



PARTNERS IN CARE

**Carers Victoria Submission to the Productivity
Commission Inquiry: Caring for Older Australians**

August 2010

Carers Victoria is the statewide voice for family carers, representing and providing support to carers in the community. We provide the following services: systemic advocacy and representation; education and training; information and support services; professional counseling; and policy and research.

Family carers provide care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.

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1. Why partnerships with family carers matter

Ageing, illness and disability are a family affair. Carers are the wives, husbands and partners, daughters and sons, sisters and brothers, nieces and nephews, friends and neighbours who care about each other and provide support and assistance often in reciprocal, interdependent ways. Family and friend carers provide the majority of care in the community (ABS 2004). They fulfil vital roles in residential aged care, where the involvement of families is a strong guarantee of the resident's wellbeing (Haesler et al 2007).

The current aged care system focus on physical health and functional abilities does not adequately recognise the importance of psycho-social wellbeing, family relationships and social networks in the lives of older Australians. The move towards person-centred care, with a focus on the rights and autonomy of the older person also has its limitations. Older people like everyone else, need to live in relationships. A future aged care system must view older people holistically – as interdependent members of families and communities. A future aged care system must focus on a full range of indicators of quality of life, particularly social inclusion as a key indicator of wellbeing. A future aged care system must also acknowledge the loss and grief associated with ageing and provide support for the emotional as well as the practical needs of older people and their families.

The current aged care system continues to view family carers variously as free resources who provide most of the care; care coordinators of formal services; co-clients who require relief of stress/burden or redundant carers when the care of the older person has been 'relinquished' to formal care service providers (Twigg and Atkin 1994). A future aged care system needs to view family carers as diverse people with their own individual needs for support even though they may have come into focus for service delivery only because of their caring role.

Current research indicates that caring may have a negative impact on the health and wellbeing of family carers (Cummins et al. 2007). Well being decreases as the number of hours caring increases. Those providing care experience higher rates of mental health problems than the general population, in particular anxiety and depression. Studies have also shown that people who care are twice as likely to be in poor physical health compared to the general population. Those caring had significantly higher incidences of chronic diseases than the general population. A South Australian longitudinal survey of adult family carers supported this finding, showing that 70% of carers report chronic conditions such as diabetes, asthma, arthritis and cardiovascular disease. Carers are at least 40% more likely to suffer from a chronic health condition than the rest of the population (Gill et al. 2007). Despite this, family carer's primary focus on the needs of the person they care for can mean they are reluctant to get treatment for their own medical or psychological conditions.

Key components of the community aged care system, the Home and Community Care (HACC) program and aged care packages are funded to reduce the potential or inappropriate need to admission to residential aged care. A key predictor of entry into residential aged care is stress in the family care relationship often due to changes in the carer's emotional or physical health or in the older person's health or behaviour. Known risks to care relationships include: high intensity care; multiple care responsibility; poor informal support and significant behaviours of concern (Eager et al 2007). A future aged care system will:

- provide preventative support to caring families
- support care needs that change over time
- identify and act on the risks to the care relationship

1.1 The Future

A future aged care system will be both person-centred and family focused.

A future aged care system will be more responsive to what older people and their families want and need; ensuring empowerment and choice.

A future aged care system will focus on health promotion for the older person and their family members, providing early intervention for mental health issues and chronic disease for those at increased risk – older people and their family carers.

A future aged care system will provide a range of supports to sustain the care situation and to preserve family carer's health, wellbeing and financial security.

A future aged care system will regard the older person, their family carers and formal service providers as partners in care.

1.2 Key issues for a Future Aged Care System

- The informal and formal workforce
- Recognition of and support to care relationships
- Balance of community and residential care
- Quality, affordable services

2. The informal and formal workforce

Australia's demographic changes and the increasing preference for older people to remain in their own homes are occurring concurrently with a changing dependency ratio and the economic need to maximise workforce participation by under-represented cohorts, e.g. middle aged women. At the same time there is a projected gap between the demand for and supply of unpaid family carers (NATSEM 2004). It is therefore imperative for the Australian government to enable family carers who wish to, to participate in the paid workforce whilst also providing care.

2.1 Family carers and work

Many family members want to work but cannot because of their caring responsibilities. Employment is important not only financially, but also for social and health reasons. Caring must be seen increasingly as compatible with paid work. People providing care must be supported to participate in the workforce to the extent that they choose. One of the main barriers to employment is the lack of substitute care for their family member while they are at work.

A future aged care system will assist families to access quality, flexible, affordable substitute care that meets the needs of the older person whilst their family carer(s) participate in the paid workforce.

These options need to be provided according to the individual needs of the care situation, but may include extended hours day centre care, in home care, community access care and overnight care. The Commonwealth government will also continue to promote carer friendly workplace practices and protect family carers from workplace discrimination. There is a need for an amendment to the Fair Work Act to allow all family carers the right to request flexible working arrangements.

Family carers of workforce age who provide care long term (e.g. dementia) can be severely disadvantaged in their capacity to pay for their own retirement. The Commonwealth government must compensate long term family carers of workforce age who are shut out of the workforce because of care responsibilities through provision of superannuation. The introduction of a Carers Superannuation Scheme for people receiving Carer Payment or other income support should be funded to at least 9 per cent equivalent of the federal minimum wage.

2.2 Education and support for family carers

There is evidence that carer education/psycho-education is an effective intervention, especially for carers of people with dementia, disability and mental illness (Eager K et al 2007).

A future aged care system will ensure that all family carers have access to education about managing the condition of the cared for person, responding to behaviours of concern and self-management e.g. loss and grief, stress.

Education would be provided through a variety of means e.g. existing carer support groups, online learning and in the carer's first language or with access to interpreters and translated learning materials. The Commonwealth government must also ensure that all family carers considering entrusting care of the older person to a residential aged care facility have access to specific education sessions on the emotional and practical aspects of the transition from home to residential aged care.

The aged care system must recognise that the majority of care for older people is actually provided by family and friends. Recognition requires working from a partnership basis, with a dual focus on what would meaningfully assist and sustain the care situation.

A future aged care system will demonstrate recognition by aged care providers of family carer's key (unpaid) role in the aged care workforce. It will provide support to family carer(s) in their caring role.

Support would be provided according to the individual needs of the care situation, and may include:

- support with occupational health and safety in the home
- access to education and training
- additional direct assistance to the older person when the family carer is on holiday
- enhanced support with key life transitions
- access to emotional support and counselling as required

2.3 A competent formal aged care workforce

All higher education and vocational qualifications awarded to staff working in community and residential aged care should have mandatory units on working in partnership with family carers in the care of the older person. For example, *CHCICS304A Work effectively with carers* is now a mandatory unit of competency within the Certificate III in Home and Community Care. At a minimum this competency unit should be mandatory for the Certificate III in Aged Care as this is the qualification that the majority of the residential aged care (and much of the community care) paid workforce completes.

A future aged care system will ensure that all community and residential direct care workers are appropriately qualified in the provision of person centred, family focused care.

2.4 A culturally competent workforce

Older migrants and refugees without good English language skills rely heavily on their younger family members for both language and cultural interpretation.

A future aged care system must ensure the cultural competence of all staff at all levels of community and residential care in providing for the diverse cultural needs of older people and their families.

Specific funding to recruit and employ bilingual/bicultural staff is an important means to increase access of disadvantaged groups such as more newly arrived ethnic groups and refugees. The care skills within refugee communities can be harnessed to provide community and residential care services when it is needed during settlement in Australia e.g. provision of additional English language tuition to enable refugees to acquire aged care qualifications. (Refer Appendix 1)

2.5 The importance of case management

Good case management is a key feature of community aged care and is an important support for caring families who are entering difficult life cycle transitions. Responsive case management is empowering and personalised to the dynamic and developmental needs of the care situation; whether care is short term or long term, or commenced suddenly following a traumatic event, or gradually as with a degenerative condition.

A future aged care system will ensure that all case managers are appropriately qualified and experienced professionals who provide access to person centred, family focused care.

A future aged care system will ensure that professional case management services are available to offer life transition care and support to all caring families when required.

3. Recognition of and support to care relationships

3.1 Shifting the focus

Care provided by family and friends occurs in the context of an existing relationship. Recognising and supporting care relationships (Victorian Government Department of Human Services 2006) moves away from a separate focus on the needs of carers or the people being cared for and towards an integrated approach that looks at the dynamic interconnections between people in caring relationships and the needs of the care situation.

A future aged care system will provide recognition that care relationships: are dynamic, diverse and can change over time; exist within cultures and communities, as part of society; have a history, with different key transition points.

Older people and their family carers should be treated with respect and dignity by aged care service providers. Family carers need to be well informed of their role and rights in access to services for the older person and their right to support for their own needs. Most important is their right to be involved in all assessment and decision making process unless the older person specifically requests that service providers do not involve them.

A future aged care system will ensure recognition by service providers of the knowledge of the carer about the older person and their expertise in the care of their family member or friend.

3.2 Reform of community and residential aged care

The improvement of community care support for older people and their families requires the focus of all funded community care programs to be on the needs of the care situation.

A future aged care system will ensure that all policy and program guidelines that govern HACC, CACPs and EACH/EACH-D are family carer inclusive.

The Commonwealth government must as part of a review of the Aged Care Act, Principles and Accreditation Standards, provide leverage to ensure improved partnership with, and inclusion of, family carers within the operation and practices of all community care providers and residential aged care facilities.

3.3 Planning for life transitions

Substitute decision making by family members where the older person has a decision making disability e.g. dementia, is a source of much stress for families and concern for formal service providers especially where representation arrangements are not in place. Many older people have not discussed their wishes should they lose capacity with their families and friends.

A future aged care system will promote to older people and their families the need to plan for the future.

This would promote the need for families to have informed discussion on matters such as enduring powers of attorney and guardianship and advance care planning as well as shared informal care arrangements between families and friends. Some work has already been done on low cost legal 'Family agreements' which support the older person and their family's decision making about how care will best be arranged to suit their individual family situation.

3.4 Primary care for family carers

A future aged care system will enhance the capacity of the primary health care system to support carers in their caring role.

This would include enhanced funding and education for general practitioners and/or practice nurses in:

- Early identification and diagnosis of the illnesses and disabilities common in older people
- Early identification of the risks to the physical and emotional health of family carers and the risks of care relationship breakdown
- Knowledge of where to refer families for assistance

3.5 Family carers in special needs groups

Veterans

The veteran community includes veterans who are carers as well as the families of veterans.

A future aged care system will recognise and respond to the impact of post-traumatic stress disorder (PTSD) on veterans and their families and the emerging issues for older people with a history of (often undiagnosed) PTSD who develop dementia.

This must include training for staff in understanding triggers and co-morbidities such as anxiety, depression and dual diagnosis (alcohol and other drugs).

Rural and remote carers

Some parts of remote and very remote areas of Australia have high rates of carers per head of the population and a large proportion of these carers are Indigenous. (Carers Australia, 2009) Many carers in outer regional and remote areas have difficulty accessing services and struggle to find employment. They have higher rates of disability or long-term health conditions than carers in inner regional areas and major cities. While the rural communities in which these carers live provide informal support by way of information and advice, carers struggle to access formal services.

A future aged care system will ensure family carers in rural and remote areas of Australia have better access to appropriate support and services that address their specific needs, including consumer directed care.

Cultural and linguistic diversity

Culturally appropriate care is a key challenge for the current aged care system and will continue to be so with a large proportion of the Australian population born overseas in non-English speaking countries.

A future aged care system will continue to address the key issues limiting access to aged care services by culturally and linguistically diverse (CALD) older people and their families.

These limiting factors include: low levels of English language competency; culturally inappropriate services and cultural family values of interdependence. This will be achieved through improved funding for interpreter services, culturally competent and targeted bilingual workforce strategies and intergenerational targeting of awareness raising campaigns and service access strategies.

A future aged care system will consider the particular impact of the refugee experience on the mental health and well-being of older refugees and their family carers and the barriers to them accessing services (Refer Appendix 1).

Ageing and disability

The emerging issue of people with long term disabilities who are ageing has become particularly apparent as a result of de-institutionalisation. In common with the rest of the community, people with disabilities are living longer, but may experience ageing differently. The Commonwealth government must provide funding to address the issues at the interface between aged care, disability, mental health and health care services. Interface issues include:

- Sustaining care relationships through enhanced access to aged accommodation and support when there is interdependence between the older family carer and the person with a disability
- Combining packages of care and support received by an ageing carer (such as CACPs or EACH) and by a person with a disability so that support to the care situation is coordinated and less disruptive to people's lives
- Streamlining funding so that older people with a disability living with very old family carers receive appropriate community care support as well as access to residential aged care
- Enhancing access to aged care assessment for people with disabilities who experience premature ageing with improved guidance for ACAS in determining ageing related conditions in people under 65 years
- Support to sustain care relationships between ageing parent carers and their sons and daughters with a disability who live separately e.g. transport
- Ageing in place initiatives for older people with disabilities living in disability supported accommodation
- Continuing access to psychiatric disability rehabilitation and support services for older people who have long term mental illness
- Improved access to Aged Psychiatry Assessment and Treatment Teams (APATTs) for support with responding to behaviours of concern
- Advocacy for the needs of older people with disabilities residing in unfunded supported residential services (SRS), especially those without family support

A future aged care system will urgently address the emerging needs of ageing people with disabilities and of ageing family carers of people with disabilities by expanding the Commonwealth government's special needs target groups to include both these groups.

Sexual diversity

Lack of recognition of gay, lesbian, bisexual, transgender and intersex (GLBTI) people by aged care providers (GRAI, 2010) has implications for recognition of significant relationships in people's lives, including carers.

A future aged care system will address the needs of GLBTI older people and their carers by expanding the Commonwealth government's special needs groups to include GLBTI people and providing funding to improve care provision similar to the partners in culturally appropriate care (PICAC) initiative.

This would include the promotion of best practice guidelines aimed to encourage management and staff to adopt practices to create an inclusive environment, which is accepting and welcoming of all GLBTI older people and their carers.

Indigenous Australians

Very few Indigenous people identify as carers and it is often culturally accepted by Indigenous workers and carers alike that there is a responsibility to 'look after our own', particularly in the care of elders. However, in common with all families, it often it is the women who have significant caring responsibilities, caring for multiple family members from multiple generations, often in very complex situations (Carers Victoria 2004).

A future aged care system will continue to improve practice in community and residential aged care in working in partnership with Indigenous concepts of family, life cycle and health.

4. Balance of community and residential aged care

The current aged care system is predominantly community based, but this is not reflected in the balance of Commonwealth Government planning ratios for community care places and residential care places. There will continue to be a need for residential aged care, but current funding models severely curtail the capacity of community aged care services to actually meet the goal of preventing premature entry into residential aged care. Community aged care requires a significant funding boost now and well into the future.

A future aged care system will significantly increase the proportion of aged care funding for community care places to improve the availability and appropriateness of services to enable older people to remain in their own homes as long as possible, either independently or supported by family carers.

This will include significantly improved provision of community services to provide practical and emotional support to family and friends in their caring role.

4.1 Community care reform

The current community aged care system is marked by fragmentation of services and complex targeting and eligibility requirements making it difficult to understand and to access for older people and their family carers. Older people choosing community care should have access to a level of resources appropriate to their needs.

A future community aged care system would be re-developed into a simplified tiered system (Aged Care Branch, Victorian government (2007) of basic care and packaged care:

- Basic care would continue to be delivered through the HACC program, with resources currently allocated to older people on HACC packaged care (Community Options/Linkages) returned to the basic care tier
- Increased per capita level of CACPs, acknowledging that older people with higher intensity needs are remaining in the community
- The introduction of further bands of packaged care at levels between CACPs and EACH/EACH-D
- Progressive reductions in the development of separately targeted small funding programs and the distribution of small amounts of program funding to a wide variety of agencies
- More consistent access to and outcomes of community care through improved eligibility and needs assessment of older people and their family carers
- Innovative use of aged care funding rounds to develop improved continuity of care in service delivery models within HACC, CACPs and EACH/EACH-D
- Improved focus of both basic and packaged care on supporting older people to maintain or re-engage with their chosen social networks

Reform of the community care system for older people will ensure that support services for younger people with disabilities and their family carers will continue to be delivered within the HACC program, over longer time periods than is usual for aged care.

A future aged care system will specifically address the specialised needs of ageing people with disabilities and ageing carers of people with disabilities by adding them to the Commonwealth government’s targeted special needs groups.

4.2 Respite care reform

The National Respite for Carers Program (NRCP) has achieved significant awareness-raising of the needs of family carers within community and residential aged care. It has developed protocols and procedures with other aged care providers to minimise duplication in assessment and maximise continuity of services.

A future aged care system will achieve:

- Better integration of NRCP with other community care programs such as HACC, CACPs and EACH/EACH-D
- Significant increases in program funding to increase access of family carers to support services and respite
- Reduction in the overall number of separately funded and targeted programs within NRCP
- Improved integration and coordination with further development of local community models such as cottage respite and employed carers funding

4.3 Choices

Good quality community aged care offers older people and their families:

- Support for ageing in place
- Case management support as needed
- Consumer directed care as wanted
- Continuity of relationships with aged care workers

Older people and caring families should have the freedom to choose increased control of the aged care services they receive. Consumer directed care should be an option in the delivery of CACPs and EACH/EACH-D (current and future configurations) with the option to return to case management should family circumstances change.

A future aged care system will offer a range of consumer directed care models to older people and their families including: individual budgets and self managed care; third party managed care and provider managed care.

Older people and their families should have the freedom to choose to ‘age in place’ in the accommodation of their choice. Current aged care funding models limit the types of support and care available to people who reside in different types of accommodation. The growth in service integrated housing (retirement villages etc) shows that linking housing provision with varying levels of support and care is a popular choice for older people and their families, but has been largely ignored by government aged care policy (Jones et al 2010).

A future aged care system will view service integrated housing as a component of the aged care system, and focus on improving access and quality, particularly to rural and remote and financially disadvantaged older people.

4.4 Health care and aged care

The current interface between hospitals and the aged care system is one of cost-shifting. Entry to a residential aged care facility for many older people occurs following an acute hospital admission. Longer recovery times and the high cost of acute health care create significant pressure on older people and their families to move out of a hospital bed and on to a ‘more suitable’ facility. Older people and their families are faced with little choice of residential aged care provider and often feel forced to accept the first available bed.

A future aged care system will provide more choice for older people and their families by ensuring that the Commonwealth government provides funding for:

- Greatly enhanced access for sub acute and post acute care for older people discharged from both public and private hospitals
- A significant funding boost for transition care community packages and facilities
- Improved access to “slow stream” rehabilitation specifically for older people – both inpatient and outpatient

5. Quality affordable aged care services

Caring families and the people for whom they care should not experience barriers to accessing the types and range of aged care services relevant to their needs. The needs of caring families are dynamic, particularly in relation to the health and wellbeing of the older person and their carers. Aged care services need to be predictive of and responsive to changing needs as opposed to intervening when there is a crisis in care e.g. residential care admission following hospital admission. At the same time there is a need to avoid shifting too great a cost on to consumers (older people and their family carers).

5.1 Equity of access

Providing equity and choice in aged care services for older people and their family carers must be paramount in considering the subsidy and fee structures of a future aged care system. Half of the primary carers in Australia are in the lowest two income quintiles, but they pay fees for both community and residential aged care. Means testing should be applied consistently according to the financial capacity the older person, avoiding the need for families to provide “top up” fee payment or for wealthier families to receive priority of access to care for the older person.

A future aged care system will ensure that both basic and packaged community care should have a nationally consistent, means tested fee structure, with a cap on maximum fees paid and access for financially disadvantaged older people.

5.2 Quality family inclusion in residential aged care

The active and positive involvement of family and friend carers in supporting their relative and in the work of aged care facilities is essential. Yet many friends and relatives find the experience of being involved in residential aged care complex, stressful and difficult to negotiate (Carers Victoria 2007).

A future aged care system will ensure that the Aged Care Accreditation Standards are modified and redeveloped with an improved framework for partnerships with, and inclusion of, family carers in residential aged care facility practices.

These would include, but are not limited to: the requirement for aged care facilities to provide for private space for the continuation of intimate and family relationships; the requirement for family carer involvement in the development of resident care plans unless they specifically opt out and that comments and complaints can relate not just to the care of the resident, but to the treatment of family and friends by the aged care facility.

The Aged Care Standards and Accreditation Agency needs to increase the number of family carer stakeholders interviewed during site audits, particularly CALD families who may require interpreter support. The Agency also needs to consistently monitor and promote best practice in family carer participation with individual residents and in the operation of the facility.

A future aged care system will ensure that residential aged care is supported by a Charter of Rights and Responsibilities for Relatives and Friends.

This will recognise and legitimise the advocacy and care provision roles played by family carers in residential aged care. The Charter would:

- Provide guidelines in relation to the rights and roles of family carers within the facility
- Specify facility obligations towards family carers
- Establish a frame work for the management of family carer complaints and concerns

Residential aged care funding must better meet the needs of residents with higher care needs and their families.

A future aged care system will ensure that the Aged Care Funding Instrument (ACFI) includes a framework for psychosocial support for the resident and family.

This will assist in allocation of staff time for responsive communication, information exchange and collaboration with residents and their families. A subsidy for the appointment of social workers to aged care facilities would also facilitate practical and emotional support for residents and families.

The Commonwealth government needs to provide funding to promote, develop and support a national network of carer support groups for carers of residents in aged care facilities (Carers Victoria 2007) focusing on the needs of carers prior to and after transition from care at home as well as for bereaved carers. Funding models would develop common operating standards, policies and procedures for new and ongoing groups.

5.3 Quality end of life care

The quality of end of life care provided to older people and their families is a key indicator of the quality of the aged care system.

A future aged care system will offer older people and their families greatly improved access to community based palliative care services and to a palliative approach in residential aged care.

This will include additional funding for improved paid staff and volunteer support for families and friends both during the dying process and after the older person has died.

5.4 A sustainable aged care system

A key indicator of quality service provision is the quality of relationships between aged care staff, their client and families. The National Aged Care Workforce Strategy must continue to expand to improve recruitment and retention of staff in order to provide high quality client centred, family focused care. There is also an urgent need to initiate an independent review to determine benchmarks for adequate staff to resident ratios in residential aged care.

A future aged care system will incorporate a review of staff to resident ratios with the National Aged Care Workforce Strategy, and will work towards wage parity between residential aged care staff and their public sector counterparts.

5.5 Re-visioning respite and support

Models of service delivery for respite in the current community and residential aged care system can create significant barriers to usage due to:

- Family carers feelings and past experiences with respite
- Older people's reluctance to use respite
- Inappropriate, inflexible and poor quality respite services

The combination of these three factors can mean that the respite care experience is less than satisfactory, and is only used as a last resort when the caring has become too much (Newman et al (1997) cited in Doyle 2008).

A future aged care system will change the dominant model of respite as a service type that provides relief of stress/burden. A future aged care system will provide individual support to the care situation that has outcomes including improved social support for the older person and respite for the family carer(s).

There is a need for more research into the effectiveness of interventions aimed specifically at family carers (Eager et al 2007), but it is essential that all current care service provision aimed at older people aims to become more family carer friendly (Dow et al (2004).

A future aged care system will offer:

- **Accessible information about support services directed at the individual needs of older people and their families**
- **Person centred and family focused, flexible, responsive and predictable support services**
- **Good quality, affordable support services staffed with caring and continuous staff with a holistic, family focused approach**
- **Innovative support services and opportunities for groups of older people and family carers to get together**

References

Aged Care Branch Victorian Government (2006). Recognising and supporting care relationships for older Victorians. Melbourne, Department of Human Services

Aged Care Branch Victorian Government (2007) Submission to the Review of Subsidies and Services in Australian Government Funded Community Aged Care Services

Australian Bureau of Statistics (2004). Disability, ageing and carers, Australia: Summary of findings. Canberra.

Australian Bureau of Statistics (2008) A profile of carers in Australia. Volume, 108 DOI

Carers Australia (2009) Position Statement on Consumer Directed Care

Carers Australia (2009) The tyranny of distance? Carers in regional and remote areas of Australia

Carers Victoria (2004) Be with us, feel with us, act with us: Counselling and support for Indigenous carers.

Carers Victoria (2007) Still largely on the outside: the caring experiences of relatives and friends of older people who live in aged care facilities in Victoria

Cummins RA (2007) The wellbeing of Australians – Carer health and wellbeing. Australian Unity Wellbeing Index Survey Special Report 17.1

Dow, B et al. (2004). What carers value; review of carer literature and practice. Report for Department of Human Services, Victoria.

Doyle, C (2008) Giving carers of elderly frail people a break: Perspectives on respite care InPsych, APS

Eager K et al (2007) Effective Caring: a synthesis of the international evidence on carer needs and interventions - Volumes 1 and 2, Centre for Health Service Development, University of Wollongong

Gill, T (2007) The health and wellbeing of adult family carers in South Australia : an epidemiological analysis 1994-2004.

GRAI (GLBTI Retirement Association Inc) and Curtin Health Innovation Research Institute, Curtin University. (2010). We Don't Have Any of Those People Here: Retirement accommodation and aged care issues for non-heterosexual populations. Perth, Western Australia

Haesler, E., Bauer, M., & Nay, R. (2007). Staff-family relationships in the care of older people: a report on a systematic review. *Research in Nursing & Health*, 30(4), 385-398. ISSN 0160-6891

Jones, A et al. (2010) Service integrated housing for Australians in later life. AHURI Final Report No. 141. Melbourne: Australian Housing and Urban Research Institute, Queensland Research Centre

Kelly, S. (2005). Who will care? The future demand for informal carers. Population ageing, National Centre for Social and Economic Modelling, University of Canberra.

NATSEM (2004) Who's going to care? Informal care and the ageing population. Report prepared for Carers Australia, Canberra

Standing Committee on Family, Housing, Community and Youth (2009). Who Cares...? Report on the inquiry into better support for carers. House of Representatives. Canberra, The Parliament of the Commonwealth of Australia.

Twigg J and Atkin K (1994) Carers perceived: policy and practice in informal care

Victorian Community Care Coalition (2006), Moving to Centre Stage: Community care for the aged over the next ten years

Appendix 1

Comments on Caring for Older Australians with an emphasis on refugees

Definition of “elderly” in the context of elderly refugees

The World Health Organization (WHO) acknowledges that developed countries have accepted the chronological age of 65 years as a definition of elderly, yet this does not adapt well to all countries. WHO states “there is no United Nations standard numerical criterion” for older person, but “the UN agreed cut-off is 60+ years to refer to the older population”¹. WHO also acknowledges that a realistic definition of elderly in Africa should be either 50 or 55 years because of life expectancy and traditional understanding of “elder”. In addition, in some countries and within the refugee experience, there is no official record of actual birth dates. In recognition of different situations, WHO has adopted 50 years of age and older as the general definition of an older person to inform policy makers.

It is recommended that the Commission consider WHO discussions when defining “elderly” in the context of elderly refugees.

Issues for elderly refugees

Australia accepts refugees from many conflicts, with the largest groups currently coming from Afghanistan, Iraq and Burma. Over the last 20 years, additional groups have come from Africa, including Somalia, Ethiopia and Sudan. In the main, only a few elderly people arrive in Australia on Refugee Visa (200), but families may subsequently sponsor their elderly relatives to come to Australia on a Special Humanitarian Visa (202).

Consequently, there are a small number of elderly people in the more recently arrived refugee communities. The Department of Immigration and Citizenship database states that 69 people over 65 years of age arrived in Victoria on Humanitarian visa during 2009. While this is a small group, the needs are likely to be high, exacerbated by the refugee experience of the elderly themselves, but also of their family carers. As stated by Atwell, Correa-Velez and Gifford², the common factor for all refugees is the experience of forced displacement and exposure to high levels of stress and trauma. This may lead to depression, anxiety or post-traumatic stress disorder, and in elderly refugees, the symptoms may be confused with dementia resulting in their mental health needs being overlooked. The UNHCR notes that: “the stresses of being forced to flee and then having to adapt in a new environment ... place untold demands on the coping ability of many elderly refugees.”

Adapting to the new environment in Australia includes experiencing isolation, due to loss of social networks and extended family, language barriers, poor access to transport and shortage of suitable places to socialize. Elderly people also experience a loss of status and identity in Australia, where no English language leaves them reliant on younger members of the family for interpretation. The dependence on family more generally can result in low self esteem, particularly in societies where elders are traditionally respected

¹ <http://www.who.int/healthinfo/survey/ageingdefnolder/en/index.html>

² Atwell RSJ, Correa-Velez I, Gifford SM of Refugee Health Research Centre, La Trobe University, “Ageing Out of Place: Health and Well-Being Needs and Access to Home and Aged Care services for Recently Arrived Older Refugees in Melbourne, Australia” in *International Journal of Migration, Health and Social Care*, Vol 3, Issue 1, July 2007

and looked to for advice. For carers in refugee communities, the demands of settling in a new country provide an additional barrier to allocating time and resources to their elderly relatives.

Even though the needs are high, there are barriers to elderly refugees and their carers accessing services. New arrivals to Australia may have limited knowledge of services which can assist them. They may have no understanding of Australian services when coming from countries where there are no formal aged care services. Families may be too ashamed to access external services, when they have traditionally provided care to family members. Families which have experienced government abuse in war may also be unwilling to trust service providers. Even were families to access respite services, professional carers are unlikely to be available in the language and culture of the elderly refugee when the community is small in number and untrained. More established and larger refugee communities may still face similar difficulties in accessing aged services, where language and culture remain alien and where the refugee experience may resonate throughout life and generations.

It is recommended that when addressing the interests of special needs groups the Commission consider the impact of the refugee experience on the mental health and well-being of elderly refugees and their carers and the barriers to them accessing services.

Workforce issues

One of the barriers to refugee families accessing respite care is presented by the lack of trained carers in recently arrived communities, yet within refugee communities, there are people skilled in caring for old people and who are keen to work. Their English language is insufficiently advanced to provide access to courses to acquire qualifications for community or residential care positions.

It is recommended that the Commission consider creative ways in which skills within refugee communities can be harnessed to provide community or residential care services when it is needed during settlement in Australia.