



Centre for Research into Sustainable Health Care

and



SILVER CHAIN



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## FINAL REPORT

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# Options, opportunities and older people: an exploration of care transitions of older people

July, 2005

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Professor Julianne Cheek; Ms Alison Ballantyne; Dr David Gillham, Ms Jane Mussared, Dr Penny Flett,  
Dr Gill Lewin, Ms Marita Walker, Ms Gerda Roder-Allen, Mr James Quan, and Ms Suzanne Vandermeulen

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Prepared by the University of South Australia, ACH Group and Brightwater Collaborative (Brightwater Care Group, Silver Chain and Perth Home Care Services) for the Australian Research Council (ARC) Linkage - Projects

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# REPORT

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**Options, Opportunities and Older  
people: An exploration of care  
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# 1. Background and rationale of the study

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Australia's population is ageing and it is predicted that it will continue to do so for the next 30 years (WHO, 2001; AIHW, 2002). Older Australians have options and opportunities regarding both where they live and the support they use to optimise health and well-being at that place. These Australians are a dynamic, diverse segment of the population, non-homogenous with individual needs, who may experience movement both forwards and backwards along a continuum of care and support provision as their needs for support change. For example, an older person may require a higher level of care and support services for a period after an adverse health event, but this requirement for services may cease or diminish once their situation has stabilised. The World Health Organisation argues for a philosophy of 'active ageing' to underpin policy and service provision for older people. Active ageing is the 'process of optimising opportunities for physical, social, and mental well-being throughout the life course, in order to extend healthy life expectancy, productivity and quality of life in older age' (2001: 17).

More than 90% of older people in Australia choose to live in the community (AIHW, 2002), utilising varying degrees and types of support to enable them to continue to do so. Of those older people who do live in residential aged care, more than half are aged 85 years and over (AIHW, 2000). These figures are consistent with studies showing that older people would prefer, wherever possible, to remain living in their own homes and to receive care in the community if required (Andrews, 2001), with institutionalisation being the last resort. This includes older Australians who are frail and who may require a great deal of support to continue living in the place of their choosing.

Cognisant of these preferences, government policy has embraced the philosophy of 'ageing in place', with an emphasis on enabling older people to remain living in the place of their choosing for as long as possible. The need for services to support ageing in place has been recognised through increased Australian Government funding for Community Aged Care Packages (CACP) and Extended Aged Care in the Home Packages (EACH). The Australian Government in conjunction with State and Territory Governments also facilitate ageing in place through the Home and Community Care (HACC) program. These initiatives are designed to provide a range of services available to older people as they move along a continuum of care and support needs. Other packages and initiatives also exist, including those that provide support when older people move into acute care and then back to their home in the community when the acute episode has passed. Examples of such packages include the Acute Transition Alliance Home Rehabilitation Support Service (a pilot program funded by the Australian Government and discussed

further in section 6 of this report), Metro Home Link (Advanced Community Care, 2005) and Hospital in the Home (Victorian Department of Human Services, 2003). All of these programs aim to enhance the functional independence of older people during periods of care transition associated with an acute crisis. They are designed to avoid premature or inappropriate admission to long term residential aged care and/or acute hospitals.

Despite the plethora of programs, many older Australians living in their homes are unaware of the relevant services available to them (Cheek & Ballantyne, 2001a; Cheek, Ballantyne & Roder-Allen, 2005). Moreover, even if they are aware of them, they may not understand the services or how to obtain them (Budge, 1998; Cheek & Ballantyne, 2001a; Cheek *et al.*, 2005). McCallum *et al.* (2001: 7) note that the number and variety of programs, often receiving funding from different sources with different sets of requirements, has 'added to the existing complexity and overlap within the Australian long-term care service system'. In addition, despite the governments' efforts to ensure sufficient availability of services, there is a high level of unmet need. The reality for many older people may thus actually be a restricted choice of options. How older people navigate the myriad of service options available, and what they do and why in relation to obtaining them, is not well understood. Similarly, little is known about the consequences for older people when services are not available and/or they have to wait for them.

Hollander (2001) used the term 'transition point' to describe some form of destabilisation in the life of the older person resulting in a change in the level of care and/or support they require. He argues that these transition points are not well recognised or identified, and are therefore often not well managed within the aged care industry. Hollander suggests that 'enhanced care at transition points to re-stabilise clients as quickly as possible' (2001: 112) is an urgent requirement. A decline in functional independence if a transition point is missed or transitional care is delayed (owing perhaps to lack of services or lack of knowledge about services) can adversely affect the health, well-being and outcomes of the older person. One risk is that the older person may end up being hospitalised unnecessarily. If hospitalised, older people are up to 9.5 times more likely to be institutionalised after discharge (for example enter residential care), with the risk of death 11 times higher once institutionalised (McCallum *et al.*, 1995: 44). Another risk is an increasing number of older Australians living less than optimal lives in the community.

This study was designed to explore what constitutes a 'good care transition' for older people, how a 'care transition point' is identified by older people and/or service providers, and what happens following care transition point identification.

## 2. Aims and objectives

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The study had two broad aims, each with associated objectives:

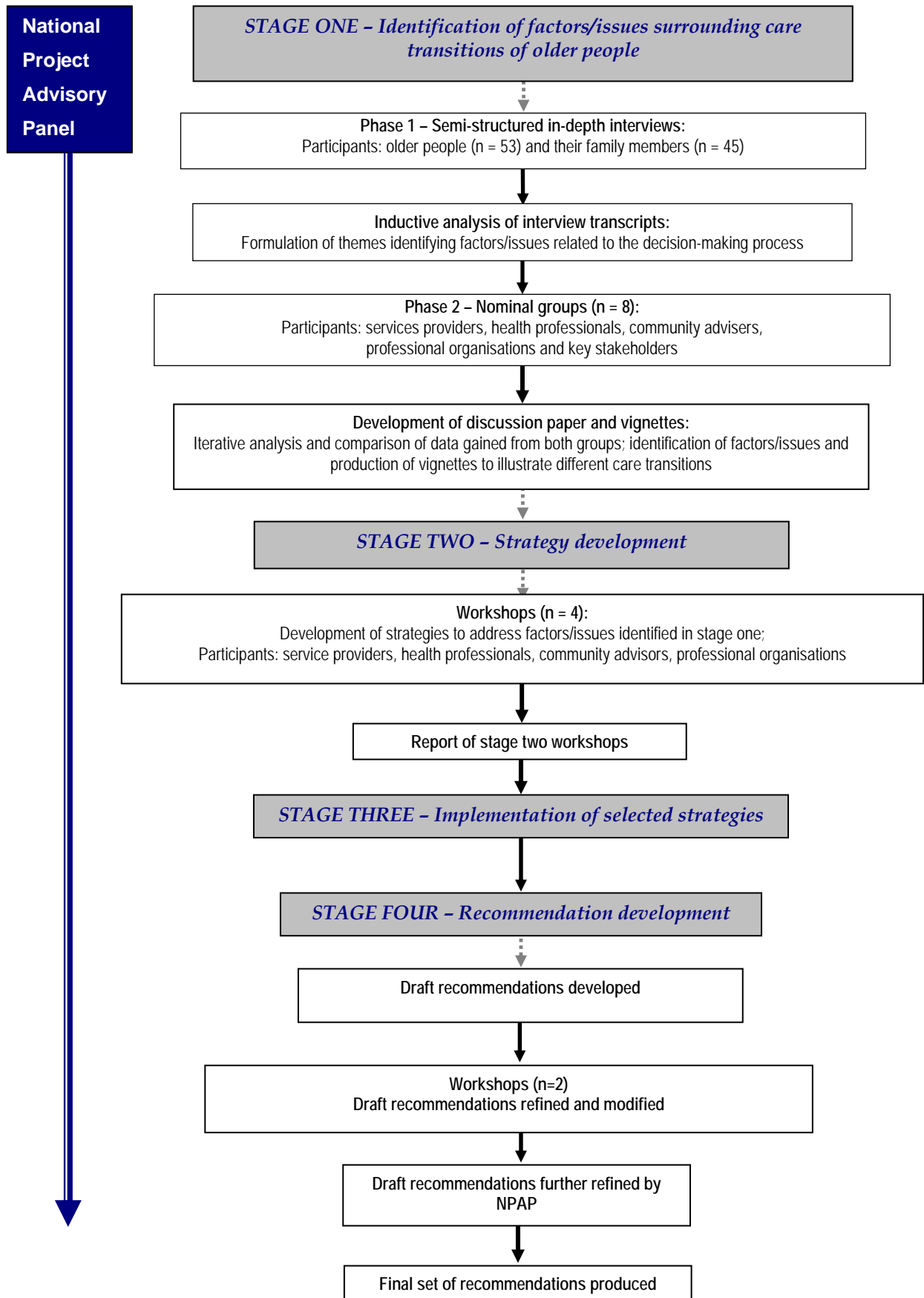
1. To provide a detailed account and understanding of care transitions for older people who seek assessment for, and/or take up, aged care services; the way in which the subsequent search and selection process for such services is undertaken; and the effect of this process itself on the older people and their families. In so doing, the study examined:
  - i) why and how the decision to seek services was made (identification of the care transition point);
  - ii) when and how the search and selection process for services began;
  - iii) important factors involved in the decision making;
  - iv) the efficacy of the decision making process, and its effect on the well-being of the individual and their family;
  - v) what assisted or could have assisted the older person to identify their care needs as being in transition and access appropriate services earlier.
2. To thereby gain understandings and insights into the decision making and factors involved in order to enhance the health and well-being of older people. Specifically by:
  - i) recommending strategies by which older people, community services, aged care organisations and hospitals can be assisted in both forward planning of the care transition process and with respect to undertaking the process itself, within and between interfaces of health care;
  - ii) providing information able to inform, assist and influence policy makers at Australian and State and Territory governments and organisational level in the area of primary health care and other supports for older people designed to facilitate active ageing;
  - iii) producing research-based publications and presentations that can contribute to the debate about this important health issue.

### 3. Method

---

The four-stage study was descriptive and exploratory and used a multi-method approach. Stage one was designed to identify and describe factors/issues surrounding care transitions of older people. Two data collection methods were employed for this purpose, namely in-depth interviews and nominal groups. In stage two, a series of workshops were conducted in order to identify and develop strategies to address the factors/issues identified in stage one. Stage three involved the implementation of selected strategies from stage two. The final stage of the study involved the development and refinement of a set of recommendations arising from the data collected in the previous stages of the study. Diagram 1 provides a schematic overview of the research design.

**Diagram 1: Schematic overview of the research design**



## National Project Advisory Panel

To ensure the relevance of the study beyond the participating organisations, a National Project Advisory Panel (NPAP) was formed. The research team, in consultation with industry partners, identified seven members of the panel from personnel involved in the provision of human services for older people at the national, policy, professional and organisational levels. The NPAP consisted of the following members:

Dr June Heinrich	Baptist Community Services
Ms Rosemary Jeffery	National Rural Health Alliance
Mr David Kemp	Australian Government Department of Health and Ageing
Dr Bob Penhall	Metropolitan Domiciliary Care
Ms Debra Petrys	COTA National Seniors
Mr Paul Sadler	Aged & Community Services Association of NSW & ACT
Dr Victoria Sutton	Royal Australian College of General Practitioners

Members were invited to participate in the study by letter and were provided with project materials to review prior to accepting the role. The NPAP met face to face three times in Adelaide during the study. Members unable to attend because of distance participated in meetings via teleconference. At the initial meeting, held in September 2003, the NPAP identified a Chair for the duration of the project and discussed the panel's role and expectations for members' contributions both as individuals and on behalf of the constituency members they represented. The second meeting, held in June 2004 at the completion of stage two data collection, commented on findings from stage one and initial strategies developed as part of stage two. The final meeting, held in November 2004, focused on reviewing and refining the final recommendations arising from the research.

## Ethics

The University of South Australia Human Research Ethics Committee approved the project. In keeping with the Guidelines approved under Section 95A of the *Privacy Act 1998* (NHMRC, 2001), principles protecting participants (informed consent, self-determination, confidentiality of information and anonymity, protection from harm) and governing the storage, access and disposal of files were adhered to throughout the study.

In addition, ethics clearance was gained from each of the participating aged care organisations prior to the recruitment of participants.

### **Sampling framework**

The study was conducted across the two Australian States, South Australia and Western Australia, in which our industry partners are located. Purposive sampling (Patton, 2002) was used to select sites and participants who were likely to be information-rich.

#### *Selection of sites*

Participants were recruited through three large aged care organisations located in each State. Participating organisations were either industry partners or were identified in consultation with the industry partners.

The development of trust and rapport, built on already-established relationships that the research team had established with aged care organisations, was significant during all stages of recruitment.

#### *Selection of participants - interviews*

Individual participant selection for each phase/stage of the study was purposive; that is, it was directed at finding information-rich participants who were able to provide information to achieve the objectives of the study (Patton, 2002). For older people interviewed, the inclusion criteria were that the person had to:

- be 65 years of age or over and
- have been involved in a care transition within the last 90 days.

The 90-day period was chosen, in line with previous studies (Cheek & Ballantyne, 2001a; Cheek *et al.*, 2005), to ensure that 'accurate retrospective descriptions of the decision process were captured' (McAuley, Travis & Safewright, 1997: 239).

For the purposes of this study, a care transition was defined as a change in the level of formally provided care along the continuum of care options and opportunities available required to maintain physical and/or emotional well-being or to return to the same or higher level of physical and/or emotional well-being enjoyed prior to the change in care/health status. Four categories of care transition were identified and used as the framework for the selection of participants. They were, in terms of service provision, the transition from:

- none to some: no services accessed; following care transition, services accessed;
- some to less/none: some services accessed; following care transition reduction or termination of services;

- some to more: some services accessed; following care transition an increase in the number and/or degree of services accessed;
- physical relocation: following care transition older person moves into another living situation, for example home (non-specific place of residence in the community) to residential age care, including emergency respite, or vice versa.

Using these categories of care transition, a sampling framework was constructed according to type of care transition and participant location, that is, metropolitan or non-metropolitan. Figures 2 and 3 show the number of older people experiencing care transitions in each category in the South Australian and Western Australian samples respectively. Information available at the time of the study suggested that approximately 25% of people aged 65 years and over in South Australia lived outside the metropolitan area. In Western Australia, 20% of people aged 65 years and over lived outside the metropolitan area. These figures were used to determine the ratio of metropolitan to non-metropolitan participants.

**Figure 2. South Australian participant matrix**

Location	Type of care transition			
	None – Some	Some – Less/None	Some – More	Physical relocation
Metropolitan	7	6	6	7
Non-metropolitan	2	2	2	2

Note: The figures include cases where the older person was represented by a family member because they were not able to participate themselves.

**Figure 3. Western Australian participant matrix**

Location	Type of care transition			
	None – Some	Some – Less/None	Some – More	Physical relocation
Metropolitan	5	5	5	6
Non-metropolitan	1	1	1	2

Potential participants meeting the criteria of the study were approached directly by the participating organisation. The contact details of potential participants who were willing to be interviewed were then passed onto the research team. This method of recruitment ensured that participants' privacy was maintained until informed consent had been given.

Older person participants who were interviewed were asked if they could nominate a family member involved in their care transition who could be approached to be interviewed. When the older person was not able to be interviewed, for example in cases of significant cognitive impairment, organisational staff were asked if they could nominate such a family member. Once identified, family members were individually contacted by a member of the research team and invited to participate. Thus, in some cases the older person and a family member were interviewed, while in others only the older person or only a family member was interviewed.

In-depth interviews were conducted with 27 older people in South Australia and 26 older people in Western Australia, totalling 53 older person interviews. Forty-five family members were interviewed; 25 in South Australia and 20 in Western Australia.

#### *Selection of participants - nominal groups and workshops*

Staff from participating organisations were invited to participate in the nominal groups. In addition, a mini-snowball technique was used to identify further participants, which included service providers, health professionals, community advisers, and professional organisations. For the key stakeholders' nominal groups, the National Project Advisory Panel and local industry partners were consulted to identify initial key players. Once identified, potential participants were individually contacted by a member of the research team and invited to participate. Workshop participants were drawn from this pool of participants. These information-rich participants enabled the collection of in-depth multi-dimensional data.

## 4. Stage one: Identification and description of factors surrounding care transitions of older people

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Two data collection methods were utilised in stage one, namely in-depth interviews and nominal groups, in order to obtain a comprehensive identification and description of factors/issues surrounding care transitions of older people. These techniques captured perspectives at the level of individual older people and their family (in-depth interviews), and at the organisational and policy levels (nominal groups).

### *Stage one Phase one: Collection of perspectives at the level of the individual older person and their family member using in-depth interviews*

Cheek and colleagues (Cheek & Ballantyne, 2001a; Cheek, Ballantyne & Byers, 2003; Cheek *et al.*, 2005) have successfully used qualitative interviewing techniques to explore issues concerning older people. In this study, in-depth, semi-structured interviews were used to explore factors surrounding care transitions of older people, the subsequent search and selection process for services, and the effect of this process on older people and their families.

The framework for the interview was drawn from Cheek & Ballantyne's (2001b) study of the search and selection process for an aged care facility following discharge from an acute care facility. Probes were used to ensure that the interviews focused on the crucial issues of the study (Patton, 2002). Specifically, respondents were encouraged to talk about and describe their experience of the decision-making involved in the care transition, the reasons for their decisions, and the effects of these decisions. The interviewer probed the five aspects identified in the aims of this study:

- why and how the decision to seek services was made (identification of the transition point);
- when and how the search and selection process for services began;
- important factors involved in the decision making;
- the efficacy of the decision making process, and its effect on the well-being of the individual and their family;
- what assisted or could have assisted the older person to identify their care needs as being in transition and to use appropriate services earlier.

All interviews were audiotaped and transcribed prior to analysis. The analysis drew on previous work conducted by Cheek and colleagues (Cheek & Ballantyne, 2001b; Cheek *et al.*, 2005) and involved the following four phases:

- study of the entire transcription to give a sense of the whole;
- identification of themes and categories;
- identification of recurrent patterns;
- development of summative themes and research findings.

Transcripts were reviewed concurrent with the interview process. An overarching framework for reviewing the transcripts was discussed and agreed upon by the research team. Transcripts were analysed in order to identify:

- factors/issues that influenced the care transition;
- factors/issues that influenced the search and selection process for services;
- any effects that the care transition had on the older person and members of their family.

The first three transcripts were reviewed by each member of the research team. Reviews were exchanged and any disagreements discussed and resolved by consensus (Van Til, MacQuarrie & Herbert, 2003). Each transcript was then independently reviewed by a member of the research team. In order to ensure consistency, at least one out of every five transcripts was reviewed by two members of the research team. Themes and issues across interviews were generated and then progressively grouped into categories of similar themes. This inductive analysis of the transcripts produced major categories of themes relating to factors/issues that surround care transitions of older people, from the perspective of the older person and their family.

*Stage one Phase two: Collection of organisational and national/State policy perspectives using nominal group technique*

Nominal group technique is a structured activity that facilitates group-based decision-making (Chapple & Murphy, 1996). It enables ‘pooling of the diverse and expert judgements of five to nine people, who deliberate on issues where there is known disagreement regarding the nature of a problem and/or its possible solutions’ (Grbich, 1999: 115). Nominal group technique has two main components: an initial activity in which individuals list issues related to an identified problem, and a group activity where all members clarify and expand on the factors/issues identified. This is followed by a ranking of those factors/issues in relation to their importance to the problem being discussed. The group is constructed so that members have both a common interest in the issue and some experience and expertise that they can draw upon to consider possible solutions.

Participants for the nominal groups were drawn from aged care service providers, acute care providers, consumer groups and community service providers. Three nominal

groups were held in South Australia and three in Western Australia. One nominal group in each State was held in a non-metropolitan area, in order to ensure that the study included a rural and regional perspective. A 'key stakeholders' nominal group was also held in both States, in order to capture the perspective of those at the policy/decision making levels with respect to service provision for older people. Participants in this nominal group were drawn from aged care organisations, professional bodies, Australian and State Government, and consumer organisations who have an interest in the provision of services to older people in Australia.

The objectives of the nominal group process were to identify factors/issues surrounding care transitions of older people and to rank the factors/issues according to their perceived importance.

At the beginning of each of the nominal groups, participants were given an overview of the project, its various stages, and the tasks involved. During the initial discussion, it was emphasised that the project would not judge individual practice.

Participants were asked to consider factors/issues surrounding care transitions of older people. Factors/issues were generated on single user cards as an independent activity. Each card was placed on a wall at the end of the room in full view of participants. This allowed participants to see the development of individual factors/issues, which stimulated the identification of further factors/issues. The facilitator performed an initial 'cluster grouping' of the factors/issues. A process of clarification and discussion followed, in which participants were able to expand on the information provided on the cards pertaining to the identified factors/issues and associated groupings. As new issues were raised through group discussion, these were added to the cluster groups. Lists of factors/issues in the care transitions of older people, as well as proposed strategies for addressing them, were generated from the various groups.

### **Endpoint of stage one: discussion paper and vignettes**

An analysis and comparison of the multiple data sources from stage one provided the rich data sought about factors/issues surrounding care transitions of older people. One strength of the study design is the central placement of older people and their families in the study and the richness of the multidimensional data collected. A further strength is the attention given to the complexity and process of care transitions, and the meanings that they have for older people, their families and those providing services or making relevant policies. A discussion paper was produced that summarised the findings of the interviews and nominal groups. Five vignette case studies were also developed, using the interview data from individual older people and their family members, to illustrate examples of care transition experiences from the perspective of the older person and

their family. The vignettes provide a snapshot of the range of care transitions experienced by older people and their families. An example vignette has been included in Appendix 1. A summary of the factors/issues identified from the stage one data now follows.

### **Factors/issues surrounding care transitions of older people**

Ten cluster groups of factors/issues surrounding care transitions emerged from the analysis of the data collected in phases one (in-depth interviews) and two (nominal groups) of stage one. They are:

1. Change in health status
2. Decision making: a multifaceted approach
3. Independence and the importance of home
4. Working within the system
5. Accessing information
6. Assessments: working for older people?
7. Availability of services: getting by
8. Financial concerns
9. Impact of services on older people and their family
10. Residential aged care: a desirable place?

#### ***1. Change in health status***

Care transitions were commonly precipitated by a change in health status of either the older person or their carer. A decline in health took the form of either a crisis, such as a stroke or heart attack, or a gradual decline, such as continence issues, decreased mobility, or cognitive decline. Such problems often meant that existing support structures, such as informal support from family, were no longer able to meet the needs of the older person, thus creating a need for additional support services or relocation. Family members reported that in cases of cognitive decline, deteriorating family relationships were frequently a trigger for care transition. They also reported that health professionals did not always fully recognise the extreme difficulties associated with managing people with dementia at home. In some instances, a decline in the health of the carer meant that the carer could no longer cope with providing support for the older person, which precipitated the care transition. Participants highlighted the need for greater support and respite for carers and a lack of information regarding carer support services.

Not all changes in health status resulted in a decline. In some instances, an improvement in health status of the older person led to a transition from some services to less services or to a termination of services.

## ***2. Decision making: a multifaceted approach***

Whilst the decision about the care transition was sometimes made by the older person alone, others such as family and health care professionals were often involved. In particular, family members were often a major influence, with many decisions to undergo a care transition largely undertaken by family members concerned for the older person's ability to cope. The older person either agreed with this opinion or, despite not necessarily agreeing, accepted the necessity of the decision – 'I accept it for the way it is. I'd rather be home if that was practical but it can't be that way.' Caring for the older person sometimes put a strain on family relationships and this influenced the need to seek a different arrangement. In some instances, health professionals intervened and helped facilitate the decision. This was greatly appreciated by family members who were no longer coping with the care of the older person – 'Yes, in the long run we needed someone to take it out of our hands.' Family dynamics or changes in the family situation also had an impact on care transitions. Changed employment, social circumstances or health status of family members often affected the family's ability to continue providing support to the older person and led in turn to the search for formal support services or physical relocation. Another significant issue identified by nominal group participants was maltreatment of the older person: older people may experience physical, psychological or financial abuse by their family, affecting decision making and options regarding care transition, including issues relating to inheritance, which are discussed in a later section of this report.

In terms of the search and selection process, older people in the study reported varying degrees of involvement. In most cases, family members played a major role in searching for and selecting services. In some cases, there was disagreement between the older person and family members regarding the best care option. Family members sometimes pressured the older person into a care transition, with the older person feeling like they had been 'talked into it'. This can lead to conflict and tensions between the older person and family members.

## ***3. Independence and the importance of home***

The decisions of older people regarding care transitions were often motivated by their desire to remain independent. The desire to remain independent often determined the extent to which participants would accept care and support from others and also the type of services they preferred, for instance support at home versus moving to a residential aged care facility. Some participants opted for as little help as they could

manage – ‘No, I didn’t need anything else. I’m capable of doing my washing, hanging washing out. I don’t have ironing; I can handle the cooking at the moment.’ Independence also related to not wanting to be a burden on the family and this often influenced the decision to accept support or relocate to a residential aged care facility – ‘They have their own family and it’s not fair on the grandchildren to have the responsibility of me.’ Lack of transport was identified as problematic, as access to transport could help facilitate independent living by enabling such things as access to shopping and other facilities. Social or environmental changes, for instance changes to the local community such as the closure of local shops or other local supports, also affected the care transition. In addition, feelings of insecurity were identified as important issues sometimes leading to a care transition.

The concept of ‘home’ also played an important role in decision making regarding care transitions, with many participants identifying the familiarity of the environment and neighbourhood as a key factor in deciding to accept services at home. The desire to avoid residential aged care also played an important role in decisions to accept home support. In some instances, the desire to avoid residential aged care facilities was a result of negative perceptions of such facilities. Cultural factors or expectations also influenced the reluctance to consider residential aged care facilities or to have help in the home from outsiders.

#### ***4. Working within the system***

Working within the system played an important role in the search and selection process for services. This term refers to the processes that participants had to go through in order to receive services. Older people and their families often relied on informal networks, such as knowing someone in the industry or someone who had already been through the process, as a means of navigating the system. Participants reported difficulty in negotiating support services – ‘I think we would have finally managed to muddle through’ – while others described the process as ‘luck of the draw’. Some older people reported poor communication between themselves and doctors, particularly in the hospital system, stating that the doctor did not explain, listen to them, or involve them in the selection process for services. However, other older persons reported good guidance, decision-making and referral by general practitioners (GPs). Nominal group participants emphasised the considerable influence of the GP upon older people’s decisions, highlighting the need for GPs to be up-to-date with information about available services. It was acknowledged that GPs often deal with difficult situations in limited available time, highlighting the need for increased remuneration for GPs. Older people and their families also reported good support from other health care professionals, particularly social workers.

Nominal group participants frequently expressed serious concern for older people who did not have an advocate or suitable supportive relative, suggesting that in these circumstances the system would fail to provide adequate care. Family members advocating for the older person, often a daughter or grand daughter, reported difficulties negotiating the system on behalf of the older person – ‘lots of hounding ... I tried not to make a nuisance of myself but I was on the phone to them regularly within a few days of one another saying “Has anything come up yet?”’ Family members also reported the need to follow up and check on the organisation and provision of services. They believed that the required services would often not be provided without such follow up.

Lack of adequate discharge planning from acute care settings was identified as problematic by some participants. Specifically, participants reported that there was no feedback mechanism allowing monitoring or improvement of discharge planning procedures, and it was also reported that there was often a lack of communication between health care professionals, for instance between doctors, specialists, and social workers.

#### ***5. Accessing information***

Participants described a ‘maze’ of services, entitlements, legal advice, rights and responsibilities. In particular, older people and their families reported difficulties with accessing information and knowing where to get that information. They reported being confused by the available information, particularly due to the use of jargon and acronyms and the complexity of the system, and they often did not know what information they needed until the situation arose – ‘Until you are sort of on your own, you don’t really know what to ask’. A lack of information on specific conditions, such as dementia, was also identified as problematic. Participants also expressed concern that the provision of inappropriate information often set up unrealistic expectations.

#### ***6. Assessments: working for older people?***

Assessment was identified as a major factor influencing the available options and outcomes for the older person undergoing a care transition. Participants emphasised the importance of accurate, high quality assessment. A number of concerns about assessment were raised. Inaccurate assessments were identified as particularly problematic, as they could limit the options available to an older person and their family and were often difficult to change. Participants also expressed concern that older people could undergo further decline while waiting for assessment; the waiting period for assessment is sometimes substantial. Another concern was the time and duplication involved in multiple assessments that repeatedly asked the same questions. Finally, concerns were raised for the need for assessments to cater to the individual needs of the

older person, and not be constrained or determined by time and resource pressures and the limitations of available services.

Difficulties with the assessment process itself were identified by family members, who reported difficulties in openly discussing sensitive issues in front of the older person during the assessment. In addition, family members reported that older people often understated their situation to assessors, preferring to put on their 'best face', which meant that the information being provided, and the conclusions drawn by the assessor, were not necessarily accurate.

### ***7. Availability of services: getting by***

The need for timely intervention was emphasised as a major factor in crisis prevention. However, access to support that met the individual needs of older people was often limited by factors such as geographic location, demand for services at a particular time during the week, transport availability, and restricted availability of services. This often meant that clients were 'fitted' to available services, rather than services being matched to the individual needs of the older person. Participants also reported the need to wait for services and a lack of home-based services for high care clients. Private services were sometimes used as an interim measure until government funded services became available or while packages were being established. Family members often acted as a 'safety net' if formal services could not be obtained at the time of need, and the availability of support from family was identified as having a significant impact on the care transition. Obtaining respite services for the older person was also difficult and this affected the carer's ability to continue providing support.

Participants reported that service availability often meant that decisions were made under pressure in a short space of time, for fear of missing out on an opportunity. This was especially the case for residential aged care placements, resulting in a limited choice of care options. In contrast, some participants reported active planning, such as seeking support services or residential aged care placement prior to reaching a crisis point.

### ***8. Financial concerns***

Financial considerations were identified as having a significant impact on the older person's ability to accept the need for change and on choices available for older people once that need was recognised. Some participants described having difficulties associated with payment for services; they expressed confusion about what needed to be paid and to whom. Nominal group participants also highlighted a lack of understanding by older people and their families in relation to the limitations of private health insurance coverage and the need, or lack of need, to sell the home to pay residential aged care facility bonds. Some older people declined fee-based services because they believed

that they should have the right to free services, and older people and their families were fearful of escalating costs for services. Older people were often unaware of free services that could assist their care needs. Some older people were very happy with the relatively low cost of services.

Nominal group participants reported that in some cases older people are reluctant to pay for necessary services, as this may reduce the amount of inheritance available to their family. They reported that some family members discourage older people from paying for services for this reason. Some older people are reluctant to reveal their financial situation to family and authorities; this too creates barriers to service provision.

From a service provider perspective, the financial considerations of trial and pilot programs were identified as problematic, as the completion of a program often left the older person with no support and options.

### ***9. Impact of services on older people and their families***

General satisfaction was reported by older people and their families with regard to the use of community services. An overwhelming majority of older people and their families reported a reduction in the burden for the family caring for the older person following the care transition. In many cases, older people and their families reported an increased sense of independence as a result of the older person being able to remain at home with support. Independence was enhanced by improvements in physical and mental health resulting from the introduction of support services. In some cases, the older person reduced the amount of support required or discontinued services following improved outcomes in their physical and mental well-being. Older people also reported feeling more secure in the knowledge that support was available to them when required. Finally, older people reported benefits associated with increased social contact with others through interaction with service provider staff, volunteers and through the development of new social networks.

Family members also benefited from the decision to use support services. They reported improved relationships and increased 'quality time' with the older person, as the focus was no longer on simply providing care. Another benefit from the perspective of family members was that they could resume their own lives and family responsibilities, as they did not have to worry about the care situation of the older person – 'It's changed our life completely. I am able to get more organised and confident. It has had an impact on the whole family.'

In contrast to these benefits, some participants felt that accepting support had led to a loss of independence and privacy as a result of having service providers coming into their home.

### *10. Residential aged care: a desirable place?*

Participants reported both positive and negative outcomes from relocating to a residential aged care facility. For instance, some participants described experiencing an increase in social interaction and enjoying spending time with other people, such as other residents and carers. For some older people, an increase in activities through participation in the residential aged care facility's social programs had led to an increased sense of independence. Participants also reported feeling safer and more secure in the knowledge that care was available at all times. This feeling of security also extended to the family, with a reduction in their concern for the health and safety of the older person.

In contrast to these positive outcomes, some older people and their families experienced a sense of resignation about the move, which they had not necessarily wanted – 'I did not like leaving [the older person] at first. I thought it was mean, but then I knew I had to.' Some family members also reported feelings of guilt at having let the older person down, particularly in cases where there were cultural expectations that the older person stays at home and is cared for by the family.

## 5. Stage two: The development of a range of strategies that address issues identified in stage one

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Building on the data collected in stage one, a program of workshops drawing on action principles was used to identify and develop strategies to address the factors/issues identified in stage one. The research team has successfully applied this approach in previous research projects (Cheek *et al.*, 2002; Cheek *et al.*, 2003). Action principles are used to create new forms of knowledge through a synthesis of the different understandings and experiences of those who take part (Rice & Ezzy, 1999: 173). This approach has evolved from health services and health management research and is ideally suited to research that must sit within an existing system while developing, implementing and monitoring of a new system (Colquhoun & Kellehear, 1993). Implementation of new practices involves the management team, health professionals, carers, professional organisations and consumers working together.

Workshops were held in South Australia (n=2) and Western Australia (n=2). Participants were drawn from a broad range of stakeholders, including service providers, health professionals, government, and consumer groups.

Prior to the workshop, all participants were sent the discussion paper, which provided an overview and distillation of the factors/issues identified in stage one of the research and a series of vignettes illustrating different types of care transitions. The final part of the discussion paper asked participants to consider how the factors/issues identified in the discussion paper, and the issues raised in the vignettes, related to their organisation or themselves, and what types of strategies could be developed to address these factors/issues. Participants were encouraged to consult widely with their colleagues prior to the workshop.

The workshops began with a brief recap and overview of the project and the aim of the workshop. Participants were then asked to choose which key factors/issues identified in the discussion paper they wanted to focus on with respect to the development of strategies. Small groups formed around the choice of factors/issues. Each group was asked to produce strategies pertaining to their chosen factors/issues, taking into consideration the issues raised in the vignettes. They were also invited to comment on the factors/issues themselves. Each group reported back to the larger group with their strategies, and whole group discussion ensued. Facilitators directed participants towards identifying strategies for the resolution of issues that emerged in the course of discussion.

A set of strategies emerged that might be used to address the factors/issues identified. These potential strategies were summarised in a paper that formed the basis for the development of recommendations pertaining to best practice for service provision for older people.

The data collected from all four workshops were analysed and grouped into broad strategies and associated sub-strategies where appropriate. The results of this data analysis form the basis of the discussion that follows. For each cluster group, the key strategies are listed and each strategy is then discussed in detail.

### ***Cluster group 1. Strategies identified to address factor/issue one: Change in health status***

- Early identification of risk factors for change in health status
- Supporting carers to care for older people
- Greater flexibility of services in response to changes in health status
- Improving the hospital system for older people – ‘age-friendly hospitals’

#### **1.1 Early identification of risk factors for change in health status**

Participants identified a need for health services to focus on prevention and early intervention rather than simply responding to health crises as they arise. Part of facilitating early intervention includes a review of the age limit for Enhanced Primary Care Medicare Benefits Scheme 75+ health assessments. Participants identified a need to lower the age limit in order to detect and respond to health needs in a more proactive manner. Participants suggested investigating opportunities to provide a ‘wellness check’ service for early intervention and prevention. They also agreed that there is a need to educate the community broadly regarding the identification of potential/future health risks and the needs of older people. Such education should begin in schools, not just later in life, so that health issues are not seen as affecting only a particular segment of the community. Participants suggested using media campaigns, such as local newspapers, to promote healthy ageing at the community level, targeting people who are well and active. Participants also suggested using local service directories and local papers to increase the profile of service providers.

#### **1.2 Supporting carers to care for older people**

Participants suggested that there is inadequate support for carers caring for older people. There is a need for early identification of carers so that support services can better assist them in their role. Participants suggested that GPs may assist in identifying carers early. In addition, early, low levels of support and education, such as training in manual handling, could help avert crises by acting as an early intervention and prevention

mechanism. There is also a need to foster greater collaboration between informal and formal support services to help build community capacity. Participants also identified the need for more flexible respite for carers. Some participants indicated that available respite is often not being utilised and that there is a need for better communication and promotion.

### **1.3 Greater flexibility of services in response to changes in health status**

Participants suggested that the current inflexibility of support services can act as a hindrance to older people obtaining the services that they may require. For example, an older person assessed as requiring high level care might be ineligible to receive community support services, even if that person has since improved and can function independently with some services. Thus, there is a need for support services to recognise improvement in people's health, not just decline. Furthermore, participants suggested that there needs to be a redirection of funding and resources from the acute system towards greater focus on prevention and early intervention programs, with the focus on proactivity, not reactivity.

### **1.4 Improving the hospital system for older people - 'age-friendly hospitals'**

Participants identified the need to develop 'age-friendly' hospitals that are more sensitive to the issues of caring for older people. Hospitals need to enhance independence and meet the needs of older people. They suggested that hospitals could allocate a ward/unit specifically for older people; this would provide specialist care that recognised the specific needs of older people. Participants further suggested that an aged care worker from the hospital could supervise the care transition following discharge.

## ***Cluster group 2. Strategies identified to address factor/issue two: Decision making: a multifaceted approach***

- Educating older people and the broader community
- Protecting the rights of older people
- The need for time to make a decision

### **2.1 Educating older people and the broader community**

Participants identified a need to educate the public, as well as health professionals, regarding services available to support older people and their families caring for them. They suggested setting up a 24-hour hotline that could give advice and answer people's questions regarding services available to older people and their families. Similarly, participants suggested developing an information package to educate older people about services available. Such a package could potentially be provided through Centrelink to all older Australians over the age of 65. In addition, participants suggested that older

people should be provided with education about potential health risks earlier on and should be encouraged to take responsibility for their own health. To this end, participants recommended the development of educational programs that are age specific, problem specific and protective of individual rights, and that also support and encourage self-advocacy. Some examples of existing programs were mentioned; these included a 'Men's pit stop' program that had been used to provide a health check for men and to raise their awareness of health issues. Participants also suggested using fridge magnets to help provide education about more general aspects of ageing. In particular, this could be used as a tool to educate older people and their families about issues of positive ageing, and what they may need to think about in order to age positively.

Participants noted that funding restrictions lock service providers into providing services and prevent them from performing a broader role that includes community education. For this reason, education should become a priority and part of the funding structure of service programs.

## **2.2 Protecting the rights of older people**

Participants suggested that older people should have access to education regarding their rights and be made aware of available choices, so that they can make informed decisions about their care. The older person should at all times be kept informed, so that they make active decisions and are not passive recipients of services. Furthermore, participants suggested the use of a 'Client's Rights' schedule to be completed at key points along the care transition. Such a process would be mandatory, to ensure that the older person's rights are protected.

## **2.3 The need for time to make a decision**

Participants agreed that decisions about care should not be rushed or made at a time of crisis, particularly after an older person experiences an acute episode and is admitted to hospital. They suggested that, whenever possible, decisions regarding care should be made at home and not when the older person is in hospital. The older person should be given time to consider all options and seek other opinions. One suggestion was a 'trial at home period', particularly in the case of older people who are considering residential care.

### *Cluster group 3. Strategies identified to address factor/issue three: Independence and the importance of home*

- Transport
- Building design
- Building on existing successful programs that support independence
- A focus on rehabilitation

#### **3.1 Transport**

Participants suggested that current transport services for older people are inadequate and do not facilitate independent living. Participants noted that any transport initiative must be equitable and easily accessible and must enable people to move within and between metropolitan and non-metropolitan areas. Transport services must also be flexible in order to meet the needs of older people; for instance, in some rural areas existing transport services only enable older people to travel to their destination and not back. Participants recommended the expansion and development of initiatives such as the Out N' About program in South Australia, which uses volunteers to teach older people how to use public transport. In addition, participants suggested exploring the use of volunteers to help transport older people to their destinations. However it was recognised that insurance issues may need to be addressed before such a service could be viable. Participants also suggested using volunteers to deliver goods and services, such as shopping, to older people's homes in a fashion similar to the Meals on Wheels program. Another idea was a 'buddy' system to assist older people with their shopping. It was suggested that high school students or more active older people in the community could perform this role. Other suggestions of ways to transport older people to their destinations included community buses and sharing taxis. The latter would require partnerships with taxi companies. Participants also identified a need to re-educate older people and their families regarding user-pays systems in order to sustain such programs.

#### **3.2 Building design**

Participants identified a need for more work with the building industry towards the design of homes that support independence. It was suggested that there is a need to promote living environments and community development models that are more inclusive of and valuing of older people. Thus there is a need to better educate and raise awareness within the building industry about approaches to design that facilitate ageing in place.

### **3.3 Building on existing successful programs that support independence**

Participants acknowledged that there are a number of existing programs that support independence, for example, Silver Chain Home Independence Program, the Arthritis Foundation self management program, and a number of falls prevention programs, such as Stay on your feet and HIP protectors. It was suggested that these programs should be more widely utilised, promoted and expanded to help promote independence.

### **3.4 A focus on rehabilitation**

Participants identified a need for greater emphasis on service provision with a rehabilitation focus in order to reduce the long term need for care services. Participants noted that current eligibility criteria and funding models restrict access to rehabilitation services and need to be reviewed. Participants suggested that intensive 6-week to 3-month rehabilitation programs incorporating physiotherapy and occupational therapy could be used following health-related crises in order to help maintain older people in their homes. Participants noted that rehabilitation might not be possible for some people, such as dementia sufferers, but it was suggested that in such cases an increase in activities might facilitate better outcomes. Participants also suggested a need for rehabilitation to go beyond just physical rehabilitation.

Participants recognised that the potential for rehabilitation was influenced not only by the older person's condition but also by the amount of informal support available to them upon their return home, for example living alone versus being cared for in the home of a family member. Participants suggested a need for services to recognise that family support is not always available in rural areas. Hence there is a need for different rehabilitation programs that recognise the different living situations of older people.

Participants also noted that in situations where the older person is living with family members, having services in the home may be invasive. They therefore identified a need for multi-purpose community based facilities that combine community activities and rehabilitation. Such facilities might also cater for younger age groups, not just focus on aged care, and provide overnight accommodation and care for clients with dementia, in order to provide respite for both the older person and their carers.

Despite the current push towards community programs, participant recognised the need for options to be available for those people who prefer non-community based care, such as residential aged care facilities. However it was suggested that residential aged care facilities need to have a greater focus on rehabilitation. Participants also noted that there is often little time allowed after a crisis before a client is assessed as either having 'potential for rehabilitation' or requiring institutional care. Participants suggested trial periods for home-based services and residential care so that decisions are not made

under pressure and older people are given time to adjust to the care transition before making a decision.

***Cluster group 4. Strategies identified to address factor/issue four: Working within the system***

- The older person needs an advocate
- Creating pathways and linkages between service providers
- Information sharing and collaboration between service providers
- Building on successful programs
- Education of health professionals

**4.1 The older person needs an advocate**

Participants noted that decisions regarding care transitions are often made under pressure and during a time of great stress. Participants suggested that use of a key contact person/ case manager/coordinator in these situations would better enable the older person to obtain and co-ordinate the services necessary to remain in the community. Such a person would assess the needs of the older person and assist the older person in sourcing services appropriate to their needs. The contact person/case manager/coordinator would assist not only in navigating the system, but also in 'digesting' the large amounts of information available. Participants suggested that it was necessary to focus on planning rather than just crisis intervention. It was suggested that funding for such a position could be provided through Medicare rebates. In addition, participants suggested that service providers could broker and manage additional services from other service providers. Such a system would provide some continuity for the older person and could limit the number of service providers and administrators that the older person and their family have to deal with.

**4.2 Creating pathways and linkages between service providers**

Participants identified the need for the effective channels of communication between all service providers involved in the provision of services to older people. Specifically, participants suggested a need for 'in-reach' programs, that is, community case managers accessing information about the acute system, in addition to the outreach programs, that is from hospital to community, already in existence. In other words it is important for community service providers to understand the services provided by the acute sector and vice versa. Participants also suggested a database of information on service availability that could be used by both community service providers and hospital discharge planners.

Participants also suggested that there is a need for pathways between service providers to increase the options available to clients. For instance, if an organisation was unable to provide a requested service it could refer the client to another, more appropriate service. Participants suggested the compilation of flow charts identifying networks of services available in particular regions. Flow charts of this type, integrated with service directories and Commonwealth Carelink, could form the basis of a referral system. Websites providing information about and/or links to services and service providers could also be established. The dementia services directory developed for the community of Albany in Western Australia is an example of this type of initiative.

#### **4.3 Information sharing and collaboration between service providers**

Participants identified a need for greater collaboration and information sharing between community service providers. In addition, they identified a need to inform families and GPs about relevant health issues upon the discharge of older people from acute care and other services. It was recognised that in some sectors, such as mental health, such information exchange is already happening. In addition, participants suggested a single document setting out a plan of care for each client; this could be shared with all providers to make the provision of care more efficient and effective. However participants noted that there may be privacy and confidentiality issues with such a strategy.

Participants also suggested initiatives at the organisational level, such as professional forums and newsletters, to facilitate information sharing between service providers, raise awareness about available services and encourage discussion about current research and pilot projects. In addition, participants recognised the need for some formal mechanism enabling service providers to provide input to the establishment of government programs. The service provider forums suggested may provide one avenue for service providers to lobby government and ultimately influence policy. Participants also identified a greater need for collaboration between service providers in the development of submissions to funding bodies.

#### **4.4 Building on successful programs**

Participants suggested that effective pathways between service providers would also ensure that information about effective programs is disseminated and enable services to build on existing successful initiatives rather than 'reinventing the wheel'.

#### **4.5 Education of health professionals**

Participants identified a need for greater education of nurses and GPs about issues facing older people. Such education should begin at tertiary level, not just on the job. For instance, participants noted that many graduate nurses are unaware of the issues facing discharge planners when planning for older people. It was suggested that nursing students could do some of their placements in community programs in addition to residential aged care facilities. Similarly, aged care needs to feature more prominently in the education of GPs, who are often the first point of contact for older people and their families regarding health and care options. However, GPs often do not refer older people to community service providers until a crisis situation has occurred. Participants suggested that a 'well aged' model should form the focus of GP education, focusing on healthy ageing and independence. Recognising that GPs have limited time and resources, participants also suggested the use of other health professionals, such as practice nurses, to assist GPs in educating patients, identifying risks, and picking up complex community problems facing older people living in the community. Participants noted that risk assessment should be multi-disciplinary in approach and draw upon the expertise of a broad range of health professionals working in collaboration in order to provide the best care for older people living in the community.

#### ***Cluster group 5. Strategies identified to address factor/issue five: Accessing information***

- Promoting the use of Commonwealth Carelink
- Creating a central registration point for residential care

#### **5.1 Promoting the use of Commonwealth Carelink**

Participants noted that in some cases Commonwealth Carelink has not been successful in providing useful information to rural residents because the organisation is not aware of issues or changes specific to a particular area. However, participants also noted that in some regions Commonwealth Carelink is being effectively utilised and that these should be used as a model for less successful regions. There is a need for greater linkages between Commonwealth Carelink and service providers to ensure that Commonwealth Carelink and in turn consumers are provided with up-to-date information. Participants also suggested making Commonwealth Carelink more accessible to consumers. For instance, participants identified a need to review the design of Commonwealth Carelink brochures, which are currently hard to read. In addition, Commonwealth Carelink booths could be located in shopping centres, providing face-to-face contact for consumers, as older people may find communicating over the phone difficult. Participants also suggested co-locating Commonwealth Carelink with Centrelink in order to increase awareness and accessibility of the service. Participants identified a need

for a formal evaluation of Commonwealth Carelink as there are currently wide variations in effectiveness.

## **5.2 Creating a central registration point for residential care**

Participants suggested the establishment of a central registration point for places available in respite and residential aged care. It was recognised that services such as the Seniors Information Service in South Australia currently provide a similar service, but it was noted that not all residential aged care operators are registered with these services. There is therefore a need for compulsory registration of all available beds.

### ***Cluster group 6. Strategies identified to address factor/issue six: Assessments: working for older people?***

- Developing a holistic assessment
- Privacy legislation

## **6.1 Developing a holistic assessment**

Participants suggested that assessments for older people should focus not only on their health but also on the supports they have available and lifestyle issues. Thus assessments should incorporate information not only from the older person but also a range of other sources such as family and friends, GPs, domiciliary care and other forms of formal or informal support. Participants also noted that assessment should not be seen as a 'one off', but rather part of a 'rolling process' that may be multi-layered, depending upon the client's needs.

Participants suggested that a standard comprehensive holistic assessment tool needs to be developed and used by all service providers. Such an assessment would minimise the duplication of assessments and provide an efficient use of time and resources, for both service providers and clients. Participants noted the trial of the single entry point (ERA) utilising an Initial Needs Identification (INI) tool and suggested further exploration of such an approach. ERA undertook the INI over the phone, which attempted to streamline low level service provision or flag the need for a comprehensive assessment if necessary.

Participants also raised the issue of the adequacy of assessors' training. They noted that some assessors do not have broad experience in the field, and are hence unable to identify cases where comprehensive assessment is necessary. Thus adequate training of assessors in this regard was considered important.

Participants also identified that in future, assessments may need to incorporate different forms of technology, such as electronic assessments. Potentially, participants could answer a series of questions which would then result in an online assessment.

Participants suggested changing the name Aged Care Assessment Team (ACAT) to Aged Care Assistance Team, to better reflect the role that ACAT plays. Participants stated that ACAT facilitates the provision of services as well as conducting assessments, particularly in rural areas.

Finally, participants identified a need to educate older people and their families about the purpose for assessments. It was suggested that a flow chart be developed that would identify the different steps in assessment and who was involved in each step.

## **6.2 Privacy legislation**

Participants noted that misconceptions about current privacy legislation sometimes prevent older people, their families, and service providers obtaining critical information related to the care of the older person. They therefore identified a need to educate service providers about exactly what information can be made available to third parties.

### ***Cluster group 7. Strategies identified to address factor/issue seven: Availability of services: getting by***

- Designing care packages around individuals

#### **7.1 Designing care packages around individuals**

Participants noted that clients are currently matched to available services, rather than services being tailored to clients; this means that clients may not receive the services they need or may receive services that they do not require. There is a need for all service providers to focus on person centred care, so that services are individually tailored to the older person's needs. Participants suggested the use of case managers who can assess the specific needs of an individual client and then 'shop' for a package of services for that client. There is also a need to educate care providers regarding the needs of individuals with specific conditions, such as mental illness, so that the appropriate support services are made available to these individuals. In addition, participants suggested a need for better coordination of funding sources.

Participants noted that many services operate under a 'nine to five' mentality that does not cater for older people who require assistance at night or during weekends. Participants therefore suggested that services should extend their hours of operations. They also suggested the establishment of program guidelines that enable the portability of services across geographical boundaries, so that a client does not lose services in the event that they move residence.

Participants identified a need for services to be equitable and be metropolitan wide, as some services were available in some areas and not others. Participants suggested that people in private hospitals also need access to a service like the Home Rehabilitation and

Support Service: Acute Transition Alliance program in South Australia, which is a service specifically for people discharged from public hospitals.

***Cluster group 8. Strategies identified to address factor/issue eight: Financial concerns***

- Dealing with funding issues
- Educating the community about Centrelink services

**8.1 Dealing with funding issues**

Participants identified the need to eliminate the division between State and Australian Government funding as currently people with State funded services are unable to use Australian Government funded services and vice versa. There is also a need for services that operate throughout all areas rather than the current 'silos' of funding that make services inequitable. Participants further identified the need for the large scale implementation of successful pilot programs, rather than continual development of new pilot programs that essentially do the same thing as previous programs. Participants recognised the diversity of services across the State and suggested the establishment of a central coordination point for services that would also monitor funding.

Participants identified the short term nature of funding as problematic in enabling continuity and providing best practice. Pilot programs are generally funded for granted two to three years; funding then ceases abruptly, causing disruption to clients. Participants identified a need for successful projects to receive ongoing funding, and also for the development of exit strategies for pilot projects so that clients are not left without services once funding has ceased.

**8.2 Educating the community about Centrelink services**

Participants identified a need to raise community awareness about Centrelink programs that are targeted towards older people and carers. For instance, Centrelink provides advice to older people and their carers about housing choices and financial issues. Participants identified a need for Centrelink to better promote itself, for instance by providing a newsletter about these issues.

***Cluster group 9. Strategies identified to address factor/issue nine: Impact of services on older people and their family***

- Getting older people thinking about future needs
- Reducing social isolation

**9.1 Getting older people thinking about future needs**

Participants suggested the use of pre-retirement sessions to introduce older people and their families to the issues they may face in the future. Such sessions would be designed to normalise thinking about future needs and options, so that older people and their

families can plan for their potential needs rather than wait for the onset of a crisis. In particular, participants identified a need to educate the community broadly about the user pays principle, which may be increasingly necessary to achieve sustainability of services. In addition to pre-retirement seminars, participants also suggested greater education in the workplace about the ageing process and ageing issues; this is particularly appropriate in view of the fact that people are remaining in employment longer.

## **9.2 Reducing social isolation**

Participants noted that social isolation is a growing issue. There is a need for government policy to understand and address social isolation and ensure that older people feel secure at home. There is also a need for increased research into the social isolation of older people, to support and guide policy.

### ***Cluster group 10. Strategies identified to address factor/issue ten: Residential aged care: a desirable place?***

- Educating the community about residential aged care facilities
- Supporting older people and their families in residential aged care facilities

## **10.1 Educating the community about residential aged care facilities**

Participants suggested using introductory seminars about residential aged care facilities in order to educate the community about these services. This could help to combat negative perceptions of residential aged care facilities by highlighting examples of successful integration into residential care. In addition, participants identified a need to educate older people and the community about the entry process for residential aged care facilities including financial bonds. Participants noted that potential clients are often unaware that a large portion of the bond paid for entry into low care is returned after the resident leaves the residential aged care facility.

## **10.2 Supporting older people and their families in residential aged care facilities**

Participants identified a need for supports for older people and in particular their families, such as grief/loss counselling, when a relative needs to move into a residential aged care facility. Social workers or counsellors could be employed to carry out this role. In addition, participants suggested providing older people with opportunities to continue attending day activities for a short period after entering residential aged care facilities, to help them gradually adjust to the care transition. Participants noted that there are not many options for married couples, and that many couples are separated when one partner enters a residential aged care facility. Participants suggested that future residential aged care facilities should be designed to cater for married couples. Participants suggested that it should be possible to provide accommodation for both

members of a couple, with one member being funded by the government and the other privately funded. Alternatively, residential aged care facilities could make provision for overnight stay of partners. Participants further suggested the construction of a new type of residential aged care facility consisting of a services hub surrounded by a series of units. Residents could then remain in their unit and use high and low care services and support from the central service point. However, it was recognised that some people prefer living in shared-room facilities, as this provides extra social contact when relatives of other residents visit. Thus a variety of options should be made available to cater to the individual needs of older people.

## 6. Stage three: Implementation of selected strategies

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In the third stage of the study, selected strategies were identified in consultation with industry partners and some of these were implemented in the two States. Strategies were selected based on the data collected in the previous stages and on the extent to which they were achievable within the given time frame. The specific strategies identified were:

- Educating consumers about options and opportunities for services and support;
- Exploring the usage of Commonwealth Carelink as an information point;
- Collaboration between organisations and sustainability of programs.

Separate approaches were employed to implement each strategy and these are now discussed in further detail.

### **Educating consumers about options and opportunities for services and support**

One of the most pertinent issues arising from this study, as well as others (Cheek & Ballantyne, 2001a; Cheek *et al.*, 2003; Cheek *et al.*, 2005), was difficulties experienced by older people and their families in attempting to navigate the system of information and services. Older people and their families have consistently reported that they have difficulty knowing how to access information about the services and support they require and that they would like help with navigating the system. In addition, organisational stakeholders state that while there is a multitude of information available, it is not coordinated in a way that allows easy access by consumers. Simply producing more information that 'sits on racks' will not assist older people and their families to navigate the information they require. The purpose of this strategy is therefore to provide older people and their families with skills to navigate the system of information and services available to them. Focusing on the process of obtaining information, as opposed to providing particular information, provides a more powerful approach to education, as consumers develop generic skills that they can use in a variety of circumstances.

Discussions were held with COTA National Seniors in South Australia to explore the possibility of adapting their Peer Education program to focus on education about how to navigate information pertaining to services and supports for older people and their families. A peer education framework was subsequently developed in collaboration with COTA National Seniors.

The peer education model employed by COTA National Seniors builds on the notion of 'community capacity building'. The model promotes and encourages the sharing of

knowledge and experiences while providing strategies that are practical. The peer education model focuses on positive ageing and is based on a wellness model that promotes and enhances the building of community networks. It encourages the individual to remain well and independent and to be an active participant in the decision making processes that affect them as they age. By utilising peers as educators, the peer education model helps bridge the gap between the community and the health professional and recognises the importance of developing an adult learning relationship based on mutual respect, openness and equality.

Based on the principles embodied in the peer education model, The Peer Education Framework was developed to provide a structure around which a project could be developed and to define the parameters within which the project would operate. Importantly, the peer education framework identifies four key messages for consumers, which link the peer education framework outcomes with the research undertaken in relation to older people and information navigation. The four key messages that underpin the education program are:

1. Getting help can lead to increased independence
2. Be prepared – know what is out there in case you need it
3. It takes time – plan ahead
4. Be an active participant in decisions about your health – do what is right for you.

A training module for peer educators, based on the second key message, 'Be prepared – know what is out there in case you need it', was developed. This module could be used as an exemplar for the development of training modules based on the other key messages. Separate training modules for older people also need to be developed in addition to the peer educator training module. The peer education framework and training module developed as part of this strategy together provide the basis for future implementation and education of older people about navigating the system of services and supports available to them and their families. In order to implement such a program, funding would be required.

### **Exploring the usage of Commonwealth Carelink as an information point**

Commonwealth Carelink Centres are an Australian Government initiative for providing information to older people, people with disabilities and those who provide care and services. These centres provide free and confidential information on community aged care, disability and other support services available locally, within the State/Territory or anywhere within Australia. The network of Commonwealth Carelink Centres was established in 2001 and there are now 65 'walk-in' shopfronts and over 90 access points

across Australia. The centres can be contacted by phoning a national free call telephone number.

Previous stages of this study – both the interviews with older people and their significant others and workshops with service providers – found that few older people or their family members had actually used the Commonwealth Carelink Centres or were aware of their existence. There were also concerns about the effectiveness of the Commonwealth Carelink Centres from the service provider perspective and about the fact that no evaluation of this strategy had been undertaken to date. Therefore, this strategy aimed to obtain more information about the use of Commonwealth Carelink Centres from both older people's and services providers' perspectives.

A survey was conducted to obtain more information about the use of Commonwealth Carelink Centres in Western Australia. A questionnaire was posted to 329 clients, together with a letter explaining the project and a reply paid envelope. Participants were older people (65 years and over) who had been referred by family/significant other or had referred themselves to a community service organisation (Silver Chain, Brightwater Care Group Inc., Perth Home Care Services) over the 3-month period June to August 2004. One hundred and forty-five clients responded, giving a response rate of 44%. In addition, 160 questionnaires were distributed to service provider organisations, together with a covering letter requesting distribution to staff who co-ordinate care for older people in the metropolitan area. Participants included co-ordinators of services to older people employed by Silver Chain, Brightwater Care Group Inc, Perth Home Care Services and ten other community service organisations within the Perth metropolitan area. Members of the Aged Care Assessment Team at eight Perth metropolitan hospitals were also included in the sample. Eighty-one service providers responded, resulting in a response rate of 51%.

Of the 145 clients who responded to the survey, only 20 (13.8%) had contacted a Commonwealth Carelink Centre. They had sought a variety of information, most commonly service availability and how to find a particular service. Of those who had not contacted a Commonwealth Carelink Centre, 63 (50.4%) had not heard of Commonwealth Carelink.

Of the 81 service provider respondents, 52 (64.2%) said that they had contacted a Commonwealth Carelink Centre; however one-half of these respondents stated that they rarely contacted a Commonwealth Carelink Centre. Service provider respondents' experiences and opinions of Commonwealth Carelink Centres were mixed. There was some acknowledgement that the Centres are a good resource of information and in many instances very helpful. However, the quality of service provided differed according to which Centre was contacted. Respondents expressed the need for more up-to-date

information on specific services, particularly in relation to information on residential care and respite availability. There were also some concerns relating to the provision of inaccurate information, with the suggestion of the need for 'live' information about availability, which is both accurate and conveyed appropriately.

Although this was a small sample survey within one State, it raises issues that require further investigation. Importantly, it reinforces the need for a large scale, comprehensive evaluation of Commonwealth Carelink Centres in order to determine the prevalence of the identified problems relating to the accuracy of information, quality of service, and low usage of Commonwealth Carelink Centres by older people, and the overall effectiveness of these centres in providing older people, their families, and service providers with the information that they require.

### **Collaboration between organisations and sustainability of programs**

One of the key themes emerging from the stage two strategy development workshops was the need to increase and improve linkages and partnerships between organisations involved in the provision of services to older people, as many issues facing individuals and operators are system wide and cannot be successfully tackled by any one organisation alone. When a particular issue was raised during the nominal groups and workshops, one or more participants often indicated that a specific but localised project was addressing the issue somewhere. Other participants often did not know about these projects. This was a recurring pattern throughout the group discussions. The proliferation of projects that are limited in scope, time and funding, with funding coming from a variety of sources, had led to a sense of a fragmented and increasingly complex service terrain. Further, the lack of ongoing funding raised issues pertaining to the sustainability of these projects. An important strategy for the aged care industry was therefore to identify ways to ensure greater collaboration between providers and make programs sustainable in a climate where short term funding is common for specific defined programs.

To address these concerns, the strategy adopted was to investigate – using existing programs – factors that assist the success of collaborative programs and how collaborative programs can be sustained over the long term. Two projects were identified in the workshops and used as exemplars of successful collaborative projects, one in South Australia and one in Western Australia.

#### ***Exemplar 1: The Acute Transition Alliance: Home Rehabilitation and Support Service***

The Acute Transition Alliance Home Rehabilitation and Support Service (ATA) in South Australia was identified as one example of a successful collaborative project. The ATA is a pilot program for older people who have been in hospital and are expected to benefit

from rehabilitation and support. The service provides short term rehabilitation and support services either in a person's own home or temporarily in a residential aged care facility. The project arose out of a need for the acute sector to address the shortage of beds in hospitals, which was caused in part by the extended periods of time that many older people were spending in hospital following an acute episode. In addition, aged care providers had identified that some older people were being inappropriately referred to residential aged care facilities, when in fact rehabilitation and a return to the community was a real possibility. Although the pilot program is auspiced by the ACH Group, the program was envisioned and has continued to operate as a fully collaborative effort between hospitals, aged care providers, and the South Australian and Australian Governments. There are currently 23 hospitals participating and referring clients to the program. Typically, referrals come from social workers, allied health professionals or the clinical nurse coordinator, depending on the arrangements that operate within each hospital. There are 19 participating aged care providers, and these include a range of residential, community and allied health services. The large number of organisations involved has meant that collaboration has been a key feature of the program. The program is supported by an in-reach Liaison Officer from the aged care sector. For further discussion of this program see Cross (2003). The following discussion describes key aspects of the program that were identified as facilitating collaboration and sustainability.

### **Principles of collaboration and sustainability from the perspective of the Acute Transition Alliance Home Rehabilitation and Support Service Program**

#### *Collaboration*

##### Having a central program idea

It is important that a program is driven by a central idea that is relevant to all participating organisations. Importantly, the idea needs to drive the development of the program, with processes being developed to facilitate achieving objectives and not developing objectives and ideas to justify the processes. Memorandums of understanding, terms of reference and other such documents should be kept simple and functional, facilitating the starting of the project rather than acting as a hindrance.

##### Flexibility of the program to achieve program objectives

The parameters of the program need to be functional and to be determined by the implementing organisation in consultation with other participating organisations. Such an approach allows flexible parameters which take into consideration the needs and capabilities of individual organisations. The advantage of this approach is that organisations feel ownership of the process, while at the same time are supported by the central body and not left isolated from the whole.

### Personal relationship building

Developing personal relationships with collaborative partners needs to be recognised as an integral part of successful collaboration. Face-to-face personal contact is one of the most significant aspects of relationship building and its value cannot be underestimated compared with less personal communicative methods such as telephone and email. Such personal relationship building can facilitate group problem solving.

### Commitment to learning and development at the organisational, professional, and personal level

Where new systems and processes are implemented, supporting the learning and development of partners is integral to maintaining collaboration. Collaborative partners should be guided to ensure that they implement and maintain new practices and do not revert to previous modes of operation.

### Leadership

All organisations need to be aware of the direction of the program, so leadership from an overall program manager is important. Collaboration also requires leadership and champions in all partner organisations in order for the venture to be successful.

### *Sustainability*

#### Adaptability of the program to changing needs

Whilst remaining focused on core principles, a collaborative venture needs to be able to adapt to the changing needs of the terrain within which it operates. This requires program parameters that provide a degree of flexibility.

#### Transferability of the principles of the collaborative program to existing programs

Sustainability should not only be considered in terms of seeking new or ongoing funding to maintain the collaborative program. It also involves how to transfer the principles and procedures developed in the collaborative program to improve existing services and practices. Then if funding for a collaborative program ceases, the knowledge gained from the experience will not be lost.

### ***Exemplar 2: The Cross Agency Project for High Care Clients***

The Cross Agency Project for High Care Clients in Western Australia was identified as the second example of a successful collaborative project. Analysis undertaken by Silver Chain over a three-year period, from 2000 to 2003, had consistently shown that a small proportion (3-5%) of the organisation's clients used 30% of the total Home and Community Care (HACC) funded services each year. Although these clients meet the guidelines for HACC eligibility, there was an awareness that this was not the target group for which the program was established in 1985. In an environment of limited

resources, with ongoing discussion about targeting and capping services, it was timely to obtain a better understanding of the requirements of this vulnerable group.

Five organisations collaborated in this project, which aimed to increase the understanding of the total package of care of clients using very high levels of HACC services (more than 15 hours per week) from one or more agencies and, where available, some non-HACC funded services, such as those funded by the Disability Services Commission. The following discussion describes key aspects of the program that were identified as facilitating collaboration and sustainability.

### **Principles of collaboration and sustainability from the perspective of the Cross Agency Project for High Care Clients**

#### *Collaboration*

##### Having a central idea for the project

The participating agencies had direct experience of providing services to high care clients. There was a common view amongst participating providers that such clients could be experiencing better outcomes and that assessment and management were being duplicated. There was a willingness to work together to gather data in order to learn more about the nature and characteristics of the group and the extent of the services they were receiving.

##### Development of relationships

Collaboration in this project has led to the development of positive relationships between senior staff of the agencies; this has in turn encouraged further development of the project. As a result, a better understanding of the similarities and differences of each service has been achieved. These relationships have made it much easier for contacts to be made and solutions found for difficult client situations, thus improving outcomes for clients.

##### Learning and development

Learning and development has occurred through the process of negotiating and documenting a set of principles in a Memorandum of Understanding. Each agency has considered how it recruits, organises and maintains supports for this client group, and ideas have been shared.

##### Leadership

Leadership within the program has been shared by all participating organisations. Coordination of the program has shifted from one agency or person to another for different stages of the project. As personnel changes have occurred, it has been important

for the founding participants to bring the new representative 'up to speed'. This has been possible because of the commitment of all participants to the outcomes of the project.

### Sustainability

#### Stickability and resilience of collaborators in seeing the project through

Determination to see the project through to completion and mutual encouragement along the way are vital in ensuring the sustainability of a program. This may be achieved through:

- setting short term goals for each stage of the project and celebrating the achievement of each milestone;
- each individual being confident enough to remind other participants about agreed tasks and follow this up until they are completed;
- willingness to consider alternative ways of moving forward when the original approach has not been successful.

Such internal motivators are particularly critical in the absence of external funding, with its associated timelines, deadlines for reporting and other external motivators.

Having presented the two exemplars, the major themes that emerged relating to collaboration were:

- Having a central idea around the program;
- Flexibility of the program to achieve program objectives;
- Personal relationship building;
- Commitment to learning and development at the organisational, professional, and personal level;
- Leadership.

Major themes relating to sustainability were:

- Adaptability of the program to changing needs;
- Transferability of the principles of the collaborative program to existing programs;
- Stickability and resilience of collaborators in seeing the project through.

## **7. Stage four: Developing recommendations for changes at the policy professional, organisational and individual level that support the use of the developed strategies**

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Two workshops, one each in South Australia and Western Australia, were held with the purpose of developing recommendations. Potential participants were identified in consultation with industry partners.

Prior to attendance, participants were provided with the stage one discussion paper, stage two strategy development paper, and a draft recommendations paper arising from the understandings gained throughout the entire project. Participants were asked to consult widely prior to attending the forum.

At the commencement of each workshop, participants were given a brief update on the progress of the project. Participants then reviewed each of the draft recommendations. Specifically, they considered the intent of the recommendations, their relevance to the project aims and outcomes, and the appropriateness of the language used. The draft recommendations paper was then revised in response to the feedback received at the workshops, and the revised recommendations were sent to participants to elicit further feedback. This process occurred separately in the two participating States. Research team members from the two States then reconvened to compare the two versions of the recommendations paper. This process resulted in a single merged recommendations paper, which was sent to the NPAP for review at the panel's final meeting. The final set of recommendations emerged from this series of iterations.

## 8. Recommendations

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Four areas of recommendations arose from the research. In making these recommendations, the research team is aware that some of the areas identified as requiring action and development are not necessarily new, with some initiatives currently or previously being undertaken to address aspects of these areas. We have chosen not to include specific examples in the recommendations, as they would not provide a complete picture of the work currently undertaken. However, our research reveals that despite such initiatives there is still much work to be done. More attention needs to be paid to expanding and extending existing initiatives rather than continuing the proliferation of new initiatives; we should 'grow the good'. This in itself is an important and significant finding of the research.

### **Area 1: Making sense of the system or making the system make more sense?**

Reducing the complexity of the system for the client is of paramount importance. Study participants ranging from older people and family members through to service providers, reported difficulties understanding and navigating the options available to them. Specifically:

- The service system is made up of many different types of services, offered at various levels of intensity, and often available from a choice of providers. The range of individual services available may be overwhelming to older people and their families particularly in times of crisis. Grouping services together can enable easier comprehension and access by older people, their families, general practitioners, and other working with older people by simplifying and reducing the amount of information that a client needs to deal with. Any such groupings would need to be person centred, which could be achieved by aggregating services according to level of need, as opposed to funding source or organisation centred.
- Encouraging service providers to provide services across the care continuum themselves or developing alliances/partnerships with other service providers whose services complement their own. This would limit the number of providers that consumers need to deal with, thereby reducing the complexity of the system for older people and their families.

Greater collaboration between formal support services, and also with funding bodies to consolidate and develop services across the care continuum. This will involve organisations adopting a less competitive orientation towards the allocation and procurement of services.

- Effective communication channels between community service providers and hospitals can ensure that both sectors are aware of and understand the services provided by the other. For example the use of updated, locally applicable internet directories of available services would aid in ensuring that service providers are aware of service options. Despite a number of initiatives in this area this remains a significant challenge for the delivery of services to older people.
- Increased professional contact between those working within the aged care and related sectors will ensure that organisations, particularly within the rural areas, are not working in isolation. Such contact may assist in disseminating information about service provision and result in better practices being adopted by a wider number of organisations. This could take the form of forums at organisational staff levels, newsletters, or other opportunities for meetings in order to facilitate information sharing between service providers and raise awareness of the different services available in different areas and discuss current practice based demonstration and/or research projects.
- It is important to ensure that effective programs developed by an individual organisation or organisations are disseminated widely. Information sharing will allow organisations to build on successful programs and reduce the duplication of pilot programs, making better use of finite resources.
- Informal support systems for individuals' care transitions need to be recognised, maintained and supported throughout the care transition. This may involve General Practitioners or other health professionals identifying and working with carers from the outset so that support services can also be targeted at carers and better assist carers in this role.
- The effect of the *Privacy Act*, unintended or otherwise, warrants further attention as this research reveals that misconceptions about the *Privacy Act* can lead to inappropriate hindrance of information flow which may be critical to the care of the older person. Specifically it is important to ensure that services providers and those caring for older people are clear about what information can and cannot be made available to third parties.

## **Area 2: Educating and preparing a diverse group of workers**

Providing services to older people is a multifaceted and multidimensional activity. All those involved in service provision now and in the future require appropriate initial and ongoing educational preparation. This involves looking beyond the traditional categories of workers or professionals identified with service provision to older people, to take into account a wider perspective of service provision for older people involving diverse groups, for example human movement students, architects, receptionists, that is anybody who is going to come into contact with older people seeking services. Specifically:

- A focus on older people should be integrated throughout education and training programs of those likely to work with older people and/or their families, not stand alone and thereby likely to be perceived as different to the mainstream. Education and training courses should continue to work to change negative stereotypes of ageing and working with older people.
- Education solely focused on short term, curative, episodic care provides a limited basis for developing workers that can contribute to the provision of services promoting positive long term outcomes for older people. Understanding chronic conditions and their impact should form a major focus for education and training programs of those working with older people. In addition continuing education and training of those working with older people should continue to develop, and ensure, a 'wellness' focus, emphasising healthy ageing and independence, as a central aspect of education in order to combat perceptions of older people's seeming inability to improve and optimise both physical and social functioning.

## **Area 3: Independence and the importance of home**

Given that older people's decisions regarding care needs and options are often motivated by the desire to remain independent, programs and initiatives which assist older people to age in place in the community warrant further exploration and development by the aged care sector in areas such as:

- Placing a system wide emphasis on service provision with a rehabilitation/enablement focus in order to reduce the long term need for care services by building on and further developing existing organisational initiatives in this area. Broadening the understanding of rehabilitation is required, with

rehabilitation perceived as a central principle underpinning all service provision rather than rehabilitation being understood as a discrete and bounded program associated with a specific medical condition.

- Placing a central emphasis on person-centred service provision in order to ensure that the needs of older people and their families are met. This will require that services are flexible and tailored to the individual – matching services to meet the needs of clients rather than matching clients to available services.
- Advocating and supporting the establishment of equitable, easy to access, metropolitan-wide transport services in order to facilitate independent living. Exploring and developing localised transport services which utilise local resources may be an effective means of providing transport services for older people.
- Fostering a sense of community building and design which is inclusive of all, including older people. Linking older people with their community could also help to reduce social isolation in addition to building on and further developing existing programs designed to address this issue.
- Working in conjunction with the building industry and local councils towards the development of community development models which are cognisant of older people's needs, for instance designing new homes or remodelling of existing homes that support independence and facilitate ageing in place.
- Examining the impact that funding models have on providing services to meet the needs of older people and their carers. For instance, the division of State and Australian government funded services can act as a barrier for the older person in obtaining services. Furthermore, the termination of funding for short-term pilot programs is problematic in terms of ensuring continuity of care for clients utilising those services.

#### **Area 4: The right information at the right time to make the best decision**

Decisions surrounding care needs are often rushed or made at a time of crisis, often as a result of an older person requiring hospitalisation. Family members play a major role in decision making. Older people and their families need time to seek, discuss and consider options regarding what happens to the older person undergoing a care transition and how best their needs can be met. Enhancing such decision making could be assisted by:

- Improving the awareness of older people and their families about available services and options facilitates proactive decisions in a timely manner prior to an

onset of a crisis. Peer education programs provide a useful way forward in this regard. In making this recommendation, it is recognised that many people may not consider such issues until circumstances make it necessary. Thus although it would be ideal to provide education or information for all older people and their families about such issues, it may be more practical in the short term to target consumers with specific conditions, for example those with chronic conditions, for whom such issues may be more salient.

- Providing education and training for older people and their families in how to advocate for older people undergoing a care transition, and supporting this process through linking with advocacy services. In particular, support should be provided to vulnerable, lone individuals. The vulnerability of older people undergoing a care transition, particularly in the case of acute care hospital admission, may result in limited options being considered and pressure to conform to the advice of service providers. Strong advocacy in such situations can assist in increasing the awareness and understanding of options available and ensure that decisions are suitable for the older person, rather than for the 'system'.
- Undertaking a systematic and formal review of the role and function of assessments in facilitating access to support services.
  - Such a review should also explore how assessment information can best be shared between relevant players in order to reduce the duplication of information collection. It should be recognised that assessment is not a 'one off' process. The development of single electronic client records would assist in ensuring that appropriate client information is obtained in a timely manner. This development must occur as a matter of urgency.
  - The role of assessments in facilitating the provision of an appropriate level of services should focus not only on physical health but also the supports that older people have available and other lifestyle issues by incorporating multiple sources of information in assessments, i.e. from carers, GPs, other health care workers.
- Older people and their families, for whom residential aged care may be an option in the future, need to be provided with the opportunity to develop more positive perceptions of residential aged care. Our research suggests that older people and their families sometimes delay decisions to enter residential aged care due to the negative perceptions about residential aged care. Increasing both the flexibility and range of services offered by residential aged care (for example,

“try before you buy”, rehabilitation) and multimedia awareness campaigns can assist in reducing negative perceptions of residential aged care.

Whilst Commonwealth Carelink was established to address the information needs of both clients and service providers, it is apparent that there remain gaps which inhibit older people and their families from navigating the system in an effective manner. Improving the access to the necessary information should be a priority. Specifically:

- The development of an up-to-date database of all residential aged care facility and respite vacancies so that such information is readily available to consumers and those working with older people.
- Information provision should focus not only on simply providing information but also the perceived integrity of that information. Personal contact, trustworthiness of the provider and the quality of the interaction can help enhance information provision.
- Improving the capacity of information providers to tailor specific information requests to meet the individual circumstances of the older person and their family such that the information provided is timely, individualised, targeted and effective.
- There are consistently wide variations reported in terms of the effectiveness of Commonwealth Carelink as an information service. Therefore the Australian Government should undertake to formally and systematically evaluate Commonwealth Carelink in terms of its role as a provider of information to consumers and service providers.

## 9. Summation

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The study has highlighted some important lessons about the transitions that older people confront. They include:

- Care transitions are more of a process than a point. It is often difficult to isolate an exact point that can be named as "the transition" with a discrete beginning and ending. Rather, there are a series of events and activities that surround a care transition and thus make it a process. Vignettes developed in this study capture and articulate the complexity of the care transition process and are useful planning and educational tools for older people, practitioners and students to better reflect the complexity of the reality in which older Australians undergo care transitions in their lives.
- Information about service options is critical. Understanding the care transition as a process is important as it highlights the need to focus on much more than simply the provision of particular services or supports. For example, no matter how good a service is, if the older person or those who are assisting them such as GPs, health professionals and family members are unaware of the existence or potential benefit of the service then it will be of little benefit to those older people. Whilst there is no doubt that the standard of the actual care or support delivered is critical, it is far too limited to concentrate only on that. Equally important is the context in which that care or support is delivered in terms of how and why older people engage or do not engage with the service and when.
- That there is a need to shift emphasis away from the negative and inaccurate assumption that older Australians who are actively ageing inevitably move only one way along what is a continuum of increasing care and support needs. The study found that important assumptions in much of the speaking and writing that is done about older people as an increasingly frail and dependent population draining Australian resources are plainly wrong. Whilst some older people do reach a point where they are unable to move back along the continuum for many other older people the move back to require fewer or even no services is a very real possibility. The insights from this study suggest ways to maximise opportunities for prevention and early intervention developments, for older people including potential rehabilitation. This will enable services/systems to be developed, in collaboration with older people and their families, to further maintain the ability of older people to actively age in place during periods of care

transition with appropriate support, mechanisms of access and pathways to well-being.

- That so-called seamless care requires a multifaceted approach. This study builds in a multifaceted approach from a grass roots level of issue identification right through to service/pathway development. Primarily, the aim is to keep older people out of residential care and, if appropriate, acute hospitals, by refocusing the efforts of the individual, organisation and community services to prevention and early intervention, employing an inter-sectoral approach of primary health care which must involve all parties, not one or the other.
- That collaboration between services and between the acute, primary care and aged care sectors is crucial to facilitating good transitions for older people. As discussed in Stage Three, collaboration around a 'central' idea was demonstrated to create a willingness and focus in the 'exemplar' projects which were part of their success.

While some of the findings and recommendations of this study may not be necessarily new, the fact is that the requirement to optimise the health and well-being for older people who undergo care transitions remains - despite findings and recommendations over a number of years and studies (Cheek & Ballantyne, 2001a; Cheek et al., 2003; Cheek et al., 2005). This in itself is a significant finding and area of concern. Further the findings and recommendations that do exist have tended to arise for studies focussing on specific aspects of a particular care transition, such as evaluating a particular program or service, rather than focussing on the care transition process *itself* and as a whole.

The findings of this study suggest strongly the need for a new emphasis by placing the care transition process centrally and positioning care and support services in relation to that process. Put another way the service and support should fit the care transition, not the care transition fit the services and supports. This is a crucial point and goes some way to explaining why it seems that for many older people, and even many health professionals such as GPs, the support available for older people remains a fragmented and difficult to navigate maze.

It was of interest that in the final stages of this project, the document *A New Strategy for Community Care: The Way Forward*, was released by the Australian Government (Australian Government Department of Health and Ageing, 2004). The document outlines the actions that the Australian Government will take in relation to community care reform arising out of the review of community care conducted in 2002 (Commonwealth Department of Health and Ageing, 2003). The *Way Forward* document states "Common arrangements will create a more efficient and integrated community

care system. Specific initiatives which will be developed through this funding include a common approach to assessment across the care continuum, a consistent approach to data collection, a consistent approach to consumer fees, standardised accountability and quality assurance and a coordinated approach to planning” (Australian Government Department of Health and Ageing, 2004: p15).

However, the way forward must also be one in which older Australians and their needs and experiences as they perceive them are central rather than other's assumptions about what these need and experiences are. The strength of the findings of this study lies in the central placement of older people and their families in the study, the richness of the multidimensional data collected, and its decided attention to the complexity, process, and meaning care transitions have for older people and those associated with them. All of this is to recognise the dynamic nature of care transitions and to expand further understandings and interpretations of ageing in place in keeping with the principles articulated by the WHO philosophy about active ageing.

Perhaps in the end it should focus on understanding, and thereby improving, the care transitions undergone by older people rather than simply building transition support based on understanding of existing service and support systems or on unexplored assumptions about what older people do and need when in the care transition process. At present supporting older Australians in care transitions they undergo, and the type and configuration of services available are not necessarily always synonymous. Herein lies the challenge from the findings of this study.

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## Appendix 1: Example Vignette

### Part 1: Older Person (“Mr Y” and wife “Mrs Y”)

#### Background

Mr and Mrs Y have been married for 50 years. Mrs Y is 75 years old and Mr Y is 90 years old. It was approximately 10 years ago that Mr and Mrs Y felt that their health and independence were starting to decline. At this time, Mrs Y developed breast cancer which was successfully treated. Mr Y was declared legally blind. Up until this time, Mr and Mrs Y had spent much of their retirement taking road trips with their caravan. The impact of Mr Y no longer being able to drive is summed up best in the following statement from him “...after seventy two years driving that affected me, it did really.”[L1035-1036]

#### Destabilisation 1: Gradual decline in health (none to some)

Five years ago Mr and Mrs Y moved to a small housing trust unit. At this time both Mr and Mrs Y lived independently with assistance from their daughter with shopping. They were able to use public transport to do some shopping and made a trip by tram into an inner city shopping precinct each week. Mrs Y is a very good cook and enjoys preparing meals for herself and her husband.

Two years ago, Mrs Y underwent a prolapse repair, it was at this time that she was diagnosed with liver cancer. Mrs Y explains; the oncologist “he give me six months to live. We all came home bawling, but anyway, next time we went up he said, “I can’t put a time on it”. But anyway, I’m doing well now with that.” [L106-108].

Mr Y has prostate cancer and is currently receiving palliative care services. In September of 2002 Mr Y suffered a minor Cerebral Vascular Accident (CVA)/ “Stroke” which left him with significant right side weakness and balance problems. Mr Y spent a short time in hospital after his CVA. During this time he was assessed by the Aged Care Assessment Team (ACAT) as ‘High Care’. Mrs Y has been his primary carer since his sight deteriorated and continued this role after his CVA. Mrs Y suffers from severe asthma and bronchiectasis. Two years earlier she was referred to Domiciliary Care<sup>1</sup> by her General Practitioner (GP) and has received three hours a week of in-home support as

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<sup>1</sup> Domiciliary Care: “This service assists the aged, frail or disabled to remain independent in their home and prevent unnecessary admission to institutional care. Domiciliary Care Services are designed to support the individual and their carers.” Accessed March 2004:

[http://www.service.sa.gov.au/ServiceCollection.asp?col=11&showall=yes#h3\\_6](http://www.service.sa.gov.au/ServiceCollection.asp?col=11&showall=yes#h3_6)

a result. Z, Mr and Mrs Y's daughter, took Mrs Y shopping each week and visited regularly.

### **Destabilisation 2: Mrs Y has a fall (some to more)**

Two months after Mr Y's CVA, Mrs Y had a fall while she was out running errands. Mrs Y fell forward onto both of her hands. Although she didn't break any bones she started to experience severe pain in her arms and hands. Four months later Mrs Y was diagnosed with Carpel Tunnel Syndrome in both of her arms.

After Mrs Y's fall it became apparent that extra in-home care was necessary. Mrs Y wasn't able to cook or dress herself or her husband properly due to pain and decreased mobility in her hands. Z started visiting each morning, before she dropped her son at school and went to work, to help get breakfast ready and make sure they were alright. The Domiciliary Care workers and Mr and Mrs Y's GP became aware of the decreased ability of Mrs Y to provide full time carer support. Increased formal support was put into place with carers coming into the house Monday to Friday to shower and dress Mr Y. Mr Y's son-in-law showered him on the weekends. Mr and Mrs Y's daughter cooked extra food for them and they were able to order food from a local community café who delivered meals to the door.

### **Destabilisation 3: Mrs Y has surgery (some to more)**

When the decision was finally made that Mrs Y would have surgery to treat her Carpal Tunnel Syndrome, Mr Y, Mrs Y and their daughter had to consider how Mr Y would cope at home while Mrs Y was in hospital. Mrs Y required separate operations on each of her arms. When she went in to hospital for the first operation Mr Y stayed at home. For the second operation the decision was made that Mr Y would go into respite care for 10 days afterwards to give Mrs Y some time to recuperate. Mr Y had been receiving treatment for his prostate cancer at a local hospital and was able to spend the 10 days in the oncology ward there.

[L 499-511]

Mrs Y: When he went into care in the hospice, he really didn't want to do it but I knew I needed a rest. He didn't want to go, but he said, "For your sake, I'll go".

Mr Y: *It was the worst time I've had in my life I think...Because my wife wasn't with me. I wanted to wake up and have her next to me in the morning...*

In preparation for the time that Mr and Mrs Y would need extra care their daughter organised additional in-home support. There were some significant problems getting this organised:

[L 550- 557]

*Mrs Y: My daughter had it all arranged that we could have respite care but then it appeared that it was only on the other side of the tram line.*

*Mr Y: The woman she spoke to this day had set it all up. She sent us all the stuff to read up. I told my daughter that I hadn't heard from anybody when there were only two weeks to go, we had to do something. She rang up and was told that the first woman shouldn't have said anything to her at all. She works the other side of the tram line, not our side.*

With two weeks to go before surgery, Z was able to organise a range of in home services. When Mr Y returned home from respite the following services were in place to assist with Mr Y's care:

- Royal District Nursing Service (RDNS)<sup>2</sup> 2 days per week to assist with showering
- Domiciliary care 3 days per week to assist with showering

Services for Mrs Y as she recovered from surgery included:

- Assistance with showering 3 days a week (Community Service Provider)
- Someone to come in and cook for Mr and Mrs Y (Mrs Y wasn't happy with the standard of cooking and asked the person not to come back after the first week)

Mr and Mrs Y felt very happy with the range of services they were provided with:

[L 544-545]

*Mr Y: They say the government isn't doing anything but really since we've been on this, we find out that they are working behind the scenes. No matter what people say...*

*Mrs Y: There's a lot of money going into it*

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<sup>2</sup> "Royal District Nursing Service offers specialist nursing services, including diabetes, palliative care, continence management, disability care, HIV / AIDS treatment, wound care and mental health management." Accessed March 2004:

[http://www.service.sa.gov.au/ServiceCollection.asp?col=11&showall=yes#h3\\_6](http://www.service.sa.gov.au/ServiceCollection.asp?col=11&showall=yes#h3_6)

## **Part 2: Significant Other (Daughter, "Z")**

### **Background**

Z is the only child of Mr and Mrs Y She is married and has one primary school aged son. As a self employed business owner, Z is able to negotiate some flexibility in her working hours to be able to assist her parents.

### **Destabilisation 1 & 2: Gradual decline in Mr Y's health and Mrs Y falls (some to more)**

After Mrs Y fell:

[L 39-46]

*Z: I was cooking extra food, when I cooked a meal for us, and going over there first thing in the morning, most mornings, and making sure that they had breakfast and that everything was going OK, and that they had something for lunch because they ate their main meal at lunchtime, so that they could just pop it in the oven or the microwave, or whatever they used and their main meal was there. I would make the bed. I guess it was taking, without adding it up too precisely, up to ten hours a week, me doing that on top of taking her shopping as well.*

Z and a carer from Domiciliary Care became aware that Mrs Y wasn't coping with caring for both herself and Mr Y as a result of the injury to her hands following her fall. In liaison with Domiciliary Care and the family GP, Z was able to get in-home assistance from Domiciliary Care and the Royal District Nursing Service (RDNS) Monday to Friday. On the weekends Z's husband showered Mr Y. Z describes this as a positive experience for both her husband and her father;

[L78-81]

*Z: He actually really enjoys it because he thinks my husband does a really good job and he knows it takes the pressure off Mum doing it, as well, so yes, he's quite happy to do that. I think it's actually created a bond between them that maybe wasn't there before.*

After several months of x-rays and tests Mrs Y was diagnosed with severe Carpel Tunnel Syndrome in both of her arms that would require surgery.

### **Destabilisation 3: Mrs Y has surgery (some to more)**

Z realized that extra support would be needed during the time Mrs Y was in hospital and while she recovered. Six weeks before her mother was due to go into hospital for the first of 2 operations, Z started to search for services.

[L 265-269]

*Z: That CareLink that the government were advertising on the TV. I thought that looked really good. Obviously an advertising agency was very creative because that was all complete, absolute rubbish! I rang them, after I went on their website and couldn't find anything decent on there, I rang them and that's how I got put through to [Government funded respite service]! But into [the wrong district]. The people didn't even know what they were doing and I don't see that as the staff's fault, I see that as a problem with the government and lack of training.*

Z was informed that a package of services would be available through the carer respite service, that everything was 'under control' and she would be contacted again before her mother went into hospital. According to the person that Z liaised with, her parents were eligible for approximately 26 hours of care. As Z explains below, things didn't work out as she thought they would:

[L 277-281]

*Z: ...When it got closer to the time and I hadn't heard from the girl from [carer respite service], I rang, because she said, "Yes I'll secure this, I'll book it in" and no one had rung me. I rang and they said there was nothing booked in and we went through the process, I had four days to find somewhere because nothing had happened.*

When Z telephoned to follow up she was informed that her parents weren't eligible for care through the carer respite service she had originally contacted because it serviced a different region. Z describes feelings of anger and frustration at negotiating her way through what seemed like a maze of services and information, particularly during a period of crisis for her and her parents. Following the news that her parents weren't eligible for the amount of services anticipated:

[L 298-302]

*Z: I got the big pack of information from Carers' Support Centres or Carers' Respite or something and they give you this big thing of information and once again, if that was going to an elderly person they would be totally confused at the amount of information they were being given because it was far too much.*

Z felt she had to push hard to get access to the care her parents needed. Without her efforts she believes that her parents wouldn't have received adequate care. Z became the coordinator of services for her parents, a link between the General Practitioner, Domiciliary Care and the palliative care doctors and nurses. It was a

supervisor at Domiciliary Care who finally put Z in touch with an aged care service provider who provides in-home support services.

*Z: We pay for it, it's not very much, it's a minimal amount and Mum and Dad do pay for it. We were happy to pay all along. That's what I was trying to say to people. We're happy to pay for care, if we can get care. They can't afford twenty dollars and hour!*

The informal support that her parents receive from friends and relatives reduces the strain on Z. On Thursdays a volunteer from palliative care services at the hospital Mr Y is treated at spends several hours with Mr and Mrs Y. Neighbours will often help out by bringing in or hanging out their washing. Occasionally neighbours will organize lunch for them as well. As Z states, *"without all that I would still be doing fifteen, twenty hours a week there at the moment."* [L441-442]

[L391-396]

*Z:...at the end of this week, [services from the community service provider] finishes. That's the end of the care they can give Mum and Dad. That means I'll have to be over there every night, at nine o'clock to help Dad get undressed, unless I can talk them into coming back of a night only, four nights a week or something, just so that, if I've got a Saturday night out or whatever. I mean, that sounds really selfish to me, that if I want time out, but you can only do so much.*

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