Hopscotch on Walking Frames

Good care should not be a matter of chance.

A response to the Productivity Commission's Issues paper, Caring for Older Australians

Older People's Reference Group
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Who we are
The Older People's Reference Group (OPRG) is a policy advice body with an ad hoc relationship with the NSW Council for Social Service. Our Chair is Mrs Sheila Rimmer AM, Secretary Ms Betty Scott, with members Marlene Brell, Anthony Brown, Emeritus Professor Sol Encel, Dr Sara Graham, Penelope Nelson, Christine Regan and Kay Robinson. Our policy interests encompass the full spectrum of issues of concern to older people, including carers, health, allied health, men's well-being, nutrition, housing, volunteering, transport and utilities, pensions and incomes, community services and aged care.

We are based in Sydney.

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The Productivity Commission issues paper, *Caring for Older Australians*, outlines the current Australian aged care system in all its complexity, and raises some pertinent questions. The future of the sector is crucially important and we applaud your study. The issues we raise in this submission stem from many concerns we have about the current system. Figure 1 on page 7 of the issues paper is a key to the elements involved in Government-subsidised aged care in Australia and (perhaps inadvertently) illustrates the barriers that the system may present to those who do not work in it.

From a consumer point of view, the need to come to terms with a complex system, complete with a dozen new acronyms (ACAT, HACC, CACPs, EACH, EACHD, etc.) represents a huge hurdle. The individual must await classification by experts. Once classified, the person may make certain moves, but only those allowed by the rules of the system, as in a board game or hopscotch grid (see broken and non-broken lines, Figure 1, page 7 of issues paper). The person in need of care becomes a minor player in what might be called ***Hopscotch on Walking Frames.***

Finding the right type of care at a time of crisis is stressful, confusing, frustrating and likely to cause great anxiety for all concerned. When a solution is found, it may entail a loss of personal autonomy. (See subheading **Institutionalisation** on page 6 in section on Residential Care below).

Older people in the wider community use few of the specialist terms. They often refer to residential care facilities as "those places".

Principles and values
We believe that any reforms to the aged care system should embody the following principles and values:

1. Autonomy and choice
Older people should have the right to make their own decisions so far as possible – where to live, who to associate with, what medical treatments to choose, and so on. The rights of the individual are paramount and far outweigh the convenience of the system. Where the individual's impairment reduces the ability to make decisions, the choices should be made by a chosen guardian, family member, advocate or carer.

2. Social inclusion and community participation
An inclusive community provides services for all age groups and avoids excluding people on the ground of age. So far as possible services should help the individual maintain community participation. Contact with friends and community activities add joy to life, and older people have much to give to others.

3. Quality, equity and affordability
The aged care system should provide a decent standard of service for all Australians, regardless of their income, social status or cultural background. It is not acceptable that some of our most vulnerable citizens sacrifice their dignity and comfort because of inadequate resources.

4. The crucial role of carers
Without the contribution of carers, Government expenditure on aged care would be far higher. Carers must be recognised as individuals in their own right. They deserve support in terms of respite care, allowances, and recognition of their role.

Information and access
Unless people know what their choices are, how can they make good decisions? It should be much easier to understand what care programs are available in the community and in residential facilities. Less jargon, more accountability, more public information and more access points are needed. Local councils are well placed to provide details of options in their areas. General practitioners, and especially the proposed new primary health care centres, are also suitable points for information.

Care in the community

As stated in the issues paper, most aged care is community based, unpaid and informal.

We strongly support all options that allow the individual to remain at home with support. Care in the community is the preferred choice of the great majority of older people who value independence even when they become less mobile or rely on others for some help. It is far more economical to provide care in the community than to move the individual to a residential facility. This is an area where community opinion and Government economic priorities coincide. We favour increasing the proportion of community care funding which is available for experimental ways of providing support. For example, start-up funding for community support systems such as London's largely voluntary membership-based Southwark Circle, www.southwarkcircle.com.uk, could save money in the long-term. The scheme facilitates different types of mutual aid – including voluntary, paid or traded services, using tokens or cash. It links people to one another, with all types of local services ranging from haircuts and community transport to help with tax returns.

Universal design, accessibility and safety

As Australia's population heads towards 30 million, with a greatly increased number of people aged 70+, and in particular 85+, design standards for dwellings will become very important. Doorways and bathrooms that can be used by someone with a walking frame or a wheelchair will no longer be the preserve of hospitals and other institutions. We applaud initiatives such as the Benevolent Society's Apartments for Life, based on a Dutch model, and recommend that other imaginative approaches that have succeeded elsewhere be investigated, and where culturally relevant, tried here. Social housing for older people must incorporate universal design, as must housing for people age 55+ built under State Environmental Planning Policy 5. There must be incentives for developers to build age-friendly dwellings.

Falls are a major source of injury, disability and death for older people. More services are needed to enable the modification of homes with suitable railings, lighting and other safety features. There is currently insufficient funding for these important modifications.

Recent research from the Older Women's Network highlights the vulnerability of some older people to physical and financial abuse where a family member has dementia, is an alcoholic, or has a gambling addiction. Care agencies need to liaise with police where abuse is suspected.

Access and continuity problems
Delays occur at many points on the hopscotch grid. There is often a waiting time of several weeks, even months, before someone is assessed by an ACAT team. It is not always easy to gain services from a local HACC service, or to be confident they will be available as long as needed.

Community transport is a vital service for vulnerable older people who live at home but need to visit doctors, dentists and allied health professionals, as well as shops, cultural and recreational activities.

Community facilities such as registered clubs, sporting clubs and shopping malls all have a role to play in encouraging older members of the community to remain active participants.

Quality, equity and choice of care
We are aware that residential care is usually the most viable option for those who require 24-hour access to help, and that many facilities are excellent and staffed by dedicated people. All providers of residential care receive similar subsidies, but the standard of provision varies widely.

The individual's entry to the residential care system seldom occurs after careful planning. The following scenario is all too likely:

> *The individual falls or suffers a serious illness. For some days or weeks she receives medical and nursing care in hospital. Then she improves slightly. There is pressure to "free up hospital beds" as politicians and economists like to put it. She is transferred by ambulance to another type of care.*
>
> *This is something of a lucky dip, depending on her location, her advocates, her health insurance status, and her attending doctor.*
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> *Lucky options include rehabilitation hospitals, where expert physiotherapists, speech pathologists, gerontologists and aged care nurses help the individual regain strength and return to individual living. Respite care in a well-run aged care facility can be a lucky option too, if there is an exit strategy for return to the community.*
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> *However, it is far too likely the individual will enter a merry-go-round of respite placements in different locations or be consigned to one that is crowded, ill-staffed, urine-scented, badly furnished, uncaring, ugly and reeking of despair. Sending anyone to such a place as the 'set and forget' option is just not acceptable. Without physiotherapy, medical care or ongoing support, it may be impossible to regain autonomy. The individual risks spending the rest of her life in residential care, not because there are no other options, but because the family or guardian is unaware of them.*

Good care should not be a matter of chance.

Residential care

The current system has shown itself deficient in some areas. A disturbing proportion of aged care residents are **malnourished** – they are simply not getting enough nutritious, varied, palatable food. Many aged care residents, particularly those with dementia, are **over-medicated**. The use of anti-psychotic drugs to keep elderly Australians, mostly powerless old women, quiet and uncomplaining, is an affront to human decency.

Too few residential facilities have outdoor walking tracks for energetic older people with dementia. Public health programs for the general community applaud outdoor exercise, but a demented patient may be labelled a "wanderer" and in need of medication.

Encouraging high standards

Good leadership, commitment, high ethical principles and dedication to creating a good workplace may be as important as Government subsidies to the creation of a superior facility. The challenging and demanding nature of the work in aged care facilities must, however, be well recompensed. The incomes of those who work in the sector should be as high as those of health care workers in other parts of the health system. Professional associations have a role to play in upgrading training and recognising excellence.

The aged care sector has a low public profile. During the promotion of current changes to the health system, television cameras followed the Prime Minister into hospitals all over Australia. High-care nursing homes were nowhere to be seen.

Institutionalisation

In high-care residential facilities, there is too often a progressive diminution of personal autonomy. It is a denial of dignity to characterise someone as incontinent rather than help her go to the bathroom, even if that is more convenient for staff. The resident who uses a wheelchair may require less staff time than the one who uses a walking frame. Noisy television programs may run all day regardless of individual choice. It is a struggle to retain individuality in a setting where staff members take charge of medications, meals and timetables.

All too often staff say things like, "They'll soon settle down." This, unfortunately, may mean *We'll institutionalise them soon enough.*

The autonomous route to residential care

We support the concept of "consumer driven care." (page 13 of issues paper)
An example:

> *Lester (not his real name) is a low-care resident of a hostel in inner Sydney. He chose to enter the facility, and to sell his flat to pay the bond, when he realised that shopping, cooking and cleaning were becoming too much for him, given his health*

problems. He knows the area, the bus and train routes, the local shops and parks, and his friends find it a convenient place to pick him up for outings. He's happy about a transition that he chose himself. By contrast, he finds many of his co-residents unsettled, angry and confused. They did not choose the move and feel betrayed by their family and GPs. In other words, Lester has no sense of social exclusion. He is still part of his community. The same cannot be said for those who had no choice.

Advocacy

As older people become increasingly frail and vulnerable they are likely to find it more and more difficult to navigate the complexities of the aged care system. Furthermore, with increased frailty people often become less able to express their wishes or exercise their rights. They become increasingly powerless. The vulnerability of those without advocates or informed family members or guardians is of great concern. We would argue that the most socially isolated, the poorest members of the community and those who lack an effective spouse or adult children are particularly vulnerable. They are often in desperate need of independent representation or advocacy. In these circumstances the need for someone to represent their interests becomes critically important.

People living alone

On 9 June 2010 *The Australian* quoted ABS estimates that there will be between 3 and 3.5 million Australians living alone by 2031, an increase of between 63% and 91%, with the trend strongest among women. There were 1.9 million people living alone in 2006, already a high figure. These demographic trends make it clear that increasing numbers of people will be reaching frail age without advocates.

Retirement village living

Retirement village living may enhance social inclusion and sense of community, but it is a minority choice. A 2009 Ernst & Young report estimated that 3.25% of Australians aged over 65 live in retirement villages, but that this could grow to 5% within the next 12 years. A new report from the Australian Housing and Urban Research Institute (AHURI), *Service integrated housing for Australians in later life* - www.ahuri.edu.au/publications/recent.asp - finds that retirement villages for independent people are becoming the preserve of those who can afford hefty purchase fees or donations on entry. AHURI research shows that people who move in a friendship group to a particular centre or village are most likely to express satisfaction. The happiest residents are those who move to a village while still reasonably energetic and open to new friendships.

Too many retirement villages are located away from other services – shops, doctors, bus stops and cinemas. Residents who no longer drive must rely on village buses, provided at the discretion of management.

Retirement villages are already heavily regulated. It is dubious whether more regulation would provide better transitions between village living and residential care. Some so-called 3-tier villages appear to offer hassle-free transitions. In truth, village residents queue up for ACAT assessments like anyone else. Better transitions will occur through the availability of more places offering quality care, and greater availability of information about options for intending care residents and their families, community care workers and GPs.

In other words, the aged care system needs to interface better with the whole community, not just "the wider health and social services sector" (page 13 of issues paper), and not just with the retirement village sector.

Catering for diversity

The perceived lack of diversity in the aged care system reflects the institutional culture of facilities where staff convenience counts for more than residents' needs. An aged care system where the individual is paramount would not need to provide separate services for people with a mental illness, those with a disability, those of a culturally and linguistically diverse background or those who have a gay or lesbian sexual orientation. Care facilities that refuse entry on any of these grounds should not be entitled to Commonwealth subsidies. It is also totally unacceptable for married couples, de facto partners and same-sex couples to be split up because they fall into separate boxes in the Hopscotch grid. Their health status should not dictate their entire life choices.

Objectives of the aged care system

We offer some brief responses to the questions on page 15 of the issues paper: *How effective has the aged care system been in addressing these objectives? What changes if any should be made to these objectives? What are the implications of any redesign of the current system?*

The assumption underlying the current Aged Care Principles seems to be the provision of services FOR older people BY professionals who know best and set the parameters. Throughout this submission we have stressed a consumer-based approach with a focus on the individual.

The National Healthcare Agreement refers to "services that are appropriate to their needs and enable choice and seamless, timely transitions within and across sectors". ***Appropriate*** is far too vague a term and is no guarantee of a consumer focus, social inclusiveness, quality, equity and affordability. A minimum staff/resident ratio should be introduced, based on the current best practice, as assessed by consumers as well as professionals.

The principles of **accountability and transparency** are more honoured in the breach than in the observance. The results of nursing home inspections must be

readily available to the public. The complaints system is intimidating to some older people and their advocates, and there is insufficient public information about care components and costs for comparisons to be made easily. The public should know what our tax dollars are (or are not) providing. Good care should not depend on good luck.

Consumers should be represented on Aged Care Advisory Committees.

Public information similar to the MySchool website would be a start; or a zero-star to 5-star system similar to that used by hotels.

(On the subject of hotels, why does your issues paper refer to linen, cleaning and meals as "hotel-like" services? They are standard residential services, provided in prisons and boarding schools as well as in hotels. They are not luxury extras.)

Who should pay and how much?
Pensioners without assets who contribute 84% of their pension, leaving only pin money, already pay a steep price for aged care. Your issues paper refers to the need to consider "taxpayers" and "the whole community", not just older Australians. It must be borne in mind that older Australians have been taxpayers and many still are.

The disparity between an average bond of more than $200,000 for low care, while none applies for high care unless "extra service" is provided, cannot be justified in the long term.

Our committee accepts that older people with assets may at some point have to contribute an entry bond for both types of residential care. However, any change that requires the family home to be sold is likely to be unpopular for a number of reasons, including:

- the sacred nature of 'the family home' in Australian political rhetoric and in public discourse – the home is the major asset and tangible result of a life's work for most older people;
- the inheritance expectations of family members who hope that the family home, unencumbered, will one day be theirs;
- the Catch-22 that a pensioner who sells the family home may fail the assets test, risk losing the pension, and face an unspecified entry bond to be "negotiated" between parties where the aged care provider has much more power than the frail person; (page 22 of issues paper)
- and finally, being left with at least $37,5000 after paying a bond (Box 4, page 18 of issues paper) is not much consolation – in today's money that is a paltry sum, much less than the average wage for one year. The sum left untouched should be at least $110,000.

Other issues

What are the critical funding implications and concerns at the interface of the aged care system with the disability and hospitals system?

At present the aged care system is much cheaper than the other sectors, because it has a lower skill base among staff, and provides less intensive treatment. Too often this is the 'set and forget' method of freeing up hospital beds. People discharged from hospital need ongoing help with mobility, psychological well-being, pain management, and decisions about ongoing accommodation and care. A more satisfactory system will upgrade the skills base of nursing homes, provide more GP, consultant physician and allied health services in aged care settings, and provide information and choice as a matter of course.

Location

A socially inclusive approach will provide aged care services close to the friends, family and community of the people receiving care. Being shunted to a distant town or suburb is distressing for older people and those who love them. Often husbands and wives are becoming frail themselves, and long travel for regular visits is hugely stressful. Public transport and community transport are both important here, but local services are more important still.

Palliative care

We see no reason why some terminally-ill residents should not be able to receive palliative care in high care residential facilities. Transfer to a hospice may be necessary in some cases, but in others it is needlessly disruptive. We support the provision of palliative care at home in the community for those terminally ill older Australians who make that choice and have the appropriate supports around them.

Advance Care Directives

We encourage the entire health sector to promote the use of Advance Care Directives by older people while they are still healthy and lucid. The existence of clear written preferences means that hard choices will not have to be made on an older person's behalf by someone else.

Further communication

Members of the Older People's Reference Group would be happy to meet with Productivity Commissioners and your staff to discuss these issues further.