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EXECUTIVE SUMMARY

Alone in a crowd: Supporting older Australians managing loneliness

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Members of the National Project Advisory Panel

The project is indebted to the guidance from members of the National Project Advisory Panel.

Ms Jane Fisher	COTA Seniors Voice
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EXECUTIVE SUMMARY

Background and Rationale of the Study

As people live longer they seek not only quantity of life but also quality of life (Grundy & Bowling, 1999; Routasalo & Pitkala, 2003). However, the research literature reports that loneliness is an increasingly pressing social and health issue that has the potential to influence quality of life of older people (Dykstra, van Tilburg & Gierveld, 2005; Ekwall, Sivberg & Hallberg 2005). Concern is further raised by the ageing of Australia's population, as this will result in greater numbers of people 65 years and over that may experience negative problems associated with loneliness. Projections show that by 2026, 41% of people living alone will be older people (Australian Bureau of Statistics, 2005). This is of concern as loneliness has been linked to numerous physical and emotional health problems, such as alcoholism, chronic health problems, anxiety, depression, suicidal ideation and suicide (Barg et al, 2006; Murphy, 2006; Tiikkainen & Heikkinen, 2005). In addition loneliness is linked to life events such as the death of a spouse and close friends and onset of disability and illness, thus preventing participation in social activities (Dykstra et al. 2005; Holmen & Furukawa 2002; Nygren, Norberg & Lundman 2007; Savikko et al. 2005).

Within the research literature loneliness is an ill defined or inconsistently defined concept. Often researchers, and practitioners alike, use the terms social isolation and loneliness interchangeably (Gardener et al. 1999). However, the terms are not the same. Not all people who live alone or have limited social contacts are lonely and conversely people with many social contacts who live with others may still experience loneliness (van Baarsen, Snijders, Smit & van Duijn 2001; Dahlberg 2007; Routasalo & Pitkala 2003). The assumption that loneliness and social isolation are one and the same may mean that people, who are lonely but not socially isolated are under-identified, overlooked and consequently under-supported thus resulting in preventable negative health and social outcomes.

The research literature also details strategies that were designed to assist older people to manage loneliness and have demonstrated mixed success. Cattan, White, Bond and Learmouth (2005) conducted a systematic review of interventions targeting the prevention of loneliness and social isolation in older people and identified 30 outcome studies published between 1970 and 2002. The review concluded that the effective interventions were group interventions with a focus on educational provision of targeted support activities; directed at specific groups; and enabled some level of participant control or consulted with the target group before intervention. It was also concluded that ineffective interventions were commonly one-to-one interventions in people's own homes. Whilst this review gave some guidance to service provision targeting loneliness for older people, the review failed to differentiate between studies that designed interventions for loneliness,

and studies that designed interventions for social isolation. Despite this limitation, the review highlighted that successful and effective programs were more likely to occur when older people were consulted and involved in the design (Cattan et al. 2005).

A review of the literature identified a gap in knowledge about older Australian's understandings on loneliness. In order to design effective interventions it is imperative to understand the needs of the older person so that their perspectives can inform effective programs and services. Furthermore, it became evident that the service providers' understandings and perceptions of loneliness also has an impact on older people as they decide on both what services are offered and how they are offered.

Aims and Objectives

The aim of the study was to provide understandings of loneliness that can inform support and service providers targeting older Australians managing loneliness. Specific objectives associated with this aim were to:

- i. Identify and describe older people and service providers' perceptions and understandings of loneliness;
- ii. Use this in-depth knowledge to develop strategies to assist older people to manage loneliness;
- iii. Work with support/service providers and older people to implement, evaluate and refine their identified strategies and;
- iv. Develop and disseminate recommendations designed to promote wide uptake of the identified strategies at the individual, organisational, professional, educational and policy levels.

Participants

Participants were recruited through four large aged care organisations: Helping Hand Aged Care Inc., ECH Inc. & Southern Cross Care (SA) in South Australia and; RSL Care in Queensland. The aged care organisations are all providers of care and services to older people, including retirement living, residential and community care in their respective States. These organisations are typical of other major providers of aged care services in Australia.

The University of South Australia and Griffith University Human Research Ethics Committees approved the project. In keeping with the Guidelines approved under Section 95A of the *Privacy Act 1998* (National Health and Medical Research Council, 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.

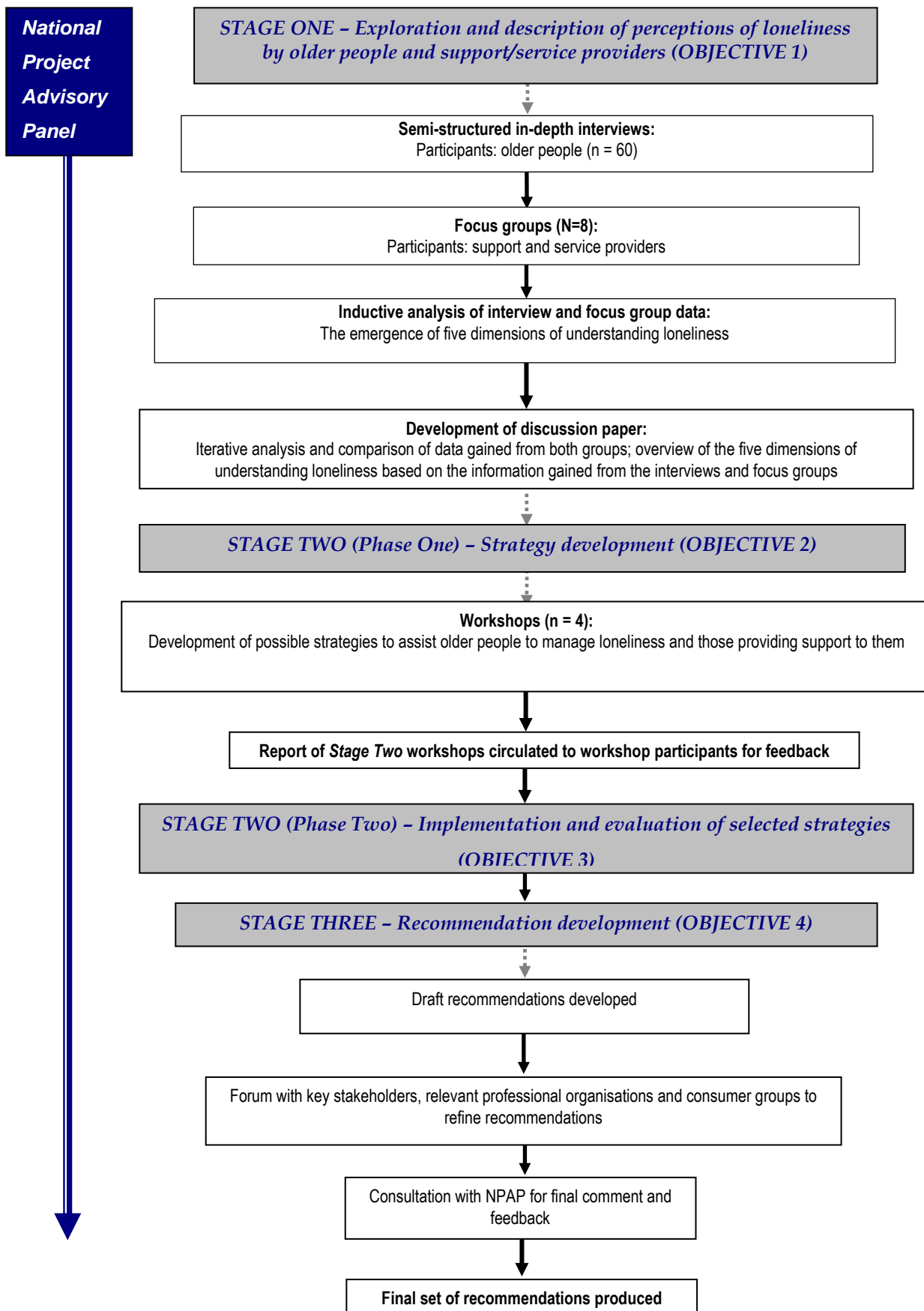
National Project Advisory Panel (NPAP)

To ensure the relevance of the study beyond the participating organisations, a National Project Advisory Panel (NPAP) was formed. Five members formed the panel representing the provision of services for older people at the national, policy, professional and organisational levels. The panel provided advice and critical feedback on four separate occasions (in May 2007 at the commencement of the project, June 2008 at the completion of stage one and commencement of stage two phase one, June 2009 at the commencement of stage two phase two and finally in December 2009 regarding stage three - the recommendations).

Approach

The three-stage qualitative study was both descriptive and exploratory. Diagram 1 presents a schematic of the three stages of data collection; strategy development, implementation and evaluation; and recommendation writing.

Diagram 1: Schematic overview of the research design



Stage One

Two data collection approaches were utilised in *Stage One*, namely in-depth interviews and focus groups, in order to obtain an in-depth description of older people's and support/service provider's perceptions of loneliness. The use of these techniques captured the understandings of loneliness at the level of individual older people (in-depth interviews), and of those who meet the needs of older people at professional and organisational levels (focus groups).

Data analysis revealed 5 dimensions of loneliness:

- Private: loneliness is a personal experience, stigmatised and often kept secret from others.
- Relational: loneliness is influenced by whether older people are able to maintain quality relationships with others.
- Connectedness: loneliness is influenced by whether older people feel like they are connected to the wider community.
- Temporal: loneliness is influenced by time, be it the time of day, or the time of life.
- Readjustment: loneliness is influenced by older peoples' ability to adapt to losses and changes in life.

A discussion paper detailing the findings of stage one was developed.

Stage Two

Phase One

Drawing on action research principles, in *Stage Two, Phase One*, a program of workshops was used to identify and develop possible strategies, as well as to provide insights into what might be important to consider when framing particular strategies to address the five dimensions of understanding loneliness. Workshops were held in Queensland (n = 2) and South Australia (n = 2) in March and April 2008 respectively. The data highlighted two separate but related sets of findings. The first focusing on a range of programs and initiatives designed to enhance, complement or replace existing practice within the following groupings:

- Education
- Building and maintaining personal needs and connections with others
- Maintaining meaning and purpose in everyday life
- Strengthening community capacity
- Getting around: transport
- Uses of media
- Flexibility and diversity in service provision

The second set of findings involved principles to guide practice:

- The person and their needs are considered foremost; that is, client-centred practice
- The focus on the person is considered at a number of levels (e.g., individual, organisation and community)
- A holistic approach to health and well-being of the person is taken into account
- The person and their feelings are affirmed/validated/valued
- The person feels they have a sense of purpose
- Activities (when used) are meaningful to the individual
- Programs are individualised as one size does not fit all
- Programs are adapted to fit the person, not the person to the program
- Barriers e.g., access to transport, using IT are acknowledged and built into programs.
- Thought is given to sustainability

Phase Two

Stage Two, Phase Two involved the selection of a project by each industry partner, designed to implement strategies which utilised the five dimensions and the guiding principles. The projects included social networking utilising the internet, evaluation of an existing model targeting social isolation and loneliness, a self-help resource folder, and an educational approach,. Each project team undertook an evaluation of their project to determine whether the aim of the project was achieved, the implemented strategies were valuable, financially realistic and sustainable. To follow is a brief outline of the four projects.

Social networking for older people using technology - aimed to reduce temporal loneliness for older persons residing in their own home by utilising an internet social networking site. The older people involved identified evenings and weekends as times when they were prone to increased feelings of loneliness when there are no other services available to fulfil their needs. The project provided one-on-one support to four individuals over three months to help them learn to use computers and the internet. The participants set up an individual profile on an identified social networking site in order to facilitate communication with others. This project found that utilising an internet social networking site and other communication mediums did have the potential to reduce loneliness; according to participant self-report. The project team recommend expanding the project to a larger sample size to determine if internet technology has a significant effect on reducing loneliness.

Living Well Model - This project was an evaluation of an existing program which aims to educate and empower residents by enhancing individual social connectedness in order to reduce

loneliness and increase independence and wellbeing. Using a framework of sustainable 1:1 interventions tailored to individual needs, aspirations and personal choice the program adopts a time limited mentoring approach, aided by an extensive assessment process, to increase the capacity of Independent Living Service clients to make sustainable community connections. The Living Well Model was evaluated utilising the dimensions and guiding principles mentioned above. As a result some changes were made to the program and the model continues to result in self reported reductions of loneliness for the clients and achievement of their goals.

Self Help Resource Folder- this project aimed to explore perceptions of a self-help print-delivered intervention aimed at encouraging social wellbeing and addressing loneliness in a retirement village community. The project centred on the distribution of a resource folder, delivered as weekly factsheets, and containing local contacts and services, as well as suggestions for resident-led activities with the intention of increasing social wellbeing and reducing loneliness in the retirement village community. The resource folder resulted in an increased awareness about loneliness and also the bringing of the issue to the forefront of village discussions. This form of intervention offered a cost effective way to raise awareness of loneliness and social wellbeing in a retirement village community. However the non face-to-face approach was unable to address issues of loneliness associated with bereavement which requires separate focussed attention.

Happy at Home - originally aimed to increase the capacity of retirement village residents to recognise and respond to their own and/or neighbours feelings of loneliness using an educational approach drawing on the five dimensions of loneliness identified in stage 1, When a group of residents were surveyed it was obvious that education related to loneliness was not required so the focus shifted to staff. A focus group with key residential services staff revealed a need for education related to loneliness at all levels within the organisation; reconsideration of the organisational structure and the place of residential services staff; a potential mismatch between the service expectations of residents and what was provided; and issues around designing common spaces that could be utilised for activities along with the environmental press for activity engagement and participation.

Stage Three

Stage Three of the project resulted in the development and dissemination of recommendations which were designed to promote wide knowledge about and uptake of the strategies that have emerged from the study. Based on the findings of the earlier stages a draft recommendations paper was written and presented to a forum of stakeholders and the NPAP. The final recommendations included feedback from these groups.

Recommendations

Five areas of recommendations have been identified as a result of the research processes.

Area 1: Loneliness is complex

Having an understanding that loneliness is complex is important. In particular:

- 1.1 Intervention programs and services targeting loneliness need to be clear whether they are addressing loneliness or social isolation. Interventions for social isolation are important but on their own overlook the full experience of loneliness.
- 1.2 Recognition and acknowledgement that the different dimensions of loneliness are often intertwined and as such design programs that account for the complexity.
- 1.3 Further research be conducted into the effectiveness of interventions that focus on the different dimensions of loneliness.
- 1.4 Further work is also necessary to develop measures that address the dimensions of loneliness for use in evaluation and outcome research.

Area 2: One size does not fit all

To understand that one approach to preventing and managing loneliness will not work for all and as such a range of approaches are required. Specifically:

- 2.1 The dimensions of loneliness (private, relational, connectedness, temporal and re-adjustment) are used to inform practice. Attention to the dimensions is needed in the assessment of the older person, the design and planning of services and throughout the intervention and evaluation.
- 2.2 Placing a central emphasis on the individual experience of loneliness will ensure that the needs of the older person are met. Therefore develop responses that are flexible and tailored to the individual with services matching the older person rather than matching older people to available services.
- 2.3 Use approaches that empower and enable older people to self manage their loneliness.
- 2.4 Promote the rights of older people to access activities that are meaningful and relevant to the individual's capacities, values and interests. Environments in which the older person interacts need to incorporate activity spaces which support activity engagement and participation.

Area 3: Education of older people, the community and service providers

Ensure that effective education programs are designed and delivered for older people, the general community and service providers which aim to increase the overall knowledge and understanding of loneliness and to reduce stigma associated with loneliness.

- 3.1 Education programs need to be targeted at the general public to combat the stigma associated with loneliness. Stigma associated with loneliness prevents older people from being able to manage their own loneliness.
- 3.2 Education for older people to empower and increase the capacity of older people to prevent and address their loneliness.
- 3.3 Education of workers in aged care organisations that provide care and services about the dimensions of loneliness so that they are better informed to assist in identifying older people who might be at risk of being lonely or who are lonely. Education needs to be provided to direct care staff and to other staff from areas such as reception, maintenance and domestic services.
- 3.4 Adoption of a broad approach to education focusing on social well-being as opposed to using words/programs to target loneliness which conveys negative elements of loneliness.

Area 4: Sustainability of programs

Given that older people and service providers become disillusioned by the establishment of new programs only to have them terminated, consideration of sustainability needs to be given higher priority. Funding of new programs needs to be dependent on inbuilt strategies for sustainability.

- 4.1 New programs do not necessarily need to be created. Examination and evaluation of current programs and services in light of the dimensions will lead to refinements rather than creating new programs/ services.
- 4.2 Where a new initiative is utilised then it must be evidence based with clearly articulated, boundaries and role designation.
- 4.3 Sustainability is built into programs and services. Funding for new programs and services only be approved if due attention is given to strategies for making the program sustainable.
- 4.4 Use approaches that enable older people to manage their own loneliness.
- 4.5 Greater integration between the sectors is required particularly in the areas of transport and housing. Planning approvals of new retirement village or residential developments should

not be granted unless serious attention has been paid to the interface with the local community and inclusion of common space for activities.

- 4.6 Examine the impact that funding models have on providing services to manage loneliness. Funding of short term programs may not be beneficial, and indeed may be problematic in terms of ensuring continuity of care for clients utilising those services.
- 4.7 Examine current service provision and funding to see how addressing loneliness might be incorporated into other service provision to make it more holistic and efficient. Taking a broad holistic approach to social well-being, not just focusing on loneliness will benefit a wider range of older people.
- 4.8 Expand the notions of social inclusion and age friendly communities to reflect a broad approach to well-being and participation in the community. If older people felt more valued and connected to the community then loneliness would be less of an issue. Such an approach will strengthen the capacity of the community to address issues for older people in general and make it a more inclusive community.

Area 5: Where to from here – Translation of research into practice

To ensure effective translation of the research findings the following activities are recommended:

- 5.1 Guidelines for best practice are developed that take into account the dimensions of loneliness and the other findings from this research.
- 5.2 An audit of all research and projects that have been undertaken on loneliness and social isolation is conducted in order to account for what has already been done, and to avoid repetition.
- 5.3 Assessment tools and outcome measures that take into consideration the dimensions of loneliness and have established reliability and validity are developed.
- 5.4 Allocate the responsibility of leadership in knowledge transfer within organisations to a person(s) who has included in their job description the role of implementing research findings into practice.

Summation

The dimensions emerging from the interviews conducted with older people and focus groups with support/service providers in this study suggest that loneliness is diverse and complex, bound to the context in which it is perceived, understood and experienced. Furthermore, evaluation of selected strategies provided outcomes that can be implemented by service/support providers, whilst also providing information that can assist policy makers and managers in the service provision area. Wide consultation across the two Australian states and input from varying stakeholders and participants ensures the relevance of these findings. In spite of its strengths the research is limited by the implementation of several small scale pilot projects. These pilot projects do however provide a basis for further research into potential strategies to reduce loneliness. Further development and implementation and evaluation of the pilot strategies are recommended.

As stated within the background of this paper, loneliness is likely to become an increasing problem within Australia if the current responses remain the same. A focus on prevention of loneliness and empowering individuals to self manage is recommended. These research based recommendations are broad with the intention that they are used by key-players to inform aged care policy, the provision of services/support, and ongoing education to prevent and manage loneliness in older people for those who work with older people as well as older people themselves.

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