Submission to The House of Representatives Standing Committee on Ageing December 2002

By The Aged-care Rights Service

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Introduction

Ageing is not an illness, it is a life journey to be embraced and celebrated....we must treat each person as an individual. No person has a use-by date.

-Kevin Andrews Minister for Ageing address to the United Nations 2nd Congress on Ageing

The Agedcare Rights Service (TARS) is a community based organisation with the objectives of advocating for the recognition and enforcement of rights of older people living in supported forms of accommodation; such as nursing homes, hostels, boarding houses and self care units. We seek to achieve better quality of life for these people. In particular we assist impoverished, distressed or helpless individuals and/or groups who are disadvantaged and lack sufficient financial or other resources or access resources to adequately protect, advance or represent their own interests. TARS serves a population of more than 90,000 people across NSW. Our client group includes 50,000 residents of Commonwealth subsidised aged care facilities, 35,000 residents of self care units in retirement villages and 7,000 recipients of community aged care packages.

The majority of TARS' client group are single women, who rely solely on the pension as their source of income. Many have physical, sensory or cognitive impairments, are isolated from mainstream society, and dependent on others for daily care and services.

For some purposes, TARS also includes within the definition of our client group, people who make up networks of support for residents. These include their family, friends and legal representatives, and allied health professionals, including social workers, Aged Care Assessment Teams and other intermediaries.

The *Commonwealth Aged Care Act 1997* safeguards the rights of older people dependent on government funded aged care services for their care. Older people who live in nursing homes and hostels and those that rely on community care services to assist them to remain at home experience heightened vulnerability due to their large dependence on other people and services for their care.

For some older people the consequences of heightened vulnerability may include social devaluation, physical and social rejection, loss of control over important areas of their lives and abuses of their rights. Loss of dignity and autonomy has been shown to lead to demoralization and depression, which then compounds the person's health problems, often making people feel even more dependant and helpless. This spiraling pit of depression and dependency can be though of as the Aged care trap. Advocacy is one response to this vulnerability and its consequences.

The Act included provision for the funding of advocacy services to meet the needs of older people requiring care. The National Advocacy Network (NAN), advocacy

services in each state and territory, receive their mandate from *the Act* to provides services to older people through the Residential Aged Care Advocacy Services Program (RACASP) which became the National Aged Care Advocacy Program NACAP in July 2002 . The Program works with individuals and the aged care sector to encourage policies, practices, and structures in aged care services that ensure that consumers' rights are protected.

Nationally, the advocacy services provide free and confidential services to assist potential consumers of aged care services as well as their representatives by providing individual advocacy, information, and support to foster improvements in the quality of life of consumers of aged care service and the services themselves.

Advocates work to empower individuals, assisting them to self advocate where possible and advocate on their behalf if necessary. Advocacy services are also able to refer particular issues to complaints and monitoring mechanisms, work to influence policy and draw the attention of government to issues in aged care that impinge on the rights of their client group.

Professional advocates are not able to solve complaints in themselves, however, they can assist their clients to use both internal and external complaints mechanisms in working to resolve issues. These mechanisms may include dispute resolution mechanism and the complaints system available to consumers under *the Act.* An advocate may provide information and advice in order to assist a person to take action to resolve their own concerns, or may take a more active role in representing the person's rights to another person or organisation that has the power to make life-affecting decisions for the individual.

Older people have the same rights as everyone else, whether they live at home or are residents of nursing homes and hostels. These rights include the right to physical integrity, moral and mental integrity, civil rights, legal integrity, socio-economic rights, and the right to a family. It is recognised in *the Act* and User Rights Principles that a person's rights are not diminished when they move into a nursing home or hostel or become dependent on others for their care. However, some residents may find it difficult to exercise their rights personally. This may occur for a number of reasons, including lack of information, lack of experience in taking action on their own behalf or fear of reprisal or retribution. A person may also experience particular difficulty in exercising their rights if they speak a language other than English, or suffer from illness, disability or dementia.

While the advocacy services are independent of government and care providers in aged care, they have adopted a partnership approach in working with the Aged Care Complaints Resolution Scheme and the Aged Care Standards and Accreditation Agency. In combination, these very different but complementary systems provide consumers of aged care services with the widest possible choice and a world best

practice quality assurance system (Commonwealth Government, 1999). Whilst adopting a collaborative approach, the advocacy services retain their independent function and dedication to representing the best interests of older people. There are many other advocacy services which advocate for the needs of different groups of vulnerable people, such as people with disabilities, people from non-English speaking backgrounds, people who suffer from mental illnesses, to name a few. It is becoming clear that a greater level of collaboration is required for members of these groups of people who are ageing.

As well as the Charter of Residents' Rights and Responsibilities included in the User Rights Principles of *the Act*, Standards and Guidelines exist for residential aged care facilities and Home and Community Care services. These safeguards provide consumers and their representatives with a sound basis for negotiations with management around particular issues, as they allow some certainty about basic entitlements.

The National Aged Care Advocacy Program (NACAP) was formed as part of the Commonwealth Government's strategy to reform the residential aged care program. A commissioned report by Ronalds, I'm Still an Individual: Residents' Rights in Nursing Homes and Hostels, (1989) highlighted a number of factors which may affect residents' capacity or decision to talk about matters of concern, within the facility, including:

- feeling isolated from family and friends and unable to participate in decisions affecting their lives
- having little knowledge of the aged care system and their rights as consumers
- loss of independence and consequent loss of self-esteem; and
- fear of possible retribution.

The advocacy services in each state and territory receive funding from the Commonwealth Department of Health and Aged Care (DH&A) to operate NACAP. The program is managed by the DH&A, with individual services being delivered through a number of community-based organizations. The National Advocacy Network 2002 –2005 Strategic Plan outlines the following objectives;

- The development of advocacy services for recipients of Community Aged Care Packages,
- The development of advocacy services for recipients of Home and Community Care;
- The development of outreach to rural and remote areas;
- The development of culturally appropriate advocacy services to people from Indigenous and culturally and linguistically diverse backgrounds;

- The improvement to communication, data collection and reporting at all levels of the Program, and;
- The clarification of roles and responsibilities and implementing standard protocols.

Placement of the program within the community sector ensures necessary independent consumer representation and allows for flexible service delivery at the local level. Since its inception, the consumer base of the NACAP has grown in response to significant trends affecting the aged care sector.

These trends have included:

- increasing emphasis and delivery of community care models, including Community Aged Care Packages as an alternative to residential;
- increasing age of admission, frailness and level of dementia amongst consumers of residential aged care services;
- increasing involvement of allied health professionals including Aged Care Assessment Teams, social workers and others as intermediaries for aged persons hence increased complexity;
- increases in the Program's overall consumer base as a result of amalgamations to nursing homes and hostels;
- the potential for medical technology to 'de-humanise' care.
- the realisation that formal human services have great inadequacies and may disempower the people they try to assist due to the conflicts of interest inherent in their practices and objectives, along with high levels of complexity and formalisation, and
- increasing longevity and global trends toward an ageing population.

As will undoubtedly be emphasised by many submissions to this committee the most significant demographic trend is the ageing of the Australian population. If one looks at changes that have occurred in the past 30-40 years and then at the various projections on ageing into the next century, it can be seen that issues and policies related to the aged in Australia will become increasingly important over the next 30 to 40 years.

It should be emphasised, that although the rate of ageing of the population is occurring relatively slowly over a long period of time so that the proportion of the population aged over 65 will increase from 12 per cent in 1997 to approximately 25 per cent in 2051; the significant correlative factor of increased life expectancy means that an increasing and cumulative proportion of the population will depend on the aged care system in future.

Since 1985 the greatest rate of 'ageing' has occurred in the over 80 years age group. Between 1985 and 1994 the size of the 80+ age group increased by 48.4 per cent compared to 25.7 per cent for the 70-79 age group and 26.3 per cent in the 65-69 age group. Over the same period there has been an increase in the proportion of males in the aged population compared with females, although in absolute terms there are still more 'aged' females than males.

The Australian Bureau of Statistics' Australian Demographic Trends 1997 describes the ageing trend as follows:

> During the late 1980s and early 1990s the population aged 65 and over grew at around 50,000 people per year. In the next decade, this rate of increase will fall to between 35,000 and 50,000, as the relatively small cohorts born in the depression enter the age group. However, after 2008, the growth in this age group will increase rapidly. In one 12 month period of 2025-26, the population aged 65 years and over is projected to increase by 120,000, or 2.7 per cent. In the decade to 2028, the population aged 65 years and over is projected to increase by more than a million people, nearly a 30 per cent increase. This represents the period when the largest group of baby boomers reach retirement age. During the early 2020s, the numbers of children in the population is projected to fall below the number of people aged 65 and over.

Perhaps the most startling statistic is that the fastest growth age cohort is those older than 90 years. In response to these trends in some other OECD countries, there has been the introduction of policies designed to reduce the level of government funded benefits by extending upwards the age eligibility at which many of the benefits can be accessed.

Unless some adjustments are made in Australia in the near term, then it is likely that much more difficult and painful decisions will have to be made in the longer term proposed by this Inquiry. Policy development of late has been driven by the economic impacts of this demographic shift. It is critical that policies related to aged care be considered holistically with the longer term social implications in mind. Additional spending in one area (for example, in home and community care and fitness programs) may impact spending in other areas (for example, hospital funding) or may delay the need for such funded to a later time in people's lives. Or it could place additional or shifting demands on other components of the System such as, the Complaints Resolution Scheme, the Aged Care Standards and Accreditation Agency , the Guardianship Boards and the Commonwealth Ombudsman or Advocacy services.

It is important that the community realizes that two related sets of issues have been conflated to create one olicy challenge:

1. There are the issues which relate to the economic, social and management planning for an ageing population which impact on policy for housing, health, welfare and transport.
2. And just as important, are the moral and ethical dimensions of these issues that are raised by this demographic shift and our policy responses to it.

Not only must we plan for an ageing society we must redefine what ageing means to our society.

As the Minister, Kevin Andrews, has emphasised in his address to the 2nd United Nations Congress on Ageing the maintenance of people's wellbeing and dignity are the key objectives of any policy, not the economic bottomline.

The increasing number of people about to leave the work force who have worked for the last 30-40 years have an expectations of a long healthy and independent retirement. They expect to relocate away from their family homes in metropolitan areas to homes in coastal areas that offer them their choice of lifestyle. They expect their superannuation to provide for them for the remainder of their lives. This expectation is founded on a number of assumptions;

- a life expectancy similar to those of previous generations,
- the continued economic growth and positive longterm financial and stockmarket performance,
- the continued willingness of a social welfare system to provides for them when their own financial resources are exhausted, and
- the level of adequate infrastructure in their chosen community to provide them with whatever services they require.

This vision does not include the realities of today's aged care system let alone the potentially degraded conditions that might prevail if we fail to build a more effective system. Imagine the scale of demoralisation if an entire generation's expectations of retirement should prove ill founded.

Ageism

There is no single age that signifies the onset of old age. We live in a society with a large focus on youth and beauty, which is encouraged and promoted by big business. Billions of dollars are spent every year on diet, exercise, and beauty products, which are designed to keep us looking young and attractive. This focus on looking good is often to the detriment of older people and the ageing process. As advertisers urge us to spend our dollars on the maintenance of health, youth, and beauty, ageing and the appearance of ageing are consequently denigrated.

Ageism has had many unfavourable consequences for older people in our society. It has generated and reinforced fear and denigration of the aging process, and has given rise to negative stereotypes and presumptions regarding the incompetence and dependance of older. Society's preoccupation with youth and beauty combined with the dominant stereotypes which imply that ageing equals debility, have largely eroded the images of wisdom, power, benevolence and respect which were once associated with elders. Negative stereotypes are dangerous not only because they influence people's attitudes behaviour and decisions concerning older people, but also because they begin to influence the way older people see and experience themselves. Research has shown that such negative stereotypes are unfortunately prevalent among doctors and nurses working within the aged care industry who in turn influence older people's images of their own self worth. All of the above issues - the nature of ageing, attitudes to older people, social. and cultural changes affecting older people - contribute to the need for advocacy for older people on both an individual and societal level.

Advocacy and inequality

The United Nations General Assembly pro-claimed 1999 as the International Year of Older People in appreciation of the often unrecognised contributions made by older people and their value to society. Five key areas of importance were identified and incorporated into the United Nations Principles for Older Persons (1991, in Office of Seniors' Interests, 1998b):

1. Independence - opportunities for employment, education or training and provision of the support required to enable older people to five at home for as long as possible.

2. Participation - an active role in decision making and communicating in the family, the community and society as a whole.

3. Care - access to health care based on need, and social, legal and other services that enhance personal security and provide a safe humane and caring environment for those in residential care or a treatment facility.

4. Self-fulfilment - personal development opportunities, with access to cultural, spiritual and recreational resources.

5. Dignity - full human rights, including respect for older persons' beliefs, privacy and security.

While there are a number of human rights instruments in place to protect the rights of vulnerable groups, none seem to address the specific situation of older people. In order to fill this perceived gap, The International Federation on Ageing (I FA) has developed a Declaration of Rights and Responsibilities of Older Persons and continues to advocate for the adoption of this declaration both within the United Nations and by governments and non-government organisations around the world (I FA, 1990).

Advocacy seeks to ensure that people whose rights are abused, or who are unable to represent themselves effectively, get a fair hearing and a fair deal. Advocacy support for vulnerable people works to alleviate the power imbalance inherent in their dependent relationship with others. Advocates assist the person they are advocating for to be beard, not as a supplicant, but as an equal.

The principles which underpin the practice of advocacy include:

- Rights - including human, legal and consumer rights.
- Social Justice - seeks just and equitable distribution of social benefits, equal rights, and equality of opportunity regardless of wealth or social status.
- Empowerment - Advocacy always takes place in situations where there is a power imbalance. The client wants someone else who has the power to make a decision influencing their life, in their favour. The involvement of an advocate acts to counteract the power imbalance and ensure that the client and the decision maker meet on more equal terms.
- Participation - is both a principle and a strategy. It is a principle because it is morally correct for people to participate in decisions which affect their lives and not have others make these for them. It is also a strategy because it contributes to empowerment and achieving socially just outcomes.

Many different social and cultural factors experienced by older people contribute to their need for advocacy. These factors include the nature of ageing, and social and cultural attitudes to older people at a broad level. At an individual level, changes in social status due to retirement from the paid workforce, isolation, decreased capacity, and the attitudes and experiences of the older person themselves may all contribute.

Ideally, an advocate should have absolutely no other interest or concern with the results of the decision so that no conflict of interest can arise. (This means that in some situations, a family member or staff member may not be the best person to act as an advocate, as they may have some personal stake in the decision that is reached. There is also a need for groups of residents to be assisted in taking joint action on issues of shared interest . In many nursing homes and hostels, residents come together in groups such as residents' committees, often with the support and assistance of staff and management. The opportunity to look at issues and concerns together, a species of group advocacy, may be a more satisfactory way for individual residents to voice their problems, alleviating fears of being singled out, and receiving support from other residents with similar issues.

Advocacy services are involved in conducting community education as well as providing individual and systemic advocacy. This is undertaken with a view toward promoting positive attitudes towards older people and raising awareness of their rights and the potential for abuse that exists. Advocates speak to residents, carers, staff and service providers, senior citizens, clients of community care services, volunteers and

allied health service workers. People who do not know their rights may be more vulnerable to abuse and may lack the language and conceptual framework to effectively self advocate. The provision of community education is a proactive form of systemic advocacy that empowers older people by reinforcing the fact that they have rights and there is assistance available to support their rights, should they require it. Growing consensus worldwide recognises that human rights education is essential in contributing to the building of free, just and peaceful societies and is also an effective strategy in preventing abuses.

One of the issues of our contemporary Aged care advocacy systems is that it is underfunded, and therefore lack the staffing to be proactive in representing people's concerns. Under the current system, the advocacy services require someone, the client or their representative, to contact the agency and alert them to the issue of concern. Therefore, if an older person requires an advocate, but is not aware of the service or unable to contact the agency, their needs may go unmet.

Advocacy usually occurs when someone feels their rights are being violated and decides to act. However, some people, due to illness, disability, age or culture, may not understand or be capable of understanding that their rights are being violated. People who suffer from dementia and other decision-making disabilities may require a more involved and long term form of advocacy. Many people in this situation have family or friends who can look out for their interests and assist them in making decisions or informally make decisions on their behalf. However, situations can arise where there is a need for a legally appointed substitute decision-maker such as a Guardian or Administrator. There are important differences between the role of an advocate and a substitute decision-maker. While advocacy is about supporting people to represent their own best interests, or speaking for people to ensure their rights are respected, the role of the substitute decision-maker is to make decisions on behalf of someone who is unable to do so themselves. If the Guardian or Administrator were to take action that is not in the represented person's best interests, the advocates role would involve upholding the rights and views of the person with the decision-making disability.

The nature and effect of dementia means that people affected by it are very vulnerable to abuses of their rights. As mentioned previously, they may have no knowledge of advocacy services and may not be in a position to ask for assistance or give their consent for intervention to take place. They may not have any relatives or friends who are able to provide advocacy or to contact the advocacy service, in their stead. Thus it is difficult to ensure the rights of such vulnerable people are protected without taking a more proactive stance.

The Office of the Public Guardian is organisation responsible for protecting the rights of people who are not able to make decisions in their own best interests. This may include people suffering from dementia, intellectual disability, psychiatric conditions and acquired brain injury. The Office of the Public Guardian provides advocates for people with decision-making disabilities to ensure their best interests are represented during Guardianship and Administration hearings, and in the community. Advocates are able to investigate complaints or allegations that the wellbeing of a person with a decision-making disability is at risk. Advocacy services of the National Advocacy Network refer clients with decision making disabilities to the Office of the Public Advocate where appropriate.

As explained above, there are a number of ways in which advocacy can be conducted. Unfortunately, not all advocacy is good advocacy. Undertaken for the wrong reasons, or done badly, advocacy can be have harmful consequences for the person who is being advocated for.

Advocacy is far from easy it may involve enagaging in distressing situations for all the people involved and a range of conflicts and dilemmas can arise. Advocates bring their own sets of values and beliefs to the advocacy effort. Occasionally, an advocate's values and beliefs may be in conflict with those of the person they are advocating for. An advocate may think they know better than the person they are trying to assist. For example a daughter may want to see her parent relocate to an aged care facility, as she is worried about her parents safety, despite the parents wish to remain in their own home.

"It is important to remember that the advocates role is to help people get justice, not to judge them, try to change their values, or influence their wishes. (Parsons, 1994).

Elder abuse

There has been growing awareness over recent years of the prevalence of elder abuse. Just as children are at higher risk of abuse because they are not physically or emotionally able to defend themselves, frail older people may be at risk for similar reasons (Westhorp et al., 1997). It has been estimated that, in Australia, between two and five per cent of people over the age of 65 are at risk of or have experienced some form of abuse (Westhorp et al., 1997). Elder Abuse crosses national, class, religious and cultural boundaries. Both men and women are abused, and older people who are physically and mentally fit are subject to abuse as well as the frail and dependent (Valsier, 1996). The abuse of older people may include physical, sexual, and emotional mistreatment, financial exploitation, neglect of basic needs and enforced isolation.

Elder abuse is defined as the wilful or unintentional harm caused to a senior by another person with whom they have a relationship implying trust (adapted from Hailstones, 1992). Abuse may be carried out by an individual, for example, a family member caring for an older person; or a number of people. The entire workforce of an organisation may be guilty of abusing all clients due to attitudes and practices which fail to recognise basic human rights, such as the right to privacy, to make choices and to be considered and treated as an individual (Valsier, 1996). In the case of financial abuse, an otherwise fit and independent older person may be taken advantage of by a carer, friend or relative. The abuse may involve misappropriation of their money, valuables or property; forcing or intimidating them into changing their will or other legal documents, or denying them access to or control over their personal finances (Hailstones, 1992).

Evidence has shown that elder abuse to be influenced by the following factors carer styles, dependency, a history of family conflict, isolation, psychological problems, and substance abuse, with 85 per cent of people abused by people who know them (American Psychological Association, 1999). In the context of residential care, studies have shown that abuse is more likely to occur in institutions where the approach by staff has become depersonalised and dehumanised to the extent that the older person is viewed as an object rather than a human being (Vaisler, 1996).

Many different factors have been blamed for the abuses which have taken place, including lack of staffing and staff training, lack of funding, and negative stereotypes of older people which lead them to be depersonalised and treated in a paternalistic manner, as if the system knows best. There is a clear need for an advocacy response to the plight of these vulnerable seniors that supports their rights without being over protective and patronising. Advocacy services, seniors groups and people in the aged care sector must work with older people to support their rights and best interests.

Older people today are more visible, active and independent than ever before. However, as the population ages, the hidden potential for abuse, exploitation and neglect of older people also increases. Ageism has already been shown to have a detrimental effect on the lives of older people in our society, let alone the examples of the rights of seniors being abused by the people they are dependent on for care and support.

As mentioned previously, seniors focussed agencies and organisations have been systemically advocating for the development of more positive community perceptions of older people. In addition, the empowerment of consumers of aged care services, the involvement of families and recognition of individual needs in residential aged care settings have been major policy thrusts of the past decade of reform in aged care. These initiatives have emerged from growing recognition of the negative effects of ageism in society and the way in which it has marginalised older people's participation in the community and contributed to individual and systemic rights abuses.

With a view towards preparing for the future of the~ ageing population, it is important for advocacy services, seniors groups and government bodies to engage in strategic planning. While the current collaborative approach to supporting the rights of older people in aged care has sought to promote a culture that recognises complaints as a positive component, the projected expansion of the population of frail aged older people (as opposed to healthy, active older people) remains a challenge for future advocacy efforts. The momentum generated as an effect of the ageing of the population presents a valuable opportunity for all interested parties to campaign for a society in which older people are recognised as valued, active and contributing participants. For the present, we are still witness to incidences of the abuse of the rights of older people by individuals, institutions, and society at large.

While such inequities exist, there will always be a need for advocacy. It has been shown that allowing human rights to be abused or ignored damages the fabric of civilised society. Therefore, advocacy is the responsibility of all people interested in building a more equitable society (Parsons, 1994).

The Current Provision of Services/Support for the Aged

Many of the services and support that exist for the elderly in Australia were developed when life expectancy was much shorter and when many people died within a relatively short period of time after becoming eligible for payments such as the Age Pension. Now many elderly people live well in to their 80s (and even their 90s) and, as a consequence of this, the cost of government funded age support is rising rapidly. For example, outlays on the Age Pension are predicted to rise from $13.4 billion in 1997-98 to $16.5 billion in 2001-2002.(21)

GENERAL OVERVIEW

The provision of services and assistance to the aged comes from a complex array of government programs (Commonwealth, State and local) plus services from the voluntary sector, the private for profit sector and the private not-for-profit sector as well as care and support from family and friends. By far the most important source of support and assistance (apart from the family and friends) provided to the aged comes from the government sector.

The Commonwealth Government provides the vast bulk of income security payments (including age pensions, rent assistance, disability payments), residential services including funding for nursing homes and hostels, medical and pharmaceutical benefits, public housing (with the States) via the Commonwealth-State Housing Agreement, acute care (with the States) hospital services and the Home and Community Care (with the States and local government) program specifically designed to help elderly people in their homes.

The States and Territories also provide a host of health, housing and welfare services for the aged. Apart from the services shared with the Commonwealth, for example the Home and Community Care (HACC) program and public housing, they also to varying degrees provide services such as referral and advocacy support, concessions to operators of retirement homes and other age specific forms of accommodation, support for organisations such as the Council on the Ageing, the regulation of private housing and land and the provision of some transport services.

The majority of the assistance and support provided is for that section of the aged population that needs it the most-the frail and disabled. For many aged over the age of 65 there is no need for specific assistance and with a general trend towards people living longer and being healthier for longer the main emphasis in terms of assistance and support is towards the 'older' aged, that is those over 75-80 years of age. It is generally understood that the greatest need for support and assistance is in the last two

years of a person's life.

HOUSING

The vast majority of Australians aged over 60 years (82 per cent) occupy private dwellings, either as an owner or purchaser and a further 11.5 per cent rent from the public or private sectors in roughly equal proportions. The remaining 6.5 per cent(23) live in hospitals, nursing homes, hostels, retirement villages and other establishments such as boarding homes, hotels and caravan parks. Thus, only a very small proportion of the population aged over 60 are in specific residential aged care establishments of the type that require large amounts of support and assistance. However, in recent years, with the tendency towards 'ageing in place' and home based care more and more older people are staying at home for longer periods with the care and support coming to them as opposed to being place in institutional care.

PUBLIC HOUSING

The main provision of public housing for older Australians comes via the operation of the Commonwealth-State Housing Agreement (CSHA). Approximately 6 per cent(24) of older Australians occupy public rental dwellings. Most older people in public housing moved into their dwellings in their younger or middle adult years and have stayed there into retirement. Specific funding for low income pensioner housing commenced via the CSHA in 1948. In that year the Pensioner Rental Housing Program was introduced so that additional accommodation for this group would be provided in the public sector. In the 1995-96 Federal Budget approximately $50 million was allocated for the Pensioner Rental Housing Program. In the following (1996-97) Budget this Program was rolled into a general funding category which means that there is now no separate identifiable program for pensioner housing.

Residential Aged Care (Nursing Homes/Hostels)

In March 1998(25) there were 138 971 residents in residential care facilities (formerly called nursing homes and hostels) in Australia. This equates to only about 6 per cent of the population aged 65 and over. However, as mentioned earlier even though a very small proportion of the aged population is in residential care, it is to this area of support that most of the funding goes, and particularly to the high care facilities (nursing homes) which house the most frail older people. As Table 5(26) shows, of the total of $2 984 million of Commonwealth residential care subsidies allocated in the 1998-99 Budget, $2 262 million went to high care facilities (nursing homes) and $722 million went to low care facilities (hostels). In 1997 approximately half of the nursing home beds in Australia were provided by the private for profit sector, approximately 38 per cent were provided by the private not-for-profit sector and the rest were provided by government.(27) With respect to hostels, over 90 per cent of beds are provided by the private not-for-profit sector.

RECENT COMMONWEALTH INITIATIVES

The Commonwealth Government announced in the context of the 1996-97 Budget that there would be major structural reforms to residential aged care. The reforms are essentially a fiscal response to the ageing of the Australian population and include an extension of the user pays system in the form of accommodation charges that will help raise the funds needed to provide adequate nursing home/hostel accommodation and upgrade existing facilities. The new arrangements mean that aged people with 'sufficient' means are expected to contribute more towards their care than was formerly the case. The main features of the reforms include:

1. a single resident classification scale (i.e. doing away with the distinction between nursing homes and hostels) which is used to ascertain the amount of subsidy for each resident

2. the introduction of resident entry contributions for all residential care. This has seen accommodation charges being imposed across the sector similar to those that had previously been levied in hostels. The changes have seen the Commonwealth essentially cease capital funding for aged residential care (with the exception of $10 million that is provided for special cases such as rural and remote aged residential care) with future capital works expected to be funded by the revenue raised from the accommodation charges and from the internal funds of the residential aged care providers themselves. Special provisions apply for financially disadvantaged people who are classified as concessional residents.

3. an accreditation system emphasising quality assurance. This is aimed at ensuring that before residential care operators can become part of the new arrangements they will need to obtain certification and show that the quality of the care they provide is up to appropriate standards

4. income testing of residential care benefits for all residents. Prior to the reforms nursing home residents only paid a standard fee per day towards the cost of their care and hostel residents paid variable fees. The new system ensures that residents pay a proportion of their private income towards the cost of their residential care.

HEALTH

The majority of health services for aged people in Australia are delivered by mainstream services such as medical practitioners and public hospitals. Older people, on average, tend to be higher users of health services. Medicare, Australia's universal health system, provides older people with equitable access to medical and hospital services at little or no cost.

The Pharmaceutical Benefits Scheme provides subsidised access to a wide range of (often quite expensive) pharmaceuticals, with a small co-payment of $3.20 per prescription for concessional cardholders, including the Pensioner Concession Card and the Commonwealth Seniors Health Card. Free pharmaceuticals are provided once the safety net of $166.40 is reached in any one calendar year. From 1 January 1999 the eligibility requirements for the Commonwealth Seniors Health Card are to be relaxed, an initiative which is estimated to benefit an additional 220 000 non-pensioners.

The Home and Community Care (HACC) program, which is jointly funded by the Commonwealth and the States and Territories, provides frail aged people with support to enable them to continue living independently in their homes for as long as possible. HACC services include home help, personal care, meals on wheels and home nursing. Fees (but not full cost recovery) are charged for HACC services.

Private health insurance premiums are community rated, which means that people cannot be charged a higher premium because they are older or chronically ill. Older single people with a taxable income of less than $35 000 per year and couples and families with a taxable income of less than $70†000 per year are eligible for the Government's private health insurance incentives which commenced on 1 July 1997. This measure is expected to cease from 1 January 1999 and be replaced by a non-means tested rebate of 30 per cent of the premium paid for private health care.

Eligible older people with hearing problems are provided with vouchers by the Commonwealth to access hearing services at either Australian Hearing Services or the participating private provider of their choice.

Social Welfare

The Australian social security system provides a minimum level of income support for people who are unable, or cannot be expected to provide for themselves. The main groupings provided with assistance are:

- the retired
- people with a disability or a medical condition which prevents them from working
- the unemployed
- people who have children in their care.

The assistance is provided in a framework designed to promote self-support through employment for those with the capacity to participate in the work force. The main forms of assistance for older people are the age pension, wife pension, the partner allowance and the mature age allowance. Unlike most other overseas social security systems (see section on the overseas experience), Australia does not have a contributory based or national insurance type system to fund payments. The contributory systems generally link entitlement to the contributions made by the individual during their working life. The funding for Government social security assistance is sourced from general revenues.

Total Budget outlays for social security in 1996-97 financial year were $40.7 billion(29) or approximately 31 per cent of total national government budget outlays. Of the $40.7†billion, $13.6 billion (33 per cent) was expended on retirement incomes.

All of the payments provided for income support are means tested. The means test is made up of both an income and assets test, with limits set at levels designed to target payment to those in most need. The levels are also designed to partially or totally preclude payments to those of substantial financial means considered able to support themselves. To qualify for the age pension a man must be aged 65 years or more (female aged 61 years as of July 1997) and have been in Australia as a legal resident for ten years or more. The claim for a pension must be made in Australia, except for those countries with an international social security agreement allowing a claim to be made overseas.

As at June 1996, 2 203 180, or 12 per cent of Australia's population of 18.4 million was aged 65 years or more. Of these, the number receiving a social security (or veterans affairs) income support payment pension was 1,764,213, or 80 per cent. Just under two-thirds (65.4 per cent) of age pension recipients receive the maximum rate of pension, with the remaining one third receiving less than the maximum rate due to the tapers that apply to the income test and the assets test. The other 438 967 (20 per cent) are self-funded retirees with income from various sources, for example, investments, employment, superannuation.

SYSTEMIC ISSUES

In recent years, there has been a determined effort by senior's organisations and government bodies to transform negative stereotypes of older people into more positive views. These efforts have resulted in the formation of organisations such as the Office of Seniors' Interests, Council on the Ageing, and the Centre for Positive Ageing, which promote positive images of seniors and lobby for their interests on state, national and international levels. Advocacy services in particular have the experience to understand how ageism works in a range of contexts.

In NSW the Aged Care Rights Service (TARS) is an active member of the NSW Aged Care Alliance. The NSW Aged Care Alliance comprises over 50 organisations concerned with the adequacy and quality of aged care services to older people in New South Wales. Convened by the Council of Social Service of NSW (NCOSS), it comprises consumer representatives, industry organisations, universities and education facilities and others actively promoting the needs, rights and interests of older people focussing on all forms of aged care, including healthy ageing. The alliance's 2003 State Election Kit provides a concise statement of the issues affecting older people. These relevant issues are raised here to emphasise these issues in any consideration of the planning for the future of the aged care system.

Economic Implications

A major study on the effects of ageing was done by EPAC in the mid 1990s. Some of the important trends and issues raised in this study included that:

- the dependency ratio (the ratio of the young and the old to those in the workforce) is predicted to rise from 50 per 100 people at present to 60 or more by the year 2051. Increasing the rate of net migration would only have a marginal effect in terms of helping slow the growth rate of the dependency ratio and the most appropriate way of dealing with an ageing population is via a range of social policies

- at present approximately 19 per cent of GDP ($64 billion) is spent on government social programs. This is expected to increase substantially with the ageing of the population There will be some 'freeing' up of resources due to a decline in young-age dependency but this will be more than countered by the ageing effect. Ageing of the population will also place some pressures on the tax base but this may be at least partly offset by policies such as later retirement and increasing the rate of superannuation accumulation for those currently in the labour force

- total expenditure on education is projected to decline as a proportion of GDP because of the smaller proportion of young people in the population. However, this may be largely offset by the increased educational demands of the mature aged

- according to one projection the total cost of health care expenditure could increase from approximately 8.1 per cent of GDP at present to 11.1 per cent in 2051. This could see the proportion of health care expenditure that goes to the aged increase from one-third (now) to in excess of 50 per cent in 2051.(13) Dealing with this projected increase in expenditures on health is likely to require control of the level of expenditure rather than just changes to administrative procedures. It is likely that there will be a need to more directly face the issue of health rationing

- as the ageing process increases over time the proportion of the population with a disability or disabilities is projected to increase from 10 per cent to 15 per cent. This is significant because this group of the population is likely to require intensive, high cost support

- changing demographic and social conditions (for example, more women in the workforce and people working longer) are likely to limit the number of carers

available to help the aged and infirm

- as the number of people entering residential aged care establishments increases there is likely to be a consequent increase in aged housing expenditure

changes in society over the next 50 to 60 years are likely to see major shifts in the obligations and roles for the old, the young, those in the workforce and those that are retired.

RURAL ISSUES

Older people in rural and remote areas generally have the same needs and desires as their urban counterparts. Aged and community care services in rural and remote areas are beset by all of the issues that affect urban services. However, the nature of rural and remote services means that the impact of these issues is intensified.

The infrastructure of smaller country towns and surrounding areas has been eroded over time – local hospitals have closed, GPs have moved to larger regional centres, small residential care facilities (most suited to rural and remote areas) are very vulnerable under current funding arrangements; and unemployment is high. This has created access difficulties for country people to the whole range of health and welfare services.

There are generally fewer options to choose from in rural Australia. For example, there may not be a dementia specific service (such as community psycho-geriatric service) with the expertise needed to provide residential care or community support to a local aged resident who has been a community member for his/her entire life. Older people in rural and remote communities may have to leave their home area to access a residential care service. Family and friends may not be able to travel long distances to visit them. Carers in rural areas have reduced access to counselling, emotional support and respite which supports them in their role. Such support services must be made available consistently across rural Australia.

Service providers in rural or remote areas are likely to face greater challenges in terms of:

Viability: Viability issues for smaller community care services may force them to either close down or amalgamate for economies of scale. While current arrangements attempt to acknowledge rural issues, the funding provided is often not adequate to maintain quality services.

New models: Service models have been created to specifically cater for the needs of rural and remote communities. In theory, models such as Multi-Purpose Services (MPS) enable co-location and integration of acute, residential and community care services based on the needs of the community. In reality, more work is needed to make these models work effectively for older people and for the local communities.

Workforce: Rural and remote workforce issues can be acute. Providers have difficulty finding staff with higher qualifications, do not have access to flexible professional development or formal training for their staff, or the funds to purchase such training .

CULTURALLY APPROPRIATE CARE

Australians from culturally and linguistically diverse backgrounds are ageing at a greater rate than that of the general population. The 1996 Census indicated that approximately 19% of the over 65s are from culturally and linguistically diverse backgrounds, compared to just 7.4% of the general population. In some local areas, nearly all of the members of particular cultural communities are over 55 years of age. This is the case for many of the Eastern European communities where immigration has ceased and this has the potential to cause isolation, vulnerability and an increased difficulty in maintaining the elderly in the community if adequate support mechanisms are not available.

Ethnic older people have specific needs and preferences arising from their ethnicity. However, ethnic communities often lack the capital, service and language infrastructure to support culturally appropriate services. Furthermore, there are still many barriers that prevent people from culturally and linguistically diverse backgrounds accessing mainstream services. Many older people need specific encouragement and education to access services that would provide benefits to them.

Informal carers in culturally and linguistically diverse communities often play a more intensive role in care than Anglo-Australian communities. This is due to language barriers and the lack of understanding by NESB older people about how the community care system in Australia works. Therefore information about community care and other services must be especially targeted in diverse ethnic communities to the carers of older people, who are often adult children or grandchildren.

STATE CO-ORDINATION

There are various strategies in place funded by both Commonwealth and State Governments, to improve access and care quality of aged care services, however these need to be co-ordinated more effectively. The best way to achieve improved access and quality of care outcomes, to community aged care and residential aged care for elderly Australians from diverse language and cultural backgrounds, is a five-year national ethnic aged care framework. This approach will provide a stronger focus and better reporting of initiatives and their effectiveness across the State. This will involve a more deliberate approach to planning for the location of culturally specific services.

At present, there is a profound absence of such information, and it is difficult for individual service providers to assess for themselves the most effective means for achieving equitable outcomes for their diverse consumers.

One of the most pressing areas of concern for culturally and linguistically diverse consumers of aged care service is the lack of a coordinated approach to fee-free

interpreting services. Interpreting services have a considerable impact on the care and clinical outcomes culturally and linguistically diverse consumers. The current ad hoc approach of concessions and funding for the Telephone Interpreter Service does not address the demand for a coordinated approach to addressing this issue.

HOME AND COMMUNITY CARE (HACC)

There seems to have been little growth in NESB consumer access to the HACC program between 1995, when the proportion of consumers from diverse language and cultural backgrounds was estimated at 12% nationally, and 2000 when the proportion for this consumer population was estimated at 13%. Assuming these access figures are correct, a dismal increase of 1% in access over a five-year period calls for a more effective coordination of access strategies, and an urgent prioritisation of equity targets. Together with the setting of access targets with clear goals and outcomes, a review of access strategies should be held, in order to identify the most successful approaches, and to consider how these can be adapted to the conditions across urban and rural areas.

MULTICULTURAL AND ETHNO-SPECIFIC SERVICES

The inaccessibility of capital funds has placed many ethnic community organisations at a disadvantage in comparison with many of the larger religious-based not-for-profit organisations, or the market-oriented private for-profit operators. Multicultural and ethno-specific services face difficulties in establishing themselves due to a variety of reasons. The major issues being language, rigid funding guidelines and a basic lack of experience in developing and managing services. Multicultural and ethno-specific services are an important component of the community care system in conjunction with mainstream services to provide a comprehensive array of access points for the community.

PUBLIC HOSPITALS

ACUTE CARE

People aged 65 and over are consuming 42% of the total acute bed care days1. Older people are more likely to present with co-morbidity requiring longer stays in an acute bed. As well there may not be a transitional bed to send them to when they no longer need intensive care but do need some medical supervision.

The demand for beds are high, with waiting lists extended to years for some procedures. Waiting times at hospital emergency centres are also unreasonable, creating greater stress for older people with complex needs.

Recognising the high demand, programs that can provide a high level of clinical care outside hospital wards become essential. Programs help people manage their illness were developed out of the recognition of the increasing burden of diseases of the aged on public hospitals. They are still in their pilot stage and are funded for three years only ending at the end of 2003. The objectives of the programs are to reduce hospital readmission rates and length of hospital stays. This should improve quality of life for people with chronic conditions. The needs of linguistic and cultural diverse groups are taken into account in the development and implementation of the program.

HOSPITAL DISCHARGE

At the present time, the transition between hospital and community is not working well for many older people. This is resulting in poor health outcomes for many consumers and undue stress on their carers. Discharge planning needs to start prior to hospitalisation for all planned admissions, and shortly after hospitalisation for unplanned admissions. Comprehensive risk screening should be in place to identify people with complex needs, and appropriate discharge plans developed for all consumers. Discharge planning needs to take into account the capacity and willingness of the carer to continue caring. Discharge planning should involve carers/family, medical, nursing (hospital and community), allied health and community care providers. The discharge planning process needs to not merely identify the services required, but to ensure that these services are available on discharge. Where essential services are not available, discharge should be deferred. NSW Health should monitor the outcomes of discharge planning to check the health outcomes for consumers, identify any breakdowns in the continuity of care for

[1] National figure provided by Aged and Community Care Services Issues Pack 2001 quoting Department of Health and Aged Care *The Use of hospitals by older people: a casemix analysis* June 2000

consumers, and identify any gaps or shortages of services in the community.

TRANSITIONAL CARE

Transitional care provides care that assists the older people moving from acute hospital care to their home or residential care. Transitional care provides an opportunity for those older patients discharged from an acute hospital setting to receive care that would enhance their level of independence and allow the opportunity to arrange for more complex service provision at home. Care can be in the form of support services through Community Aged Care Packages, health and community services or a specific short term residential service.

Transition care can reduces the incidence of premature or inappropriate admission to long-term residential care facility. A recent transition pilot in Newcastle found that about 30% of clients improved to the extent of being able to return home with community support. These findings lend support to the effectiveness of transitional care for older persons which is cost effective in the long term.

COMMUNITY CARE

There have been increases in the Home and Community Care Program and other community care funding in recent years. However, there is not enough funding in the system to enable all those who require support to remain at home to either receive a service or to access the nature and level of support they need.

1998 ABS data highlights that 29% of people aged 65 years and over in NSW reported needs that were not fully met. The main types of assistance required were personal care, transport, housework respite, meals and home maintenance. Many users of services, especially those with family carers, are rationed to receive only low levels of community support a week when their needs are in fact much higher than this.

The Productivity Commission's expenditure analysis shows that at $327 per person aged 70 years and over, NSW had the lowest HACC expenditure of any jurisdiction in 1999/2000, although there have been some increases since the date of the Productivity Commission's data. Inadequate provision of home and community services may result in individuals suffering declining health and well-being or being unnecessarily and inappropriately admitted to hospital or nursing home care. In 1994, the Australian Institute of Health & Welfare estimated that the HACC program only addressed approximately 50% of identified need for home support services. While additional funding to HACC and related community care programs has been very welcome in the meantime, it has not kept pace with either existing needs or the known growth in demand.

Community care services are particularly important for indigenous communities and people from culturally and linguistically diverse backgrounds. These groups tend to make **less use** of residential aged care and consequently require **higher levels** of community care support. The following key actions need to be taken:

actively participate in a national review of the community care system which will create a sensible and flexible structure to meet consumer needs, reduce consumer confusion and reduce resources wasted by services on reporting and managing the plethora of separate community care programs across State and Commonwealth departments.

increase HACC funding by at least **20%** as an initial re-injection to enable a more appropriate level of care to be offered to existing clients to be followed by sufficient growth funding to match future growth in demand.

expand the availability of comprehensive carer support services by the development of a comprehensive package of coordinated carer services tailored according to the needs, preferences, culture and age of the carer as well as the person(s) in need of support. The 'package' of carer services needs to include:

- a range of flexible respite care options (delivered in the home, community and in residential and other facilities)
- in-home support services
- financial concessions for carers on low incomes
- emotional support and counselling, including the use of IT for innovative programs
- education and training that supports the carer in their role
- access to quality residential care.

replace the inequitable indexation models currently used. This includes lobbying the Commonwealth Government to replace the Commonwealth Own Purpose Outlays (COPO) indexation method and ensuring indexation methods used by the State Government compensate for actual cost increases.

research the real cost of providing community care as current poor data sometimes leads to the unrealistic setting of unit costs and ultimately quality may be compromised.

DEMENTIA

Dementia is widespread and increasing rapidly in NSW

55,000 people in NSW have moderate to severe dementia.

Another 55,000 are probably in the early stages of dementia.

Over 200,000 people in NSW are affected by dementia in their families.

There are around 6,000 people newly diagnosed with dementia every year in NSW.

At age 85, one in four people have dementia.

Half the people diagnosed with dementia live in the community.

Half of the people in aged care homes (hostels and nursing homes) have dementia.

Dementia is a leading cause of disability and death in older people.

Inadequate funding means that Alzheimer's Association services reach only 5-10% of those in need. Reach is even lower in ethnic groups, indigenous communities and rural and remote communities where service costs are higher and awareness is lower.

- Dementia is not being diagnosed early in many cases, denying people:
  - treatment for reversible conditions which have dementia-like symptoms
  - early legal and financial planning, e.g. enduring powers of attorney; enduring guardianship
  - evaluation of driving ability (putting themselves and others at risk)
  - assistance to adjust to the diagnosis, plan for their future and learn about dementia management
- Many GPs are uninformed about advances in dementia diagnosis and management. The diagnosis of dementia is often communicated in an insensitive manner. There is not enough respite suitable for people with difficult dementia-related behaviours.
- The effectiveness of psychogeriatric unit (PGU) assistance for people with challenging behaviour needs review. NSW has one such unit based in the Illawarra. No support of this kind is available elsewhere in NSW.
- Community service workers need to be well trained in dementia management to provide quality care.

30% of residents in low care facilities and 70% of residents in high care facilities have a diagnosis of dementia, but fewer than 5% of residential care beds are dementia-

specific.

- It has been very difficult to find residential care places for people with more difficult dementia-related behaviours.
- Carers/family members need education in understanding dementia, its symptoms and management. This will enable them to continue caring for longer, if they choose to do so.
- Residential care staff and management do not have access to dementia-specific training to enable them to provide quality care.
- Dementia-specific training should be obligatory for residential care staff and management to enable them to provide quality care.

COMMUNITY HEALTH

Health Promotion

Health Promotion is focused on keeping healthy people healthy, improving the health of the community and responding to people who need treatment and care. It can include such things as: maintaining good health and preventing people becoming ill (eg local programs to reduce smoking and fall prevention), and helping people with chronic illness to prevent complication or admission to hospital. Most health care occurs in community settings and accordingly community health should not be seen as the "poor relation" of acute care.

Older people must be informed and actively engaged in the decision making process concerning their health in order to improve their quality of life and functional independence. This will require changes to the content and methods in the educational component of any health promotion program.

Oral Health

Oral diseases, including dental caries, periodontal disease and the conditions of people without teeth, are among the most prevalent diseases in our community today, though they are very much a neglected area. Inadequate funding for public dental health services by the State Government mean that some groups of older people, particularly those on a low income and disadvantaged groups, are waiting unacceptable periods of time for service. In rural areas, the access to public dental treatment is even more neglected. A solution may be to attach dentists to the multipurpose units in large country towns, but there would still be a shortage of dentists in smaller towns.

Allied Health

Due to insufficient resources there is a shortage of allied health workers, particularly social workers, radiographers, nutritionalists, physiotherapists, podiatrists and occupational therapists. Podiatrists, for example, play an important role in maintaining the mobility of many older people and people with disability. Approximately 58% of persons who consult a podiatrist are aged over 65 years. Projections of the use of podiatry services indicate that the demand for these services is increasing at approximately 2.3% per annum, because of the growth and ageing of the population. In a caring situation, the maintenance of mobility of older people lessens the amount of physical exertion required of informal carers. Access to allied health services for people in rural areas is particularly problematic and requires deliberate strategies. Optimal nutritional status underpins the well-being of older people and can directly affect the outcome of any illness, resulting in increased hospital admissions, increased morbidity and mortality. Recent research indicates that 85% of chronic diseases or disabilities can be prevented or ameliorated through

appropriate nutritional intervention.

Mental Health

It is important to note that the numbers of people with major psychiatric disorders such as schizophrenia and bipolar disorders growing to an older age are increasing. They will need specialist intervention and accommodation as this occurs. There are special need groups within the older population such as people from culturally and linguistically diverse communities who need services sensitive to their needs and access to health interpreters. Carers of people with mental health issues must be informed, educated, supported and involved during service provision to their loved one.

Geriatric Rehabilitation

Such services are essential at the interface between acute in-patient care and the next phase, be it "transitional care", home or long-term residential care. Indeed, geriatric rehabilitation facilities should be available for those older people living in the community who have developed disabilities which may be remediable without admission to the acute hospital system.

Palliative Care

Quality palliative care is essential to the person and their family in the final stages of an older person's life. Palliative Care must be easily available to people who are terminally ill. Caring staff and adequate resources are necessary to ensure the comfort of those in need of care.

PEOPLE WITH LONGSTANDING DISABILITY WHO ARE AGEING

For the first time in history, people with longstanding disability are living into old age. This is a measure of our success as a society in assisting this group through advances in medical technology and other services.

Figures from the Australian Institute of Health and Welfare provide an indication of the rapid increase in number of people with disability living into older ages:

In 1998, 5.5% of the population (954,900 people) had a severe or profound core activity restriction. The rate rises significantly with age.

Survival to older ages is now a reality for some people with an early onset disability, with 11% (30,200) of those aged 45-64 and 4% (13,000) of those aged 65 or over with severe or profound core activity restrictions reporting an early onset disability (ie. acquired before age 18).

Between 2000 and 2006 the total number of people with a severe or profound core activity restriction is expected to increase by 11.6% (137,600 people).

The growth in numbers is attributable to a rapid increase in size of the age groups 45-64 years (19.3% or 59,500 people) and 65+ and over years (15% or 76,300). Older people will live to an older age and there will be a rapid ageing of the working age population.

In 1999, 15.8% of disability service users were aged 50 years and over, with 6.1% aged 60 and over.

Recent research indicates people with longstanding disability who are ageing experience an earlier decline in function than do others of a similar age in the population and that the changes can be more pronounced. As a group they can also experience "secondary disability" or health complications which can arise as a result of the long-term effect of the disability itself.

There is a range of possible directions that would improve our capacity to provide relevant services to people with longstanding disability who are ageing. Some of these include:

- Providing comprehensive assessment for people with complex care needs (incorporating carer's assessment) and ongoing reassessment to respond to changing needs.
- Challenging perceptions within the disability and aged care sectors to ensure

flexible, appropriate and timely services for people with longstanding disability who are ageing.

- Developing responsive, integrated models of service provision that support collaboration and address the transition issues for people with longstanding disability who are ageing.
- Developing effective training strategies for staff across disability services, aged care services and community care services about the needs of people with longstanding disability who are ageing.
- Improving access to advocacy services for people with longstanding disability who are ageing to provide up-to-date information and access to appropriate services.
- Improving access to advocacy services for people with longstanding disability who are ageing to ensure access to up-to-date information on and access to appropriate services

ABORIGINAL AND TORRES STRAIT ISLANDER ELDERS

Aboriginal and Torres Strait Islander people have been disadvantaged for many years without access to many of the opportunities other Australians take for granted. The issues for Aboriginal and Torres Strait Islander elders are complex and require deliberate attention.

Because indigenous people have lower life expectancy than other people in the population, their timely access to aged care services and other supports can be delayed and the appropriateness of those services can be diminished without attention to individual needs and cultural responsiveness.

Aboriginal and Torres Strait Islander carers play a fundamental role in providing care within the indigenous community. Many Aboriginal and Torres Strait Islander carers find the provision of mainstream services too inflexible to meet their changing needs. In fact, many Aboriginal and Torres Strait Islander people do not identify as having a caring role despite their cultural commitment to the support of their elders. To be responsive to the needs of Aboriginal and Torres Strait Islander carers, mainstream services must be flexible and understanding of the access needs of indigenous people eg. by employing Aboriginal and Torres Strait Islander staff, providing cross-cultural training, recognising the need for emotional support for carers.

In 2000 in New South Wales, a Statewide Gathering of Aboriginal and Torres Strait Islander managers of Community Care and Disability Services determined that the most important ways to provide equitable access to culturally appropriate services were to progress the self-determination of services delivered to indigenous people by indigenous people with quality training, proper representation within decision-making systems as well as a designated investment in Aboriginal and Torres Strait Islander service provision.

Aboriginal and Torres Strait Islander services operate throughout NSW. It is, however, increasingly necessary to strengthen services and build capacity in the face of growing need. Partnerships between Aboriginal and Torres Strait Islander services and mainstream providers are essential to provide a responsive service framework for Aboriginal and Torres Strait Islander elders in NSW.

HOUSING

Older people have some of the highest levels of home ownership. In 1996, 79% of older people lived in a home fully owned by a member of the household, with a further 5% living in homes with mortgage payments still being made. This total of 84% living in homes owned or mortgaged compares to 69% for younger age groups.

For those in their own homes, some key issues are:

- Effective and accessible urban design, ensuring communities are age and disability friendly
- Encouragement of adaptable housing, able to be changed to meet the needs of people as they age or develop disabilities
- Access to transport services, allowing people to participate in their communities and access essential services such as shops, banks and medical care
- Access to affordable and reliable home and garden maintenance, particularly for frail older people or people with disabilities.

Retirement Villages

A significant number of older people choose to live in retirement accommodation designed for people aged 55 years and over. In many cases these developments are regulated under the *NSW Retirement Villages Act 1999*.

There are two main areas for concern:

- Planning for genuine retirement village developments has become fraught since the State Government changed State Environmental Planning Policy No. 5 (SEPP 5) in 1998 to dilute the requirements for care provision in developments. The objectives of SEPP 5 should be protected in the application of the policy. The incentive for medium density developments should be separated from planning tools for aged persons housing.
- The Retirement Villages Act was established to provide protection to residents. Any changes to the Act or regulation should not be to the detriment or reduction in protection to residents.

Social Housing

Some older people require assistance with access to affordable housing. There may be many reasons for this including low income, long-term disability or recent health condition.

Key issues include:

- Increasing the investment in new properties for social housing to address the 96,000-person waiting list for the Department of Housing.
- Reversing the decision to introduce renewable tenancies and change rental bond schemes which will disadvantage people on the waiting list for social housing. A number of categories of sitting tenants who transfer between properties will also be affected.

Older People and Homelessness

The Supported Accommodation Assistance Program (SAAP), funded jointly by the Commonwealth and State governments, provides accommodation support including refuges to disadvantaged people throughout Australia. NSW has a higher proportion of older SAAP clients at 32% than the national average of 26%. 67% of older SAAP clients used services in capital cities and metropolitan centres and 61% of all older SAAP clients were male. As compared with the general population, older indigenous people were 16 times over-represented in SAAP services, representing only 1.1% of the older population but comprising 17% of older SAAP clients. Unlike the general older SAAP client base, 54% of older indigenous SAAP client were female. Despite this, older people accessed SAAP services at a rate 5 times lower than younger people, ie 15 older people in every 100,000 people used SAAP services compared to 75 younger people in every 100,000. Preliminary information from the Commonwealth Department of Family and Community Services also indicates that the reasons that many older clients approached SAAP included: domestic violence, drug & alcohol problems, sleeping rough, usual accommodation was no longer available, financial problems, recent arrival in the area with no supports, psychiatric illness. SAAP services report difficulty in accessing HACC and other support services due to the homeless status of older clients

TRANSPORT FOR OLDER PEOPLE

Public transport should be considered integral to the working of a socially just society. It provides an affordable way for older people and other members of society to take part in activities and contribute to the social good. It is fundamental to many people's independence. Independence is something that older people, like all of us, value most strongly.

Because public transport assists in maintaining older people's independence, it also contributes to their health and well being. By using a reliable public transport system, older people are able to access medical services as necessary, attend exercise classes and provide for themselves household essentials we all require such as food and clothing.

Public transport allows its users to avoid social isolation – a contributing factor to depression, the most common mental illness in Australia and one to which older people are vulnerable.

For these reasons and more, public transport in NSW must be expanded and improved as the population ages, grows numerically and spreads. Public transport should be extended into areas where it does not yet exist.

Many areas report inadequate community transport services for older people. This is especially critical in rural and regional areas where little or no other transport infrastructure exists. Community Transport, which relies on volunteer drivers for many services, is facing unresolved driver accreditation issues, sometimes impeding opportunities for expansion of services. The NSW Aged Care Alliance fully supports the call for funded transport development workers based in community organisations in every region to promote the development and advancement of transport infrastructure throughout this State.

Early discharge and short stay hospital visits means a greater reliance on health-related transport for older people to attend outpatients, day treatment and doctor's visits. People are travelling further, more frequently and older people sometimes require support while travelling. Health-related transport is essential for older people and is critically under-resourced.

Existing public transport services should be improved both in terms of accessibility and reliability. The buses, trains and ferries should also be upgraded so people's safety and comfort are assured as much as possible. Timetables between different modes of transport (ie buses and trains) should be co-ordinated and vehicles should be designed for easy and modified access by older people.

Implementation Issues

Many recent reforms affecting aged care and other related service providers have been designed to improve the quality and delivery of services to older people. There has been, however, a tendency to introduce simultaneous reforms, without regard to other pressures on providers. The resultant costs to agencies, both in dollars and client services, has been crippling at times. Similarly, reforms outside the aged care sector, eg Health and transport, have significant peripheral impacts on services to older people. Smaller, medium and some specialised providers often have fewer resources to respond to the vigorous implementation of multiple reforms. The NSW Aged Care Alliance believes that a diversity of providers (size, nature and location) must be maintained to enable the best service mix to older people. Also, a deliberate program of support is necessary to assist providers to appropriately respond to the reform process. A reform schedule could minimise unintended consequences on service providers as well as possibly identify areas needing specific supports. The Alliance calls for the same degree of co-ordination between government agencies, around reforms and other provider obligations, that the government expects of service providers. The Alliance also calls for adequate monitoring of the requirements on providers and appropriate infrastructure supports for the operations of service providers.

Workforce Issues

Most aged care and other services to older people rely in the main on government funding to provide services. Recent very welcome increases in the Social and Community Services (SACS) Award have put added pressure on providers especially where Commonwealth funding is involved. Most community care and other services to older people rely totally or in part on Commonwealth funding and to date no supplementary funding has been made available to support Award increases related to Commonwealth funding. Other employer obligations such as superannuation increases also put added pressure on services just as demand for those services is escalating. Recruitment and retention of staff is increasingly difficult for government funded services to older people, especially in rural & regional areas, for Aboriginal and Torres Strait Islander services and for staff providing support services to culturally and linguistically diverse communities.

Volunteers

Many aged care and other services to older people involve the generous time and energy of volunteer workers as a critical part of their service provision. As the funding base does not keep pace with demand there is a tendency to load volunteer workers with unreasonable responsibilities, to expect more with greater personal liabilities.

The recruitment base of volunteers for services to older people is diminishing, arguably due to increasing expectations of responsibility and commitment, and this also impacts on volunteers on local management committees. The same issues for volunteers mirror those of paid workers within Aboriginal & Torres Strait Islander communities, within culturally & linguistically diverse communities and in rural & regional areas.

Public Liability Insurance

The recent crisis in insurance provision has adversely impacted on providers of services to older people. Public liability coverage, while no longer a condition of incorporation, is a requirement of funding agreements between government agencies and non-government organisations. The Alliance fears that increased insurance costs will affect service provision to clients. Insurance cover is essential to aged care and other services for older people and the availability of coverage at affordable premiums is critical to ensure the continuation of quality service provision.

Paperwork

Support services for older people have increasingly been required to perform along business lines despite increasing recognition that the principles of a perfect market do not apply in human services. This has resulted in an overwhelming contractual and regulatory demand for paperwork. While the intention was to improve the efficiency of service provision, the result is actually reducing the amount of time providers can spend with clients. This is exacerbated for providers that receive funding from a number of different sources, with different reporting requirements.