OLDER PEOPLE
issues and innovations in care

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The fourth edition of a book is testament to its utility and popularity. It is clear to see why. *Older People: Issues and innovations in care (4th edition)* presents a rich tableau of topics relevant to the care of older people. The book is grounded in current Australian practice; it is scholarly yet practical and very readable, enlivened by quotes and vignettes sprinkled through each chapter. The reflective questions challenge readers to give deeper consideration to issues and to their own practices. The scope of the 25 chapters is comprehensive and the content is up to date with current developments in aged care such as the Australian aged care reform and Living Longer Living Better, as well as medical developments. The authors, who are leaders in aged care in Australia, are highly regarded. *Older People: Issues and innovations in care* differs from most geriatric books in that it focuses on applied and organisational issues relevant to everyday practice.

Now, more than ever, we need books like this to enhance knowledge and improve aged care practice. The media frequently highlights negative stories such as the epidemic of ageing, the tsunami of dementia, scandals in nursing homes, egregious examples of elder abuse, crises in aged care and bed blockers in hospitals. Admittedly there are current gaps in services and room for improvement and there is a need for more skilled professionals and better policies; however, Australians can rejoice and take pride in stories of positive ageing (e.g. see Chapter 3 on centenarians), the excellence and humanity in the provision of quality care and the advances in practice that are occurring.

Population ageing is a global phenomenon. In the next generation about one in four people in the developed world will be older than 65 years of age and there will be twice as many older people as there are children. The developing world is catching up quickly; China and India between them will have half the world’s population with dementia by 2050. Aged care is core business in healthcare and the lessons from this book are relevant beyond Australia.

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PREFACE

The previous editions of this book were well received by health professionals, students and others involved in providing care to older people and undertaking research into ageing and dementia. Subsequently there was a need for a fourth edition to update the knowledge from new research and acknowledge government policy changes that have occurred. We have endeavoured to do this through our contributors and by including new chapters and a greater emphasis on dementia.

We have maintained the use of vignettes, study questions and innovative approaches to care delivery that enable the reader to test their knowledge and to appreciate how others change their practices. Critical reflection on practice is acknowledged as a fundamental instrument for change and we hope this book will encourage this in daily work.

This is not a ‘how-to’ book, but rather a text that will encourage the reader to explore care issues and use evidence-based practice to improve the care of older people and their families.

Person-centred, evidence-based, interdisciplinary care is the foundation for successful care outcomes, whether it is delivered at home, in acute care, in residential aged care facilities, in palliative or in rehabilitative units. Older people often have multiple chronic healthcare problems that lead to complex care needs. Assessment and interdisciplinary discussion, ensuring that the person’s goals and strengths are central to that discussion, is the best way to plan interventions and monitor outcomes.

Family members, with the consent of the older person, are collaborators in care. They are not difficult interruptions. Issues of advanced care planning and substitute decision making for people who have cognitive impairment should be discussed early in the care process. Regular involvement of family or significant others, together with the older person, can assist timely detection of changes, enable alterations in care planning and delivery and ensure collaborative decision making.

Issues such as lack of medical specialists, care staff with only basic skills, monitoring of funding and insufficient professional staffing levels are still evident. Quality care may be very different from quality of life but one impacts on the other and both should be monitored closely. This text does not propose any particular model of care or tools for assessments but rather encourages the reader to examine what is available and suitable for the purpose they want to achieve.

At the time of writing this text the National Disability Insurance Scheme had been through the political process and legislation is now completed. The
actual implementation of the scheme is yet to unfold so the reader will need to examine what is happening in each state and territory as the work progresses. Our understanding is that older people will continue to receive care under the *Aged Care Act 1997*, with amendments, but it is not clear whether younger people residing in aged care facilities will be eligible.

**ORGANISATION OF THE VOLUME**

The text is organised in a similar fashion to the previous editions, as this creates an easy-to-read format and relates the information in a logical way. Three sections are organised to discuss broader issues, policy and possible future directions. The first section discusses the issues surrounding policy matters and the impact of an ageing population. The second part raises the importance of evidence-based practice and the need for ongoing research. There is still a need to explore the delivery of person-centred approaches to care and what this means to the older person. Innovations in action form the basis for the third section and the possibility of change in direction for care of older people and their families is raised. We have deliberately included the voices and opinions of people who write from their experiences and you will find few references in these chapters. We urge you to similarly value the voices, verbal or non-verbal, of the older people with whom you work. It is essential that we consider the evidence to include clinical judgment and consumer choice.

**SECTION 1: CONTEXTUAL ISSUES AND INNOVATIONS**

Glenn Rees provides a perspective from many years of listening to consumer viewpoints about access to, and transparency of, services for older people, especially those who have a dementia. The lack of choice and complexity of accessing what is available is daunting for older people and their families.

The issues of an ever-increasing ageing population have far-reaching impacts on the healthcare system. Swerissen and Taylor stress the importance of developing a stronger and more flexible primary healthcare focus with more community involvement.

McCormack brings us more from his longitudinal study of the ‘old-old’, where he found increasing numbers of people living to 100 years and older. The needs of this age group may create different issues for governments and policy development.

Greenway-Crombie, Disler and Threlkeld discuss the issues of growing old in rural communities and the provision of resources required for this group.

The younger age group residing in residential aged care is increasing in numbers. Garratt and Kelly remind us of the lifestyle gap and expectations of younger people who have limited choices in how and where they live.

Wells and Ryburn give an overview of community services available for older Australians and the need for a systems overhaul and new directions for service delivery.
SECTION 2: PRACTICE ISSUES AND INNOVATIONS

Person-centred care has become the focus for care provision. Nay, Fetherstonhaugh and Winbolt believe there is much to still be done to see this approach to care in practice. They emphasise the importance of all stakeholders being ‘persons’ and person-centred care being practised at all levels and in all relationships.

Ibrahim and Davis remind the reader of the difficulties in maintaining a balance between risk taking and maintaining safety while also providing quality care.

Healthcare of older Aboriginal and Torres Strait Islander people requires complex assessments based on cultural understanding and knowledge of what services are available for this group. The chapter by LoGuidice, Flicker and Smith outlines some of the issues involved in delivering care in isolated areas of the country that can be translated to city circumstances.

Bauer et al stress the importance of relationships between staff and family, staff and clients and clients and family. The continuation of these relationships is vital for quality care outcomes.

Hospitals are not good environments for older people. Reports indicate confusion, nutrition and hydration issues; falls are increased in this adverse environment. Ames and Nay indicate improved systems in community healthcare may reduce the number of hospital admissions, and improve more effective discharge.

Person-centred comprehensive geriatric assessment is an interdisciplinary team effort and is the best way to gain an insight into the care needs of older people. Garratt and Pond also highlight the importance of family or significant others in the ongoing care delivery process.

Summers offers a good overview of causation and pathological changes in the brain in dementia. His research on neuroplasticity is particularly encouraging.

Neville and Byrne raise the complexity in diagnosing older people who may have depression and who are at risk of suicide. The clinical differences between dementia and depression are very similar and require thorough investigation. Treatment for clinical depression is essential and must not be confused with loss and grief.

Gibson et al address the assessment and treatment of persistent pain in older people. The use of assessment tools and alternative methods of pain relief are raised.

Sexuality issues with older people are discussed by Bauer, Nay and Beattie. This chapter addresses one of the major taboo topics in healthcare.

Kurrle raises issues surrounding the assessment and intervention required in cases of elder abuse and neglect. The legal aspects of intervention and guardianship must be understood by caregivers, especially if family members are involved.

End-of-life decision making for older people is becoming more widely accepted, but as each state and territory in Australia has different laws and approaches to this issue it is important that the correct documentation is...
completed and families understand the consequences. Fetherstonhaugh and Tarzia discuss the implications of this issue.

SECTION 3: INNOVATIONS IN ACTION

Garratt and Baines explore the meaning of self, dignity and self-esteem in understanding dementia. Knowledge of the person’s lifestyle and what is important to them is fundamental to explaining how these concepts affect the quality of life of people who have dementia.

Accreditation, quality and risk are factors necessary to provide positive care outcomes. Brandon describes the components involved in maintaining quality health outcomes for older people, especially those who live in residential care.

Environments that enhance dementia care can be adapted and adopted with careful planning and leadership. Fleming and Bennett address some of the ways in which the environment can be changed to become a more positive experience for older people and care staff.

Horner, Soar and Beattie discuss the future involvement of technology in care. Technology designed to assist in safety, to maintain independence and to monitor health patterns will become more acceptable and used to allow older people to remain in their homes for longer.

Nay, Katz and Murray describe the changing patterns of work in healthcare and the need for innovative change to meet the future. Flexible work hours, improved education and the use of technology will shape a new direction for the aged care workforce and lead to transparency and improved continuity in care.

Carr invites the reader to join her in understanding the family concerns when dementia is diagnosed in a parent. When both parents develop the disease the need for support from healthcare workers and community is essential. Finding out where to access this help is fraught with difficulty and often increases the carer’s despair.

Daly, Jackson and Nay discuss the components of good leadership and the necessity to develop such leaders in aged care. Without sound leadership, changes to improve quality care outcomes and meaningful lifestyles for older people will not occur. The future depends on leaders who have vision, capacity for change and commitment to aged care and the workforce involved in delivery of care.
CHAPTER 6

COMMUNITY SUPPORT FOR OLDER AUSTRALIANS: ISSUES AND FUTURE DIRECTIONS

Yvonne Wells and Bridget Regan

Editors’ comments

Older people say they prefer to ‘stay at home’ if possible until they die. This requires care and support to be delivered in the community. While we would all agree this sounds great it does have consequences and relies very heavily on families, friends and communities. This chapter provides an overview of the current situation, a vision for community cares and explores some of the barriers that need careful consideration and planning.

Yvonne Wells features in Session 1 of Evolve.

INTRODUCTION

Our focus in this chapter will be on government funded programs that provide assessment and community services to older people living in the community. We will be looking at emerging issues and new directions in the provision of community care to older people.

In Australia, the system of care and supports for older people is broadly divided in two streams—residential care, which is provided in hostels and nursing homes, and community care, which is provided in people’s homes and community settings. However, older people also use a range of other services and supports. They are high users of health and hospital services; people over the age of 65 account for approximately half of all patient days in public hospitals (Australian Institute of Health and Welfare (AIHW) 2012). They use public and private housing services; about 5% live in retirement villages (Retirement Villages Association 2010). Finally, transport and other community services are vitally important to older people (World Health Organization (WHO) 2007).
Australian and state governments currently fund a range of community care programs. Generally, these are of four broad types: assessment and information; the Home and Community Care (HACC) program; a range of packaged care programs, which provide case management as well as direct assistance; and services that are directed to specific subgroups of older people.

It is important to understand the context in which these services are provided. Most significantly, the community care system for older Australians may be about to undergo radical change as a result of the recent Productivity Commission inquiry (Productivity Commission 2011) and the Australian Government’s policy response, Living Longer Living Better (Department of Health and Ageing 2012a).

THE AUSTRALIAN COMMUNITY SERVICE SYSTEM

The Australian aged care system is characterised by a mix of types of provision and a high degree of collaboration between all levels of government, service providers and the community (AIHW 2007). The Australian Government has the major role of funding both residential and community aged care services. It establishes the policy directions in consultation with state and territory governments and the aged care industry and consumers, and provides the bulk of administrative support.

In Australia, community services are provided by local government, not-for-profit, and for-profit organisations. Not-for-profits (NFPs) are defined as agencies that do not distribute profits or surpluses to personal owners or shareholders. They provide a substantial proportion of community care in Australia. Most (about 84%) of community care packages are delivered by charitable and other not-for-profit community-based providers. The remaining 16% are provided by commercial organisations, and state, territory and local governments (Department of Health and Ageing 2010). NFPs are critically important in providing aged care tailored to particular culturally and linguistically diverse (CALD) communities (Productivity Commission 2011).

Although residential care continues to receive most of the funding (about 66% of the 11 billion Australian dollars spent in 2009–10 on aged and community care (Productivity Commission 2011), a shift in funding towards community care has occurred and is likely to continue in the future. The following sections describe the major service types available in Australia.

AGED CARE ASSESSMENT PROGRAM

Since it was established in 1984, the Aged Care Assessment Program (ACAP) has been an important and integral part of Australia’s aged care system. The core objective of the ACAP is to assess the needs of frail older people comprehensively and to facilitate access to available care services appropriate to their needs. Aged care assessments also determine eligibility for Australian Government-subsidised residential aged care and packaged care services.

The ACAP has been a gatekeeper for access to intensive levels of care in both residential and community settings and has enabled the Australian
Government to implement planning targets for subsidised care. However, state and territory governments are responsible for the day-to-day operation and administration of the ACAP.

In 2009–10 the ACAP completed nearly 170,000 assessments of people in their target group, which is defined as people aged 70 and older or Indigenous people aged 50 or older; about 7.5% of all people in the target group received an assessment. Nearly half of the assessments (41%) were of people aged 85 years or older. More than 114,000 people were given approvals to enter residential care, and 69,000 were approved to use packaged care (Productivity Commission 2012).

The ACAP has developed differently in different places, and the scope and role of the ACAP varies to some degree between the various states and territories. However, reforms adopted since 2006 are addressing inconsistency by setting key performance indicators, implementing a set of validated assessment tools, and providing national training resources for ACAP staff. All Australian jurisdictions are actively involved in redeveloping assessment processes to better meet the existing and emerging needs of older Australians and to reduce the burden of assessment to provider and client.

HOME AND COMMUNITY CARE

The HACC program is the main provider of home-based care services in Australia. It provides a range of services to both frail older people and younger people with disability as well as their carers. The program was created in 1984 (via the Home and Community Care Act 1985) and brought together into one system a range of separately funded programs.

The HACC program provides maintenance and support services for people in the community whose independence is at risk. The program aims to prevent premature or inappropriate admission to residential care (Productivity Commission 2012). A wide range of services is provided under HACC, including assessment, domestic assistance and home maintenance, personal care, food services, respite care, transport, allied healthcare and community nursing. Services provided under HACC are not rationed by the Australian Government, and provision varies between states and territories. In 2009–10 more than 930,000 people received support from HACC and almost 13 million hours of services were provided. In addition, HACC provided over four million meals, nearly two million transport trips, and over six million dollars’ worth of home modifications. While two-thirds of HACC clients are aged 70 years or older (69%), HACC also supports younger people in the community with disabilities, and almost 11% of people who use HACC are aged under 50 years (Productivity Commission 2012).

In the past, HACC has been funded jointly by the Australian Government and state and territory governments. The state and territory governments were responsible for managing the program while the Australian Government maintained a broad strategic role. However, from July 2012, the Australian Government took full funding, policy and operational responsibility for HACC services for older people in all states and territories (except Victoria and Western Australia, where basic community care services will continue to be delivered under a program funded by both the Australian Government and the
state government). The state and territory governments will continue to fund and administer HACC services for people under the age of 65 or under 50 for Aboriginal and Torres Strait Islander people.

Since 2006 the nature of services provided under the HACC program has been changing, particularly in Victoria and Western Australia, in response to a range of pressures, including changing philosophies of care (described in more detail below) and a recognition by state governments that the service system needed to be re-designed. These shifts in HACC have been towards wellness and re-ablement approaches. In Western Australia, the Home Independence Program (HIP) targets older home care clients when first referred for assistance, while the Personal Enablement Program (PEP) is designed to meet the needs of clients who are exiting an acute episode of care in hospital. These programs are targeted at clients with no dementia. In Victoria, the approach has been developed as the Active Service Model (ASM).

PACKAGED CARE

In addition to the HACC system, the Australian Government supports aged care packages in the community and residential care places. The costs of packaged care are borne by the Australian Government, with some co-contributions from clients. Packaged care provides case management as well as direct care services, and eligibility is determined through an ACAP assessment. Packaged care, like residential care, is rationed. The Australian Government has set targets of 113 places per 1000 people aged 70 or older: 44 in high level residential care, 44 in low level residential care, and 25 in packaged community care. Over three-quarters of approved providers of packaged care are private, not-for-profit agencies (AIHW 2012).

A key feature of community packaged care is that care services are provided to approved care recipients on a planned and managed basis. Community Aged Care Packages (CACPs) are intended to provide community-based ‘low level’ care to people who would otherwise require a low care (hostel) residential place. The CACP program was established in 1992, and has grown rapidly; in 2009–10, nearly 60,000 people received a CACP (AIHW 2012).

In 1998 the Extended Aged Care at Home (EACH) program was introduced as a pilot program for frail older people with complex needs who require a high level of in-home care. The program was supplemented in 2004–05 by the EACH-D program, which provides care packages for people with dementia who experience behaviours of concern and psychological symptoms that impact on their ability to live in the community. In 2009–10 more than 10,000 people received an EACH package and 4800 people received an EACH-D package (AIHW 2012).

Table 6.1 provides rates of operational aged care places per 1000 in the population aged 70 or older for the 12 years from 1999 to 2011. Operational
### Table 6.1

Provision of residential care and aged care packages per 1000 aged 70+

<table>
<thead>
<tr>
<th>Year</th>
<th>HIGH-CARE RESIDENTIAL</th>
<th>LOW-CARE RESIDENTIAL</th>
<th>CACPS</th>
<th>EACH</th>
<th>EACH-D</th>
<th>TRANSITION CARE</th>
<th>TOTAL</th>
</tr>
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<tbody>
<tr>
<td>1999</td>
<td>45.7</td>
<td>40.5</td>
<td>8.5</td>
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<td></td>
<td></td>
<td>94.7</td>
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<tr>
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<td>44.2</td>
<td>40.3</td>
<td>10.9</td>
<td></td>
<td></td>
<td></td>
<td>95.4</td>
</tr>
<tr>
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<td>39.4</td>
<td>14.3</td>
<td></td>
<td></td>
<td></td>
<td>97.3</td>
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<td>15.0</td>
<td></td>
<td></td>
<td></td>
<td>97.9</td>
</tr>
<tr>
<td>2003</td>
<td>42.2</td>
<td>42.0</td>
<td>15.5</td>
<td></td>
<td></td>
<td></td>
<td>99.7</td>
</tr>
<tr>
<td>2004</td>
<td>41.6</td>
<td>42.4</td>
<td>15.6</td>
<td>0.5</td>
<td></td>
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<td>2005</td>
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<td>43.4</td>
<td>16.3</td>
<td>0.9</td>
<td></td>
<td></td>
<td>102.4</td>
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<td>2006</td>
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<td>43.8</td>
<td>18.2</td>
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<td>0.3</td>
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<td>19.0</td>
<td>1.7</td>
<td>0.6</td>
<td>0.8</td>
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<td>44.5</td>
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<tr>
<td>2009</td>
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<td>19.9</td>
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<td>1.1</td>
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<td>3.8</td>
<td>1.9</td>
<td>1.5</td>
<td>114.3</td>
</tr>
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</table>

Data from various Productivity Commission Reports on Government Services, Operational care places per 1000 people aged 70 years or older, available at <www.pc.gov.au/gsp/rogs>.
care places do not include places or beds that have been approved but are not yet filled, and the number of operational care places is a measure of access. As can be seen from the total column in this table, the provision of aged care places per population aged 70 and over has been growing steadily. However, the number of places in residential care has been levelling off or even decreasing, while the number of funded packages has been increasing. This recognises increasing demand for community care in preference to residential care.

RESPITE

The aim of the National Respite for Carers Program (NRCP) is to contribute to the support and maintenance of caring relationships between carers and care recipients by facilitating access to information, respite care and other support appropriate to the carer’s individual needs and circumstances, and those of the care recipient (Department of Health and Ageing 2012b). The NRCP assists carers with information, respite care and support. More than 650 respite services and 54 Commonwealth Respite and Carelink Centres across Australia are funded under the program.

For the purposes of this program, respite care is defined as a care arrangement whose primary purpose is giving the carer a short-term break from their usual caring role or assistance with the performance of their caring role on a short-term basis (Department of Health and Ageing 2012b). Respite services are delivered to carers and the people they care for in a variety of settings, including homes, day centres, host families and residential overnight cottages. In 2010–11 the NRCP assisted nearly 130,500 people (Productivity Commission 2012).

The vital role of carers was recognised in the government’s National Carer Strategy, which was designed following a community consultation process and launched in 2011. The strategy is intended to improve the current provision of assistance for carers and complements reforms which are currently occurring across the aged care system and in related healthcare systems.

The vital role of carers was recognised in the government’s National Carer Strategy, which was designed following a community consultation process and launched in 2011.

OTHER COMMUNITY CARE SERVICES

The Australian Government supports a range of other relatively small programs to provide community care for older people. Services similar to those funded under the HACC and packaged care programs are provided to by the Department of Veterans’ Affairs (DVA) under the Veterans’ Home Care and Community Nursing programs. In 2009–10 there were about 77,000 clients of the Veterans’ Home Care program, making it second only to the HACC program in terms of the numbers of older people it assists (AIHW 2012).
The Transition Care Program was established relatively recently, in 2004–05, as a jointly funded initiative between the Commonwealth and states and territories. The Transition Care Program is for older people who would otherwise be eligible for residential aged care. To enter the program, clients must be assessed by an Aged Care Assessment Team (ACAT) while they are still a hospital inpatient. A TCP provides goal-oriented, time-limited, therapy-focused care to help older people at the conclusion of a hospital stay. It may include low-intensity therapy (such as physiotherapy, occupational therapy and social work) and nursing support or personal care. It is intended to help older people complete their restorative process and optimise their functional capacity, while assisting them and their family or carer to make long-term care arrangements. Transition care can be provided either in a home-like residential setting or in the community. The average duration of care is seven weeks, with a maximum duration of 12 weeks that may in some circumstances be extended by a further six weeks.

Finally, a range of services is provided in mixed delivery settings that are designed to provide flexible care or specific support. For example, multipurpose services (MPSs) support the integration and provision of health and aged care services for small rural and remote communities where standard programs may not be viable if provided separately: day therapy centres deliver services such as physiotherapy, occupational therapy, podiatry and speech therapy to individuals or groups of clients to assist them to maintain or recover their independence; the National Aboriginal and Torres Strait Islander Flexible Aged Care Program aims to provide flexible, culturally appropriate aged care to older indigenous people close to their homes and communities; the Long Stay Older Patients initiative funds acute care services to support older people to maintain function while waiting for an appropriate residential care place to become available; and the Innovative Pool supports programs where mainstream aged care services might not meet the needs of specific locations or target groups and trials of new programs prior to them being rolled out as part of mainstream service provision. For example, the Consumer Directed Care (CDC) program is currently supported by Innovative Pool funding.

CARERS AND THE INTERFACE BETWEEN FORMAL AND INFORMAL CARE

Formal, publicly funded services represent only a small proportion of total assistance provided to frail older people. Extended family and partners are the largest source of emotional, practical and financial support for older people: about 76% of people aged 60 and over living in the community in 2009 who required help with any task received assistance from informal care networks of family, friends and neighbours (compared with 56% who received help from formal services: ABS 2009). Many people receive assistance from both formal aged care services and informal sources. In Australia, the essential role of informal carers in assisting older people to remain in the community is recognised through the provision of HACC services to carers and services such as the National Respite for Carers Program (NRCP).
Formal, publicly funded services represent only a small proportion of total assistance provided to frail older people.

The literature on long-term care for the older population has focused on trade-offs among different types of personal care in order to address the ‘woodwork effect’; the concern that public coverage for home care could cause a reduction in informal care (Agree et al 2005). However, studies have generally found that formal home care does not substitute for, or crowd out, informal care, and, in many cases, supplements informal care (Tennstedt et al 1996). Cohen et al (2000), in a North American study of informal carers, found that whether or not formal care substitutes for informal care is related to the characteristics of the caregiver. For adult children formal care sometimes substitutes for informal care, but this is not generally the case for spouses. Where the informal caregiver provides eight hours per week or less of help with activities of daily living (ADLs), paid help also tends to be low, but where the informal caregiver is providing large amounts of ADL help, paid help is also used for large blocks of time.

Informal carers actually facilitate formal care provision. Few older clients, either in the United Kingdom or the United States, receive formal care alone (Davey & Patsios 1999). Similarly, our analysis of the ACAP minimum dataset (Howe et al 2006) shows that clients with no carer are less likely to be using services than clients with a carer, and clients with co-resident carers are the group most likely to be using HACC and CACPs.

Little attention has been paid to where the cultures of the formal and informal sectors clash. A gulf may develop between the ways in which families perceive the task of care provision for someone who is sick or disabled and the way in which professional carers approach the task (Levine & Murray 2004). This gulf can lead to mutual incomprehension, disagreements, and even conflict. At worst, professionals ignore families’ perceptions and preferences, while families fail to comply with healthcare directions; professional carers perceive well-meaning family carers as interfering, while family carers see professionals as uncaring and unsympathetic; and each views the other as incompetent. This is particularly a risk where formal care is highly medicalised and removed from everyday experience.

TENSIONS AND PRESSURES IN THE AGED CARE SYSTEM

The combined effects of population trends, fiscal pressures and developments in service delivery models have increased pressure to ensure that resources available to the community aged care services are used in the most effective manner. This section of the chapter introduces some of these pressures and the next section describes some key concepts and solutions suggested to address them.

POPULATION

As with many western nations, our dramatically ageing population poses significant challenges for governments (WHO 2002). The large baby boom
generation is ageing and the number of older people is projected to increase rapidly. As the youngest of the surviving baby boomers reaches 65 years of age in 2031, the population aged 65 years and older is projected to reach 5.4 million in Australia (more than double the number in 1999) and will represent 22% of the total population (compared with 12% in 1999). As the youngest baby boomers reach 85 years of age in 2051, importantly, the population aged 85 years and older is projected to reach 1.3 million (more than five times the number in 1999) and to represent 5% of the total population (Trewin 2001).

In spite of steady growth in funding, all providers report that demand for services exceeds their capacity to supply them. Factors such as an increase in the number of clients remaining at home with complex care needs; difficulties accessing residential care; shorter hospital stays; more outpatient and day treatments; lack of post-acute home care provision from private hospitals; and higher community awareness and expectations about the benefits of the HACC program have all contributed to rising demand (Wittenberg et al 2004).

In spite of steady growth in funding, all providers report that demand for services exceeds their capacity to supply them.

In some countries, this increasing demand has resulted in longer waiting lists for clients assessed as having low level care needs. This is cause for concern, as research has suggested that risk may be imposed on clients if delivery of small amounts of critical services—targeted at clients at the time need is expressed—is delayed, or if services are not available at all (Elkan et al 2001, LaPlante et al 2004). If people with lower level needs are neglected, the opportunity to provide restorative services, at a time when clients are likely to retain sufficient capacity to maximally benefit, may be lost. It should be noted that a person’s need for services is related not just to their level of functional dependence, but also to their circumstances, especially the extent to which they have support from their family and community.

The steadily rising demand for services also continues to place pressure on many traditional community care providers to maintain services, sometimes over many years—for example, the provision of domestic services or meals-on-wheels—to all eligible clients in the community (Howe et al 2006, Parker 2001, Pilkington 2006). In some countries, this has resulted in longer waiting lists or cessation of service for those clients assessed as having low-level care needs.

In the absence of any further improvements in the effectiveness of our health and community care systems, it is unlikely there will be any deceleration in the growing demand for home care services. Rather, systemic issues are likely to have an increasing impact, including ongoing difficulties recruiting and retaining community care staff and the projected decline in family care with an increase in women entering or remaining in the workforce.
FUTURE AVAILABILITY OF CARERS

In the 1990s considerable concern was expressed about the future availability of carers for frail older people. Reasons for anticipating a potential decline in informal care include: declines in family size (Clarke 1995) and the proportion of older people who live with their children (Grundy 2000); rises in divorce rates, childlessness and employment rates among married women (Clarke 1995, Hancock 2002, Rowland 2007); and shifts in the nature of kinship obligations, especially in relation to filial responsibilities (Gans & Silverstein 2006).

In response to this concern, Carers Australia commissioned the National Centre for Social and Economic Modelling (NATSEM) to examine demographic and carer data from the Australian Bureau of Statistics (NATSEM 2004). The study projected a significant increase in the numbers of older people likely to need informal care in Australia between 2001 and 2031 along with a smaller increase in the numbers likely to be carers. At the same time, shifts in the composition of the disabled and carers’ populations were also projected, and both were predicted to include higher proportions of older people. Hence, there may well be increasing pressures on informal carers in the future. This, however, is not necessarily a cause for panic. Other OECD countries have already met the demands of the changing population structure that Australia is expected to encounter in the next few years.

COMMUNITY EXPECTATIONS

Both the community and governments have been aware for many years that the provision of community care services results in an overall improvement in the quality of life and maintenance of a basic standard of living for many frail older adults in the community and may reduce or delay high intensity, high cost services such as residential care or hospital admission (Elkan et al 2001). The majority of services were previously provided in a largely standardised way to all eligible clients, and often acted to substitute for activities previously undertaken by the individual prior to them experiencing difficulties with looking after themselves.

A growing number of critics suggested that community care programs in Australia were not as successful as they could have been because they relied on an outdated ‘dependency’ model of service provision rather than a newer focus on activity, independence and successful ageing (Baker 2006, Glendinning et al 2008, Hallberg & Kristensson 2004, Lewin et al 2006, O’Connell 2006). Services have often lacked an emphasis on the promotion of healthy lifestyles and daily routines, social support, exercise, and autonomy and control, despite strong evidence that these are strongly linked to the maintenance of health and independence in older adults (Peel et al 2004, Seeman & Crimmins 2001).

Many approaches to community care provision still give insufficient attention to an individual’s rehabilitative potential, and, via well-meaning attempts to assist, may actually prevent people from participating in important physical and social activities (e.g. shopping and cooking). Older people may become entrenched in a ‘sick role’, characterised by an absence of self-
motivation, and the view that because they are aged or unwell they must remain dependent upon continuous professional management of care (O’Connell 2006). The funding mechanisms that underpin many services also limit the capacity for services to provide restorative care. Many services are funded for short, task-focused events, which makes it difficult to use a flexible, goal-oriented approach to underpin a more restorative program (Ware 2002). Some staff may also believe that bed rest is beneficial for a frail or sick older individual, despite considerable evidence to the contrary (Baker 2006). Staff may exacerbate this situation by emphasising task completion and doing as much as they can for the client, rather than trying to assist the client to do things for themselves.

The funding mechanisms that underpin many services also limit the capacity for services to provide restorative care.

Such practices within community care services for frail older adults contrast sharply with the highly progressive movements that have occurred with other groups in developed countries over the previous 50 years. Older adults have not been entitled to the same empowerment-oriented and independence-focused approaches as other groups with disabilities: for example, the concepts of normalisation and social role valorisation, which transformed approaches to the management of intellectual disability (Wolfensberger 1972), the large-scale deinstitutionalisation of people with psychiatric and intellectual disabilities, the emergence of more flexible community management models (Mansell 2006), and, more recently, the chronic disease self-management movement from the US (e.g. Chodosh et al 2005). As the highly educated and proactive baby boomer generation enters retirement age, criticism of outmoded approaches is likely to intensify (Someya & Wells 2008).

KEY CONCEPTS IN COMMUNITY AGED CARE

Changes in community expectations have been mirrored in gerontology and the development of new models of community aged care. The discussion below outlines some of these concepts.

SUCCESSFUL AGEING

A key concept that has emerged in attempting to rethink how to address the needs and maximise the health and wellbeing of our ageing population is that of ‘successful ageing’ (Browning & Kendig 2003, 2004). Impetus for a conceptual shift towards more active, restorative models of care is mirrored by conceptual developments that have occurred within gerontology about what constitutes successful ageing.
Many traditional approaches to aged care emphasised rest, comfort, assistance and support. It has been suggested that this dependency model shares some features with the outdated ‘disengagement theory’ (Cumming & Henry 1961), popular in gerontological research in the 1960s. This theory proposed that in the normal course of ageing, people gradually withdraw or disengage from social roles as a natural response to lessened capabilities and diminished interest, and disincentives from the broader society to participate. Older people are viewed as happy to retire from work or family life, in order to make room for younger individuals. While winding down and preparing for death, they are then free to pursue other solitary, passive activities.

Recent theories of successful ageing have undergone a major shift in emphasis. The focus is now much more on the promotion of activity and active participation in society in order to maximise the physical and mental wellbeing of people as they age, rather than any suggestion that older adults should disengage from activities or society (Buys & Miller 2006).

Over the previous 15 years, broad-based theoretical frameworks have been developed to articulate the components of healthy ageing and relevant outcome measures (Buys & Miller 2006). A variety of terms have been used to describe these frameworks, including ‘healthy ageing’, ‘productive ageing’ and ‘successful ageing’. WHO published an ‘Active Ageing’ framework (WHO 2002), designed to overcome key criticisms and incorporate all the most important aspects of previous frameworks. The term ‘active ageing’ was chosen to emphasise the valuable contribution older people make to their families, communities and society. It is defined as: ‘the process of optimising opportunities for physical, social and mental wellbeing throughout the life course, in order to extend healthy life expectancy, productivity and quality of life in older age’ (WHO 2002 p 12). The framework emphasises the value of continued involvement across six life domains: social, economic, civic, cultural, spiritual, and physical. The phrase ‘engaged in life’ captures its underlying philosophy.

Conceptually, WHO’s definition of active ageing comprises three key pillars:

- participation: lifelong learning, paid and unpaid work
- health: achieving and maintaining good physical and mental health in later life
- safety: ensuring the protection, safety and dignity of older people by addressing the social, financial and physical security rights and needs of people as they age.

While the quality of the ageing experience will be determined by all three key pillars, there is some ongoing dispute about their relative importance. The West Australian Active Ageing Taskforce has suggested that participation, not health, should be the central pillar of the model. They also suggested that engagement in social and family connections should be placed under the participation pillar rather than the health pillar (Government of Western Australia 2003). Australian survey findings on older people’s perceptions of what constitutes successful ageing are consistent with the Western Australian perspective; that participation, including participation in social activities, is central to older adults’ views of what constitutes successful ageing (Buys & Miller 2006).
RESTORATIVE CARE AND PROMOTION OF WELLNESS

The concept of ‘wellness’ has been used for at least 30 years, but over the previous decade it has become a key concept in approaches to community care for older adults. Wellness refers to a state of optimal physical and mental health, especially when maintained by a healthy diet, exercise, and other habits. From an ecological viewpoint, wellness depends on the dynamic relationship between people and the quality of their physical and social environment (McMurray 2007). The term wellness has been used to emphasise a substantially broader definition of health than the more traditional one narrowly focused on the presence or absence of symptoms of illness (Crowther et al 2002).

The focus within health services has shifted over the previous 50-year period from treatment to prevention. Only half a century ago, community services were scarce and people typically went to their local hospitals for one-off treatment for an acute event or illness. Medications and technologies to prolong the lives of people who were frail or elderly were largely ineffectual. Improvements in medicine have resulted in individuals living much longer and chronic conditions (e.g. diabetes, arthritis, obesity and depression) are now more common. These conditions often require ongoing treatment in the community, and choices about lifestyle, such as exercise, diet and social connectedness, contribute to their emergence. Thus governments have focused on primary prevention of disease directed at all age groups (e.g. exercise promotion or quit smoking campaigns). Secondary prevention involves the early identification of disease or illness in order to teach individuals self-management strategies to avoid further exacerbation or decline. Tertiary prevention, in which efforts are made to rehabilitate remaining function wherever possible, is also effective in many cases (Godfrey 2001).

Evidence suggests that adopting wellness strategies is advantageous in all age groups, including the oldest (McWilliam et al 2000, Ryburn et al 2009). Strategies to enhance wellness include physical activity (e.g. through shopping, cooking and gardening), utilising aides and equipment, improving nutrition, developing new coping strategies to deal with episodes of depressed mood or stress, and increasing supportive social networks to avoid social isolation.

Restorative approaches to home care have been proposed as a way of reducing dependency in home care provision and to improve our capacity to cope with growing demand for care, via more timely and preventative services. An emerging body of evidence suggests that such programs are effective, including health promotion, occupational therapy and assistive technologies, physical therapy and social rehabilitation (McWilliam et al 2000, Ryburn et al 2009).

Governments in Australia have become interested in restorative programs following the success of re-enablement teams within the UK, where in 2010...
88% of councils had a scheme in place or were establishing one (Pilkington 2010). Re-enablement typically refers to intensive and time-limited multidisciplinary home care service interventions developed for people with poor physical or mental health, to help them learn or re-learn the skills necessary to manage their illness and to participate maximally in everyday activities. The majority of programs are relatively unselective and target clients at the beginning of their home care career, while others are targeted to specific clients post-discharge from hospital. Programs vary widely in their structure, staff skill mix, and nature of interventions, although they share general principles, such as a focus on helping people ‘to do’ rather than ‘doing to or for’, a specific outcome focus, and defined maximum duration. Each service provides comprehensive assessments and time-limited (up to two months) programs of rehabilitation in the client’s own home. Teams usually comprise occupational therapists, social workers, and home care agency staff; some teams also include physical therapists. Usually, these services are available to the range of frail older adults and younger people with disability who would be eligible for home care services in the UK. Some councils have made participation in such a program compulsory prior to commencement of home care services as usual.

Evaluations of the approach have supported it as having benefits for both service providers and older people. The City of Edinburgh Council Home Care Re-ablement Service, introduced in 2008, had been shown to reduce the number of hours of support required by clients at the end of their six-week period of re-ablement—by some 41%. Clients liked the service because it allowed them to regain their independence quickly and gave them the confidence to undertake tasks for themselves (McLeod & Mair 2009).

A prospective longitudinal study of home care re-ablement services examined the immediate and longer term impacts of home care re-ablement, the cost-effectiveness of the service, and the content and organisation of re-ablement services. People who received home care re-ablement were compared with a group receiving conventional home care services, and both groups were followed for up to one year (Glendinning et al 2010). Re-ablement was associated with a significant decrease in subsequent service use. However, these lower costs were almost entirely offset by the higher cost of the re-ablement intervention itself. Equally important, re-ablement also resulted in improvements in users’ health-related quality of life and quality of life up to ten months after re-ablement, in comparison with users of conventional home care services.

In Australia several pilot studies involving time-limited multi-component restorative home care programs have been trialled. These include the development and evaluation of the Home Independence Program (HIP) by the private home care provider Silver Chain in Western Australia (Lewin et al 2006, Silver Chain 2007), the Supported Independent Living Collaborative in Queensland, and the implementation of pilot programs across the state of Victoria. The West Australian state government has also funded the rollout of a broad-based training package within a range of existing home care providers outlining the principles of restorative care. The Wellness Approach to Community Homecare, or WATCH (O’Connell 2006) has now been formally recognised as a key priority for its home care system.
Lewin and Vandermeulen (2010) evaluated the HIP model by following up 200 clients both at the end of the re-ablement service and three and 12 months later. While this evaluation showed promising results, a later randomised controlled trial in which 750 community dwelling older people received either HIP or usual HACC home care services was more convincing. This trial showed that at three months, 78% of those who received restorative care no longer required a support service, compared with 31% of the control group, and at 12 months 86% of the intervention group no longer required a service, compared with 57% of the control group. Furthermore, over two years, the HIP group was less likely than the control group to use hospital emergency services (Lewin 2010).

The Victorian Department of Health (formerly the Department of Human Services) has developed a new service delivery model, the Active Service Model (ASM) (Department of Human Services 2008), in response to the perceived limitations of current approaches to service provision and increasing demands on the home and community care system. The model aims to incorporate conceptual developments in service delivery which have emerged from disability care provision in other sectors, an understanding of factors known to promote successful ageing, and theoretical developments in gerontology.

The Department of Health funded eight pilot projects in HACC from 2006 to 2008. These projects included a range of HACC activities, such as home help and garden maintenance, nutrition and physical exercise, and continence management. A series of evaluations concluded successful programs require both a shared vision and understanding about the aims and objects of the project from as early as possible in the planning and strong, ongoing leadership. Interventions were well-received by clients and were most successful when they forged strong relationships between staff and clients. Improved assessment processes and access to allied health expertise was highlighted as fundamental to success. Finally, workforce development and resources were seen as necessary for further development of the program (see Department of Health 2012a). Several programs to train staff in the ASM approach have since been instituted.

In Victoria all HACC-funded agencies developed an ASM initial implementation plan for 2010–11. The plan was to focus on identifying a summary of strengths, challenges and opportunities the organisation could see in moving to an ASM approach. In 2011–12 agencies were asked to review these plans and build on their experiences to develop new plans.

The adoption of an active service model involves a paradigm shift in the organisation of care, with substantial changes in service culture and challenges to the perception of ageing. The key features of the new active service model include:

- an emphasis on capacity building or restorative care to maintain or promote a client’s capacity to live as independently as possible (the overall aim is to improve functional independence, quality of life and social participation)
- an emphasis on a holistic, person-centred approach to care, which promotes client wellness and active participation in decisions about care
- an attempt to provide more timely, flexible and targeted services capable of maximising the client’s independence.
Implementing the ASM with a client may refer to very specific work involving just a single component (e.g. assisting a client to regain capacity for personal care following an acute episode such as a stroke), but it could also involve a broader range of services targeted at someone whose independence has slowly diminished, because of frailty or a chronic condition, with the aim of helping them to regain a degree of functional autonomy, self-confidence and connectedness with the outside world. In any case, an active service model implies a coming together of a range of strategies and services to promote wellness and independence within the limitations imposed by disease or disability for each individual.

Vignettes

The following vignettes have been adapted from the ASM pilot projects that have operated throughout Victoria. They are intended to highlight how some of the Active Service Model core components can be operationalised.

Mrs Andelucci

After a stroke left her with limited use of her left arm and poor mobility, Mrs Andelucci experienced depression and short-term memory loss. She was heavily reliant on social support and home help. She was rarely cooking for herself or taking care of even basic housekeeping tasks.

During the activity and nutritional program offered at the planned activity group that she regularly attended, Mrs Andelucci identified four goals:

- to improve her stamina and flexibility (a physiotherapist developed a strength training program and her home care worker encouraged her to carry it through)
- to learn to dance
- to do more cooking (she asked the home care worker to support her to buy ingredients and prepare basic meals in advance)
- to get involved in her community as a volunteer.

Mrs Andelucci quickly reaped the benefits of this focus on her own wellbeing. Within three months she felt she had turned a corner, happily observing her new ‘get up and go’. Mrs Andelucci had become more motivated about doing some of her housework, and was thoroughly enjoying cooking with the support staff and having food in the freezer. She felt physically more confident and was enjoying seeing new friends at the dance classes she had started attending.

ASM components

Health promoting
Capacity building
Access to skilled staff
Holistic
Social inclusion
Flexible and responsive

The planned activity group staff utilised goal setting and care planning to identify the tasks Mrs Andelucci valued. Access to the most appropriate support
was coordinated to provide services that were flexible and tailored to her needs; providing opportunities for health promotion, capacity building and social inclusion.

Mr and Mrs Cooper

Mr and Mrs Cooper were referred to their local council by their general practitioner for a home care service. The assessor found that Mr Cooper used to do most of the house cleaning tasks prior to his recent hospital admission for a fall and other complicated medical issues. Mr Cooper had reduced mobility and was not able to vacuum or wash the floor. Mrs Cooper was on 24-hour oxygen and experienced shortness of breath after minimal exertion during cleaning tasks.

Following assessment, a plan was put in place to increase both their physical capacity as well as strategies to facilitate their ability to resume cleaning tasks. Mr Cooper was referred to physiotherapy for an ongoing exercise group to increase his mobility following hospitalisation and Mrs Cooper was engaged in home care tasks with alternative techniques and equipment.

On review, Mrs Cooper had purchased her own motorised carpet sweeper and was cleaning a few rooms at a time. She had purchased a microlite mop and was managing to wash the floors well. The local council instituted a reduced ongoing service of 0.5 hours per month to vacuum the corners. Mrs Cooper commented: ‘There’s a big difference. The gadgets you’ve recommended have made cleaning a lot easier. Now I can last longer.’

Mrs Cooper received a timely and coordinated service to respond to a need that was only evident to the home care staff. The home staff member had been provided with training and support structures to assist him to connect Mrs Cooper to an appropriate service. This had a significant impact on her quality of life and confidence to reconnect to her community and family.

ASM components

Detailed assessment
Capacity building
Skilled staff
Functional exercise
Flexible and responsive

Without a detailed assessment, it is likely that Mr and Mrs Cooper would have received an ongoing fortnightly home care service that would have completed tasks for them. They were motivated to do as many of these tasks themselves and were assisted to simplify the tasks and build their capacity.

The council also provided a monthly service to address their unmet need.

Source: Department of Human Services 2008

Restorative approaches have also been implemented in New Zealand. Research here on the perceptions of paid caregivers showed that the restorative home care intervention has a substantial positive impact on paid caregiver job satisfaction. This appeared to be due to improved training, increased support and supervision, and improved flexibility. The intervention also resulted in substantially reduced staff turnover (King et al 2012).
PERSON-CENTRED CARE

The notion of ‘person-centred care’ has been adopted in several developed countries (Dowling et al 2006). Described in more detail elsewhere in this book (see Ch 7), it refers to a range of approaches that share a common goal: the prioritisation of the holistic range of care needs of the person receiving care and their carers (Department of Human Services 2003). Such approaches can be contrasted with services that are more oriented towards the priorities of an organisation or its staff (i.e. routines, time and tasks) or towards the provision of expert treatment for a specific illness or body part. Such services often provide a relatively mass produced or wholesale type of service, and take a very traditional view that service users are passive recipients of expert care, who do not need to be involved or take an active part in decision making or the development of services.

The concept of person-centred care aims to re-orient service delivery in two main ways. First, it counters the emergence of organisation or illness-centric systems that may be detrimental to the quality of holistic client care (Mansell & Beadle-Brown 2004). Second, it is a set of techniques that enable people to take a lead in planning all aspects of how the service they receive is delivered (Mead & Bower 2000).

Within the UK, person-centred care has been adopted as a central pillar of public policy for the development of health and community support for people, and has been clearly articulated within key policy documents since the late 1980s (Dowling et al. 2006), including the recent white paper, Our health, our care, our say: A new direction for community services, which placed emphasis on a person-centred approach (Department of Health 2006). Within Australia there has also been an emphasis on the concept of person-centred care in the release of the policy Improving health care for older persons: A policy for health services (Department of Human Services 2003). The development of the active service model for home care provision also falls within this framework, as it aims to increase the effectiveness of the HACC sector in improving health and quality of life outcomes, via the adoption of a more person-centred approach to care delivery.

A review of the literature on person-centred care concluded that evidence in the literature on the approach was limited but largely supports its effectiveness (NARI 2006). An Australian comparison of person-centred care, dementia care mapping (an approach that attempts to identify experiences from the resident’s point of view) and usual care for people with dementia in residential care concluded that both interventions were successful in reducing agitation (Chenoweth et al 2009).

CONSUMER-DIRECTED CARE

Consumer-directed care (CDC) is a practical extension of a person-centred care model, with its emphasis on client and carer choice, empowerment and self-management. Under this approach participants choose the services they receive and have a say in the choice of staff and timing of services. Participants may in some cases be able to manage an individual budget for services. In some
models, participants have been allowed to hire friends or family to provide care. In the past few years, consumer-directed care has come to denote particular services in which consumers are allowed to hire, train, supervise and pay their own workers, and, if necessary, to fire them.

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**Consumer-directed care is a practical extension of a person-centred care model, with its emphasis on client and carer choice, empowerment and self-management.**

Innovative programs have been developed in Europe and the US, and various types of programs have been tested internationally. In a review, Tilly and Rees (2007) argued that the evidence suggests that consumer-directed care may, in some cases, result in better care and greater satisfaction for participants and their families than for those who receive services from home care agencies. Quality of care has been found to be at least as good as it is in traditional programs, and there has been no systematic evidence of abuse or neglect of participants in CDC programs.

In 2004 the American National Council on Disability (NCD) conducted a literature review on consumer-directed care. It found the best studied examples of consumer direction have been in the area of long-term care, where consumer control of resources and direction of caregivers has been tested as an alternative to agency-directed community care. The review indicated that while virtually all consumers express a preference for community-based care, interest in consumer-directed or consumer-oriented healthcare models varies. Younger individuals seem to be more interested in consumer direction than older individuals. Nevertheless, interest in consumer direction is evident across a range of disabilities and ages. The conclusion of the review is that most studies of consumer-directed care demonstrate positive outcomes in terms of consumer satisfaction, quality of life, and perceived empowerment. There is no evidence that consumer direction compromises safety. Individuals who have participated in consumer-directed systems express strong preference for consumer direction and satisfaction with their care. However, there is conflicting evidence on the issue of cost effectiveness, perhaps due to variations in study design (NCD 2004).

Consumer-directed care has now been trialled in Australia. An early qualitative evaluation (Ottman et al 2009) indicated that CDC had the potential to empower people with disabilities and their carers. In 2010–11 and 2011–12 the Innovative Pool Program funded 1,000 consumer-directed care (CDC) packages and 400 consumer-directed respite care (CDRC) packages. The evaluation of this initiative (KPMG 2012) set out to assess the effectiveness of consumer-directed care approaches in the Australian community aged care context by examining the implementation, operation, impact and cost of the initiative. The predominant model implemented here offered participants ‘enhanced choice’ (KPMG 2012) of supports with providers maintaining responsibility for coordinating and managing packages. Other models incorporated different
levels of participant control and self-management. As participant control increased and participants moved towards managing their package themselves, the level of support, coordination and management undertaken by providers decreased. The evaluation found that most participants were able to manage their package to some degree. However, few took on a substantial self-management role. Even after a short period of operation, CDC appeared to have a positive impact on participants’ level of satisfaction with various aspects of their life, such as their ability to participate in social and community activities, and their health and wellbeing. The packages provided considerable benefits for carers from being able to plan supports and from being simply involved—sometimes for the first time—in the planning process. However, providers incurred some set-up and ongoing costs.

TARGETING

Targeting is one possible response to financial constraints. It can be defined as the principles and practices which providers adopt in making decisions about the allocation of services to individual clients and between clients among the client population they serve. Given that the resources available to HACC are limited, targeting necessarily requires consideration of the outcomes that can be achieved for different clients, taking into account their relative needs (NARI & BECC 1999).

The focus of discussion on targeting is usually at the individual client level. However, some decisions about resource allocation are also made at other levels as funds move from government to provider organisations in different regions, and from organisations to services (NARI & BECC 1999). These levels of decision-making shape the level and mix of services that can ultimately be allocated to clients and carers. Decisions made by providers about allocating resources in smaller or larger amounts to one or another individual client cannot be considered in isolation from the other levels of decision-making. Even at the individual client level, resource allocation decisions are not one-off, but repeated as the client moves along the pathway from initial eligibility for service, to assessment and care planning, to possible review and re-assessment, and to eventual discharge when the service is no longer needed or because of a change in care arrangements or move to residential care (NARI & BECC 1999).

The debate about targeting of community care services in the US began in the 1980s when extensive demonstration projects that aimed to establish whether community care could reduce the use of nursing home care were initiated under the umbrella of the National Long-Term Care Channelling Demonstration. By the early 1990s, a large body of literature reporting evaluations of these projects was available. The results of most of these evaluations—based largely on aggregate accounts of outcomes for total client populations—were, at best, ambiguous. The failure to produce more conclusive results was frequently attributed to poor targeting. Calls for ‘better’ targeting in turn opened up discussion as to what this might mean and how it could be achieved (Howe et al 2006).

More convincing evidence of the effectiveness of community care began to emerge from a modelling exercise using data from the Channelling
Demonstration (Greene et al 1995). The authors argued that much of the failure to find convincing evidence for the efficacy of community care was due to design shortcomings in most of the earlier evaluations, particularly the failure to disaggregate the effects of particular kinds of services for particular groups of clients. Greene et al (1995) went on to develop a transition probability model and used data from the Channelling projects to show more effective outcomes could have been achieved with different distribution of the same resources.

The most recent formulation of the targeting debate in the US was set out by Weissert et al (2003), who analysed home and community care in the US over more than three decades, discussed several longstanding shortcomings in existing targeting policy, and proposed an alternative called ‘titrating’. This model suggests that simple ‘in or out’ targeting should be replaced with an approach that takes account of the effectiveness (E) of home care services in mitigating the risks, the risk (R) of adverse outcomes and the value (V) of the outcomes achieved relative to those avoided. The ERV model calls for titrating care rather than targeting clients. The proposed titrating model would be generous in eligibility—that is, access to services would be relatively easy—but the number of resources actually allocated to each client would be carefully calibrated. The ERV model does not deny any services to low dependency clients, but allocates more services to high dependency clients only when the additional inputs will achieve a cost effective reduction in risk of an adverse outcome.

Robust evidence from diverse studies shows that small amounts of service, provided early, are worthwhile. Provision of small amounts of service is effective in restoring functional decline in particular, and also protects against a range of adverse outcomes. Elkan et al (2001) provided an excellent systematic review and meta-analysis of the impact of home-based support on older people. They reviewed 15 studies of home visiting, of which 13 were randomised controlled trials and two were quasi-experimental designs. The home visit could comprise of surveillance, support, health promotion, and the prevention of ill health, but excluded specialist visits such as district nursing or community psychiatric nursing. The study demonstrated a positive impact of home visits on reducing mortality and admission to residential care. The effectiveness of an intervention did not depend on whether it was targeted at at-risk older people or more widely.

The evidence of the benefits to clients of using only limited services is particularly strong in comparison to those using no services and reporting unmet need for assistance. In Australia and elsewhere, many of those receiving no formal assistance are at high levels of dependency and so face considerable risks of adverse outcomes.

Specific allied health interventions are among those for which there is strong evidence of positive outcomes. For example, Lin et al (2004) demonstrated the effect of low intensity home-based physical therapy (only once a week for 10 weeks) on activities of daily living and physical motor function in clients who had suffered a stroke. A Cochrane collaboration meta-analysis showed that individual exercise programs, as well as group programs and tai chi, are effective in reducing falls and the risk of falling in older people living in the community (Gillespie et al 2009). These and similar studies support the development of more active interventions within the HACC system to support client
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independence. The evidence to support the benefits of aids and equipment is also strong, particularly to support walking among the population aged 80 years and over (Freedman et al 2006).

The evidence for case management is more mixed. However, some studies have shown that provision of case-managed services can delay admission to residential care for people with dementia. In the UK, for example, Challis et al (2002) showed that fewer people in an intervention group that received intensive case management were admitted to residential care during a two-year period than people in a control group. In the US, Gaugler et al (2005) analysed data on more than 4700 carers and 5300 care recipients. They showed that early use of community services is likely to be of more benefit both for carers and care recipients than if service use is delayed. For carers in the earlier stages of their role, use of in-home services such as personal care or help with chores predicts a delay in admission to residential care. The authors suggested that earlier results which had shown equivocal relationships between use of community services and admission to residential care may be attributed to the studies’ lack of consideration of the timing of service provision.

In Australia Doyle et al (2005) reviewed the literature on the use of case management for people with dementia living in the community. They concluded that although earlier studies indicated that case management could precipitate admission to residential care, more recent studies have generally found that case management delays admission. Importantly, some evidence indicates that the earlier community services are provided, the longer the delay in admitting a person with dementia to residential care.

The evidence is mixed in relation to the outcomes of additional levels of services, including case management. An underlying reason for limited success is that higher levels of service provision are generally associated with higher levels of dependency, making it increasingly difficult for additional services to moderate the effects of multiple dependencies. A second reason is the lack of consistency in allocation of services to clients; variations in provision are often unrelated to client dependency or other relevant characteristics.

The evidence suggests that a combination of strategies that maintain the current broad-based eligibility and access to the basic tier of services, and a refinement of comprehensive assessment and access to progressively higher levels of care, could achieve more consistency in access and improved effectiveness of service delivery at different levels of care.

THE ROLE OF ASSESSMENT

A shift towards restorative models of service provision has demanded a change in assessment practices. However, by itself, assessment of older people requiring care is a valued service that may lead to positive outcomes. Randomised controlled trials have shown that comprehensive assessment of older people has demonstrated benefits in terms of functional status and quality of life (Kuo et al 2004). Among well-functioning older people, comprehensive assessment can delay the onset of disability (Büla et al 1999) and reduce re-admission to acute care. For example, Caplan et al (2004) reported a randomised controlled trial of elderly patients at Prince of Wales Hospital, Sydney, who, on discharge, either
received a comprehensive geriatric assessment and interventions or the usual care. Patients who received a comprehensive geriatric assessment as well as a multidisciplinary intervention maintained physical and mental function better than those who did not. The authors recommended that all patients aged over 75 presenting to an emergency department should be referred for comprehensive assessment.

**A shift towards restorative models of service provision has demanded a change in assessment practices.**

While the major provider of assessment services in Australia, the ACAP is not the only provider. The complexity and potential duplication of assessment processes for older adults within the community sector was analysed by Eagar et al (2005), who identified at least eight types of assessment ranging from collection of basic demographic and personal information to determine eligibility for specific services to wide-ranging in-depth assessment across physical, social, and psychological and cognitive function. Multiple assessment systems and tools are employed in the community aged care sector with wide variation in the use of standardised assessment procedures. For example, the screening tools that are widely used in HACC, the ACAP assessment and CACP assessment differ substantially from one another (AIHW 2004).

Foreman et al (2004) reported a similar high level of variation between regions and providers in comprehensive assessment processes, tools, point of entry and balance between breadth and depth.

As noted previously, a move to more standardised and integrated approaches to assessment has been a theme of the reform agenda, along with what is being assessed and how the assessment is conducted. Assessment, no matter how streamlined and standardised, is only useful to the extent that it can inform effective service provision. The challenge for the current assessment reform agenda is not only to improve assessment processes in terms of reducing duplication of assessment, introducing more standard, valid and reliable processes, and facilitating transfer of assessment information between care settings and care episodes, but also to deliver assessment outcomes that can contribute to the new models of care emerging in the sector. This means moving away from reliance on a deficit-focused assessment and towards an approach that encompasses client strengths and assets and informs goal-setting that is client-centred and restorative in nature. In addition, assessment processes should recognise that, for a frail older person, as care needs change with time so assessment processes need to be both progressive (more information will be required over time as the older person’s support needs increase), and recursive (the person’s status in relation to service requirement should be reviewed on a regular basis).

In an attempt to move assessment away from a deficit model, Victoria has introduced the Living at Home Assessment (LAHA) as part of the HACC program. This person-centred assessment of the person and their family or carer’s needs leads to a care plan and individualised service responses (Department of Health 2012b). The first step in implementation of the HACC Assessment Framework was to designate 100 HACC-funded organisations as...
HACC Assessment Services. A mix of local councils, health and community health services, nursing services, Aboriginal community controlled organisations and community service organisations were so designated early in 2008.

THE PRODUCTIVITY COMMISSION REVIEW AND AUSTRALIAN GOVERNMENT RESPONSE

The National Health and Hospitals Reform Commission, in its report *A Healthier Future for All Australians* (2009), indicated that the aged care system needed significant reform to meet the challenges of an older and increasingly diverse population. In response, the Australian Government commissioned the Productivity Commission to develop detailed options for redesigning Australia’s aged care system to ensure that it could meet the challenges it will face in coming decades. In 2010–11 the Productivity Commission conducted an extensive public inquiry into the future of aged care in Australia. In the course of this inquiry, the commission consulted widely with older Australians, their carers, aged care providers, government agencies and other interested parties. The PC released a final report in August 2011 (Productivity Commission 2011). This report highlighted a significant number of challenges in the aged care system. It described the system as difficult to navigate, and services and consumer choice as limited. The quality of services is variable, with inconsistencies and inequities in coverage of needs, pricing, subsidies and user co-contributions. Workforce shortages are exacerbated by low wages, and some workers in the system have insufficient skills to meet the tasks they are required to perform.

The Productivity Commission’s report included a series of recommendations in 10 key areas, which included: funding mechanisms; the nature and quality of care and housing services; an emphasis on diversity; support for carers and volunteers; the need for better policy research and evaluation; and a possible implementation timetable. Importantly, the PC recommended that there be a single gateway for accessing services, a single system of integrated and flexible care packages, and a focus on re-ablement. The Productivity Commission also recommended that the basis for provision of aged care services shift from a rationed system to an entitlement-based one in which people would be funded to receive care and support according to their assessed needs.

The Australian Government responded to the Productivity Commission’s report firstly with a series of community consultations by Minister Butler and COTA (Council on the Ageing 2012) and secondly with a policy initiative: Living Longer Living Better. This aged care reform package is intended to ‘build a responsive, integrated, consumer-centred and sustainable aged care system, designed to meet the challenges of population ageing and ensure ongoing innovation and improvement (Department of Health and Ageing 2012a p 16).

Other key government directions include a range of proposals to assist people to remain living at home, to support carers, to change the funding of residential care, to up-skill the workforce, and to promote research and evaluation. Special areas of attention include better healthcare, including primary care, tele-health and palliative care, and attention to dementia and diversity. The government has proposed new ways to access the system,
including a national call centre and a My Aged Care website. Finally, the government has endorsed a positive ageing agenda.

The government has recognised that limited data and evidence are available in aged care. This means that both providers and users of aged care are not as well informed as they could be in making decisions about care and support needs. More research is needed to evaluate current services and to provide an evidence base for future directions.

The reforms will be implemented in three phases from 2013–14 to 2021–22 and include funds to support the development of more residential aged care facilities in areas of greatest need (including rural and remote areas) and to expand home care services. Two new types of home care packages will be introduced from July 2013 to allow a seamless continuum of care at home. The new packages will support people with basic and intermediate care needs and will complement the existing CACP and EACH packages. A new dementia supplement will also be introduced from July 2013 to support people with dementia receiving care at home and in residential care settings (AIHW 2012).

There has been broad agreement with the government on the general direction set in the new policy. In mid-2012, Kendig commented:

*The reforms outlined in the Living Longer Living Better report align with important values about what older people (and their carers) want—to stay in their own homes for as long as possible. There’s an emphasis on a fairer, more accountable, and more sustainable financial system. Inconsistencies in existing funding arrangements will be addressed and consumer protections strengthened. And the proposed Gateway and My Aged Care website service have potential to improve transparency and access to services.*

(Kendig 2012)

However, since then, aspects of the implementation of the policy, including the redirection of funds away from residential care to workforce training, have become highly contested. In addition, it is not clear to what degree the current Opposition would implement Living Longer Living Better if elected. Without bi-partisan political support, it is difficult to know what the future of the policy reforms might be.

**CONCLUSION**

Community care is an essential and growing component of aged care services in Australia. Demand for community services is likely to grow in response to population ageing and this growth in demand is likely to be accelerated if existing social and demographic trends result in decreased availability of informal carers, as has been predicted. Moreover, future users of community care services are likely to have more complex and diverse needs as the current trends in dependency levels among community-dwelling older Australians and differential ageing rates among different migrant groups in Australia carry forward into the future as expected. Increased demand on community aged care service will continue to direct attention to the need to develop effective strategies that ensure the best use of funds and to the related but more general question of what we should be trying to achieve through the provision of such services.
The challenge for the community care sector in this context is to ensure the projected expansion of community care occurs in parallel with movement towards more coordinated, responsive effective care that enhances the autonomy and dignity of older Australians. Emerging models of care which are more closely aligned with broader conceptualisation of positive ageing and client-centred and consumer-directed care provide examples of what may be possible in terms of service delivery and point the way for development of the sector. It is to be hoped that the broad directions pointed out by the Productivity Commission’s review will guide change and reform in community aged care in coming years.

Reflective questions

1. The three key pillars of active ageing (WHO 2002) will impact on the ways in which services are delivered in Australia. How can local communities act to facilitate these positive changes?

2. If participation is the most important way to improve a sense of wellbeing and improve social inclusion, then a funding shift will need to occur. What impact will this have on services?

3. Promoting wellness and independence through a restorative approach to care is an exciting approach and is already affecting service delivery in Australia. What barriers might prevent this approach reaching its full potential?

4. In Australia, an entitlement approach may well replace rationing in community aged care. What are the costs and benefits of this approach for older individuals and service providers?

References


Levine, C., Murray, T.H. (Eds.), 2004. The cultures of caregiving: conflict and common ground among families. JHU Press, USA.


Lewin, G., Vandermeulen, S., Coster, C., 2006. Programs to promote independence at home: how effective are they? Silver Chain, Perth, Western Australia.


Pilkington, G., 2006. Homecare re-ablement workstream: executive summary. Care Services Efficiency Delivery Program, Department of Health Kingdom, United Kingdom.


