efficient use of resources devoted to caring for older Australians and broadly equitable contributions between generations.***

## **4.4 Criteria for assessment**

Based on the wellbeing framework discussed above and the Government's stated objectives for the current system set out in the *Aged Care Act 1997* (chapter 2), the current system for care and support for older Australians should be assessed against the criteria of: equity (access), efficiency, effectiveness (choice, quality, appropriateness) and sustainability. The Commission's proposed reforms have also been developed based on the wellbeing framework and these criteria. Each of the criteria is examined below.

---

## Equity

Equity is a multifaceted concept. In the context of access to care and support, equity has several dimensions.

- *Equity of financial access* — that access to care is not denied because of an individual's inability to pay. Subsidies and co-contributions (based on income and asset tests) should be based on ensuring that care is affordable for those who need it, having regard to their ability to pay and the ability of society more generally to fund the subsidies.
- *Equity of physical access* — that the necessary physical and human resources for the provision of care are available in a suitable location. This does not mean, however, that it is inappropriate for the range of aged care services to vary in response to the cost of delivering these services or the number of individuals seeking a given service in a particular location.
- *Equity in terms of standards of care* — that the care provided meets a benchmark standard of care that addresses the needs of each person. This does not rule out allowing people to pay for additional services over and above acceptable quality standards.

Equity of access also has a dynamic dimension. It is not only important when an older person first accesses care and support services, but also as the person's circumstances and needs change over time.

There is also the issue of 'fairness' or equity in terms of who pays for aged care and providing protection against excessive or catastrophic costs of care.

## Efficiency

The efficiency criterion is essentially about getting the most out of the limited resources devoted to aged care, so as to maximise overall welfare and living standards. Efficiency has a number of dimensions.

- *Allocative efficiency* — requires that funding arrangements provide incentives for achieving an allocation of resources among the different modes of aged care (and between health and other related services) that produces the combination which best meets users' demands and results in an efficient overall level of aged care spending. Allocative efficiency depends primarily on resources being used where they are valued most — this is problematic in the current system where prices may not always be an adequate reflection of value.

- 
- *Technical efficiency* — involves the delivery of an appropriate level and quality of care with the least use of resources. The system needs to provide incentives for providers and users to encourage the efficient delivery of services and avoid the wasteful consumption of care services.
  - *Administrative efficiency* — involves designing regulatory and funding arrangements that avoid unduly complex or ambiguous procedures and rules. Unnecessary complexity gives rise to avoidable costs for providers and consumers alike.
  - *Dynamic efficiency* — refers to the capacity to improve efficiency over time. This can mean finding better products (or more highly valued products) and better ways of producing goods and services. It can also refer to the ability to adapt quickly, and at low cost, to changed (and changing) economic and social conditions.

## **Effectiveness**

Effectiveness covers choice, quality and appropriateness of services in relation to needs. It refers to the extent to which the outputs produced by the system lead to the outcomes desired by individuals and the wider community.

Funding and regulatory arrangements must be able to support standard benchmarks of care and facilitate the maintenance of quality standards over time. Achieving these benchmarks of care is also dependent on having access to a sufficient and appropriately trained workforce.

## **Sustainability**

In the context of an aged care system, sustainability can be thought of broadly as the ability over the longer term to provide services of an appropriate standard and in a way that meets community expectations in relation to their accessibility, affordability, and quality. Sustainability has a number of dimensions.

- *Fiscal sustainability* — the extent to which financing arrangements can accommodate projected changes in the number of older Australians (in absolute and relative terms) requiring care over the longer term and changes in the value of that care.
- *Provider sustainability* — the financial viability of aged care providers in the long term. Under current arrangements, aged care providers operate within a highly regulated environment and the design of regulatory and funding

---

arrangements should not undermine the financial viability of providers or distort signals for new investment.

- *Workforce sustainability* — the ability of the aged care industry to attract and retain people with the requisite skills needed to provide the level of quality care expected by the community. This dimension of sustainability focuses on whether future models of care are able to be supported by the available workforce.
- *Social sustainability* — the ability to maintain social harmony within the community concerning the fairness of the distribution and use of available resources.

### **Assessing the achievement of the objectives in practice**

The overarching objective of providing care and support to older Australians that enhances their wellbeing is only useful to the community if governments can, in a practical sense, assess whether this objective is being achieved. In practice, this requires that objectives are clearly identified along with indicative guides to desired outcome measures to facilitate an effective assessment of the system's performance.

Table 4.1. sets out some indicative outcome measures against the stated objectives of Australia's aged care system.

The next chapter assesses the current aged care system against these indicative outcome measures.

**Table 4.1 Some indicative outcomes measures against proposed objectives of Australia’s aged care system**

<i>Objectives</i>		<i>Some indicative outcome measures</i>
To promote independence and wellness of older Australians and their continuing contribution to society	⇒	Measures of individual functioning, reduced rates of some disabilities and need for assistance with daily living activities. Intensity of care, reduced ‘continuous’ use of community and residential care, lower hospitalisation rates. Higher social participation, lower rates of depression among older Australians.
To ensure that all older Australians needing care and support have access to person-centred services that can change as their needs change	⇒	Measures of unmet need, waiting lists (assessment, care and support), use of care and support by different groups (Indigenous, regional, special needs access). Better continuity of care, greater emphasis on restorative care, rehabilitation, improved satisfaction.
To be consumer-directed, allowing older Australians to have choice and control over their lives and to die well	⇒	Capacity of older Australians to self-direct funding (if so chosen) and to choose services within entitlements and to choose providers. Perceptions of choice, control and satisfaction. Reduced complaints about service.
To treat older Australians receiving care and support with dignity and respect	⇒	Improved satisfaction of older Australians with care and support provided. Reduced complaints about service.
To be easy to navigate, with older Australians knowing what care and support is available and how to access those services.	⇒	Improved satisfaction of older Australians and their families in terms of ease of access to information. Greater certainty for individuals about the cost of care.
To assist informal carers to perform their caring role.	⇒	Access to respite care, lower rates of depression/improved wellbeing of carers.
To be affordable for those requiring care and for society more generally.	⇒	Affordable co-payments, protection from catastrophic costs and a fair balance between public and private contributions. Fiscal sustainability.
To provide incentives to ensure the efficient use of resources devoted to caring for older Australians and broadly equitable contributions between generations.	⇒	Costs per unit of output, lower rates of multiple assessments, savings on future costs, more cost-effective use of technology, lower costs of complying with regulation.

