Our Ref: HD4883

Friday, 31 October 2008

Mr Jude Perera MLA
Chairman
Family and Community Development Committee
Parliament House
Spring Street
East Melbourne  VIC  3002

Dear Mr Perera

Inquiries into Supported Accommodation for those with Disability and Mental Illness

Many thanks for the opportunity to provide input to this important review on behalf of my constituents.

From a regional and rural perspective, the Government is failing to provide adequate supported accommodation and respite services for Victorian with a disability and/or mental illness despite their best efforts.

As background, I receive regular representation from parents and carers from across East Gippsland who experience major distress and difficulties associated with accessing short-term respite care for their children. Travelling long distances effectively negates any of the benefits of utilising the service due to the distance from their respective home bases to the current closest option in Sale. The establishment of local facilities to provide for unmet need in East Gippsland should be a high priority.

Whilst I am aware that the Department of Human Services will shortly undertake a project to examine current availability and demand to inform the implementation of future respite services across Gippsland, it remains critical that the parents, carers, community and support groups of those individuals requiring housing and respite services have improved accessibility to services in East Gippsland and not have to travel and/or access services out of the region.
Similarly there is extremely limited suitable accommodation in the region for those younger people with disabilities, including acquired brain injuries, many of whom are placed in residential aged care, residential institutions, in other forms of inappropriate supported accommodation, or are living with elderly adult carers.

The Summer Foundation recently released a report ‘Younger people in residential aged care: Support needs, preferences and future directions’, "Winkler, D., Sloan, S., & Callaway, L. (2007), which will be used by the Department of Human Services to inform service planning and development. I commend this report (summary attached) to the Committee as providing a best practice future direction that should be embraced by Government.

Rights, opportunities and choices are integral to current Victorian disability policies and guidelines, the State Disability Plan 2002-12, and the Disability Act (2006) and so important to those people in our community who are marginalised and disadvantaged as a result of their disability and/or mental illness.

It is essential that people with a disability and/or mental illness have a framework of support that maximises their independence and participation in all areas of life and the community generally.

There are many significant challenges ahead for the Government in funding and delivering service models that fulfill identified current needs and provide for future demographic, social and economic changes. A better whole of Government approach must be progressed if disability services are to be effective, meet an improved service standards and quality framework, and be sensitive to the diversity of those people in our community who require services and support.

Yours sincerely

Craig Ingram MLA
Summary

Younger People in Residential Aged Care:
Support needs, preferences and future directions
by Dianna Winkler, Sue Stann, Libby Callaway
Prepared by: Summer Foundation Limited
PO Box 486, Brentford Square, VIC 3131, Australia
Telephone: +613 8812 2511 Fax: +613 9894 1130
admin@summerfoundation.org.au
www.summerfoundation.org.au

Prepared for: Victorian Government Department of Human Services

Design by Grey Worldwide


The moral right of the author has been asserted.

This report is Copyright © 2007 Summer Foundation Limited and with unlimited license to the Victorian Government Department of Human Services and must not be reproduced in whole or in part without written permission from the Summer Foundation Ltd.

Acknowledgements

Thanks to the participants in the *my future my choice* planning process and their support networks, for their time, efforts and willingness to share their experience and wisdom.

Thank you to the planners from Annecto, Care Connect, Bendigo Health Care Group, Karingal Inc., Melbourne City Mission, Moreland Community Health Centre, Multiple Sclerosis Victoria Ltd, Owens & King Community Health Service for their assistance in data collection.

A special thank you to Ami Seabrook and Conrad Truscott for their diligent work in data management, collation, analysis and the production of the final report.
Background

Approximately 221 people under 50 years live in residential aged care (RAC) in Victoria (Commonwealth Department of Health and Aging, 2006). At its February 2006 meeting, the Council of Australian Governments (COAG) agreed that, the Australian Government, states and territories would, from July 2006, work together to reduce the number of younger people with disabilities in RAC. Governments jointly established and funded a five-year program, providing $244 million, with the initial priority being people aged less than 50 years. The Victorian initiative, my future my choice aims to provide better living options for younger people in, or at risk of entry to, RAC.

As part of the my future my choice initiative in Victoria, people less than 50 years of age living in RAC were offered an individualised planning and assessment process to assist them and their family or key others to consider their specific healthcare and accommodation needs, aspirations and other important lifestyle factors. It provided an opportunity to explore options and consider models of care to best meet each individual's needs and preferences. The process also provided information about the needs and preferences of this group as a whole. The purpose of this summary is to provide participants and their families with this broader information. This document is a summary of a larger report that provides detailed information about the target group called Younger people in residential aged care: Support needs, preferences and future directions. If you would like a copy of the complete report, please visit www.summerfoundation.org.au or phone (03) 8812 2511.

How was information obtained?

Eight organisations were engaged to undertake individual planning and assessment across Victoria. The Summer Foundation Ltd was engaged by the Department of Human Services to:

- develop a planning and assessment framework
- train the planners from the eight organisations
- support the planners during the planning and assessment process
- aggregate the data obtained from all of the assessments and plans.

Approximately 140 people consented to meet with planners to discuss their participation in the my future my choice planning and assessment process. Of these, approximately 126 underwent an assessment of their support needs and had an individual plan developed. This report summarises the findings from the first 105 people who had individual plans and assessments completed between February and August 2007 as part of the my future my choice initiative.
Demographics

A comprehensive profile of the types of individuals under 50 years of age living in residential aged care (the target group) across the state of Victoria is included in this report. The majority of the 105 individuals in this sample are in the 40 to 50 year age group with only 28 people under 40 years of age. Of the 105 individuals in this population, 61 are male and 44 are female. Thirteen people were from a non-English speaking background. The majority of individuals (66 people) lived in metropolitan Melbourne while the remaining resided in regional and rural areas.

Disability

Younger people in RAC have a diverse range of disabilities, health issues and support needs with the most common disability type being acquired brain injury (61 people), followed by multiple sclerosis (14 people) and Huntington's disease (9 people). In addition to these disabilities, many people had sensory impairments, symptoms of mental health issues and secondary health conditions.

Figure 1 - Disability Types

Hospital admissions and Health

Hospital admissions and secondary health conditions were identified as key issues during the planning and assessment process. Many people in the sample had periodic admissions to acute health services. In total, 44 of the 105 participants had an admission to an acute hospital in the preceding 12-month period, with some people experiencing multiple admissions. Of the total sample, 17 people were reported to have had an elective admission in the preceding 12 months. Reasons for elective admissions included orthopaedic issues (4 people), PEG (Percutaneous Endoscopic Gastrostomy) related issues (3 people), catheter insertions (2 people) and Gynaecology related issues (2 people). Thirty-one people
were reported to have had a non-elective admission to an acute hospital in the past 12 months resulting from PEG related issues (4 people), chest infections or pneumonia (4 people), seizures (3 people) and psychiatric issues (3 people).

Secondary health conditions commonly experienced by this sample included pressure areas (33 people), contractures (33 people), urinary tract infections (24 people) and chest infections or pneumonia (19 people). The planning and assessment process identified a wide range of health conditions in participants and found that most people had complex combinations of health needs. Ninety-two people had three or more health problems.

Figure 2 - Number of Health Problems

![Graph showing the number of health problems and their frequency.](image)
Level of Awareness

Many people in the sample (63 people) were fully aware of their environment and oriented to time, place and person. Thirty-three people were assessed as partially aware – they were conscious and awake but had profound memory difficulties and significant levels of confusion. Nine people were minimally aware of their environment. Fifty people had difficulty communicating their basic needs and seven people were prone to wandering or getting lost.

Figure 3 - Level of Awareness

Mobility

Many younger people in RAC are restricted in their ability to move. Many people were highly physically dependent with 42 people requiring assistance with moving in bed and 49 people needing assistance for mobility inside the RAC facility. Seventy people required assistance to get in and out of the place they live and 75 people required assistance to get around in their local community. A large proportion of the sample required specialised equipment such as hoists, wheelchairs and pressure care overlays.

Challenging behaviour

Challenging behaviour is behaviour that causes distress to the person with the disability or is disruptive to other people causing them distress or making them feel uncomfortable. Eighty-two people displayed at least one challenging behaviour of varying severity. Many people displayed complex combinations of challenging behaviours with 41 people having three or more challenging behaviours. Lack of initiation and verbal aggression were the most common behaviours identified. A holistic approach to behaviour management, focusing on developing communication skills, enhancing participation in meaningful activity and improving living environments is likely to make a significant difference to the levels of challenging behaviour observed in the target group. However, for behaviours at the more severe end of
the spectrum, this holistic approach will need to be supplemented with formal behavioural programs.

**Figure 4 - Number of Challenging behaviours identified (n=105)**

![Bar graph showing frequency of challenging behaviours](image)

**Community inclusion and role participation**

Many people in the sample were effectively excluded from participation in community life. Thirty two people never participated in community-based activities such as shopping, recreation or leisure. Many people did not participate in activities organised by the RAC facility either, with 30 people participating in these activities less often than once per month. Many people in the sample had very limited opportunity to make everyday choices such as the time they go to bed or the content of their meal and the majority had lost several valued life roles such as friend, caregiver, worker and home-maintainer. One person was working part-time and a few people had maintained roles such as part-time student (4 people), volunteer worker (3 people) or caregiver (6 people). The caregiver role maintained by some people is likely to be related to the fact that 28 people were parents of children under the age of 17 years.

**Additional services**

Sixty three percent of this group were receiving one or more additional services from external providers with the most common additional supports being attendant care (39%), case management (37%), physiotherapy (33%), occupational therapy (31%) speech pathology (27%) and community based recreation groups (11%). Thirty two percent of the participants accessed additional services funded by Disability Services such as Support & Choice or Assisted Community Living packages, and 23% had additional services funded by the ABI Slow to Recover Program.
Preferences

In addition to information regarding current health, participation, and support needs, data was obtained and analysed specifically to inform service planning and development. Sixty eight people and their support networks indicated that they would like to explore alternative accommodation and support options while 27 people indicated that they would prefer to remain living in the current RAC facility. The preferences of ten people were not known at the time of finalising this report. Of the people who were interested in moving, nine people indicated they would like to live in a private or family residence, 56 would like to live in shared supported accommodation and three people indicated a preference for other options. Other options included living independently in a unit with individual support and living in a unit attached to a hospital.

Support Needs

Planners were asked to estimate the level of support each person would require in a community based setting. The support needs of the sample were diverse so, rather than describing the average support needs for the whole sample, the sample was divided into three homogenous sub-groups: a Very High Care Needs group (52 people); a High Care Needs group (35 people); and a Moderate Care Needs group (16 people). The Very High Care Needs group generally required 24 hour supervision, daily nursing support and a high level of physical assistance for basic daily activities, often by more than one staff member. The High Care Needs group also had significant support needs but overall were less complex to manage and most did not require regular nursing care. The Moderate Care Needs group had minimal physical support needs and few medical complications but required assistance with more complex household activities, day to day problem solving and financial management.
Future Direction

Clearly there are not adequate existing shared supported accommodation facilities to provide the type of support to meet the specific needs of the target population and more community based accommodation places need to be provided offering a broad range of options and innovative solutions. Accommodation options need to be available in a range of locations so people can remain connected or reconnect with family, friends and their local community. Some outreach services are restricted to particular disability types, funding bodies or regions and the target group require access to these services regardless of their disability type, where they live or how they obtained their disability. Community based services need to be available for people who choose to live at home. Step down and step up programs need to be more widely available to people in the target group. Currently these services provide care to people with recently acquired injuries who require an extended opportunity to recover, however these units could also be used when people in the target group are readmitted to acute health or when reassessment is required due to changing needs or life circumstances.

The assessment and planning process revealed a range of support needs in the target group and while some of these relate to meeting the basic care needs of the group, others focus on enhancing their quality of life. The four areas of support relating to meeting the basic needs of the target group include: health; equipment and consumables; eating, swallowing and communication; and behaviour. The three support areas relating to enhancing quality of life involve: role participation; community inclusion; and social and family relationships.

Conclusion

The information in this report will be used by the Department of Human Services to plan systemic change and develop services to meet the needs of younger people in RAC or at risk of admission to RAC. The report identifies a range of potential approaches to help prevent future admissions to RAC, improve the health and well-being of the target group and enable them to participate in the community as well as pursue a lifestyle of choice.

The my future my choice initiative has the potential to make a real difference to the lives of a group of people who are currently marginalised in our society. Given the relatively small numbers involved, the detailed knowledge of the target group, the expertise available in Victoria and the initial resources made available jointly by the State and Federal Governments, there is a tremendous opportunity to develop a range of pragmatic alternatives to younger people living in RAC.