SUMMER
FOUNDATION

Younger People in Residential Aged Care:

Support needs, preferences and future directions

my future my choice

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Victoria The Place To Be

Younger people in residential aged care: *Support needs, preferences and future directions*

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List of Abbreviations

ABI	*Acquired brain injury*
BMI	*Body Mass Index*
CANS	*Care and Needs Scale*
CIQ	*Community Integration Questionnaire*
CHART	*Craig Handicap Assessment and Reporting Technique*
COAG	*Council of Australian Governments*
DHS	*Department of Human Services*
HoNOS	*Health of the Nation Outcome Scale*
HoNOS-ABI	*Health of the Nation Outcome Scale – Acquired Brain Injury Version*
OBS	*Overt Behaviour Scale*
PEG	*Percutaneous endoscopic gastrostomy*
RAC	*Residential aged care*
RC	*Roles Checklist*
RCS	*Residential Classification Scale*
SCSI	*Secondary Conditions Surveilliance Instrument*
SPSS	*Statistical Package for the Social Sciences*
WHIM	*Wessex Head Injury Matrix*

About the Authors

Dianne Winkler, Sue Sloan and Libby Callaway have extensive experience in the areas of occupational therapy, case management, neuropsychology, teaching, research and publication. Our vision for developing alternative community based accommodation and support options for people with high care and complex needs commenced in 1994 when we first worked together at Ivanhoe Private Rehabilitation Hospital. At that time, we facilitated the deinstitutionalisation of long term residents, working collaboratively with individuals, families and funding bodies to develop innovative solutions.

In 2003 we developed the Planning for Living Manual, which provides an individualised and flexible approach to planning accommodation and support solutions for people with a severe disability. This framework and its underlying principles were presented at a Victorian Brain Injury Recovery Association conference in 2003. The Planning for Living Manual has been used by 8 occupational therapists from two occupational therapy practices (Osborn Sloan & Associates and Neuroskills) specialising in community-based rehabilitation for people with neurological conditions. These therapists have used the Planning for Living Manual to assess and plan accommodation and support solutions for over 30 people with an acquired brain injury, 20 people with an intellectual disability, 3 people with a congenital neurological disability, and 4 people with multiple sclerosis. Osborn Sloan & Associates and Neuroskills clinicians have assisted 8 individuals with complex neuropsychiatric conditions to transition from the Brain Disorders Unit at Royal Talbot Hospital to community settings. The assessment and planning framework utilised in this report is based on the Planning for Living Manual.

As part of her PhD at Monash University, Dianne Winkler has completed three studies focussing on people under 60 residing in residential aged care in Victoria. Both Libby Callaway and Sue Sloan hold lecturing positions at Monash University in the departments of Occupational Therapy and Psychology, respectively. Libby and Sue are regularly involved in the training of health professionals and attendant carers.

The Authors: *(left to right)*
Libby Callaway,
Sue Sloan and Dianne Winkler.

About the Summer Foundation

The Summer Foundation is dedicated to overcoming the concerns of a section of our society that is overlooked, namely younger people living in residential aged care. Our foundation focuses on practical research and seeks to provide workable solutions to improve the health and well-being of this group.

Vision

That younger people with acquired and late onset disabilities and complex care needs will have inherent value as members of our society, with access to services and accommodation that support their health and well-being.

Mission

To foster the development of the next generation of services and solutions that promote the health and well-being of people with acquired and late onset disabilities and empower them to participate in the community.

History

The perplexing issue of younger people living in residential aged care is a challenge which has faced Dianne Winkler throughout the 15 years of her career as an Occupational Therapist working with people with severe disabilities. Further work in this area through PhD research at Monash University revealed that younger people in aged care and their families are frequently very isolated, with limited access to information about alternative accommodation and support options. While reports and information has been produced by various bodies, it is often inaccessible or impossible to locate.

Dianne initiated the formation of the Summer Foundation in January 2006 to meet the clear need for ongoing practical research focussing on younger people in aged care and to work towards better options and outcomes for these people. In June 2007 the Summer Foundation launched a DVD and information booklet called *From a home to their home*. This information pack provides alternatives to living in aged care and enables younger people with disabilities and families to make informed choices about their future accommodation and support.

The Summer Foundation is endorsed by the Australian Taxation Office as a Deductible Gift Recipient, and is funded by private donors and charitable trusts. You are invited to visit www.summerfoundation.org.au for more information.

Executive Summary

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.

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.

CHAPTER 1: INTRODUCTION

- **Background**
- **Method**

CHAPTER 2: CHARACTERISTICS & CURRENT SITUATION

- **Demographics & Disability**
- **Pathways to Residential Aged Care**
- **Health**
- **Mental Health**
- **Challenging Behaviour**
- **Social Networking & Contacts**
- **Recreation & Community Inclusion**
- **Choice & Role Participation**
- **Support Needs**

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 details 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.

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. Chapter 1 provides some background on the issue of younger people living in residential aged care and outlines the method used for collecting information. Significant overall characteristics of the 105 individuals and their support needs are described in Chapter 2. Chapter 3 provides data relating to accommodation and support planning including the estimated level of support the people with complex care needs would require in a community setting. Key themes from the Individual Plans developed with participants are also discussed in this section. Finally, Chapter 4 outlines the implications for service planning and development and systemic change emerging from the information obtained during the planning and assessment process.

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. Fourteen people are from a non-English speaking background. The majority of individuals (66) lived in metropolitan Melbourne while the remainder resided in regional and rural areas.

CHAPTER 3: ACCOMMODATION & SUPPORT PLANNING

- Support Needs of Three Sub-groups
  - Very High Care Needs Group
  - High Care Needs Group
  - Moderate Care Needs Group
- Summary of Individual Plans

CHAPTER 4: FUTURE DIRECTIONS

- An Integrated Service System
- A Choice of Living Options
- Meeting the Needs of the Target Group
  - Basic Needs
  - Enhancing Quality of Life
- Systemic Issues & Solutions

Information obtained about the factors leading to each person's initial and current RAC admission revealed a variety of pathways to RAC. Preceding their first placement in a RAC facility, 58 people had an interim stay in an acute or rehabilitation hospital and, prior to the current RAC placement, people were living in their own home (36 people), their parents' home (8 people), another RAC facility (24 people), or other supported accommodation (11 people). Some of these people were in acute care before their transfer to RAC and seventeen individuals were in hospital for more than six months prior to their placement in the current RAC facility.

The people in the sample 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. 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).

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 health issues such as PEG management (4 people), chest infections or pneumonia (4 people), seizures (3 people) and psychiatric issues (3 people).

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.

Many people were highly physically dependent with 42 people requiring assistance with moving in bed and 49 people needing assistance with 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.

Eighty-two people displayed at least one challenging behaviour of varying severity. Challenging behaviour is behaviour causing distress to the person with the disability or is disruptive to other people causing them distress or making them feel uncomfortable. 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, focussing 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.

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.

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.

In addition to information regarding characteristics and life circumstances, 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.

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.

In addition to the data gathered on health, participation and support needs, each planner worked with the younger person and their support network to facilitate the development of individualised person-centred plans. Key issues identified in the individualised plans and recommended strategies to address these issues are detailed in the report.

The final chapter of this report describes the implications of the aggregate data obtained for service development and systemic change. Although the disability service system is not currently geared to divert people from RAC and support the target group in the community, there are pockets of specialist skills that can be harnessed to train and build the capacity of the rest of the disability and health sectors. A model of an integrated service system designed to achieve and sustain community living for the target population is outlined and most of the elements and services in this system already exist in Victoria in some form. These services are currently being utilised by some people in the target group who are funded by the ABI Slow to Recover program and people with disabilities who have compensation through the Transport Accident Commission or WorkSafe. An opportunity exists to partner with these service providers to expand, modify or duplicate services in different locations to meet the specific needs of the target group.

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. Step down and step up units in acute health care 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 report describes each of these support needs and identifies opportunities and potential solutions for meeting the needs of the target group. 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.

Finally, systemic themes emerging from the data collected are examined. These themes include workforce issues; rural and regional issues; and information. Each of the systemic issues is identified and potential solutions described. A key step for developing an effective service system is to conduct an audit of the eligibility criteria of existing services relevant to the target population. Information obtained from this audit can be converted into an accessible resource for people with disabilities, families, workers and service providers to ensure that everyone in the target population is aware of, and able to access, the available services. The information from the audit will also identify services that can be modified to meet the needs of the target group and to identify gaps in the service system.

To date, decisions about service planning and development for the target population have been based on limited quantitative data and anecdotal evidence. The information in this report paints a clear picture of the characteristics and lives of younger people living in RAC in Victoria and offers a range of pragmatic solutions to prevent future admissions to RAC, enabling people in the target population to participate in the life of the community and pursue a lifestyle of choice. The specialist skills and innovative services developed in Victoria over the past fifteen years can be harnessed and utilised to build the capacity of the wider disability and health care sectors to effectively address the unmet needs of the target population.

Given the relatively small numbers involved, the detailed knowledge of the target group, the expertise available in Victoria and the joint resources provided by the State and Federal Governments there is an opportunity to provide better health and quality of life outcomes for younger people with complex care needs and, over the next decade, to resolve the issue of younger people in aged care.

Chapter 1: Introduction

Background

Approximately 3770 people under 60 years of age reside in aged care facilities throughout Australia (Australian Institute of Health and Welfare, 2007). The recent Senate Inquiry into Aged Care asserted that it was deleterious for young people with disabilities to be housed in residential aged care (RAC) (Senate Community Affairs References Committee, 2005, p. 1). Reflecting this, research in Victoria found that younger people who lived in RAC led impoverished lives, characterised by loneliness and boredom (Winkler, Farnworth, & Sloan, 2006). Winkler et. al. (2006) concluded that younger people in aged care were often socially isolated from peers and effectively excluded from community life. Despite such findings, the Senate report noted that the numbers of young people with disabilities accommodated in RAC across Australia increased significantly over the past decade (Senate Community Affairs References Committee, 2005, p.1).

At its February 2006 meeting, the Council of Australian Governments (COAG) agreed that from July 2006, the Australian Government, states and territories will work together to reduce the number of younger people with disabilities in RAC. Governments jointly established and funded a $244 million five-year program, with the main focus being people under 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. This will be achieved through the development of innovative support models that respond to complex clinical and health care needs, whilst also enabling people to participate in the community and pursue a lifestyle of choice. The initial priority is to achieve this for people aged less than 50 years. In Victoria, there are approximately 221 people under 50 years currently living in RAC (Commonwealth Department of Health and Ageing, 2006).

The initiative has three strategic objectives:

- *To provide alternative supports:* Provide better living options for younger people with a disability in RAC settings, where these can be made available and where this is what the younger person chooses.
- *To enhance disability supports within RAC:* Promote a more age appropriate response to those younger people with a disability who choose to remain in RAC, or for whom RAC remains the most suitable supported accommodation option available.
- *To minimise future admissions to RAC:* Provide alternative responses, where possible, for younger people with a disability who are at risk of admission to RAC (Department of Human Services, 2006).

Little is known about the specific support needs and preferences of younger people living in RAC.

The Australian Institute of Health and Welfare provides only limited data about this population, such as age, location and length of stay (Australian Institute of Health and Welfare, 2006). There have been three State-based postal surveys, one in Victoria (Winkler, Farnworth, & Sloan, 2006), one in Queensland (Cameron, Pirozzo, & Tooth, 2001) and another in New South Wales (Moylan, Dey, & McAlpine, 1995) where managers of RAC facilities have provided information specific to their younger residents. The Victorian study included 330 residents under 60 years and found that younger people in RAC experienced increased levels of social isolation from peers (44% received a visit from a friend less than once a year or never) and limited community access (21% went outside seldom or never). Moreover, many people in the sample were effectively excluded from life in the community (34% almost never participated in community-based activities such as shopping, leisure activities, or visiting friends and family) (Winkler, Farnworth, & Sloan, 2006).

Winkler, Farnworth, Sloan & Brown (2006a) completed a qualitative investigation into the perspectives of seven people with ABI who had made this transition from RAC to community living in Victoria. Five people had funding from the ABI Slow to Recover Program and two individuals were funded by the Transport Accident Commission (TAC). At the time of the interviews, two people were living with their spouse, two people were living with their parents and three people were living in shared supported accommodation. Results from a series of semi-structured interviews with individuals and their support networks identified positive outcomes in seven key areas of their lives including improved continence, getting about more, decreased challenging behaviour, increased occupation, increased community participation and more contact with friends and family. Individuals and their support networks were also asked to specify the factors in their living environment that facilitated these positive outcomes. Informants reported that a key difference between the RAC environment and community based living was that they had more 1:1 support and more consistent support from paid workers in their community based accommodation. Individuals and their families also reported that living in close proximity to family, friends and their local community was a key factor in improving their quality of life.

Recent research into people with ABI living in shared supported accommodation in Victoria found residents were generally more involved in community life than people with ABI living in RAC. Winkler, Farnworth, Sloan and Brown (2006b) surveyed 40 supported community housing

facilities for people with ABI to obtain information about the characteristics and lives of the residents. Information was obtained about 131 residents, most of whom had compensable injuries funded by the TAC, with 8 hours of attendant care each week to assist them to access the community. The data obtained about the life circumstances of this group were compared to the data collected on 166 people with an ABI living in RAC (Winkler, Farnworth, & Sloan, 2006). The two groups required similar levels of support yet, despite this, results indicated a number of statistically significant differences between the two groups. People with ABI living in RAC were visited by relatives more often than those living in the community while residents in community-based facilities were more likely to go outside, access the community, participate in recreational activities, and visit family and friends in the community. This study also found nothing intrinsic in the severity of people's disability that meant they needed to be cared for in RAC, as people with similar clinical needs were being supported in alternative living environments, a conclusion also supported by research in New South Wales (Strettles, Bush, Simpson, & Gillet, 2005).

Other Government and Non-Government reports have largely relied on qualitative data and anecdotal evidence to outline the problems and offer some potential solutions to the issue of younger people in RAC (Fyffe, McCubbery, & Honey, 2003; Strettles et al., 2005; Stringer, 1999). Some of these reports document existing services providing housing and support solutions for this population (Department of Human Services, 2005; Disability ACT, 2006) while others provide a critique of specific existing projects developed as alternatives to younger people living in aged care (Cox, 2003; Gallop, 2001; Jones & Lawn, 1999a, 1999b).

Given the limited detailed information about the characteristics, needs and preferences of younger people in aged care, a key focus of the *my future my choice* initiative was individualised planning and assessment. People less than 50 years of age living in RAC were offered individualised planning and assessment to assist them and their family or key others to consider specific healthcare and accommodation needs, aspirations and other important lifestyle factors. It was an opportunity to explore options and consider models of care to best meet each individual's needs and preferences. Eight organisations were engaged to undertake planning and assessment across Victoria: Care Connect Ltd, Melbourne City Mission Inc, Moreland Community Health Service Inc, Multiple Sclerosis Ltd, Annecto Inc, Bendigo Health Care Group, Karingal Inc and Ovens and King Community Health Service Inc. 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 and support the planners during the planning and assessment phase. The Summer Foundation Ltd was also responsible for aggregating all of the data obtained from the assessments and plans in order to provide an evidence base for service planning and development.

The individualised planning and assessment process had three key objectives:

- *Assessment of current situation:* Planners gathered very detailed information about the issues faced by each individual including their care and support needs.
- *Individualised planning for the future:* Based on the discussions with the individual and their support network, planners assisted them to develop a plan for the future outlining aspirations, goals, preferred options and strategies to achieve these. It also included some immediate actions towards achieving these goals.
- *Inform new service development:* The planners collected data on each individual that could be aggregated to provide direction for future service planning and development on a regional and State-wide basis.

Method

Participants

The Australian Government Department of Health and Ageing disclosed data to the Department of Human Services, including the names and contact details of everyone under 50 in Victoria living in RAC. The information disclosed is protected under the Aged Care Act 1997 and was released for the purpose of contacting residents in relation to this initiative. All people currently living in RAC under the age of 50 were sent a letter from the Department of Human Services (DHS) inviting them to participate in the *my future my choice* assessment and planning process. Consent was obtained from the younger person in RAC, their next of kin or guardian prior to providing planners with their contact details. The planners then met with the younger person in RAC and their support network to explain the planning and assessment process and obtain their informed consent to participate. Information about the *my future my choice* initiative and planning process was also provided to RAC providers, relevant peak bodies, other stakeholder groups, family members and guardians. Family members, carers and friends were encouraged to be involved.

The participants in this study were the first 105 people under 50 years of age living in RAC in Victoria who underwent the assessment and planning process as part of the *my future my choice* initiative. Planning continues for others at the time of publication. As of the 1st September 2007, there were approximately 140 people who initially responded to the letter from DHS and agreed to meet with a *my future my choice* planner. Six people decided not to participate in the planning process after meeting with the planner. Four people had died in between responding to the letter and the planner attempting to make initial contact. Two people were found to be ineligible for Disability Services and therefore ineligible for the *my future my choice* planning process; one person was funded by the Transport Accident Commission and one person had a psychiatric disability with no other disability.

There were an estimated 81 younger people in RAC who did not respond to the letter inviting them to participate. Some people or their families replied to the letter from the DHS and indicated that they did not want to participate. However, many of these 81 people did not respond at all to the DHS letter. Follow-up phone contact was made with the managers of RAC facilities of people who did not respond to the letters. The recruitment process has therefore introduced some potential biases into the sample. It is possible that the people who did not respond to the letter of offer had less social support to facilitate their response to the invitation. It is also likely that people who were already in receipt of additional services were more likely to respond, as service providers reported anecdotally that in many instances they supported and encouraged people to participate in the initiative.

Measures

The Summer Foundation planning and assessment tool (Winkler, Sloan & Callaway, 2007) developed for the *my future my choice* planning process is a customised battery of measures drawing on published instruments, supplemented with targeted questions and functional assessments, aiming to capture key information pertinent to individualised accommodation and support planning with people with complex needs.

The assessment and planning tool was developed after extensive review of the literature and analysis of current clinical practice. In considering the use of an assessment and planning framework, it was found that existing tools were largely developed for people with congenital disabilities (Bruininks, Hill, Weatherman, & Woodcock, 1986; Department of Human Services, 2004; Morreau & Bruininks, 1991). They did not capture the multiple complex care, medical, and behavioural support needs specific to the initiative's target group (i.e. people with acquired or late onset disabilities, primarily neurological in nature). Our clinical expertise and past research of younger people living in RAC offered a working knowledge of the complexities of this group and their support needs. Given this knowledge, and the need to offer an assessment and plan to people with a range of different disability types, often with dual diagnosis, a customised battery of measures was developed. The development of this assessment and planning tool was undertaken in consultation, and checked at various stages of development, with consumers, clinical experts and key stakeholders.

Health

Younger people are often placed in RAC because there are limited number of established community based service models to meet high levels of health and clinical care needs (Department of Human Services, 2005). As part of the *my future my choice* assessment and planning process, it was essential to identify the specific health issues experienced by the target group to inform service development.

Health was measured using a number of indicators. Body weight and height were used to calculate body mass index (BMI). Other health indicators included information such as the number of admissions to an acute hospital in the past 12 months and the number of days in bed in the past week due to illness or injury. The Secondary Conditions Surveillance Instrument (SCSI) (Ravesloot, Seekins, & Walsh, 1997), measuring the prevalence, severity and interference of 40 secondary conditions, was considered for use in this project. Secondary conditions are those conditions that may be experienced by an individual after they have a primary (or first) disability (Marge, 1988). The SCSI emphasises secondary conditions associated with people with spinal cord injury. In consultation with a medical practitioner and a nursing practitioner, both specialised in working with younger people in aged care, we expanded the range of conditions listed on the SCSI to reflect the medical issues commonly experienced by people in the target group. The SCSI rating scale, which specifies the number of hours per day that activities are limited by each condition, provided a level of detail that was not useful in the context of accommodation and support planning. The Summer Foundation planning and assessment tool asked the planner to indicate if the health issue was present or not and to elicit some qualitative information about the current and recommended management of the health issue and the implications for support in the community.

Mental Health

The Health of the Nation Scale - Acquired Brain Injury (HoNOS-ABI) (Fleminger et al., 2005) was used to measure the mental health of participants, covering 12 dimensions of health and wellbeing. The HoNOS scales are a collection of clinician-completed measures of health and social functioning. Versions have been tailored to different populations such as the aged and people with an intellectual disability. The HoNOS-ABI (Fleminger et al., 2005) is a measure of neuropsychiatric sequelae in people with ABI. The ABI version was utilised because ABI is the largest disability type represented in the target group. Using the HoNOS-ABI, each participant was scored from 0 (no problem) through to 4 (severe to very severe problem) on each of the 12 dimensions, where scores of 2, 3 or 4 indicate the need for clinical intervention. The HoNOS-ABI is a relatively new scale for which initial data regarding psychometric properties is limited but promising (Coetzer & DuToit, 2001; Fleminger et al., 2005).

Behaviour

The Overt Behaviour Scale (OBS) (Kelly, Todd, Simpson, Kremer, & Martin, 2006) was used in this study to measure the range of challenging behaviours frequently observed following neurological conditions. These behaviours include:

- verbal aggression
- physical aggression against objects
- physical acts against self
- physical aggression against other people
- inappropriate social behaviour
- perseveration (repetitive behaviour)
- wandering or absconding
- inappropriate sexual behaviour
- lack of initiation.

The OBS was selected over other measures of challenging behaviour because it is suitable for use in a community setting and with a range of disability groups, and it covers a broad spectrum of challenging behaviours.

Resident Choice

One of the key limitations of institutional living is the limited opportunity to make everyday choices. The Resident Choice Scale (RCS) (Hatton et al., 2004) was designed for use with people with intellectual disabilities to assess service practices for promoting choice. This scale has 26 items and is administered by interview with a key informant. This study reports on the 13 items most relevant to younger people living in RAC.

Role Participation

The Role Checklist (RC) (Oakley, Kielhofner, Barris, & Reichler, 1986) was utilised to elicit information about participation in everyday roles (e.g. friend, family member, hobbyist). The RC lists ten life roles and elicits information regarding the person's past, present and future participation in each role (Part 1) and the degree to which each of these is valued by the person is measured on a three point scale (Part 2). This study gathered data from Part 1 of the RC only.

Pathways to Residential Aged Care

In order to assist in developing strategies for diverting younger people from admission to RAC, the Summer Foundation planning and assessment tool elicits information about the causes and pathways leading to admission to RAC and is based on questions from a recent survey of younger people in RAC (Australian Healthcare Associates, 2006).

Community Inclusion

The Community Integration Questionnaire (CIQ) (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993) was used to measure community integration. The CIQ is the most widely used and researched measure of community inclusion in the rehabilitation literature (Cusick, Gerhart, & Mellick, 2000; Hall, 1996; A. M. Sander et al., 1999; A. M. Sander et al., 1997; Seale, 2002; Tepper, Beatty, & DeJong, 1996; Willer, Ottenbacher, & Coad, 1994). Responses on the CIQ can be used to derive a total score and a score on each of three subscales: home integration, social integration and productivity to determine the level of community integration experienced by the individual.

Social Integration

In addition to obtaining information from the social integration subscale of the CIQ, this study also used the social integration subscale of the Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992). The CHART was designed to provide a simple, objective measure of the degree to which impairments and disabilities result in handicaps (participation restrictions). The social integration subscale measures the person's ability to participate in and maintain customary social relationships. The CHART, originally developed for use with people with spinal cord injuries, has since been found to be an appropriate measure for use with individuals with a range of physical or cognitive impairments (Walker, Mellick, Brooks, & Whiteneck, 2003).

Support Needs

The Care and Needs Scale (CANS) is an eight-category scale, which measures the type and extent of support needed in daily life and was developed specifically for application with people with ABI in the post-acute rehabilitation stage (Tate, 2004).

The CANS has two sections. Using a checklist of 24 items, grouped in accordance with International Classification of Functioning, Disability and Health (2001), Section One elicits information about support needed in a range of everyday activities necessary for a person to live in the community. Specific items range from tracheostomy management, nasogastric feeding and personal hygiene through to medication, money management and the provision of informational and emotional supports. Subjects are assigned to one of five groups (Groups A to E) based on the type of activities in which they require support.

Section Two of the CANS indicates the level of support needed, ranging from a very high level of care and support (i.e. Level 8 – 'cannot be left alone') to very low levels (i.e. Level 2 – 'can be left alone for more than a week' or Level 1 – 'can live in the community, totally independently'). Responses within the activity checklist in Section One of the CANS are used as the basis upon which to determine, using clinical judgement, the length of time that the person can be left alone and, therefore, the level of support required.

Level of Awareness

The assessment of people who have neurological conditions and present with altered consciousness and awareness can be extremely challenging. However, in providing people with appropriate support it is vital to tailor input to the individual's awareness and capacity to understand and respond. A review of recent literature (Barker, 2005; Bates, 2005; Coleman, 2005; Giacino & Kalmar, 2005; National Health & Medical Research Council, 2003; Shiel et al., 2000) and available tools was undertaken. On the basis of this review, the planning and assessment tool provided guidance for planners in making the distinction between three key levels of awareness. Planners were asked to assign people to one of the following descriptive rather than diagnostic categories:

Fully Aware: The individual is awake and alert and consistently demonstrates an awareness of themselves and their environment, and is oriented to time, place and person.

Partially Aware: The individual is conscious and awake but may demonstrate rapid forgetting, disorientation to time and place and significant levels of confusion.

Minimally Aware: The individual's conscious state is severely reduced. There may be inconsistent behaviours that suggest some awareness of self and/or environment. This includes people variously described as in a minimally conscious state, vegetative state and post-coma unresponsiveness.

Unable to Assess: The individual could not be assessed/relevant data could not be obtained.

This distinction was made through:

- The observations of staff and family members
- Questions and answers (e.g. relating to knowledge of time, place and person) if the individual was able to communicate (verbally or via assisted means)

- Behavioural indicators of awareness and orientation (e.g. wandering, agitation and social behaviours)
- Administration of the Wessex Head Injury Matrix (WHIM) (Shiel et al., 2000) by a neuropsychologist as necessary. Both the highest (most advanced) behaviour noted on the 62 items and the total number of behaviours observed were recorded.

Procedure

The Department of Human Services engaged eight different organisations across Victoria to undertake the *my future my choice* planning and assessment with the target group. Some planners from these organisations were allied health professionals and most had some experience in the case management of people with disabilities. In February 2007, during two half-day sessions, the Summer Foundation trained 24 planners in the administration of the planning and assessment tool. Planners were allotted 40 hours of planning time for each participant.

The *my future my choice* assessments and plans were completed between February and August 2007. People from Non-English speaking backgrounds, or who had limited support participating in this process, were offered interpreting or advocacy (via Action for Community Living) services. Not all of the participants in this study had the cognitive and communication abilities to be their own informants. The informants for the assessment and planning process also included family members, RAC staff and external service providers with the consent of the individuals.

Data analysis

Planners entered quantitative data from the planning and assessment tool into a custom built internet based survey (Zoomerang, 2007). The data from this survey was exported to the Statistical Package for Social Sciences software package (SPSS, 2005), which was used to produce descriptive statistics. The sample was also divided into three homogenous sub-groups using a statistical method called k-means cluster analysis.

The answers to open ended questions from 50 of the completed planning and assessment tools and 40 individual plans were exported into NVivo (QSR International Pty Ltd, 2002) for qualitative analysis. Data was coded into meaningful conceptual units then each category was examined for shared tenets. Key themes identified from the workbooks were integrated into the results section alongside relevant quantitative information. The key themes identified in the individual plans are summarised at the end of Chapter 3.

Chapter 2: Characteristics and Current Situation

This chapter provides detailed information about the demographics, health needs and life circumstances of the 105 people in the sample. A small amount of missing data accounts for some Tables and Figures displaying a smaller sample size. The percentages in the tables have been rounded so that some columns may not add up to exactly one hundred percent.

Demographics and disability

FINDINGS

- The mean age of the 105 participants was 42 years
- 58% of participants had an acquired brain injury and 31% had a degenerative neurological condition
- 60% of participants were oriented and fully aware of their circumstances

The participants in this study were the first 105 people under 50 years of age living in RAC in Victoria who participated in the *my future my choice* planning process. The total population of people under 50 living in residential aged care in Victoria at this time was 211 (Commonwealth Department of Health and Ageing, 2006).

Fifty eight percent of participants were male and the mean age of participants was 42.2 years (SD ± 6.9). Thirteen percent of participants were from a non-English speaking background with eight languages represented. Nearly all participants (93%) were on the Disability Support Pension. Most people were single (52%), with 31% divorced and 12% either married or in a defacto relationship.

Figure 2.1 - Age of Participants

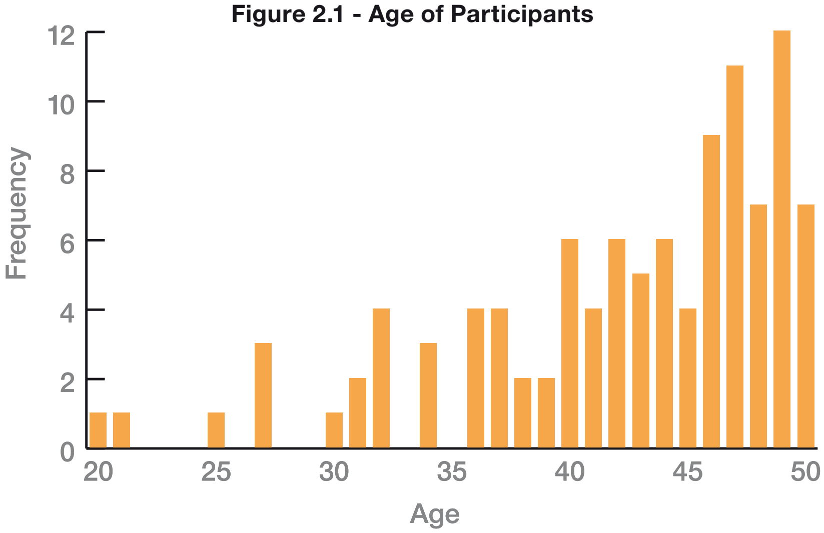
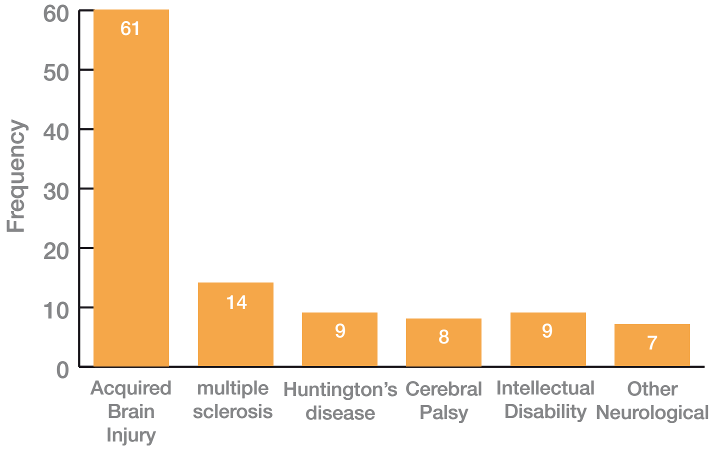


Table 2.1 – Demographics (N=105)

Demographics	n	%
Sex		
Male	61	58%
Female	44	42%
Language		
English speaking background	91	87%
Non-English speaking background	14	13%

Acquired brain injury (ABI) was the most common disability type (61 people) (Figure 2.2). There was a higher percentage of people with ABI than previous studies (Moylan et al., 1995; Winkler, Farnworth, & Sloan, 2006). ABI is defined as any type of brain damage that occurs after birth and includes trauma, hypoxia, and infection. Neurodegenerative diseases such as multiple sclerosis and Huntington's disease were identified separately. Thirty one percent of people had a neurodegenerative disease.

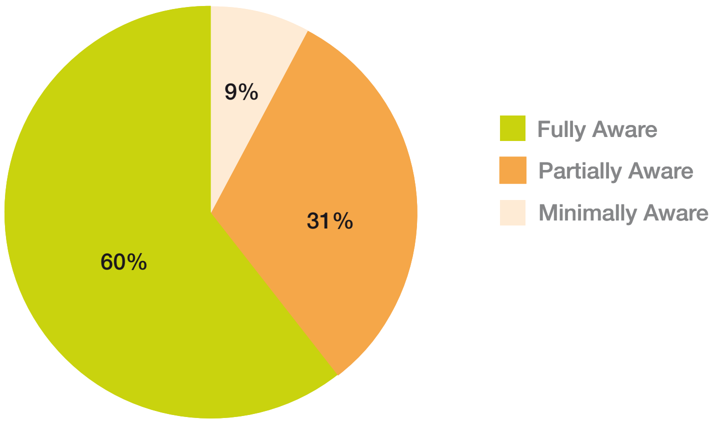
Figure 2.2 - Disability Types



Most people had one disability type (88%), 10% had two disability types and 3% had three disability types. In addition to the disabilities outlined above, 64% of participants had one or more sensory losses such as vision impairments (46%), hearing impairments (5%) and hypersensitivity to sensory stimuli (21%).

Sixty percent of the sample was assessed as fully aware (alert and oriented to time, place and person). Thirty-one percent were partially aware (awake but had profound memory difficulties, were disoriented and had significant levels of confusion). Nine percent of the sample were minimally aware. The category of minimally aware included people who may have variously been described as being in a minimally conscious state, vegetative state or post-coma unresponsiveness.

Figure 2.3 - Level of Awareness



Health care decisions were most often made by a family member (46%) though 28% of participants made their own decisions relating to health care and 11% had a medical power of attorney appointed. 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.

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- Support systems need to be flexible in order to cater for people with both stable and degenerative conditions as well as those with the potential to benefit from slow stream rehabilitation
- Care and support needs to be individualised and tailored to manage varying levels of orientation and awareness
- Services need to cater for people from many different cultural backgrounds

Pathways to Residential Aged Care

FINDINGS

- 59% had an interim stay at an acute or rehabilitation hospital immediately prior to their first admission to a RAC
- 38% of participants were residing in their own home prior to moving to the current RAC
- 33 people indicated that provision of increased support at home would have enabled them to stay in the community longer

Prior to their first admission to a RAC, most of the participants (59%) had an interim stay in an acute hospital or rehabilitation centre. The mean combined length of stay in acute and rehabilitation hospitals was 27.32 weeks (SD ± 34.42). Ten people were in hospital for less than six weeks and 20 people were in hospital for more than 6 months. These admissions provide an opportunity to partner with acute hospitals and rehabilitation facilities to implement strategies to divert people from RAC. Practical initiatives may include increasing the number of step-down facilities that may enable the individual to more fully recover and obtain rehabilitation; increasing the number of community based supported accommodation options; and informing families and discharge planners about the service system, options and possibilities (Department of Human Services, 2005, p. 43).

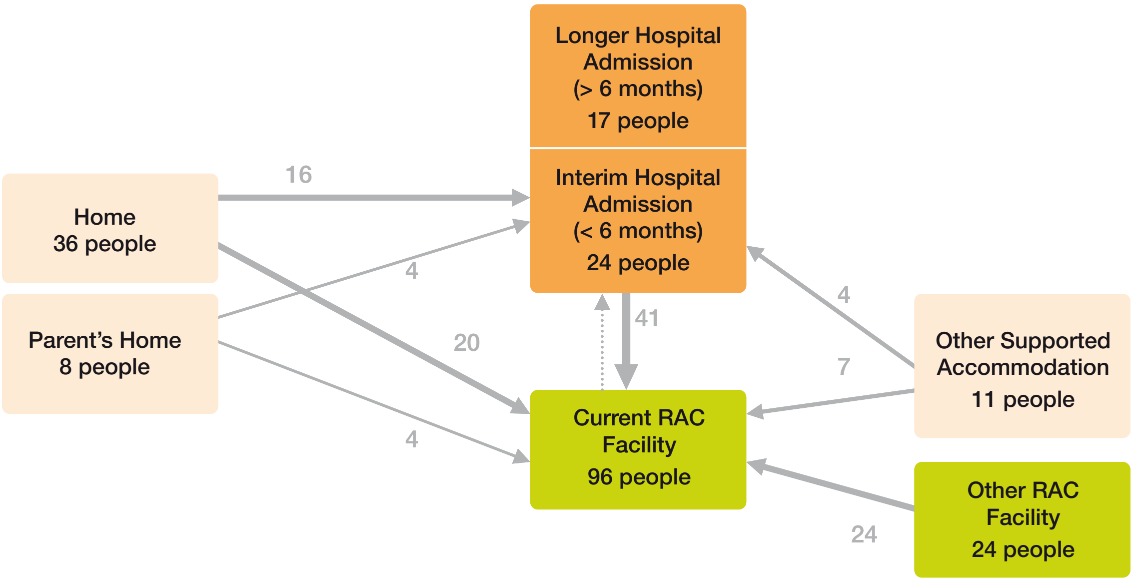
Table 2.2 summarises where people resided prior to their admission to the current RAC facility and Figure 2.3 outlines the pathways people took to enter the current RAC facility. This study had complete data for 96 people.

Table 2.2 – Residence prior to admission to the current aged care facility? (N=96)

Residence prior to admission to RAC	n	%
Home	36	38%
In hospital longer than six months	17	18%
Other aged care facility (high care)	17	18%
Other supported accommodation	11	12%
Parent's home	8	8%
Other aged care facility (low care)	7	7%

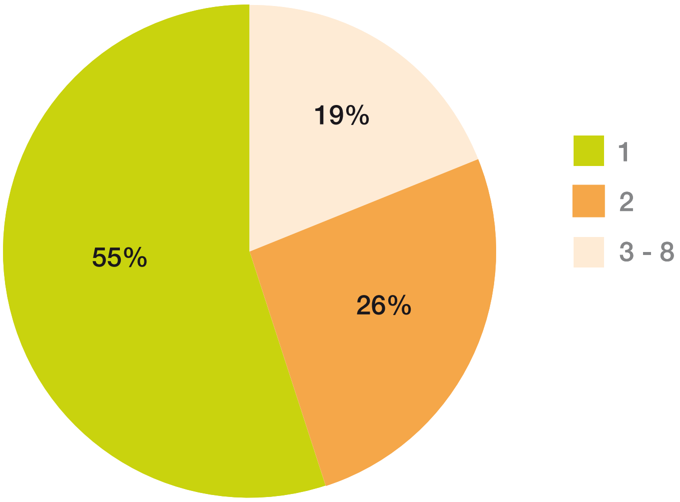
Prior to their current RAC placement, 36 people were living at home. Sixteen people had an interim stay in a hospital prior to the RAC admission while others went directly from home to RAC. Eight people were living in their parent's home prior to the current admission, four people went to RAC via hospital and four people went directly to the current RAC facility. Seventeen people had a hospital stay of longer than 6 months prior to their admission to the current RAC facility. Eleven people were living in other supported accommodation services prior to their current admission and four of these entered RAC via hospital. Twenty-four people were admitted to the current RAC from other RAC facilities.

Figure 2.4 – Pathways to the current RAC facility



In Figure 2.4, a total of 41 people entered the current RAC via hospital. At first this figure appears to be lower than expected because earlier data showed that 59% of people had an interim hospital admission prior to their first RAC placement. However these figures are consistent because Figure 2.4 focuses on pathways to the person's current RAC facility and the 59% figure refers to admissions to their first RAC facility.

Figure 2.5 - Number of Aged Care facilities lived in



Many (55%) of the participants in this study had only lived in one RAC facility, while 26% had lived in two and 19% had resided in between three and eight different facilities (Figure 2.5). The mean time since admission to their first RAC was 4.3 years (SD ±3.7 years) with one person residing in aged care for 15 years.

> ***"Prior to living in the current RAC, where he has resided for the past 11 years, Hayden lived with his parents in Croydon. Hayden relied on his mother to meet all of his care needs. However his mother, due to ageing and health issues, was unable to continue caring for him and, as a result, he was initially placed in the current RAC for respite. At that time the general practitioner advised the family that given the mother's ailing health, Hayden should not return to the family home."***

Anecdotal evidence suggests that younger people move from one aged care facility to another either to be closer to family members or because the person has challenging behaviour that cannot be contained or managed in a particular facility (Department of Human Services, 2005, p. 20).

In order to understand the pathways into RAC and identify opportunities for preventing admissions, this study asked the individual and their support network "What led to the move to an aged care facility?" The two key reasons for admissions (Table 2.3) related firstly to a change in support needs through the onset of disability (e.g. ABI) or an exacerbation of an existing condition (e.g. MS); or secondly through a change in circumstances, in particular a reduction in available support (e.g. ageing parents).

Table 2.3 – Factors leading to admissions to RAC (N=99)

Factors leading to admission to RAC	n	%
They experienced an increase in care needs as a result of a degenerative condition, injury or illness	58	58%
Someone who previously cared for them was no longer able to provide the support required	16	16%
They previously lived in some other type of residential accommodation facility (not an aged care facility) however this place was no longer able to accommodate them	16	16%
They were previously receiving support from a community or disability support service in their own home, however this support was no longer available, or was insufficient to enable them to continue to live at home	6	6%
They developed a need for equipment that was not available in their previous place of residence	3	3%

Planners asked informants why people were admitted to RAC rather than alternative accommodation and support options (Table 2.4). The most common reason (54%) for choosing RAC was the lack of alternative options in the local area and that living in RAC allowed people to remain close to family, friends and their local community. For 37% of people the key issue was that other types of residential facilities in the area could not offer the type or level of support required. For 24% of participants, the possibility of living in another type of residential facility was not explored.

Table 2.4 – Reasons for admission to RAC rather than alternative accommodation and support options (N=99)

Reason	n	%
There were no other types of residential facilities in the local area and living in RAC allowed them to remain close to their family and friends	53	54%
Other types of residential facilities in the area could not offer the type or level of care required	37	37%
The possibility of living in another type of residential facility was not explored	24	24%
Other residential facilities in the area did not have any places available	13	13%
There were other types of residential facilities in the area, with places available, however moving to RAC was preferred	1	1%

Participants living in the community with a disability and supports prior to their admission to RAC were asked if increased support and resources would have enabled them to stay in their home longer. Thirty three people responded in the affirmative and Table 2.5 outlines the types of services and supports that participants and their support networks reported would have enabled them to remain at home for longer.

Table 2.5 – Support services and resources that would have enabled staying at home longer (n=33)

Support services and resources	n
Case management	30
Physiotherapy	25
Provision of an attendant care program	23
Domestic services	22
Respite	21
Activity program outside the home	21
Occupational therapy	21
General practitioner	18
Continence advisor	18
More attendant care hours	17
Community nurse	17
Neuropsychology	16
Speech pathology	16
Home maintenance	15
Medication	15
Dietician	14
Laundry	13
Gardening	13
Administrator	7
Podiatry	6
Medical specialist	4
Guardian	3

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- Acute and rehabilitation hospitals are a key focus for developing strategies to divert people from admission to RAC
- Increased support in the home and community could prevent one third of admissions into RAC
- Case management, physiotherapy and attendant care were the key supports identified to enable people to remain living at home

Health

FINDINGS

- 42% of participants had an admission to hospital in the past 12 months
- 36% of participants had an accidental injury in the past 12 months, the majority of which were falls
- 67% of participants had an illness or infection in the past 12 months, with 22% of those contracting chest infections or pneumonia

Younger residents typically experience a range of health issues that significantly impact on their need for medical and nursing support. One of the key systemic reasons why younger people are admitted to RAC is that there are not enough community-based alternatives that combine residential support with complex clinical care (Department of Human Services, 2005).

Younger people with very high care needs living in RAC have, potentially, many years of life ahead of them. However, some people in this population have been described as having a 'narrow margin of health'. This means that they are highly susceptible to secondary conditions that can make them critically ill or result in premature death.

A recent Department of Human Service report (2005) found that between July 1999 and June 2005, 150 people under 50 living in RAC died, with an average of 21.4 deaths per year. During the same time period, a further 101 people had 'other reasons' for permanent discharge, including discharge to an acute hospital (Table 2.6). It is probable that death was the outcome of some of these other permanent discharges. Degenerative conditions and cancer are likely to account for some of these deaths; however a recent study found that less than 28% of people under 60 years in RAC had a degenerative condition such as Huntington's disease and only 1% had cancer (Winkler, Farnworth, & Sloan, 2006). Given the relatively small incidence, these conditions alone do not account for the high rate of death.

Table 2.6 – Permanent discharges from RAC for persons aged less than 50 years (Department of Human Services, 2005)

Discharge Type	FY1999	FY2000	FY2001	FY2002	FY2003	FY2004	FY2005
Death	17	23	19	23	28	23	17
Return to Family Home	11	7	6	11	10	11	5
Other Reason (e.g. hospital)	16	26	13	6	16	11	16
Total	**44**	**56**	**38**	**40**	**54**	**45**	**38**

Sixty seven percent of participants in the current study had developed an illness or infection within the past 12 months and of those, 15% had been unwell in the last week. Of the 68 participants who had a specified illness or infection in the past 12 months, the most common ailments were chest infections (22%), and urinary tract infections (15%). In the past 12 months 36 people had accidental injuries, with over 50% of these injuries resulting from falls.

Table 2.7 – Specified illness or infection in the past 12 months (N = 68)

Illness or infection	n	%
Chest infection or pneumonia	15	22%
Urinary tract infection	10	15%
Cold or flu	7	10%
Skin infection	5	7%
Cellulitis	4	6%
Allergic reaction	4	6%
Seizure	3	5%
Tooth abscess, decay or disease	2	3%
Bladder infection	2	3%
Eye infection	2	3%
Other	14	21%

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. Orthopaedic issues (4 people), PEG related issues (3 people), catheter insertion (2 people) and gynaecology related issues (2 people) were reasons given for elective admissions. Thirty one people were reported to have had a non-elective admission to an acute hospital in the past 12 months.

Non-elective admissions resulted from PEG related issues (4 people), chest infections or pneumonia (4 people), seizures (3 people), and psychiatric issues (3 people). Several families reported that acute hospital admissions are often distressing for people with limited communication, behavioural problems or complex care needs; and one family reported spending many hours in acute hospital facilities to provide additional support and to ensure the person could communicate their basic needs.

Most participants were reported to get out of bed every day in the past seven days (72 people). One person only got out of bed one day in the past seven days and two people did not get out of bed at all. Of the people (n=28) who did not get out of bed every day, the most common reason for remaining in bed all day was illness or physical injury (11 people). Other reasons for people remaining in bed included individual choice (8 people), pain or fatigue management (5 people), pressure care (4 people) and neuropsychiatric or behavioural issues (3 people). It was reported that four people remained in bed because of a lack of equipment or seating and two people remained in bed due to lack of staff assistance.

Lack of appropriate equipment such as hoists and pressure care mattresses and lack of appropriate seating were issues consistently raised in the qualitative data recorded as part of the *my future my choice* planning process. Younger people in aged care facilities are not eligible for the Victorian Aids & Equipment Program because they are accommodated in RAC (Hogan, 2004). It is currently the responsibility of RAC facilities to provide equipment for residents. However, as will be described throughout this section many participants have high and complex needs that necessitate specialised equipment not generally required by the rest of the aged care population and therefore not commonly provided in RAC settings (e.g. customised or motorised wheelchairs with specialised supported seating).

Planners asked informants about the presence of a range of health conditions common in this population (Table 2.8).

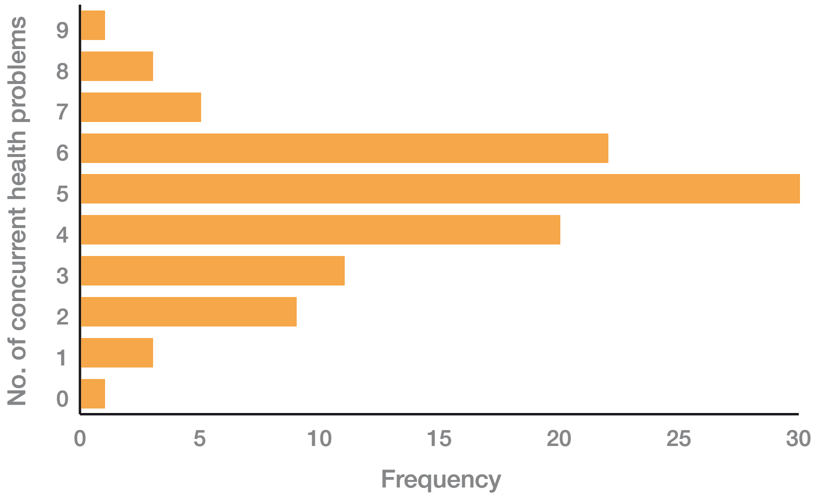
Table 2.8 – Health issues identified (N = 105)

Health Issue	n	%
Heart and circulation		
Heart or blood pressure problems	20	19%
Limb swelling	21	20%
Swallowing, eating or drinking		
Swallowing difficulties	44	42%
Saliva management	21	20%
Special dietary needs	35	33%
Problems with appetite regulation	17	16%
Weight problems	44	42%
Breathing		
Recurrent chest infection	19	18%
Difficulty coughing, clearing secretions or sputum	15	14%
Muscles and Bones		
Altered muscle tone, spasticity or muscle spasm	62	59%
Contractures	33	31%
Involuntary movements	35	33%
Paralysis, loss of movement of arms or legs	34	32%
Osteoporosis	18	17%
Fatigue	45	43%
Pain		
Chronic pain problems	31	30%
Skin Problems		
Pressure areas or pressure care	33	31%
Skin rashes	40	38%
Bladder		
Urinary incontinence	72	69%
Urinary tract infections (UTI)	24	23%
Bowel		
Faecal incontinence	49	47%
Diarrhoea or Colitis	57	54%

Health Issue	n	%
Other		
Epilepsy or seizures	30	29%
Sleep disturbance	13	12%
Arousal problems	9	9%
Diabetes – non-insulin dependent	11	11%
Diabetes – insulin dependent	8	8%
Shunt inserted	8	8%
Thyroid problems	5	5%
Dysreflexia/Dysautonomia	3	3%

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 (Figure 2.6). Ninety-two people had three or more health problems.

Figure 2.6 - Number of Health Problems



Planners recorded the participant's height and weight to calculate their body mass index (BMI) to determine whether people were underweight or overweight. Data was available on both height and weight for 77 participants. BMI was found to range from 15 to 44, with a mean of 27.6 (SD ± 7.01). Of the 77 participants 32 had weight problems, with six people underweight and twenty-six people obese.

Table 2.9 – Frequency of body mass index categories (N=77)

BMI Category	n	%
Underweight	6	8%
Acceptable	30	39%
Overweight	15	20%
Obese Class 1	11	14%
Obese Class 2	10	13%
Obese Class 3	5	7%

Of the six people who were underweight, five were reported to have difficulties with swallowing including three people who were PEG fed. At present there is limited information to guide long-term enteral nutrition services for younger people with neurological conditions to assist them to reach or maintain a healthy weight range (Voevodin & Haala, 2007). There are significant pressure care implications for people who are underweight and this was found to be an issue for two participants. During the planning process it also became evident that being significantly overweight has implications for the provision of support. There were 26 people who were in the obese range. Obesity, combined with high levels of physical dependence, requires more staff for manual handling and specialised equipment such as reinforced wheelchairs and hoists.

Thirty three people had contractures and 19 of these people managed increased tone with thermoplastic splints, positioning wedges or lycra splints. Four people had intrathecal baclofen pumps and eight people had insulin dependent diabetes. Of these, at least two participants were noted to have brittle diabetes, requiring nursing care for blood tests and insulin injections several times a day. All participants had prescribed medication but only 11 people were able to administer their own medication.

Planners reported that some younger people, dependent for their personal care in RAC, did not have their teeth cleaned regularly. Support staff found it particularly difficult to provide good oral care for people with oral hypersensitivity, swallowing difficulties or minimal levels of awareness. Few very physically dependent people had regular dental check-ups.

An added complication for many younger people in RAC is the interaction between their various health conditions. For example, poor oral hygiene and dental care can increase the risk of chest infections (Azarpazhooh & Leake, 2006). Increased tone and contractures combined with the lack of appropriate supported seating meant that some people spent most of their time lying down. Lack of movement and opportunities to sit upright also increases the risk of chest infections (Diab & Johnston, 2004). Many people had swallowing difficulties and were prone to aspirating. Lack of appropriate supported seating and poor positioning increases the risk of aspiration, resulting in chest infections (Mackay, Morgan, & Bernstein, 1999).

There is an assumption that younger people with complex care needs are ‘safer’ in RAC where they have access to 24 hour nursing care. However, given the frequency of falls and hospital admissions outlined in this study, and the high death rate outlined in a previous

report (Department of Human Services, 2005), our conclusion is that RAC facilities may not provide the level of support required to manage the health care needs of some people in the target group. Many of the episodes of illness and the resultant hospital admissions appear to be predictable and preventable and further research is required to determine if health promotion and preventative measures can improve the health outcomes for this population. This presents an opportunity to work with general practitioners, nurses and acute health outreach services in order to develop medical care plans aiming to prevent secondary conditions or, at least, ensure early intervention. A co-ordinated approach to managing these conditions has the potential to decrease hospital admissions and improve the health and longevity of both younger people who move out of RAC and those who remain living in RAC.

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- **Participants have high levels of complex health conditions which require daily care and a range of specialist expertise and equipment**
- **Accommodation services need to develop strategies and supports to integrate management of complex health needs with residential support**
- **Acute health care needs may be managed within the person's own home or community accommodation settings by a combination of proactive care plans and outreach medical services to avoid admissions to hospital**

Mental Health

FINDINGS

- 71% of participants displayed symptoms of recent mental health problems
- 52 people displayed clinically significant symptoms relating to depression
- Mental health problems were found to be complex as evidenced by high levels of co-morbidity

Scores on the HoNOS-ABI provide descriptive indicators of mental health issues rather than specific diagnoses. Responses on the HoNOS-ABI indicated that 71% of participants displayed evidence of mental health issues of varying severity in the two-week period preceding the assessment. Nine people in the sample resided in a facility specifically for people with the dual disabilities of brain impairment and psychiatric disturbance.

Table 2.10 – Level of severity of mental health problems

Mental health symptoms	Level of Severity			
	Minor	Mild	Moderate	Severe
Depressive symptoms (n = 67)	15	31	14	7
Self-directed injury (n = 5)	2	2	0	1
Problems associated with hallucinations/delusions/ confabulations (n = 13)	4	7	1	1
*Other (n = 39) See Table 2.11	6	16	9	8
		Clinically significant range		
TOTALS	**27**	**56**	**24**	**17**

Figure 2.7 - Number of Mental Health Problems per Person

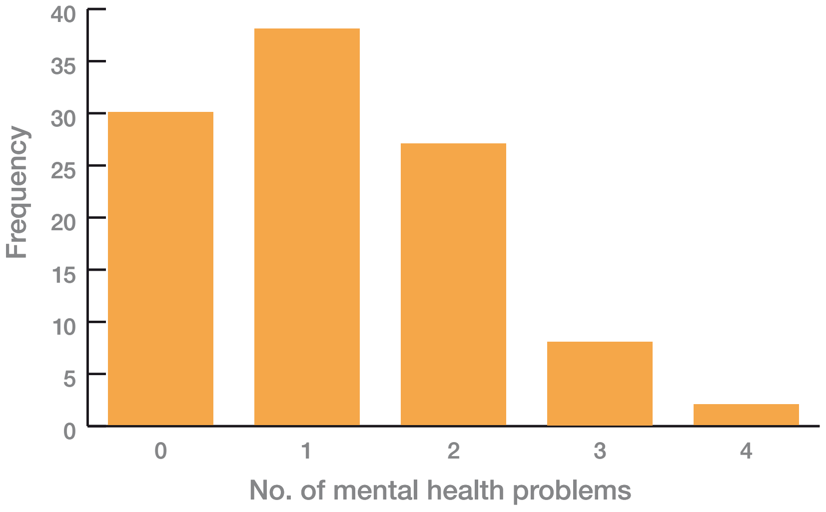


Table 2.10 provides a breakdown of the incidence of specific mental health symptoms and reveals that 67 people displayed behaviours indicative of depression in the two weeks prior to administration of the HoNOS-ABI. For 21 of those participants, depression was rated as moderate or severe. Clinically significant symptoms associated with hallucinations, delusions or confabulations were evident in 9 people and there was a high incidence of ‘Other’ problems (n=39). The level of severity of mental health issues was wide ranging, with 27 mental health problems rated as minor and 97 falling within the clinically significant range, of which 41 were rated as moderate or severe.

Table 2.11 provides the incidence for the range of mental health symptoms noted under the ‘Other’ category in Table 2.10. It can be seen that anxiety and stress were most common mental health issue identified.

Table 2.11 – Other mental health problems (n = 39)

Other mental health symptoms	n	%
Anxiety and panics	21	20%
Stress	10	10%
Obsession and compulsive problems	6	6%
Sexual problems	4	4%
Eating disorder	2	2%
Somatisation†	2	2%
Dissociative (‘conversion’) problems	2	2%
Sleep problems	1	1%
Phobic	1	1%

† Persisting physical complaints in spite of full investigation and reassurance that no disease is present

Incidence of co-morbidities was found to be high with 35% of the participants displaying two or more mental health problems.

Data from the HoNOS-ABI suggests a high prevalence of mental health issues in the sample. Problems at the milder end of the spectrum could, no doubt, be managed conservatively and may well respond to positive changes in the person’s living environment, including support to address their underlying social isolation and occupational deprivation. However, for others with more severe mental health conditions (e.g. psychosis, major depression and obsessive-compulsive disorders), or where co-morbidities complicate treatment, specialist neuropsychiatric input is warranted.

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- Specialist expertise is required for the diagnosis and management of mental health issues
- Mental health issues compound the management of other disability related impairments
- Some mental health issues (e.g. stress and anxiety) may arise from environmental factors and could be improved by provision of more appropriate accommodation and support options

Challenging Behaviour

FINDINGS

- 78% of participants displayed evidence of challenging behaviours, with lack of initiation and verbal aggression being the most common
- Complexity of challenging behaviours was also common, with 56% of participants displaying two or more behaviours
- Despite the high incidence of challenging behaviours only one quarter of participants had received specialist behavioural intervention

In a recent survey of younger people in RAC, Winkler et al. (2006) found challenging behaviour the most common complex care need identified. This was endorsed for 63% of people in the sample and a recent investigation of accommodation options available in New South Wales for people with ABI found that within nursing home environments, cognitive problems and challenging behaviours were the most common difficulties faced by staff (Strettles et al., 2005).

> ***"Mary had past issues with wandering but it is no longer an issue because the facility is locked. Mary says she tries to escape because she doesn't like the older residents or the smell."***

There was a very high incidence of challenging behaviour reported in the current sample, with 78% of the total sample displaying one or more of the behaviours assessed on the Overt Behaviour Scale (OBS). 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 uncomfortable. Table 2.12 provides a breakdown of the frequency of specific behaviours identified with lack of initiation (56%), verbal aggression (44%) and inappropriate social behaviour (42%) being the most frequently noted.

Table 2.12 – Frequency of overt behaviours identified (n = 99)

Overt Behaviour	n	%
Lack of initiation	55	56%
Verbal aggression	44	44%
Inappropriate social behaviour	42	42%
Perseveration / repetitive behaviour	25	25%
Inappropriate sexual behaviour	20	20%
Physical aggression against other people	17	16%
Physical aggression against objects	9	9%
Wandering / absconding	9	9%
Physical acts against self	4	4%

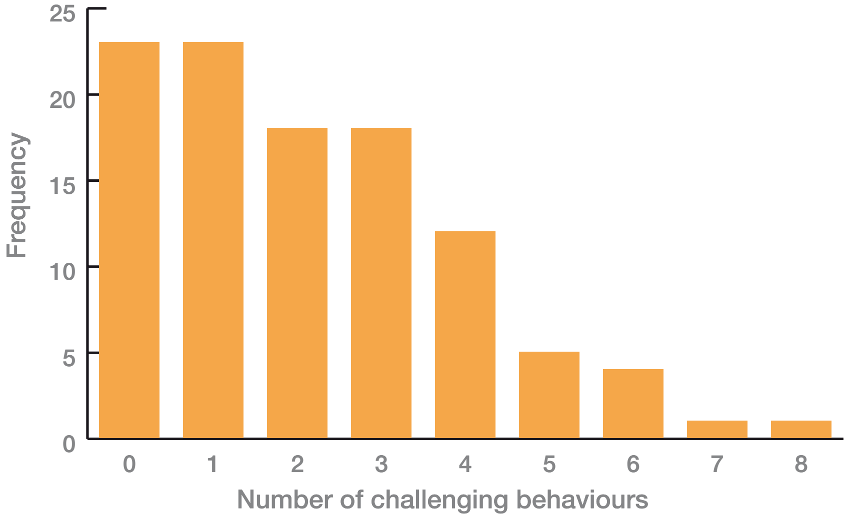
Table 2.13 provides a breakdown of the level of severity of each of the behaviours and demonstrates that Level 1 behaviours were the most frequently recorded (110 instances), followed by Level 2 behaviours (67 instances). These less severe behaviours are often successfully addressed by managing the background factors and associated triggers. For instance, providing people with choice and control over their day to day lives, supporting engagement in meaningful occupation, providing less stressful living environments as well as managing underlying mental health issues will all assist to reduce the incidence of these behaviours.

Table 2.13 – Levels of severity for each challenging behaviour

Verbal aggression (n = 44)			
Level 1 (e.g. shouts angrily)	Level 2 (e.g. mild personal insults)	Level 3 (e.g. moderate threats)	Level 4 (e.g. threats of violence)
25	18	16	5
Inappropriate social behaviour (n = 42)			
Level 1 (e.g. socially awkward)	Level 2 (e.g. nuisance / annoyance)	Level 3 (e.g. oppositional)	Level 4 (e.g. unlawful behaviour, risk to self or others)
18	22	22	6
Perseveration (n = 27)			
Level 1 (repetition of non-harmful behaviour)	Level 2 (behaviour causes minor physical harm)	Level 3 (behaviour causes serious harm)	N/A
22	2	0	
Inappropriate sexual behaviour (n = 24)			
Level 1 (sexual talk/ touching others, non-genital)	Level 2 (exhibitionism/ masturbation)	Level 3 (touching others, genital)	Level 4 (coercive sexual behaviour)
17	6	5	0
Physical aggression against others (n = 17)			
Level 1 (threatening gestures)	Level 2 (strikes, kicks)	Level 3 (attack causing mild/ moderate injury)	Level 4 (attack causing severe physical injury)
13	6	2	1
Physical aggression against objects (n = 9)			
Level 1 (e.g. slams doors)	Level 2 (e.g. throws objects)	Level 3 (e.g. breaks objects / smashes windows)	Level 4 (e.g. sets fire/ throws objects dangerously)
6	7	1	1
Physical acts against self (n = 4)			
Level 1 (e.g. hits self)	Level 2 (e.g. bangs head, throws self)	Level 3 (e.g. inflicts small cuts or bruises)	Level 4 (e.g. mutilates self)
3	2	0	0
Wandering / absconding (n = 9)			
Level 1 (e.g goes to prohibited areas, low risk of harm)	Level 2 (e.g. leaves safe environment, high risk of harm)	Level 3 (e.g leaves secure premise, may physically resist attempts to stop)	N/A
6	4	1	
Total Level 1 Behaviours = 110	**Total Level 2 Behaviours = 67**	**Total Level 3 Behaviours = 47**	**Total Level 4 Behaviours = 13**

Overt behaviours at the more severe end of the spectrum (60 instances of Level 3 and 4 behaviours) place the safety of the individual and others at risk and also contribute to the loss of opportunities to participate in social and recreational activities. Although primarily organic in origin, these behaviours can usually be traced to the presence of significant unmet needs. Often the behaviour is the only mechanism for the person to express and attempt to have their needs met (e.g. for pain relief, comfort, control). For those displaying such behaviours interventions as noted above need to be supplemented by more formal behavioural programs to provide carers with guidance on how to respond in challenging situations.

Figure 2.8 - Number of Challenging behaviours identified (n=105)



The need for specialised input is further emphasised by the finding that only 22% of participants displayed one type of challenging behaviour, while 56% of participants displayed two or more behaviours (Figure 2.8). This data points to the complexity of the behaviour change and the challenges in developing effective individualised management strategies.

Sixty nine percent of participants with challenging behaviour had a written behaviour plan and only 25% received specialist behavioural intervention. Referral for such services was recommended for a further 21% of participants.

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- Specialist expertise is required for the development of individualised strategies to manage challenging behaviours, particularly where complex combinations of more severe levels of behaviour are present
- Staff require ongoing training to effectively implement behaviour management plans
- Improving living environments, enhancing participation in meaningful occupation and developing communication skills is likely to lead to long-term behavioural change

Social Networking and Contacts

FINDINGS

- 53% received a visit from a friend less often than once per year
- 23% were visited by a relative on most days
- 11% received a visit from a relative less often than once per year

A previous study (Winkler, Farnworth, & Sloan, 2006) found that younger people living in RAC were extremely isolated from peers, with 44% receiving a visit from a friend less often than once per year. The current study also found that participants were socially isolated, with 53% of participants receiving a visit from a friend less than once per year.

> ***"Family and friends have had to confront not only their family member's issues, but challenging behaviour being displayed by other residents."***

Table 2.14 – Frequency of visits from friends and family (N = 105)

Frequency of visits	Friends *		Relatives †	
	n	%	n	%
Most days	2	2%	24	23%
1-3 times per week	10	10%	44	42%
1-3 times per month	17	16%	13	12%
5-11 times per year	13	12%	4	4%
1-4 times per year	7	7%	9	9%
Less than once per year	11	11%	4	4%
Never	44	42%	7	7%

* "On average, how often are you visited by a friend?"

† "On average, how often are you visited by a relative?"

Also indicative of the social isolation experienced in this group, 82% of residents surveyed reported that they seldom or never visited friends in their home (Table 2.15). Participants and/or their informants were asked "Do you have a best friend in whom you can confide?"; and for 34% of the sample the answer was "yes".

Table 2.15 – Frequency of visits to friends and family (N = 101)

Response	Visit relatives in their home Ω		Visit friends in their home §	
	n	%	n	%
5 or more times per month	5	5%	0	0%
1-4 times per month	24	24%	4	4%
5-11 times per year	3	3%	7	7%
1-4 times per year	12	12%	7	7%
Seldom/Never	57	56%	83	82%

Ω "Approximately how often do you usually visit relatives in their home?"

§ "Approximately how often do you usually visit friends in their home?"

> “Seeing Sarah in a nursing home is difficult in terms of loss of what might have been.”

Similar to the previous study, considerable variation exists in the frequency of visits by relatives. Twenty three percent were visited by a relative on most days, 11% received a visit from a relative less often than once per year (Table 2.14) and the frequency of visits to relatives in their home was low, with 56% of residents seldom or never visiting relatives (Table 2.15). The high frequency of relatives visiting on most days represents the high burden of care experienced by some families who feel the need to be at the RAC one or more times per day to complement the care provided by paid staff. Some families are actively involved in the physical care of their family member (e.g. meal assistance) because they perceive that paid staff do not have enough time to provide the care required. Some families also feel that they need to visit daily to compensate for the lack of stimulation experienced by many younger people in the RAC environment. Participants and informants were asked “Is it important for you to live close by to your friends and family?”; 85% of respondents said “Yes”.

> “The only visitor Simon has had over the past couple of years is me (his mother) – I visit him every day to feed him a home-cooked meal.”

From qualitative analysis of data and planner feedback, several key themes were identified in relation to social contact with family and friends. Informants reported that relationships with family and friends were often complicated by grief and loss issues related to acquired or late onset disabilities. This was most evident when family or friends were present or involved in the cause of the injury.

People with hereditary disorders (e.g. Huntington’s disease) sometimes had one or more family members who were experiencing a similar or increasing level of disability or had died, thus further reducing social networks.

Limitations in the expressive communication levels of the individual, and their capacity to participate in shared activities, was reported as making visiting difficult. A progressive deterioration in communication skills or physical capacity was seen to further impede the frequency and success of visiting. Some complex care needs (e.g. PEG feeds or insulin regimes) also had an impact on the timing of social contact and community access. Planners reported that the provision of suitable wheelchairs, affordable and accessible transport and access to augmentative communication would enhance social contact.

> ***"I visit once a month for about 10 to 15 minutes – I find it very awkward, I don't know what to say."***

Lack of space and privacy during visits at the RAC facilities was reported. Additionally, an aged care environment was seen as off-putting or threatening for some visitors and as a barrier to the facilitation of age-appropriate social relationships, including that of parents with young children.

Four key strategies for fostering social contact were identified in the qualitative data:

- Ensuring the individual lives close to family, friends and their local community
- Ensuring the individual lives within walking distance to an accessible café or other community facility (e.g. library)
- Providing paid supports, accessible transport and mobility equipment to facilitate social contact in the community or the homes of family and friends
- The provision of private meeting spaces for visits by family and friends (both in RAC and shared supported accommodation).

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- **Funding and support services need to actively support social relationships including assistance with transport or support to visit family at home**
- **Services need to be actively involved in supporting any existing friendships and fostering new friendships**
- **Funding for communication assessment, resources, and support for family and friends regarding communication**
- **Support to assist family and friends identify suitable shared activities either in the RAC facility or local community**

Recreation & Community Inclusion

FINDINGS

- 30% participated in recreation activities organised by the RAC facility less often than once per month
- 32 people seldom or never participated in shopping or leisure activities outside the RAC facility
- 13% of participants seldom or never went outside (e.g. into the garden of the RAC facility)

Participation and level of independence in home or community-based recreation and leisure was restricted by a range of issues. These included the physical abilities of the person, their access to 1:1 support, suitable transport or mobility or adaptive recreational equipment, and limited disposable income to spend on leisure.

> ***"Don would like to be more involved in previous hobbies. His sister described his love of reading, doing puzzles, listening to music and watching movies and documentaries. When discussed with Don, he expressed a real interest in having the chance to do these things again."***

Younger people living in RAC tend to be uninvolved in the in-house recreation activities offered. Thirty percent of the sample participated in recreation activities organised by the RAC facility less often than once per month while 25% of the group undertake recreation independently of the RAC most days and 33% are involved in recreation activities organised independently of the RAC less than once per month (Table 2.16).

> ***"He's on the Disability Support Pension so he can't access leisure activities he has to pay for himself."***

A common theme identified in individualised planning was the desire to share accommodation with younger people so that home and community social and recreational opportunities could be shared.

Table 2.16 – Frequency of participation in recreation activities (n=101)

Response	Recreation organised by aged care facility *		Recreation independent of aged care facility †	
	n	%	n	%
More than once a day	5	5%	4	4%
Almost every day	21	21%	25	25%
Almost every week	34	34%	29	29%
Almost every month	11	11%	10	10%
Seldom/never (less than once per month)	30	30%	33	33%

* "On average, how often do you participate in recreation activities organised by the aged care facility?"

† "On average, how often do you participate in recreation activities organised independently of the aged care facility?"

In this sample, over half of the group (55%) went outdoors almost every day or more often. However, in contrast, 13% seldom or never went outside. While 31% of the sample reported travelling out of the RAC almost every day or more often, 23% seldom or never travelled (Table 2.17).

> *"Grant is 'trapped' inside the facility as he does not have a modified wheelchair to access the outside. He spends most of his time in a tub chair, which is inappropriate for his needs."*

Table 2.17 – Frequency of going outside and frequency of travel outside the RAC facility (n=101)

Response	Going outside *		Travel outside RAC †	
	n	%	n	%
More than once a day	25	25%	4	4%
Almost every day	32	32%	27	27%
Almost every week	26	26%	34	34%
Almost every month	3	3%	13	13%
Seldom/never	13	13%	23	23%

* "On average, how often does the person go outside (e.g. into the garden)?"

† "On average, how often does the person travel outside the aged care facility?"

Many younger residents seldom or never participated in shopping (47%) or leisure activities (45%) outside the RAC facility (Table 2.18). Thirty-two people seldom or never travelled outside the RAC for shopping or leisure.

Table 2.18 – Frequency of participation in activities outside the RAC facility

Response	Shopping * n=99		Leisure Activities † n=101	
	n	%	n	%
5 or more times per month	14	14%	17	17%
1-4 times per month	21	21%	18	18%
5-11 times per year	10	10%	8	8%
1-4 times per year	8	8%	13	13%
Seldom/Never	46	47%	45	45%

* "Approximately how often do you participate in shopping outside the aged care facility?"

† "Approximately how often do you usually participate in leisure activities such as movies, sports, restaurants outside the aged care facility?"

The scores on the Community Integration Questionnaire (CIQ) (Table 2.19) show that the people in this study were effectively excluded from participation in the community. It is difficult to find a comparison group to assist in the interpretation of these scores. To date, most studies have only included people with ABI. The mean score for this sample of young people living in RAC is much lower than the total means scores for any samples from previous studies, which range from 13.02 – 19 (Colantonio, Dawson, & McLellan, 1998; Corrigan & Deming, 1995; Corrigan, Smith-Knapp, & Granger, 1998; Fleming, Tooth, Hassell, & Chan, 1999; Sander, Kreutzer, Rosenthal, Delmonico, & Young, 1996; Sander et al., 1997; Schmidt, Garvin, Heinemann, & Kelly, 1995; Willer et al., 1993). All of these samples included people with severe traumatic brain injury more than one year post-injury.

Table 2.19 – Community Integration Subscale Scores and Total Scores (N=105)

CIQ score	Min	Max	Mean (SD)
Home integration (out of 10)	0	7.25	0.94 (± 1.03)
Social integration (out of 12)	0	7	2.38 (± 1.77)
Productivity (out of 7)	0	5	1.59 (±1.18)
CIQ total score (out of 29)	0	13.25	4.92 (±3.00)

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- Younger people who remain in RAC require support to access outdoor areas and their local community
- Limited financial resources can be a barrier to participation
- Recreation support and adaptive recreation equipment is required to assist people to develop and pursue interests both at home and in their local community
- Consideration of geographical location and proximity of local accessible community services is an important component of accommodation planning

Choice & Role Participation

FINDINGS

- Many people in the sample had very limited opportunity to make everyday choices such the timing of everyday activities
- Most people in the sample experienced the loss of several valued life roles and very few people had replaced these roles with other life roles

Providing the support people with complex care needs require to make everyday and life choices is crucial to fostering dignity and self-determination (Department of Human Services, 2002). There is enormous potential for making a significant difference to the lives of the people in the target group by increasing their sense of choice and participation in every day activities.

> ***"I would like to dictate times I can get up in the morning, and when I go to bed. I would like a shower every day, as (the) current facility policy is once every two days."***

Qualitative data analysis identified two main areas in which participants and their support network desired greater choice:

- the timing and frequency of personal care routines (e.g. showering, mealtimes)
- choice regarding meaningful occupation undertaken within both the RAC facility and community settings.

Table 2.20 provides information about the level of support and opportunity people in the sample were given to make choices with regard to various areas of life. The planners conducted interviews with informants (the individual, their support network and paid staff) about the person's participation in making choices. Based on this information, the planner rated the person's level of participation in each area of life listed in Table 2.20. A score of 1 indicates that the individual had no opportunity to make choices in this area, or the informants considered the person was unable to make choices in this area. This study found that many younger people in RAC have very limited opportunity to participate basic everyday choices such as the timing of meals, when they go to bed and their participation in daytime activities. The sample's ability to participate in making choices is clearly influenced by the fact that 9% of people were minimally aware and 48% had difficulty communicating their everyday needs. However this highlights the need for formal support to ensure people have maximum opportunities for choice making.

Table 2.20 – Areas of life that people are supported to make choices (N=99)

Area of Life	No opportunity * 1	Unlikely to give real choice † 2	Final say doesn't rest with person § 3	Procedures in place ∆ 4	NA
The content of their evening meal	48%	29%	10%	10%	3%
The timing of their evening meal	71%	15%	6%	5%	3%
The leisure activities they take part in indoors	23%	18%	10%	49%	
Going out (e.g. pub, cinema)	40%	11%	19%	29%	
The time they go to bed in the evening	34%	22%	20%	21%	2%
The clothes they wear each day	29%	16%	8%	46%	1%
Keeping pets	72%	8%	6%	2%	12%
Removal of unsuitable staff	79%	10%	5%		6%
Involvement with girlfriends or boyfriends	55%	7%	9%	14%	14%
Their daytime activities	23%	23%	22%	31%	1%
The time they spend in the bath or shower	51%	26%	10%	13%	1%
Access to a private area	40%	12%	11%	37%	
The furnishings in their bedroom	25%	25%	22%	27%	

* Nothing mentioned, no opportunity, person considered by informant to be incapable of making choices in this area

† Some procedure(s) mentioned but nothing likely to give the person much real choice

§ Some procedure(s) mentioned through which person can express preferences but final say does not rest with the person

∆ Procedures in place for person to express preferences and these are final unless clearly inappropriate or dangerous

It is essential that everyone has the same opportunities to participate in the life of the community and choose the role they want to play in society alongside other citizens (Department of Human Services, 2002). A role is defined as the expected pattern of behaviour associated with occupation of a distinctive position in society (Heard, 1977). Adult occupational, family, avocational and social roles allow people to participate in society and satisfy human needs (Oakley et al., 1986). This study examined roles utilising the Roles Checklist (Oakley et al., 1986) and found that most people in the sample had lost many valued life roles. Life roles that were most often lost included the role of worker, student, home

> *"The most important role Susan identified is a continued and improved role in her son's life, including room for her son to stay within her accommodation and available funds to entertain him and an opportunity to holiday with him."*

maintainer and caregiver. Life roles that were most often preserved included family member and friend. Role gains were very limited however some people (24%) increased their involvement in hobbies and small gains were made by some people who took on roles such as volunteer worker, religious participant and participant in an organisation. In the sample, four people were students, three were attending adult training support services and one person was studying part-time at TAFE. One person was doing some part-time paid work in a supported enviroment.

Table 2.21 – Frequency of role change (N = 99)

Role	Role Loss	Role Maintained	Role Gain	Never Performed
Student: Attending school on a part or full-time basis	91%	4%		5%
Worker: Part-time or full time paid employment	90%	1%		9%
Volunteer: Donating services, at least once a month, to a hospital, school, community, political campaign, and so forth	27%	3%	2%	68%
Caregiver: Responsibility at least once a month for the care of someone such as a child, spouse, relative or friend	54%	6%		40%
Home maintainer: Responsibility at least once a month, for the upkeep of the home such as housecleaning or yard work	77%	1%		22%
Friend: Spending time or doing something, at least once a month, with a friend	44%	50%		6%
Family Member: Spending time or doing something at least once a month, with a family member such as a child, spouse parent or other relative	14%	85%		1%
Religious Participant: Involvement at least once a month, in groups or activities affiliated with one's religion (excluding worship)	18%	22%	2%	58%
Hobbyist or Amateur: Involvement at least once a month in a hobby or amateur activity such as sewing, playing a musical instrument	18%	22%	24%	37%
Participant in Organisations: Involvement at least once a month, in organizations such as Rotary, Guides, Book Club, Freemasons, Football club and so forth	25%	11%	1%	63%

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- There is an opportunity to make a significant difference to people's lives by increasing their participation in making everyday choices and decisions about their lives
- Younger people who remain in RAC and those who move require support and resources to enable them to live lives of connectedness by participating in valued life roles and community life

Support Needs

FINDINGS

- There is tremendous variation in support needs of this group
- 43% require the highest level of physical support on the Residential Classification Scale
- 37% of people cannot be left alone and require supervision 24 hours per day (CANS)
- 23% require a 'hostel' level of care

Overall support needs were assessed using the Residential Classification Scale (RCS) (Ageing and Aged Care Division, 2005) and the Care and Needs Scale (CANS) (Tate, 2004). Results on these two measures identified tremendous variations in the support needs of this sample. The RCS is an instrument used by the Department of Health and Ageing to measure the relative care needs of each resident and allocate funding to RAC facilities. This instrument was designed for use with the frail elderly and does not capture all the support needs of younger people with disabilities and complex care needs. As shown in Table 2.22 most (79%) of the people under 50 in RAC required high care (RCS Level 1-4), with 43% requiring the highest level of care (RCS Level 1) and 23% requiring a 'hostel' level of care (RCS Level 5-7).

Table 2.22 – Residential Classification Scale (RCS) (N=105)

Level of Care	n	%
Level 1	45	43%
Level 2	21	20%
Level 3	10	10%
Level 4	6	6%
Level 5	10	10%
Level 6	9	9%
Level 7	4	4%

Section 2 of the CANS provides eight levels rating how long a person can be left alone. In this sample, 37% of people required the highest level of support, indicating they cannot be left alone and require nursing care and/or surveillance 24 hours per day (Table 2.23).

Table 2.23 – Length of time person can be left alone (CANS Section 2) (n = 103)

CANS Level	n	%
Cannot be left alone. Needs nursing care, assistance and/or surveillance 24 hours per day	38	37%
Can be left alone for a few hours. Needs nursing care, assistance and/or surveillance 20-23 hours per day	20	19%
Can be left alone for part of the day but not overnight. Needs nursing care, assistance, supervision and/or direction 12-19 hours per day	18	18%
Can be left alone for part of the day and overnight. Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills	20	19%
Can be left alone for a few days a week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional support a few days per week	5	5%
Can be left alone for almost all week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once per week	2	2%
Can live alone, but needs intermittent (i.e. less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support	0	0%
Can live in the community, totally independently. Does not need contact	0	0%

The key elements of the day to day support needs of the whole group are outlined in Table 2.24. Many of the participants are very physically dependent on others for bed mobility (40%) and mobility inside (50%). Sixty three percent were incontinent. Forty eight percent had difficulty communicating basic care needs and 49% required assistance with meals.

Table 2.24 – Support needs of the whole groups

Support Needs	n	%
Incontinence* (n=105)	66	63%
Assistance positioning is critical (e.g. in bed, wheelchair or chair) (n=99)	56	57%
Assistance required with mobility inside (n=98)	49	50%
Assistance required to get in and out of the place they live (n=99)	70	71%
Assistance required to get around in their local community (n=97)	75	77%
Wanders or gets lost * (N=105)	7	7%
Assistance required bed mobility (e.g. turning)* (N=105)	42	40%
Exhibits behaviours that have the potential to cause harm to self or others* (N=105)	23	22%
Has difficulty communicating basic needs* (N=105)	50	48%
Meal assistance* (N=105)	51	49%
PEG feeds* (N=105)	16	15%
Thickened fluids (N=105)	23	22%
Meals with special consistency or texture (N=105)	30	29%
Baclofen pump (N=105)	4	4%
Assistance required with taking medication (n=101)	90	89%

* Items from the Care and Needs Scale (CANS) Part A

There is tremendous variation in the level and type of support required by the whole sample. To assist with service planning and development, the sample was divided into smaller homogenous sub-groups. Chapter 3 describes the characteristics, support needs and accommodation preferences for each of these sub-groups and summarises the themes identified in the individualised plans.

IMPLICATIONS FOR SERVICE DEVELOPMENT AND DELIVERY

- Alternative accommodation and support options need to be set up to manage a range of complex care and support needs
- A range of solutions are required to meet the various sub-groups within this population

Chapter 3: Accommodation and Support Planning

Support Needs of Three Sub-groups

Given the wide range of support needs represented in this sample, cluster analysis was utilised to identify sub-groups of participants with similar levels of support needs. Details of this analysis are available in Appendix B.

The cluster analysis revealed three sub-groups:

- *Very High Care Needs* group
- *High Care Needs* group
- *Moderate Care Needs* group

Table 3.1 outlines the characteristics of each group. Tables 3.1 to 3.4 only contain the results of the health issues, characteristics or life circumstances that were statistically significantly different between groups. The *Moderate Care Needs* group were predominantly males with acquired brain injuries who were fully aware. The *High Care Needs* and *Very High Care Needs* groups had a more even mix of males and females and disability types. All minimally aware people were in the *Very High Care Needs* group.

Table 3.1 – Characteristics that vary across the three subgroups

Characteristic		Very High needs (n=52)	High Needs (n=35)	Moderate Needs (n= 16)
Sex	Male	28	18	14
	Female	24	17	2
Disability Type*	Acquired Brain Injury	33	15	11
	Multiple Sclerosis	9	5	
	Huntington’s Disease	5	3	1
	Intellectual Disability	5	2	2
Level of Awareness	Fully aware	22	26	14
	Partially aware	21	9	2
	Minimally aware	9		

* This table only lists the most common disability types

As expected, the *Very High Care Needs* group had more health issues such as altered muscle tone, swallowing difficulties and pressure care issues associated with higher levels of disability compared to the other two groups (Table 3.2).

Table 3.2 – Health issues that vary between the three sub-groups

Health Issue	Very High needs (n=52)	High Needs (n=35)	Moderate Needs (n= 16)
Diarrhoea or colitis	39	18	0
Altered muscle tone	36	21	5
Swallowing difficulties	33	9	2
Contractures	24	8	1
Pressure areas or care	20	12	1
Recurrent chest infections	16	3	0
Urinary tract infections	14	10	0

The *Very High Care Needs* group required more physical assistance than the other two groups, indicated by the RCS level of 1-3 (Table 3.3), requiring between 20-24 hours of supervision each day (CANS Level 7-8). The physical assistance required by the *High Care Needs* group is quite varied, revealing a range of 1-7 on the RCS, however, this group required less constant supervision than the *Very High Needs* group. The CANS indicated between 11 and 23 hours of supervision during the day for this group and some people in the *High Care Needs* group could manage alone overnight. The *Moderate Care Needs* group required little hands on assistance, up to 11 hours of assistance during the day and did not need support overnight.

As shown in Table 3.4 and 3.5 the *Very High Care Needs* are highly dependent on others for positioning, mobility, communication, and meal assistance. Some people in the two higher care groups are more prone to wandering or getting lost and more people in these two groups exhibit behaviours that have potential to cause harm to themselves or others.

Table 3.3 – RCS and CANS levels of the three sub-groups

Support Needs	Very High Needs (n=52)	High Needs (n=35)	Moderate Needs (n= 16)
Level of physical assistance (RCS range)	1-3	1-7	4-7
Level of supervision (Score on CANS Part 2)	7-8	5-7	3-5

Table 3.4 – Mobility of the three sub-groups

Support Needs	Very High Needs (n=52)	High Needs (n=35)	Moderate Needs (n= 16)
Assistance required bed mobility (e.g. turning)*	27	15	
Assistance positioning in critical (e.g. in bed, wheelchair or chair)	37	18	1
Assistance required with mobility inside	40	9	
Assistance required to get in and out of the place they live	47	20	3
Assistance required to get around in their local community	47	25	3
Wanders or gets lost *	5	2	

* Items from the Care and Needs Scale (CANS) Part A

Table 3.5 – Support Needs of the three sub-groups

Support Needs	Very High Needs (n=52)	High Needs (n=35)	Moderate Needs (n= 16)
Incontinence*	43	22	1
Exhibits behaviours that have the potential to cause harm to self or others	17	5	1
Has difficulty communicating basic needs*	37	11	2
Meal assistance*	37	14	
PEG feeds*	16		
Assistance required with taking medication	50	32	7

* Items from the Care and Needs Scale (CANS) Part A

For each subgroup, a case illustration is provided to illustrate a ‘typical’ person in each group. Any identifying information in these case illustrations has been altered. Accommodation and support preferences and characteristics are outlined for each sub-group.

Support Needs of the Very High Care Needs Group

CHARACTERISTICS OF THE VERY HIGH CARE NEEDS GROUP

- Most people require the assistance of one or two staff and specialist equipment for positioning, mobility, transfers and personal care activities
- Multiple and complex nursing and medical needs are prevalent, including PEG feeding, catheterisation, pressure care and infection management
- Communication abilities are severely limited with 71% of people having difficulties communicating basic day to day needs
- 81% of the Very High Support Needs group display one or more challenging behaviours

Case Illustration: Leanne

Leanne, a 45-year-old primary school teacher, was diagnosed with Multiple Sclerosis twenty five years ago. Leanne grew up in the outer eastern suburbs of Melbourne, where her parents and two siblings still live. Leanne's interests include current affairs and sport; in particular she is an avid supporter of the Geelong Football Club.

When Leanne was first admitted to the RAC facility her parents, on their initial visit, found her sitting by a window with a scenic view. Leanne, however, was unable to see anything because her head was bowed over looking at her chest, saturated from her own saliva. Her father decided that he and his wife would need to visit Leanne on a daily basis to ensure her care needs were fully met.

Although unable to speak, Leanne uses a communication board with all the letters of the alphabet in rows, allowing her to spell words and phrases (via eye contact with each letter in the word), supplemented with facial gestures. This method of communication is effective with people who know Leanne well and for those who have the time to spend with her. Unfortunately, nursing staff do not support her to use the communication board so her parents have taken on the role of advocating for her on a day to day basis.

Leanne is dependent upon staff to meet all her personal care needs. Due to altered muscle tone she is unable to use her limbs at all. She uses an electric wheelchair which needs to be operated by someone else. Two staff are needed to transfer her using a ceiling hoist. She receives all her fluids and nutritional needs, including all her medications, via a PEG. She is fed via the PEG eight times during a 24-hour period. The PEG tube is replaced by the Hospital in the Home Program.

Leanne also has a catheter which is routinely changed every three months, although it often becomes blocked thus requiring more frequent changes. The catheter is changed by the qualified nursing staff at the RAC facility. Leanne frequently experiences urinary tract infections, which are treated with medication *prescribed by the General Practitioner who visits her as required at the RAC facility. She has a pressure care mattress on her bed and her parents recently spent $500 to replace the pressure care seating on her wheelchair.*

Leanne's father visits in the morning and her mother visits in the afternoon for hours at a time. While they are at the RAC facility, her parents assist with Leanne's personal care needs including giving her PEG feeds and cleaning her teeth. They also read the newspaper to her, watch television together and converse. Leanne's sister, Fiona, and her brother, Steven, visit her on the weekends. She also receives regular visits from a voluntary community visitor from the Multiple Sclerosis Society.

Both Leanne and her parents do not believe she receives the amount of individual attention she requires from RAC staff. They feel that staff have limited time to complete all their work tasks and do not have time to spend with Leanne. Her father stated that when he goes home at night, he leaves notes to prompt staff to meet Leanne's basic needs, for example to change the station on her television so she can watch a particular program at night.

Leanne wants to move out of the RAC facility into supported accommodation with people of her own age. She expressed the wish to continue to receive nursing care, but preferred this to be delivered in a more personalised way by staff who have the time to communicate with her. Leanne said she would like to have more contact with her friends and people her own age. She would prefer to have a normal relationship with her parents and not be as dependent upon them for the direct care they provide during their daily visits. She also wants to remain living in the outer eastern suburbs of Melbourne so she can be close to her family.

Characteristics of the Very High Care Needs group

There are 52 people in the *Very High Care Needs* Group who require a high level of physical assistance and most require 24 hour supervision. People in this group have a mix of disability types, with 63% of this group diagnosed with an ABI (Table 3.6). Forty five people in the *Very High Care Needs* group had one disability type, six people had two disabilities and one person had three disabilities.

Table 3.6 – Disability types in the *Very High Care Needs* group (n=52)

Disability type	n	%
Acquired Brain Injury	33	63%
Multiple Sclerosis	9	17%
Huntington's Disease	5	10%
Intellectual Disability	5	10%
Cerebral Palsy	3	6%
Paraplegia	2	4%

Individuals in the *Very High Care Needs* group have high physical support needs and are generally very limited in their mobility. Positioning was reported as critical for 37 people of this group (Table 3.7). The reported risks of incorrect positioning were serious and included pain (26 people), pressure sores (28 people), choking (21 people), and respiratory tract infections (10 people). Forty five people required assistance with mobility and transfers and at least 38 people use a wheelchair for mobility. Forty people in this group are unable to get around inside the place they live without help, and 47 people are unable to get in and out of the place they live without help (Table 3.7). No one in this group was found to be participating in domestic and community activities of daily living. These figures point to marked limitations in access to daily activities within both accommodation and community settings, in addition to the need for high levels of staffing support (e.g. transfers or personal care).

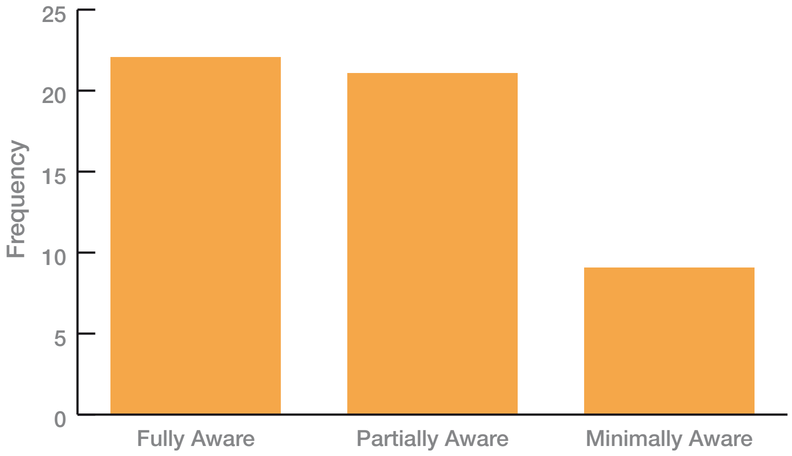
Table 3.7 – Positioning and mobility support needs of the *Very High Care Needs* group (n=52)

Support Needs	n	%
Positioning		
Critical to position correctly	37	71%
Risk of incorrect positioning – pressure sore	28	54%
Risks of incorrect positioning – pain	26	50%
Risk of incorrect positioning – choking	21	40%
Risk of incorrect positioning – respiratory tract infection	10	19%
Risk of incorrect positioning – challenging behaviour	9	17%
Mobility		
Bed mobility *	27	52%
Assistance with transfers/mobility *	45	87%
Assistance required to get around inside without help	40	77%
Assistance required to get in and out of place where they live without help	47	90%

* CANS A

Forty two people in the *Very High Care Needs* group display one or more challenging behaviours on the OBS, with 12 people displaying physical aggression towards others and nine people displaying inappropriate sexual behaviour. The impact of these behaviours on other people was typically rated as moderate to extreme; understandable given the Occupational Health and Safety implications. Sedation was more often used (10 people) as a means of managing challenging behaviour in this group than in the other two groups. These findings should be considered in conjunction with the high physical support needs of this group and common triggers of challenging behaviour, including pain, reduced expressive communication, the requirement for close proximity of carers during personal care and mobility tasks, reduced access to daily activities and altered level of awareness. All people who were assessed as minimally aware (9 people in total) were in the *Very High Care Needs* group (Figure 3.1).

Figure 3.1 - Levels of awareness for *Very High Care Needs* group



Forty eight people in the *Very High Care Needs* group had urinary incontinence and 26 people experienced faecal incontinence (Table 3.8). Thirty three people had difficulties with swallowing, 37 people required mealtime assistance and 16 people required nasogastric or PEG feeds. Sixteen people had difficulties with recurrent chest infections and 12 people had problems coughing and/or clearing secretions or sputum (Table 3.6). Thirty seven people had difficulty in communicating basic needs due to language impairments.

Table 3.8 – Personal care support needs of the *Very High Care Needs* group (n=52)

Personal Care Support Needs	n	%
Urinary incontinence	48	92%
Faecal incontinence	26	50%
Difficulty swallowing	33	63%
Nasogastric / PEG feeding	16	31%
Recurrent chest infections	16	31%
Problems coughing or clearing secretions	12	23%
Contractures	24	46%
Altered muscle tone	36	69%

Thirty six people had altered muscle tone such as spasticity or muscle spasm and 24 people had contractures (Table 3.8). Three of the four people with intrathecal Baclofen pumps, used to manage severe spasticity, were in the *Very High Care Needs* group.

The *Very High Care Needs* group were high users of consumables such as absorbent bed sheets (33 people), pads or pull-ups (44 people), topicals (19 people), enteral feeds and PEG devices (16 people) and clothing protectors (16 people). This group also required a range of equipment, including shower chairs (38 people), shower trolleys (10 people), commodes (17 people), hoists (35 people), wheelchairs (38 people), specialised seating (25 people), pressure care mattresses and overlays (35 people) and environmental control units (11 people).

Table 3.9 – Consumables and equipment requirements of the *Very High Care Needs* group (n=52)

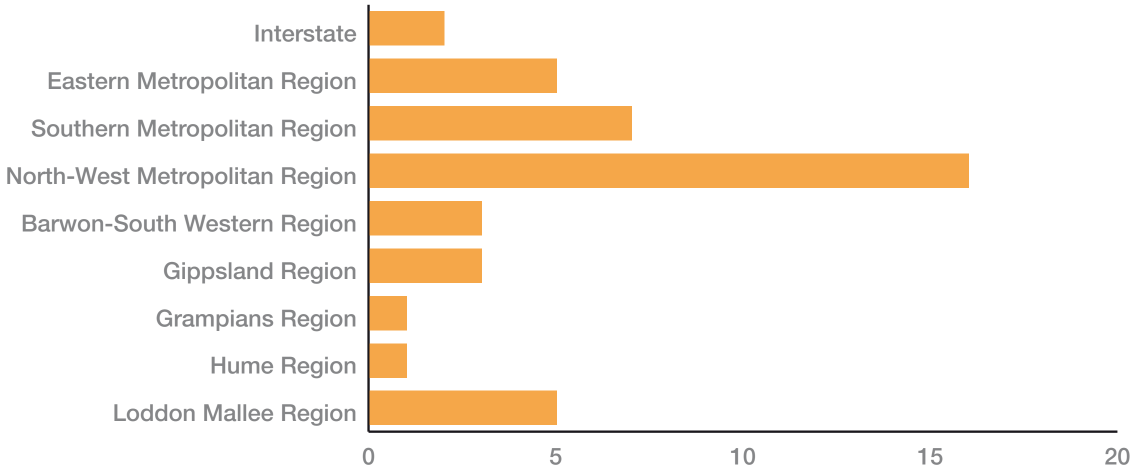
Consumables and Equipment	n	%
Absorbent bed sheet	33	64%
Pads or Pull-ups	44	85%
Topicals	19	37%
Enteral feeds and PEG devices	16	31%
Clothing protectors	16	31%
Shower chairs	38	73%
Shower trolleys	10	19%
Commodes	17	33%
Hoists	35	67%
Wheelchairs	38	73%
Specialised seating	25	48%
Pressure care mattresses and overlays	35	67%
Environmental control units	11	21%

The marked difficulty people in RAC experience in maintaining and making friends was evident in the fact that 22 people in the *Very High Care Needs* Group were never visited by a friend and a further 9 people were visited less than once a year. Only 6 people were visited weekly by friends. Forty seven people did not visit friends, further demonstrating issues within this group relating to the high physical support needs and subsequent limitations in community access and integration. To try to compensate for social isolation, some relatives reported that they visit more often. The fact that 17 people in the *Very High Care Needs* group are visited by a relative on most days and a further 21 people 1-3 times per week verifies their reflections. Only one person in the group was never visited by a relative and thirteen people in the *Very High Care Needs* group went out to visit relatives weekly or monthly. Over half of this group (34 people) never visited relatives.

Very High Care Needs Group Accommodation & Support Preferences

Four people in the *Very High Care Needs* group indicated that they would like to remain in RAC with no immediate change. Ten people would like to remain in the existing RAC but would like additional disability supports. These additional supports are described in Chapter 4.

Figure 3.2 - *Very High Care Needs* group original DHS location



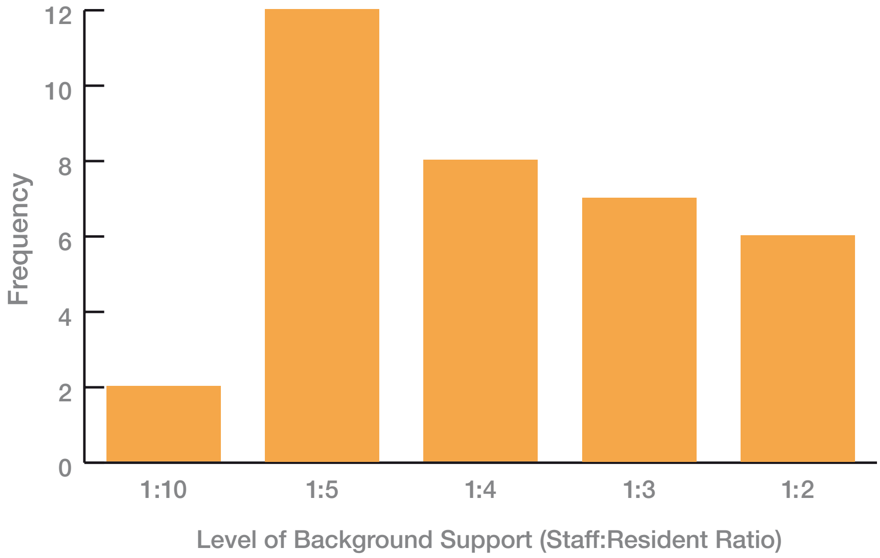
Thirty-five of the people in the *Very High Care Needs* group would like to explore the possibility of moving to an alternative accommodation and support option. Four people would like to return to a private or family residence, 29 specified a shared supported accommodation option and two people specified an 'other' accommodation and support option. One person would like to live independently and one person would like to live in a unit attached to a hospital. Information regarding accommodation and support preferences was not available for 3 people because their individual plans were not complete at the time of writing this report.

Very High Care Needs Group Level & Type of Support Required in a Community Setting

Planners were asked to estimate the level of shared 'background' support that each person would require during waking hours (i.e. from 7.00am-11.00pm) for community based living. In conjunction with this background level of support, planners were also asked to estimate the level of 1:1 and 2:1 (staff:resident) support that the person would require. Planners estimated that 12 people in the *Very High Care Needs* group required a 1:5 level of background support and 8 people required a 1:4 level of background support. Seven people were estimated to require a 1:3 level of support and another six people required a 1:2 level of background support (Figure 3.3). These estimates of staff to resident ratios are consistent with the high levels of physical and medical support needs identified in this group.

In addition to this background level of support, planners estimated that the people in the *Very High Care Needs* group required an average of 18.4 hours (range 0 – 86 hours) of additional 1:1 support per week. Planners also estimated that people in this group required an average of 6.1 hours (range 0-63) additional 2:1 (staff:resident) support per week. Such high staffing ratios would be expected for personal care, transfers and positioning tasks given the high physical support needs of this group.

Figure 3.3 - People requiring background support



Planners reported that 25 people in the *Very High Care Needs* group require nursing care on a regular basis. The mean number of nursing care hours for these 25 people was 29.9 hours per week (range 1 – 168 hours). With regard to overnight support requirements, planners estimated that 9 people of the *Very High Care Needs* group required two carers awake in order to provide care overnight, 15 people require one carer awake and available overnight, 5 people require a carer to sleep overnight and provide occasional assistance during some of these shifts, and 6 people require a carer to sleep overnight.

Additional supports required to ensure an appropriate model of care for this group include the services outlined in Table 3.10. Although not listed, behaviour management and support (e.g. neuropsychology) would be required for some people in this group, given the presence of high levels of challenging behaviour. However it is anticipated that when people from this group move to a more home-like and stimulating environment, with staff trained to manage their specific needs and able to provide more time, many of these behaviours will reduce.

Table 3.10 – Supports required in a community setting for the *Very High Care Needs* group (n=48)

Supports required in a community setting	n	%
Case Management	34	65%
Physiotherapy	33	63%
Occupational therapy	31	60%
Speech pathology	27	52%
Dietetics	28	54%
Continence advice	26	50%

VERY HIGH CARE: SUPPORT NEEDS SUMMARY

- Extremely high physical support needs requiring the assistance of one or two people for personal care, management of incontinence, transfers and positioning
- Extensive equipment needs
- Multiple and complex medical conditions (averaging 5 but up to as many as 8) requiring frequent medical specialist input, daily nursing and complex care plans. Medical conditions are potentially unstable and may be deteriorating, requiring continual adjustment of care plan
- Generally require 24-hour daily support, including support of one to two carers awake overnight
- Domestic and community activities including management of financial affairs, performed by others
- There tends to be a high level of family involvement on a daily basis and family members are integral in the person's life
- High levels of challenging behaviour (42 people) may be compounded by additional mental health issues requiring structured behaviour programs consistently implemented by trained workers
- People who wander require a safe setting
- Minimum of 1:1 support to access community activities
- Skill development programs designed by therapists, focussing on basic needs such as communication and mealtime assistance, to maximise function
- Sub groups who require specialist assessment and input include:
  - Minimally conscious state (9 people)
  - Physical aggression towards others (12 people)
  - Physically able and wandering (5 people)
- Some people will require formal or informal administration and guardianship for decision making

Support Needs of the High Care Needs Group

CHARACTERISTICS OF THE HIGH CARE NEEDS GROUP

- Support needs of the *High Care Needs* group are significant, but overall they are less complex to manage than the *Very High Care Needs* group and most do not require nursing care
- People in this group have a greater capacity to actively participate in daily activities, to communicate and to make choices
- 86% of people in this group display one or more challenging behaviours

Case Illustration: David

David is a 43-year-old man who had a severe acquired brain injury four years ago when he was assaulted while taking his dog for a walk.

When he moved into the RAC, six weeks post-injury, he had minimal awareness and required full care in bed, PEG feeding and 24-hour supervision and support. Over the past few years David has regained full awareness and made many functional gains. Though still requiring the use of a wheelchair, he is slowly increasing his independence and can now assist in personal care activities and is independent in his mobility. He no longer requires overnight assistance, except in the case of an emergency.

David is highly motivated to regain a range of skills but, in his current RAC setting, he faces significant barriers to achieving his goals, including lack of resources and staff attitudes. David has implemented actions such as not allowing staff in his room overnight, refusing assistance if he is "not ready", taking his medication when he feels like it, eating and drinking when he wants to and leaving the facility when he chooses. David's behaviour is viewed as "challenging" and he has numerous clashes with certain nursing staff when scolded for his actions. He feels he is "treated like a child" and states that he likes to be seen as an "adult capable of making his own decisions". David wants to be given choice and have his decisions respected.

David is extremely unhappy with his living situation. He said he stopped making friends with the elderly residents after he went to three funerals in one week. To insulate himself from the distress of making friends and losing them, he now isolates himself from other residents.

David described himself as desperate to move to more appropriate accommodation. David's goal is to live in a community setting with people his own age, with adequate supports so he can continue to increase his independence and access within the community. David has indicated that he would prefer to live in the Northern region, an area familiar to him and close to his siblings, who are limited in their ability to visit him at the RAC due to their other commitments. The planner emphasised that it will be extremely important to include David in managing the transition from RAC and to support him to make decisions and set his goals for his future.

Characteristics of the High Care Needs group

There are thirty five people in the *High Care Needs* group. Twenty six people are fully aware and nine people are partially aware. The *High Care Needs* group consist of a mix of disability types including acquired brain injury (15 people), multiple sclerosis (5 people), cerebral palsy (4 people), Huntington's disease (3 people) and other neurological disabilities (3 people) (Table 3.11).

Table 3.11 – *High Care Needs* group distribution of disabilities (n=35)

Disability type	n	%
Acquired Brain Injury	15	43%
Multiple Sclerosis	5	14%
Cerebral Palsy	4	11%
Huntington's Disease	3	9%
Other neurological disability	3	9%
Intellectual Disability	2	6%
Paraplegia	2	6%
Motor Neurone Disease	1	3%
Spina Bifida	1	3%

This group are dependent on others for their personal care and mobility, but less so than the *Very High Care Needs* group. Twenty-one people in this group have altered muscle tone, spasticity or muscle spasm, one person in this group has an intrathecal Baclofen pump to manage spasticity and spasm and eight people have contractures. Fifteen people require assistance with bed mobility (e.g. turning) and 20 people require assistance with transfers and mobility (Table 3.12). Nine people require assistance to get around inside the place they live without help. Twenty people require assistance to get in and out of the place they live and twenty five people require assistance to get around in the community. Two people were prone to getting lost or wandering. For half of the *High Care Needs* group, correct positioning by staff is critical. The consequences of incorrect positioning include: pain (11 people), challenging behaviour (3 people), pressure areas (11 people) and choking (2 people) (Table 3.12).

Table 3.12 – Positioning and mobility support needs of the *High Care Needs* group (n=35)

Support Needs	n	%
Positioning		
Critical to position correctly	18	51%
Risks of incorrect positioning – pain	11	31%
Risk of incorrect positioning – challenging behaviour	3	9%
Risk of incorrect positioning – pressure sore	11	31%
Risk of incorrect positioning – choking	2	6%
Mobility		
Bed mobility (CANS A)	15	43%
Assistance with transfers/mobility (CANS A)	20	57%
Assistance required to get around inside	9	26%
Assistance required to get in and out of place where they live	20	57%

Nine people in this group experience swallowing difficulties however no one has a PEG feed (Table 3.13). Twelve people have issues with pressure areas or care and 14 people require mealtime assistance. Twenty-two people in the *High Care Needs* group experience urinary incontinence and 17 people experience faecal incontinence. Eleven people in the *High Care Needs* Group have difficulty in communicating their basic needs due to speech or language impairments. Thirty people in the *High Care Needs* Group displayed one or more challenging behaviours on the OBS.

Table 3.13 – Personal care and communication support needs of the *High Care Needs* group (n=35)

Support Needs	n	%
Urinary incontinence	22	63%
Faecal incontinence	17	49%
Mealtime assistance	14	40%
Regular urinary tract infections	10	29%
Difficulty swallowing	9	26%
Recurrent chest infections	3	9%
Insulin dependent diabetes	3	9%
Problems coughing or clearing secretions	1	3%
Difficulty in communicating needs due to language impairments (CANS A)	11	31%

This group are also high users of consumables. Sixteen people in this group use absorbent bed sheets, 18 people use pads or pull-ups and 5 people use topicals.

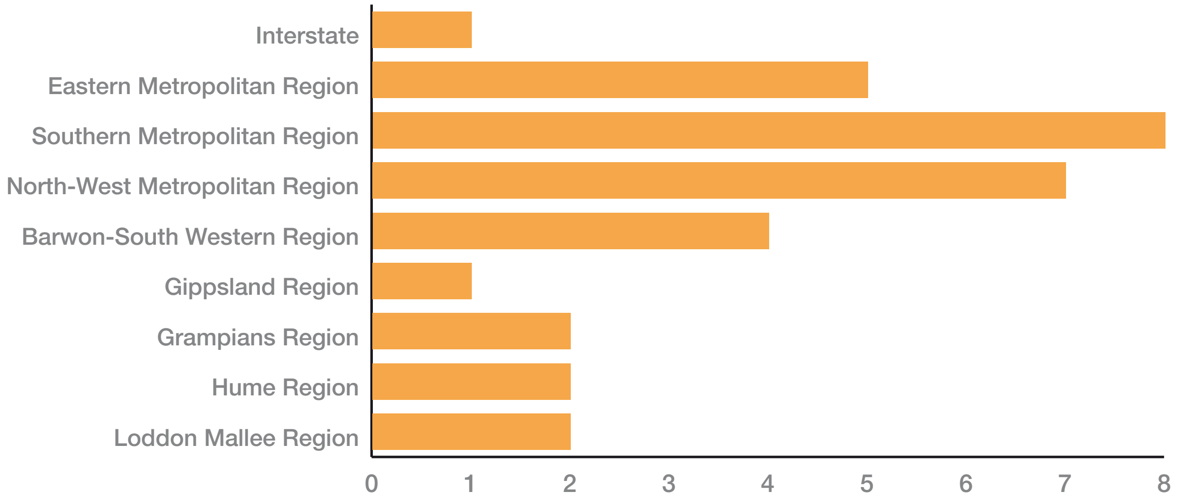
Many people in this group also require equipment for personal care, transfers or mobility. Four people require a shower trolley, 22 people require a shower chair and 15 people require a hoist. Twenty-two people use wheelchairs and 7 people require specialised seating. Seventeen people require a pressure care mattress or overlay and one person requires an environmental control unit.

Table 3.14 – Consumables and equipment required by the *High Care Needs* group (n=35)

Consumables and Equipment	n	%
Absorbent bed sheets	16	46%
Pads or Pull-ups	18	51%
Topicals	5	14%
Shower chairs	22	63%
Shower trolleys	4	11%
Hoists	15	43%
Wheelchairs	22	63%
Specialised seating	7	20%
Pressure care mattresses and overlays	17	49%
Environmental control units	1	3%

Thirteen people in the *High Care Needs* group were visited by a friend weekly or monthly, with only one person receiving a visit from a friend on most days. Almost half of the group (15 people) were never visited by a friend and only 8 people went out to visit friends. Frequency of visiting by relatives remained high with 7 people visited most days and a further 20 people weekly or monthly. Only one person in this group did not receive visits from relatives. Twenty six people in the *High Care Needs* Group seldom or never went to visit friends and 14 people seldom or never visited relatives.

Figure 3.4 - *High Care Needs* group original DHS location



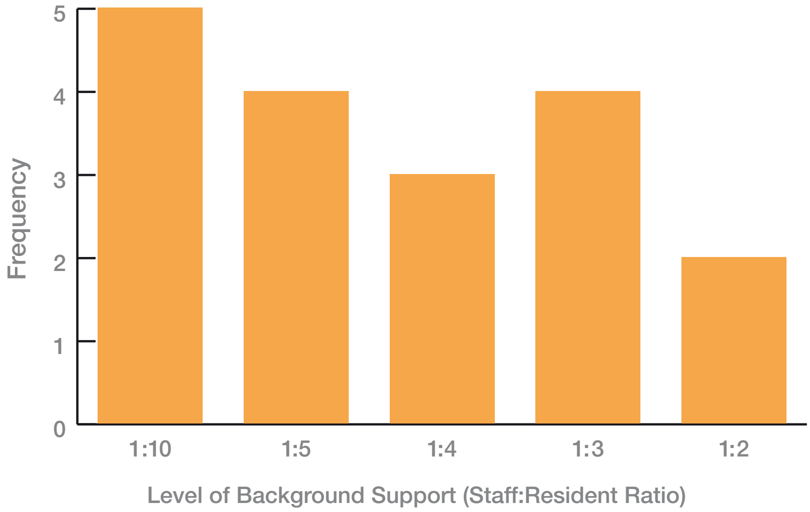
High Care Needs Group Accommodation & Support Preferences

Nine people in the *High Care Needs* group would like to remain in the existing RAC but would like additional disability supports (see Chapter 4). Twenty four of the 35 people would like to explore the possibility of moving to an alternative accommodation and support option. Three people would like to return to a private or family residence and 19 specified a shared supported accommodation option. Complete information regarding accommodation and support preferences was not available for 4 people because their individual plans were not complete at the time of writing this report.

High Care Needs Group Level & Type of Support Required in a Community Setting

Twenty four people in the *High Care Needs* group indicated a preference to move and planners estimated that one person requires 24-hour on call support, 5 people require a 1:10 level of background support and 4 people require a 1:5 level of background support. Three people were estimated to require a 1:4 level of support and four people require a 1:3 level of background support. Two people were estimated to require a 1:2 level of background support (Figure 3.5).

Figure 3.5 - People requiring background support



In addition to this background level of support, planners estimated that individuals in the *High Care Needs* group require an average of 22.8 hours (range 0-65) of additional 1:1 support per week. Planners also estimated that people in this group require an average of 1.73 (range 0-21) hours per week additional 2:1 support. Planners reported thirteen people in the *High Care Needs* group require nursing care on a regular basis. The mean number of nursing care hours for these thirteen people was 14.1 (range 2-53) hours per week.

Planners reported that one person in the *High Care Needs* group required two carers awake in order to provide overnight care, 7 people required one carer awake overnight, 5 people required a carer to sleep overnight and provide occasional assistance during some of these shifts, and 4 people required a carer to sleep overnight. Three people in this group did not require any assistance or supervision overnight.

Additional supports required to ensure an appropriate model of care for this group include the services identified in Table 3.15. As with the *Very High Care Needs* group, case management and physiotherapy were the services most often required.

Table 3.15 – Additional supports required by the *High Care Needs* group in a community setting (n=24)

Supports required in a community setting	n	%
Physiotherapy	18	75%
Case Management	18	75%
Occupational therapy	15	63%
Dietetics	14	58%
Continence advice	11	46%
Speech pathology	10	42%

HIGH CARE: SUPPORT NEEDS SUMMARY

- 24-hour on-site support required, with most people able to be left alone for short periods of time with distant on-site supervision
- Overnight support generally required but carer able to sleep, providing only occasional assistance
- High cognitive-behavioural support needs (30 people displayed one or more challenging behaviours)
- Moderate to high physical support needs (20 people require assistance with transfers and mobility, 22 people require wheelchair use and 15 people require hoist transfers). Some 2:1 (staff to resident) support is required for manual handling
- Requires 1:1 hands-on or stand-by assistance for all personal care, domestic activities and community activities as a result of cognitive and physical impairments
- Twenty five people in this group require assistance to access the community. Community inclusion maximised through opportunities for shared support to participate in social, recreational and vocational activities and close proximity of accommodation to accessible transport and community services (e.g. shopping centre)
- People in this group have an average of 4 medical conditions that require monitoring and periodic input, with thirteen people requiring some weekly nursing input
- Given potential to develop skills and reduce support needs over time, many people in this group will benefit from periodic therapy input and opportunities to integrate skills into everyday routines. Support staff will also benefit from ongoing training and support to maximise skill development, safety during manual handling, and to develop and consistently implement positive behavioural routines
- People in the *High Care Needs* group will require a significant amount of day-to-day coordination by residential staff and overarching Case Management support to coordinate care and address life crises
- Some people may require advocacy or Administration and possibly Guardianship for decision making

Support Needs of the Moderate Care Needs Group

CHARACTERISTICS OF THE MODERATE CARE NEEDS GROUP

- People in *Moderate Care Needs* group have minimal physical support needs and few complex medical issues
- The moderate group were predominantly males with acquired brain injuries who were fully aware

Case Illustration: Samantha

Samantha, a 45-year-old woman, was driving her car when she had a bleed from an aneurysm, resulting in a severe brain injury. She said she remembered feeling unwell and pulled over to the side of the road. The next thing she knew, she woke up a month later in hospital. She underwent rehabilitation at the Royal Talbot Hospital and the ABI Slow to Recover Program funded community based therapy once she was discharged back home, six months later.

When Samantha went home she received 34 hours per week of funded attendant care to assist with personal care and domestic tasks. Other care was provided by her husband on a gratuitous basis, however Samantha's husband struggled to provide her with the amount of help she needed. He was also looking after the couple's three school-aged children and did not feel that Samantha was safe to leave alone in the family home for more than one hour at a time. As a result Samantha was admitted to RAC.

During 2006, Samantha lived, for a few weeks at a time, in several RAC facilities because permanent accommodation could not be found until November 2006. She currently lives in a low care RAC where she receives the assistance she requires. Samantha has a left hemiplegia so has only the use of her right arm and hand. She eats using a spoon and a deep sided bowl and staff cut up her food to enable her to eat by herself. She is able to move herself from her bed to her wheelchair and commode chair by herself

and is able to, with extra time, shower and dress herself and clean her own teeth. To get about inside the RAC she uses a manual wheelchair which she propels with her right hand and her feet. She has an electric scooter which she uses to get about outside the RAC to go the local shopping centre, five minutes away from where she lives. However, the physiotherapist is concerned that Samantha places herself at risk when crossing roads in her scooter because of impaired vision and impulsivity. Samantha's speech is slow and difficult to understand although she is quite happy to repeat what she has said to get her message across.

Samantha likes to be independent, preferring to do what she can for herself. Two of the nursing staff describe her as "stubborn" when it comes to insisting on doing things for herself however, they also describe her as always being polite, friendly and well mannered to staff.

Samantha does not like living in an aged care facility and generally eats her meals on her own in the private dining room rather than with other residents. Samantha usually does not mix with the elderly residents in the RAC facility and spends her time in her room or playing Solitaire on a computer in one of the lounge rooms at the facility.

Samantha and her husband are now separated and he no longer supports her apart from bringing her children to visit once a fortnight. Samantha wants to move into a home on her own in Croydon close to where her children and friends live. She said that before her brain injury she went to church every week but now only attends once a month when a friend takes her. She feels that, by living in Croydon, she could attend church more frequently and have more contact with her friends.

Characteristics of the Moderate Care Needs group

There were sixteen people in the *Moderate Care Needs* group. Fourteen people were fully aware and two people were partially aware. Two people in this group had difficulty communicating their basic needs due to language impairments. Ten people in the *Moderate Care Needs* group displayed one or more challenging behaviours on the OBS and one person in this group exhibited behaviours that had the potential to cause harm to themselves or others.

This group are less dependent on others for their personal care and mobility and are more integrated into the community. People in the *Moderate Care Needs* Group were more actively involved in the domestic and community activities of daily living. The *Moderate Care Needs* group consisted of a mix of disability types shown in Table 3.16 and four people had more than one disability type.

Table 3.16 – Disability types in the *Moderate Care Needs* group (n=16)

Disability type	n	%
Acquired Brain Injury	11	69%
Intellectual Disability	2	13%
Arthritis	2	13%
Other Neurological	2	13%
Cerebral Palsy	1	6%
Huntington's Disease	1	6%
Paraplegia	1	6%
Parkinsons Disease	1	6%

Three people in the *Moderate Care Needs* group use a wheelchair for mobility. No one in the *Moderate Care Needs* group requires assistance with bed mobility (e.g. turning) and only one person requires assistance with transfers and mobility. Everyone in this group was able to get around inside the place they lived without help and most (13 people) were able to get in and out of the place they live and around in the community without help. No one in the *Moderate Care Needs* group was prone to getting lost or wandering. Correct positioning is critical for only one person in this group (Table 3.17).

Table 3.17 – Positioning and mobility support needs of the *Moderate Care Needs* group (n=16)

Support Needs	n	%
Critical to position correctly	1	6%
Assistance with transfers/mobility (CANS A)	1	6%
Assistance required to get in and out of place where they live without help	3	19%
Assistance required to get around the community without help	3	19%

Two people experience urinary incontinence and six people experience faecal incontinence. No one in this group has a catheter or reported experiencing recurrent urinary tract infections. No one in this group has non-insulin dependent diabetes although two people have insulin dependent diabetes and six people have epilepsy.

Five people in the *Moderate Care Needs* group have altered muscle tone, spasticity or muscle spasm and one person has contractures. From data previously outlined regarding this group it appears that these changes do not impact significantly on independence, mobility and transfers. All individuals are independent with eating though two people have difficulty with swallowing. A small number require consumables such as absorbent bed sheets (2 people), pads or pull-ups (1 person) or topicals (1 person). No one in this group requires a hoist, shower trolley, specialised seating or environmental control, however some require adaptive equipment such as shower chairs (3 people), wheelchairs (3 people), or a pressure care mattress or overlay (1 person).

Table 3.18 – Consumables and equipment required by the *Moderate Care Needs* group (n=16)

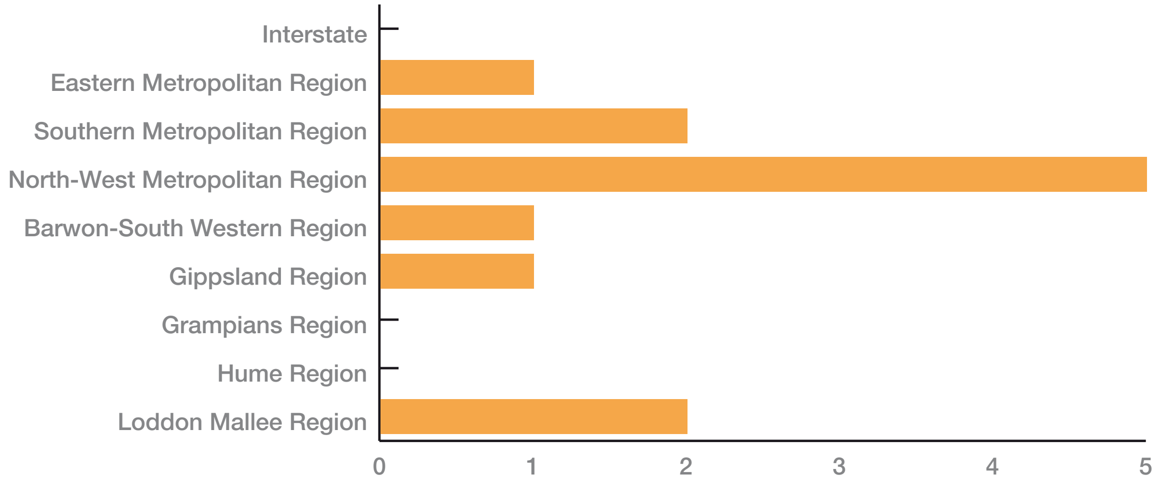
Consumables and Equipment	n	%
Absorbent bed sheets	2	13%
Pads or Pull-ups	1	6%
Topicals	1	6%
Shower chairs	3	19%
Wheelchairs	3	19%
Pressure care mattresses and overlays	1	6%

Ten of the *Moderate Care Needs* Group display one or more challenging behaviours on the OBS. Lack of initiation (9 people), verbal aggression (3 people) and inappropriate sexual behaviour (3 people) were the main categories of challenging behaviour reported. Social connections appeared more preserved in this group than in people with higher support needs. Although no one in this group is visited daily by friends, 6 people were visited weekly or monthly. Seven people in the *Moderate Care Needs* group were never visited by a friend. Family were less involved with the moderate care needs group than the other two groups. No one in this group was visited daily, however 7 people were visited weekly. Ten people seldom or never visited friends at their home and nine people seldom or never visited relatives.

Moderate Care Needs Group Accommodation & Support Preferences

Four people in the *Moderate Care Needs* group would like to remain in the existing RAC but would like additional disability supports. Eleven of the people in the *Moderate Care Needs* group would like to explore the possibility of moving to an alternative accommodation and support option. Two people would like to return to a private or family residence, four specified a shared supported accommodation option and two people specified an 'other' accommodation and support option. One person would like to live in shared accommodation in a lead tenant model and another person would like to live independently in a rented unit. The accommodation preferences of four people are unknown.

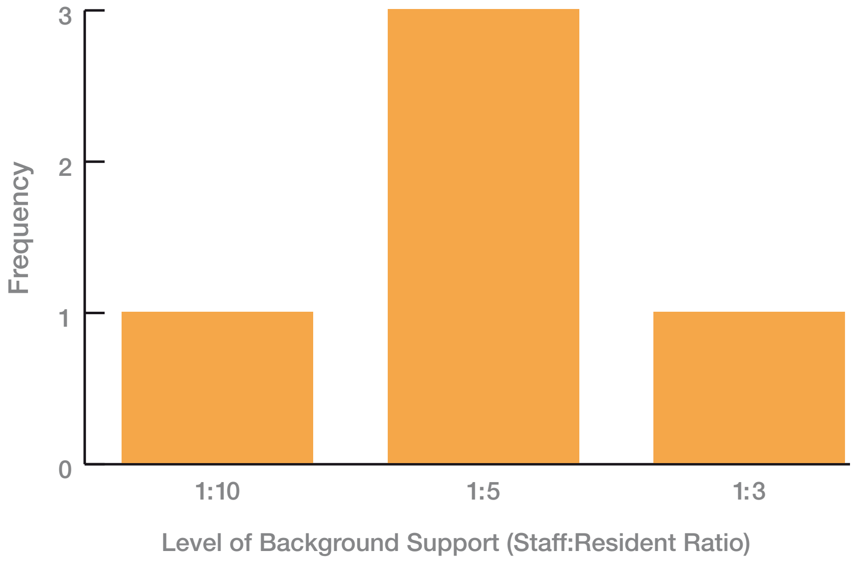
Figure 3.6 - ***Moderate Care Needs*** group original DHS location



Moderate Care Needs Group Level & Type of Support Required in a Community Setting

Of the eleven people indicating a preference to move, planners estimated that one person required a 1:10 level of background support and three required a 1:5 level of background support. One person required a 1:3 level of background support (Figure 3.7) and six people required no background support.

Figure 3.7 - People requiring background support



In addition to this background level of support, planners estimated that individuals in the *Moderate Care Needs* group required an average of 7 hours (range 0-40) of additional 1:1 support.

Planners also estimated that people in this group required an average of 1.9 hours (range 0-28) additional 2:1 support. Planners reported that three people in the *Moderate Care Needs* group require nursing care on a regular basis and that the mean number of nursing care hours for these 3 people was 7.5 hours per week (range 0.5-14 hours).

Planners reported that three people in the *Moderate Care Needs* group require a carer to sleep overnight and one person requires a carer to sleep overnight with the carer doing an occasional active shift. Six of the people in this group did not require any support overnight.

Additional supports required to ensure an appropriate model of care for this group included case management (9 people), and allied health (Table 3.19).

Table 3.19 – Supports required in a community setting for the *Moderate Care Needs* group (n=16)

Supports required in a community setting	n	%
Case Management	9	56%
Physiotherapy	4	25%
Occupational Therapy	5	31%
Speech Pathology	3	19%
Neuropsychology	4	25%
Dietetics	5	31%

MODERATE CARE: SUPPORT NEEDS SUMMARY

- Primarily cognitive support needs. May be independent or only require prompting for basic personal care & routine domestic tasks. Require 1:1 support for more complex domestic tasks and community activities (e.g. cooking, shopping and banking)
- Six people in this group do not typically require support overnight, but may need someone on stand-by and four people require inactive overnight support with only occasional active assistance
- Monitoring and periodic input to manage depression, anxiety and other psychiatric conditions required
- Ongoing behavioural support needs, particularly social behaviours in community settings, including structured behavioural programs consistently implemented by trained workers
- Community integration maximised through creating opportunities for shared support or structured weekly routines to participate in homemaking, social, recreational and vocational activities
- Given potential to develop skills and reduce support needs over time, individuals will benefit from periodic therapy input and opportunities to integrate skills into everyday routines
- Most (13 people) are able to achieve community access without assistance. In conjunction with targeted therapy input, consideration of location of accommodation close to accessible services (e.g. shopping centre, bank) and user-friendly transport (e.g. train) is important to further facilitate skill development and independence
- May have 2-3 medical conditions that require monitoring and periodic input by GP with only occasional specialist input. Three people require some nursing input
- Will require overarching Case Management support for managing more complex issues and life crises
- May require advocacy, administration or possibly guardianship for decision-making

Summary of Individual Plans

A key component of the *my future my choice* initiative was individualised planning with participants. Each planner worked with the person and their support network (where available or appropriate) to facilitate the development of an individualised, person-centred plan with key goals and strategies to achieve these objectives. Within the allocated planning hours there was the capacity for planners to implement some of the strategies identified.

As part of the results analysis, information from a random sample of 40 individual *my future my choice* individualised plans was exported into NVivo (QSR International Pty Ltd, 2002) for qualitative analysis. Each category was examined for shared tenets and coded into meaningful conceptual units. A summary of the key qualitative themes emerging from these individualised plans and the strategies recommended by planners follows.

Key themes identified within individualised planning

Ageing caregivers, burden of care and caregiver support

Ageing participants, degenerative conditions, loss of existing skills and changing care needs over time

Access to current or future meaningful occupation

Community access and inclusion

Facilitating choice and control

Ongoing case-coordination and planning

Providing opportunities for skill development

Maintaining or enhancing social relationships

Maintaining or enhancing health

Maintaining or enhancing quality of life

Meeting spiritual or religious needs

Provision of accessible and affordable transport

Transition planning for future community accommodation and support

Key strategies recommended

Funding allocated for:

- paid 1:1 carer support
- accommodation costs
- case management
- allied health input (including physiotherapist, speech pathology, occupational therapy, neuropsychologist, dietician and recreation worker)
- structured exercise program
- accessible transport
- transition planning
- specialised rehabilitation, mobility or personal care equipment

Referral to existing interest-based community groups, recreational programs or organisations

Referral to existing programs that could be provided in RAC (e.g. Community Visitor program, Visiting Pets program)

Referral to existing advocacy agencies

Referral to transitional living / living skill development programs

Identification of community members who could support participation (e.g. volunteer driver, church member)

Utilisation of accommodation and support planning resources provided by The Summer Foundation (e.g. accommodation model DVD and information booklet)

Facilitation of specialised service access (e.g. access to a dental service for people with profound physical disabilities)

Chapter 4: Future Directions

There is increasing understanding of the lifetime support needs of people with complex health issues associated with both acquired and degenerative disabilities. Further insight into these lifetime needs has been illustrated by the findings of the *my future my choice* assessment and planning process. This data suggests that RAC facilities do not provide the amount or type of support required by many people in the target group.

To ensure best practice, the disability and health care service systems must be proactive in managing the lifetime support requirements of people with complex care needs. There is evidence that, provided with the right environment and support, people have the potential to maintain or increase their independence and reduce their life-time care costs (Gray, 2000; Riudavets et al., 2005). A key challenge for the disability service sector is to respond in a way that enables these people achieve their potential and empowers them to participate in the community and pursue a lifestyle of choice (Department of Human Services, 2002).

As outlined earlier in this report, many people in the target group have fundamental health issues and support needs, the management of which should be incorporated into the person's accommodation setting. This Chapter outlines a proactive, integrated service system and details a range of accommodation and support alternatives to younger people with disabilities living in RAC. Strategies to meet both basic health needs and enhance the quality of life of the target group and opportunities to address gaps in the service system and other systemic issues are also examined.

An Integrated Service System

The findings of this report provide an evidence base for the services and strategies that could be developed to move younger people currently in RAC and to prevent future admissions to RAC. Development of an integrated service system would enable people with complex care needs to live in the community with appropriate supports and achieve better long-term outcomes.

Encouragingly, some of the elements of an effective service system already exist and are being accessed by some younger people with complex care needs who are funded by Disability Services, the ABI-Slow to Recover Program, the Transport Accident Commission or WorkSafe Victoria. Sixty three percent of the sample in this study were already receiving additional services from external providers. In Victoria there is already a range of outreach services that have expertise in working with the target population. These services include case management, specialist nursing (e.g. wound management, PEG support), allied health services and behaviour management support. Community based recreation groups, some of which are specifically for people with neurodegenerative conditions and others for people with an acquired brain injury, have also been implemented. There is an opportunity to develop partnerships with service providers to modify and extend existing services and build their capacity to meet the needs of the whole target population. In addition, it is critical that a comprehensive range of services are available to everyone in the target group regardless of their disability type or where they live.

Figure 4.1 – Service systems pathways to community living

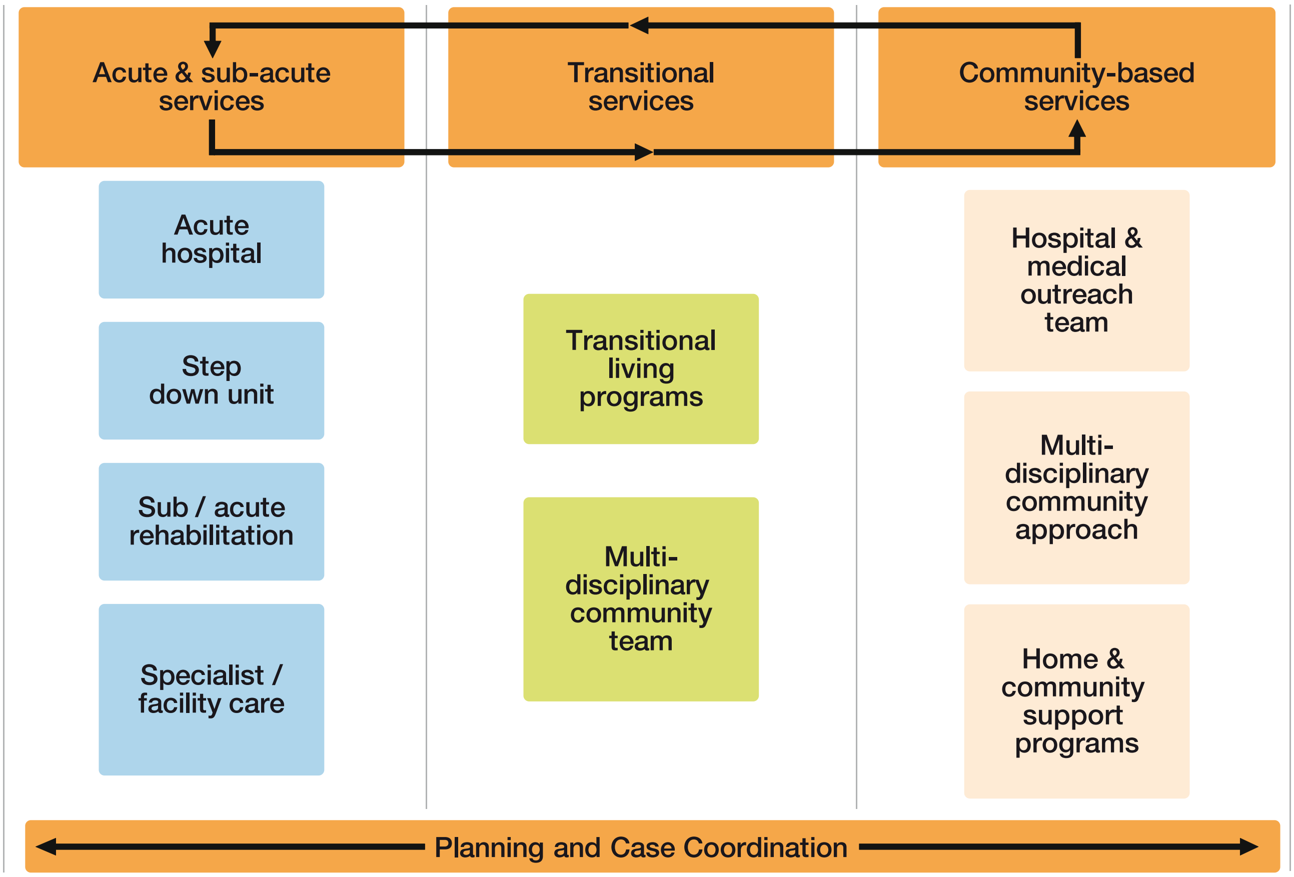


Figure 4.1 depicts an integrated service system designed to assist people with complex care needs to achieve and sustain community living as an alternative to RAC placement. There are three phases to this continuum of care: acute/sub-acute health services, transitional services, and community-based services. Within each of these service system phases there are critical elements. The arrows demonstrate that people can move in both directions through the continuum. The primary pathway to community living is from an existing RAC or an acute health service however this report has found that many younger people with complex care needs may be periodically re-admitted to acute hospitals. The service system needs to evolve to ensure that the target group receive ongoing assessment and individualised planning so that they can be discharged to the least restrictive setting following an acute hospital admission. The health sector has acknowledged many of these issues and has begun to address these in the wider population through the introduction of initiatives such as the Sub-Acute Ambulatory Care Services Framework. It is important for the Disability and Health systems to continue to build the interface between the two sectors. Younger people with complex care needs require access to targeted rehabilitation input, the prescription and provision of

equipment and transitional living programs. In a proactive service system, a hospital admission could be utilised as an opportunity for re-assessment and planning for people who have changing support needs or life circumstances. Long term systematic monitoring and follow up is required for this group.

Planning and Case Coordination

In Figure 4.1, Planning and Case Coordination is represented as a continuous process spanning the three service system phases. It is vital that a proactive and systematic method is employed to: identify younger people at risk of RAC placement, monitor their situation, and provide them with information and access to equipment and services over their lifetime and as their support needs change. These services must be provided in a timely and responsive manner to maximise their effectiveness.

The first step in an integrated service system would be a referral for assessment and planning. This referral would be triggered once it is identified that a younger person with complex care needs is at risk of admission or re-admission to RAC. At this time, the person may either be in an acute or sub-acute health setting or living in the community. The key trigger would be similar to the current trigger for an Aged Care Assessment Service assessment (i.e. recognising that the young person has support needs that exceed the resources available in their natural/existing social and support network).

Planners would undertake a comprehensive, individualised assessment and planning process, which may be based on the tool developed by the Summer Foundation for the *my future my choice* initiative. Referral for planning would enable community-based alternatives to RAC to be fully explored and appropriate community supports to be implemented. The individualised plans should be reviewed on an annual basis, at minimum. These reviews would provide the opportunity for readjustment of goals and strategies, targeted bursts of therapy input, equipment prescription or modification and an appraisal to ensure that the accommodation and support option is meeting the specific needs of the individual. The model of providing regular (e.g. annual) reviews for younger people with complex care needs could be based on the services provided to people with spinal cord or road accident-related trauma in Victoria (i.e. the Victorian Spinal Cord Service, the Transport Accident Commission). As with the annual reviews routinely conducted in the disability service system, these reviews would involve individualised

planning with an emphasis on self-determination, community membership and citizenship. However, these reviews would also have a significant focus on clinical care, promoting health and preventing secondary complications. People with changing needs would require a significant amount of reassessment, including a review to determine if support services are able to meet their current needs and, in some cases, a review of potential accommodation options. Given the complex care needs identified in this report, many of the people in the target group would need these reviews to either be conducted by providers with specialist knowledge and expertise or involve a significant amount of secondary consultation.

The transition of people in the target group from acute settings or existing RAC facilities to a community-based accommodation option is complex, posing challenges for the individual, family and support staff. Ideally, this process should be coordinated by a consistent and experienced case manager or planner. Effective coordination will help to ensure that each step in the transition process is well managed; that key elements of an integrated service system are harnessed; and coordinated care plans are developed to address the complex array of support needs in the target group.

Four key elements that require expansion to enable the service system to more effectively meet the needs of this target group include: step-down / step-up units in the acute health system; slow stream transitional rehabilitation programs (offering services to people who are ineligible for existing transitional rehabilitation services); hospital and medical outreach services; and community-based rehabilitation teams.

Step-Down / Step-Up Programs in the Acute Health System

Step-Down / Step-Up programs provide a cost-effective model integrating health care maintenance with rehabilitation for post-acute, severely neurologically impaired patients. Such patients are typically deemed inappropriate or not yet ready for traditional rehabilitation programs. Step-down / step-up services allow younger people with complex care needs the time they require to progress following an acquired injury or stabilize in the case of exacerbation of a degenerative disease process. This prevents premature decisions regarding placement (especially RAC admissions) and provides the person with an opportunity to demonstrate their rehabilitation potential. Outcome studies of one Step-Down program operating in Melbourne indicate that 80% of patients admitted were discharged to a rehabilitation program and, at 12 months, 79% of past Step-Down patients were living at home (New, Lea, Edwards, & Gilmore, 2005). The provision of Step Down / Step-Up programs attached to acute hospitals would provide an appropriate discharge option for people in the target group who may otherwise be blocking beds in the acute health system.

As depicted in Figure 4.1, Step-Down / Step-Up programs could be multi-functional, providing an opportunity to review those people experiencing a hospital readmission, as well as offering outreach or secondary consultation services to community-based accommodation services and RAC facilities. During hospital readmission or at critical stages of the person's life-cycle or degenerative disease process, Step-Down / Step-Up units could offer a targeted burst of specialist input or review of accommodation, equipment and support needs. At present a Step- Down program is only available to people in the target group who live in the Southern Health region. Ideally a Step-Down / Step-Up service attached to an acute hospital should be developed in each health region. Alternatively one or more Step-Down / Step-Up programs could provide a state-wide service.

Slow-stream Transitional Rehabilitation Program

For some people, a move straight from an acute or sub-acute health setting or RAC facility to community accommodation will be too great a step and be, therefore, unlikely to succeed. Transitional and ongoing accommodation services which embed opportunities for rehabilitation over an extended time frame within community settings would enable some people in the target group to optimise their potential. Such services would provide people with the opportunity to maxmise their independent living skills and abilities, live in the least restrictive environment and, over the longer term, reduce life time support needs and cost of care.

The models of rehabilitation provided to people with more severe and complex care needs are typically referred to as 'slow-stream', a term that implies a more extended time frame required to achieve small, but functionally significant, gains. The length of stay in a slow-stream transitional program would be in the vicinity of 6-18 months and require coordinated multi-disciplinary allied health input. The environment should be made safe for people who display complex cognitive behavioural issues that would otherwise preclude them from transitional programs (e.g. wandering / absconding). Rehabilitation provided in the context of transitional living services has been shown to reduce the impact of disability and have the potential to decrease lifelong costs of care and improve quality of life (Ponsford, Harrington, Olver, & Roper (in press)).

Hospital and Medical Outreach

Given the chronic health needs of some people in the target group, they require access to nursing, medical and hospital outreach services. These services can provide targeted input to manage and prevent health conditions and to provide regular reviews and secondary consultation to support staff or primary carers. Such input could also provide links to neuropsychiatric and specialist medical services (e.g. anti-convulsant review in the case of epilepsy) as required.

Ideally nursing outreach services that combine direct care with a 24-hour on call service should be developed to meet the needs of the people in the target group who require regular nursing care. Each individual receiving this service would be seen by a small team of nurses who provide them with regular direct care. This team of nurses would also provide a 24-hour on-call service. The nursing service would work with the individual, their support network and doctors to develop an action plan to monitor and address predictable medical conditions (e.g. recurrent urinary tract or chest infection). These action plans would enable support staff to proactively identify early warning signs and initiate appropriate intervention. The support staff or primary carer would be able to phone a nurse familiar with the person 24 hours per day. The nurse would assist the support staff or primary carer to determine the course of action (e.g. reposition individual, nurse to attend, phone general practitioner, phone medical specialist or call for an ambulance). The nursing service could also liaise with other health care providers (e.g. dentist) and monitor general health checks (e.g. prostate or breast screen). This proactive health planning is likely to reduce the incidence of secondary complications and acute hospital presentations.

The nursing service could also be proactive in the event of an acute hospital presentation. A brief summary of each person's medical history and current medical management should be developed, maintained and sent with them to the Emergency Department or medical appointment. The nursing service could also liaise with the local acute health service to develop alternatives to people in the target group presenting at their Emergency Department and enduring long waiting periods. Long waits in emergency departments need to be avoided for people in the target group who have reduced skin integrity or challenging behaviour. It may be possible for people in the target group to be fast tracked through their local Emergency Department. As previously mentioned, admission into a Step Up / Step Down unit rather than a general hospital ward would provide expert care for people in the target group and an opportunity for a more thorough review if required.

Community-Based Rehabilitation

Access to community-based rehabilitation is essential to assist people to maximize their abilities and acquire the skills that will enable them to participate in the community and pursue a lifestyle of choice. Community-based rehabilitation may specifically target: physical function; home and community mobility; daily living skills; behavioural routines; social communication skills or community inclusion. Multi-disciplinary rehabilitation teams may include a physiotherapist, occupational therapist, speech

pathologist and neuropsychologist. Given the range of multifaceted support needs identified in this report, the team members need to have expertise in working with people with multiple and complex needs or specific diagnoses. People in the target group require a ‘slow-stream’ rehabilitation model which integrates person centred principles as well as an understanding of how to facilitate participation in valued life roles. Such a model has been successfully implemented within the ABI-Slow to Recover Program, which has demonstrated improvements in the quality of life of people receiving services and positive cost-benefit outcomes (Olver and Gee 2005). It is vital that people have timely access to rehabilitation and case management services, embedded within home and community environments, as delay in intervention results in the development of a range of secondary problems (e.g. contractures, challenging behaviours) and a loss of residual skills (e.g. loss of continence). As such, there should be timely access to slow stream rehabilitation for people with ABI in the target group. For people with other disability types, support packages of targeted case management and community-based rehabilitation are also required.

A Choice of Living Options

The participants in the *my future my choice* assessment and planning process nominated three main preferences regarding their living situation:

- Remain in RAC with additional supports
- Return home (i.e. family or own home) with flexible support
- Move to an alternative accommodation and support option.

Additional Support for People who Remain in RAC

Of the 105 people in the sample, 27 indicated that they want to remain in their current RAC facility. Reasons for remaining in RAC include: the person has adjusted to the RAC setting; some live in rural settings and choose to be close to family; and others report that their current accommodation provides a good level of care.

For people who choose to remain in RAC, services to enhance their health and quality of life need to be developed. Planners identified a range of potential options individualised to the person's goals, interests and needs. Recommended enhancements frequently included equipment prescription, as well as the provision of additional 1:1 support to enable the person to participate in age-appropriate activities or access their local community. Other recommendations related to enhancing family relationships, allied health assessments, case coordination, transport and continence aids. Enhancement packages, for people who choose to remain in RAC or for whom there is no suitable alternative accommodation option, could be implemented with the support of a case manager or coordinator.

Flexible Support to Remain at Home

Nine people nominated returning to a private or family residence as their preferred accommodation option. To make this transition, planners identified that the person required significant levels of funded, in-home support to supplement the unpaid care provided by family members. Other resources required to enable people to make this transition include allied health and specialist services, equipment and paid support to participate in recreation activities, valued life roles and access to the community.

People with degenerative conditions in this study were less likely to be interested in exploring alternative accommodation and support options. However, it is imperative that more intensive and flexible support services are developed to enable people with conditions such as Multiple Sclerosis and Huntington's Disease to maintain their functional skills and remain living in their homes for as long as possible. For many, entry to RAC could have been avoided or significantly delayed by providing additional supports and equipment in the home setting. When people in the target group have increasing care needs due to the progression of their condition or where ageing carers are less able to provide required support, the provision of significant, graduated support packages for community living would enable people to remain in their home for longer and delay their admission to RAC.

Development of Alternatives to RAC

Of the 105 people in the current study, 68 expressed a desire to move to an alternative accommodation option. Commonly, people preferred to live with others and to live in areas close to community facilities and existing social networks. There are already some community based shared accommodation and support options in Victoria that would meet the needs of some people in the target group. However, there are not nearly enough places available and more facilities need to be developed that provide the level and type of support required by the target group. A broader range of alternatives in more diverse locations is required so that people have real choice regarding their accommodation and can live closer to their local community. Developing partnerships with other funding bodies would enable the development of viable alternatives to RAC in rural and regional areas. Innovative and customised solutions should be fostered to meet individual needs and desires for community living as an alternative to RAC.

Key elements of successful accommodation and support for people with complex care needs

To comprehensively address the individual's full range of needs, accommodation and support options that integrate the management of complex care needs with support, to maximise role participation, are required. This requires a goal-oriented, team approach with disability support workers, therapists, nursing and medical staff, and family members working in conjunction with the individual to ensure their needs are met. *my future my choice* planners frequently identified the need for ongoing case coordination and specialist services. As previously depicted in Figure 4.1, multi-disciplinary rehabilitation and acute health outreach services would continue to work with accommodation providers or the primary carers to support the individual. Strategies to incorporate slow stream rehabilitation and skill development into daily routines will enable individuals to reach and maintain their full potential. To ensure consistency of services, a set of minimum standards for community accommodation should be developed with key performance indicators. These standards and performance indicators should include a focus on staff training and support, retaining staff and developing a positive staff-resident culture.

Figure 4.2 – Key elements of successful accommodation and support for people with complex care needs

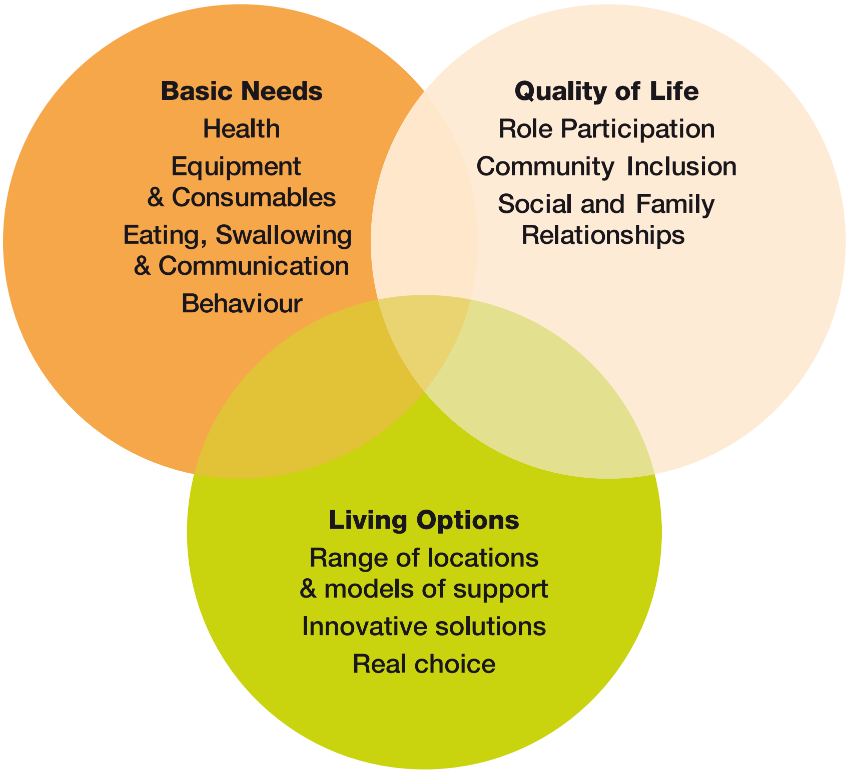


Figure 4.2 shows the three key elements to achieve successful accommodation and support options for people with complex care needs. These elements are:

- A range of accommodation and support options which enable real choice
- Strategies to meet basic daily needs
- Strategies which focus on quality of life.

Developing accommodation and support options

Support

Overall, the target group have complex care needs but, as seen in Chapter 3, there was tremendous variation in the level of support required. There were also a variety of preferences expressed as to where people wished to live, although a common theme was the desire to live close to family. The data collected therefore points to the need for a range of accommodation and support options available throughout metropolitan and regional areas.

Understanding the individual's support needs helps to decide the accommodation models within which this support can be delivered. The full range of personal, domestic, community, vocational and avocational activities the person participates in across the week needs to be considered. Different activities will probably require different amounts and types of assistance, which dictates the development of a flexible model of accommodation and support.

Support may be provided by family members or significant others on an unpaid basis. Support may also be purchased (most commonly provided by paid disability support workers). However, some people reject paid carer support and may be more accepting of normalised assistance (e.g. cleaner, gardener, personal assistant). There is a need to develop more flexible support services tailored to the specific needs of the individual. For example, there are some people that do not require 24 hour on-site supervision but would manage well with 24 hour on-call support from people who know them well and can assist with problem solving and planning. Often, a combination of supports is required. The level of support may vary from direct one-to-one supervision and assistance 24-hours a day, to weekly phone contact and occasional visits.

Table 4.1 displays a summary of the key support needs of the three sub-groups that were described in Chapter 3 and broadly identified within the *my future my choice* planning and assessment process.

Table 4.1 – Key support needs of the three sub-groups identified

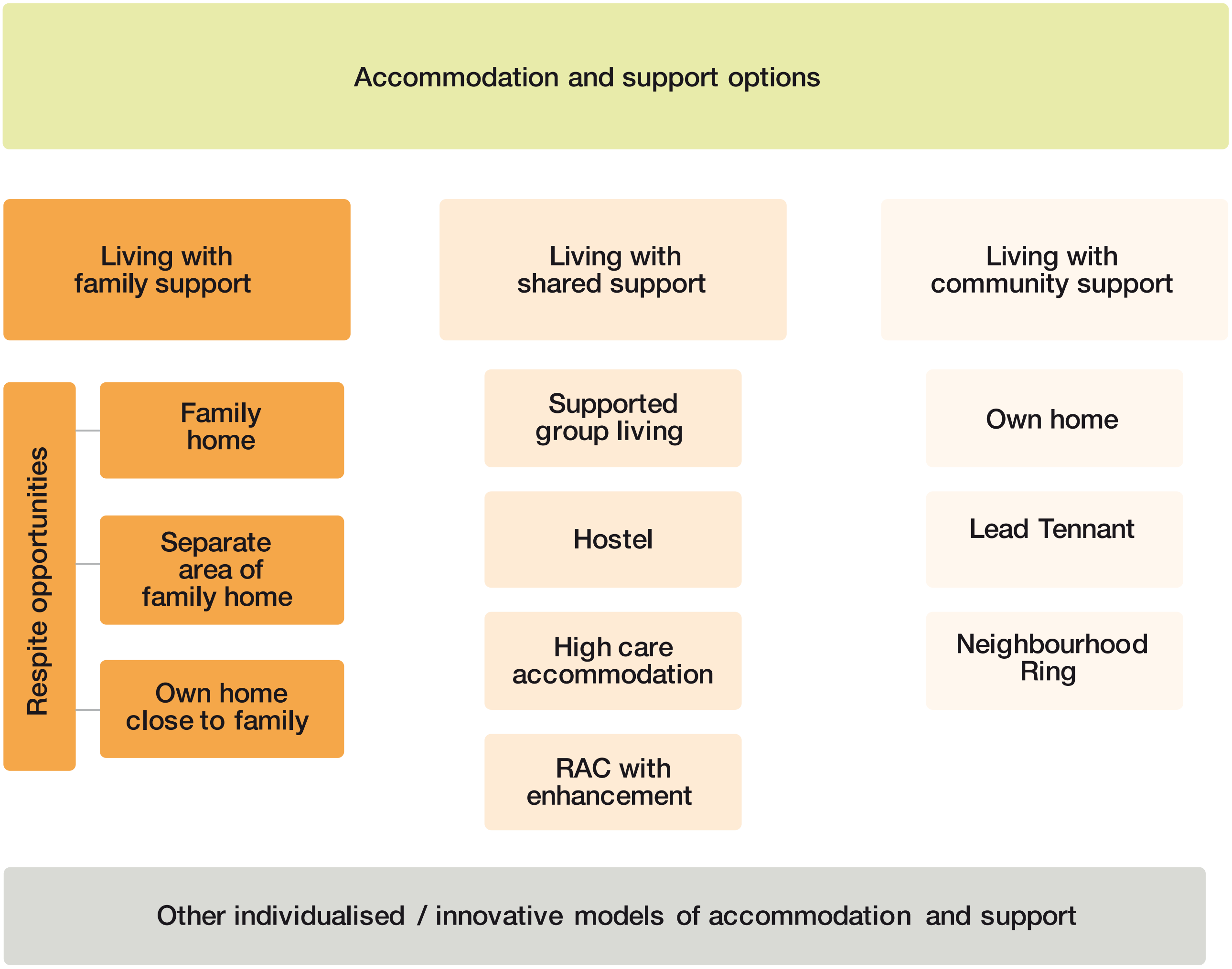
Very High Care Needs **Group**	***High Care Needs*** **Group**	***Moderate Care Needs*** **Group**
24-hour care and support, 7 days per week: • Minimum of 1:1 support for almost all daily living tasks, with additional 2:1 support for specific tasks • Overnight support of 1 to 2 people awake and available	24-hour shared care and support, 7 days per week: • 1:1 support for specific daily living tasks, with occasional 2:1 support for a small number of people • Overnight support of 1 person sleeping but available to assist if required	On-site or on-call 24-hour care and support, available 7 days per week if required: • 1:1 or shared support for specific daily living tasks • On-site or on-call overnight support of 1 person sleeping but available to assist if required
Daily or multiple daily nursing input	Nursing input averaging 4.5 hours per week	Occasional nursing input for a small number of people
Ancillary services (including cleaning, meal preparation, laundry, home maintenance)	Ancillary services or 1:1 support for cleaning, meal preparation, laundry and home maintenance	Ancillary services or 1:1 or shared support for cleaning, meal preparation, laundry and home maintenance
1:1 or 2:1 (staff:individual) support for community access	1:1 support for community access	Independent or shared support for most community access Some 1:1 support for community access
Daily care coordination	Daily to weekly care coordination	Weekly to fortnightly care coordination

Within these broad support structures, there are many levels and combinations of support which are, ideally, individualised according the person’s specific needs. The specific support structures developed for any individual will be influenced by a range of additional factors including: specific medical and physical issues, secondary issues (e.g. drug and alcohol issues; psychiatric issues), levels of independence, individual preferences and goals, family involvement and wishes, age, degenerative processes and life-cycle circumstances.

Accommodation Models

There are a range of accommodation models that can provide the community housing and support required by people with complex care needs. Potential options are summarised in Figure 4.3 and examined below. The accommodation options are organised in a way to link individuals to the primary mode of support provided – that is, living in settings with primarily family support; shared support; or community support. In reality, most people will have a range of secondary supports available that supplement and extend the input offered by the primary providers.

Figure 4.3 – Potential accommodation and support models



Living with family support

The family home

Living with family is typical for most people at different stages of their life. For the person with complex care needs, this option may offer a transition from hospital or residential aged care to more independent living. For others, it will be a more permanent accommodation option. Flexible funding packages should be provided to enable people to purchase in-home or community support tailored to their individual needs and choices. This could be provided by disability support workers, allied health assistants or ancillary staff (e.g. gardener or cleaner). Typically, individuals living in the family home results in relatives providing some level of unpaid care to their family member.

Separate area of family home (e.g. extension or bungalow)

Returning to live with family may not mean re-entering the family home. Other options include extending the home to offer self-contained accommodation or the use of bungalows or moveable units placed on the family property. Such options may offer increased privacy and independence for both the individual and the family. Again, flexible funding packages should be provided to enable people to purchase in-home or community support. Typically, people living in a separate area of the family home results in relatives providing some unpaid care, possibly on a stand-by or more distant basis.

Own home close to family (e.g. next door, same street or suburb)

People may choose to live independently, but close to family. This would enable the individual to achieve a degree of independence but still receive family support on a regular basis. Again, flexible funding packages responsive to people's in-home and community support needs are required. External case coordination and on-call support by a consistent person who is familiar with the individual's support needs is important to ensure the success of this model.

Respite

In this study, planners reported that access to respite services for 21 people would have enabled the person with a disability to remain at home for longer. People with complex care needs living within family settings require access to age appropriate respite services. Respite planning should be a key component of planning the transition of someone from RAC or acute care to the family home. Organising regular respite is vital for the individual and their primary caregivers in order to offer a break from the high demands associated with providing daily support to people with complex care needs. The placement of people in the target group in the family home is not viable in the long term without the development of age appropriate respite options.

A range of respite services are required to meet the needs of the target group. These include opportunities for breaks of varying length (e.g. one day a week; one weekend a month; two weeks a year) and respite with different goals (e.g. where the focus is on a holiday for the individual, an opportunity for a burst of rehabilitation input, or trial of an alternate supported community accommodation option). Typically the provision of respite will require additional resources to replace the unpaid care normally provided by family members. In the case of respite provided out of home, additional support may be needed because many people in the target group will require an increased level of support to manage in an unfamiliar environment.

Living with shared support

Small scale shared supported accommodation

There are many existing shared supported accommodation services established by both Disability Services and private organisations in Melbourne and country Victoria. These services are typically located in three to five bedroom houses and are staffed by disability support workers, usually on a 24-hour basis, and overseen by a house manager or key worker. Typically, such houses offer targeted support to people with specified disabilities (e.g. acquired brain injury; multiple sclerosis) or with similar support needs (e.g. a staff person available and awake overnight to provide support versus someone asleep on the premises overnight who is available to provide assistance as required). Some of these houses already provide the type and level of support required by many people in the target group.

Larger scale shared supported accommodation

There are a few existing larger scale shared supported accommodation services in metropolitan Melbourne that specialise in the provision of large group accommodation (i.e. 15 – 20 beds) for younger people with complex care needs. These facilities are also staffed by disability support workers, usually on a 24-hour active basis, and overseen by a manager. However, they may have more institutional ancillary services than supported group homes (e.g. industrial kitchen / laundry) and tend to have a higher number of rostered staff each week, given larger resident numbers.

High care accommodation

The *my future my choice* planning process revealed that some family members had never considered an alternative to RAC for their loved one. Given the complex medical or nursing care needs of some people in the sample, some individuals and families were sceptical about these needs being met in community-based services. Some individuals and families specified a larger shared supported accommodation facility with more than eight people and nursing staff rather than small-scale accommodation or individualised support. Some people, given the complex care needs identified, (e.g. frequent, daily nursing input or specialist medical support), are likely to require and choose larger scale shared accommodation with more intensive nursing support.

Living with community support

Co-located housing

Co-located housing allows people to live relatively independently but in close proximity to others requiring a similar level of support (e.g. living in a shared block of units or a flat at the back of a supported group house), thereby offering the capacity to share care. Co-located housing may offer a centralised, funded service providing flexible shared support to a group of people living in a similar area. People may also receive varying levels of 1:1 disability support worker assistance to facilitate engagement in specific activities of daily living. Ideally, co-located housing should not be segregated into a group, but rather dispersed within larger housing developments for the general population.

Neighbourhood ring

Neighbourhood rings provide shared support and opportunities to establish social contact with others living independently but within an accessible distance from each other in the community. This model aims to enhance links in the community and build a sense of connectedness. Some funded support is typically provided, but this may be set up as an outreach model from a community organisation designed or to facilitate the development of more natural supports over time, rather than being located at a specified or centralised accommodation.

Lead tenant model

A person with a disability, or group of people with disabilities, lives with a lead tenant who is a non-disabled resident volunteering (with subsidised rent and living expenses) or employed to create a normalised relationship characterised by the provision of incidental support, companionship, extra household assistance and socialisation opportunities. One person in the report specified that they would like live in a lead tenant model of housing.

Other innovative accommodation and support models

The needs and desires of inidividuals with complex care needs are diverse. Not all wishes for community living will be met by existing accommodation and support models. Services and funding will need to be person-centred and flexible in order to foster innovative or one-off models to meet the specific needs of individuals. Secondary consultation with experts who have track record in the development of innovative community-based support options for people with complex care needs may be required. In addition, the target group should be afforded the same opportunities to change accommodation options over their life-span as the rest of the population. People should have the opportunity to move or change accommodation and support, or adjust it in a flexible manner at various life stages. Funding packages should be portable to enable people to move from one accommodation option or region to another. The key services outlined in Figure 4.1 (i.e. episodic / ongoing planning and case coordination; step-down / step-up units; slow stream transitional rehabilitation services; hospital and medical outreach; and community-based rehabilitation teams) will be important components in the assessment of support needs at specified times over a person's life span. These services will also assist in detailing care requirements as they relate to the development or adjustment of sustainable models of accommodation and support.

Meeting the Needs of the Target Group

Regardless of the accommodation model selected, there are a range of essential strategies to ensure successful outcomes for people with complex care needs (Figure 4.2). Seven key themes to emerge from the findings of the *my future my choice* initiative fell into two main categories: those that addressed basic or fundamental daily needs (i.e. health; equipment and consumables; nutrition, swallowing and communication; and behaviour) and those focusing on improved quality of life (i.e. role participation; community inclusion; and social and family relationships).

Health

ISSUE

- 77% of participants living in RAC each had four or more health conditions
- 42% had a hospital admission in the past 12 months
- 36% of people had accidental injuries in the past 12 months, with over 50% of these resulting from falls
- Oral care needs were difficult to meet and a small but significant number of participants had poor dental health
- Families report that acute hospital admissions without the support of someone who knows them well are traumatic for some people in the target group

A range of complex health conditions were identified in the target group, some of which were unavoidable (e.g. epilepsy) however a number of which were potentially preventable (e.g. contractures, pressure areas, chest infection, obesity). Planners reported that some people did not have comprehensive primary health care by a consistent general practitioner. They reported that there was limited consultation between medical specialists and primary physicians regarding management of specific diagnoses (e.g. Huntington's disease). Planners found that the target group often did not have routine health screening (e.g. pap smears, breast checks). The planners also reported that very few people with high physical support needs had regular access to dental health services. A small but significant group of people, totally dependent on others, did not have their teeth cleaned on a regular basis because of difficulties staff experienced with opening the person's mouth due to either the physical limitations of the individual or challenging behaviour. In the *Very High Care Needs* and *High Care Needs* groups, the ability of the person to attend community medical, dental or specialist appointments was limited by their inability to transfer to the doctor's plinth or dentist's chair for examination, lack of staff support to attend appointments and lack of a suitable wheelchair or accessible transport.

There is significant potential for improving the quality of life of the target group and reducing long-term health costs through health promotion and prevention. The costs of Accident and Emergency presentations and acute hospital admissions are significant. These admissions have implications for the health and well being of the person with a disability, as well as the burden experienced by caregivers and lost productivity for the primary support network. Several families reported that acute hospital admissions have been traumatic for people who have severe physical disabilities, communication difficulties or behavioural issues. While the individual was in hospital, the family provided many hours of assistance and supervision to decrease the distress experienced by the individual and be an 'interpreter' between the person with the disability and hospital staff. Where a hospital admission is unavoidable, people in the target group need the support of a paid carer who knows them well. Preventative outreach services, community-based care and specialist secondary consultation with accommodation support staff has the potential to improve the health and well-being of the target group and decrease the costs of health care.

HEALTH: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- Development of capacity to provide timely and responsive primary care and medical services to people in the target group
- Development of partnerships between community-based accommodation providers and local general practitioners
- Development and consistent implementation of individualised daily care plans, routine health and dental checks, early detection and action to reduce the incidence of secondary conditions
- Routine reviews of swallowing and the development of measures to prevent chest infections prior to people in the target group having an elective surgical admission
- Specific and individualised training on personal care routines for people with high physical support needs (e.g. structured oral care / desensitisation program)
- Allocation of a key support person and the development and maintenance of a written summary of the individual's skills, communication ability and support needs, to aid timely information sharing between the accommodation and acute hospital setting in the case of hospitalisation
- Adequate funding for customised equipment prescription and supply (e.g. seating, pressure care)
- Episodic secondary consultation and education of accommodation support staff by a community based allied health team experienced in working with people with complex care needs
- The development or enhancement of partnerships with existing outreach services through acute health service providers (e.g. PEG outreach services). Such partnerships would also ensure that the prevention of complications would be achievable within community settings even for those people in the *Very High Care Needs* group
- Enhancement of links between the individual and their support providers with existing community organisations that specialise in specific diagnostic groups (e.g. Multiple Sclerosis Society of Victoria, Huntington's Disease Association)
- Identification and capacity building of general practitioners and dentists who specialise in the care of people with complex care needs
- Smaller scale accommodation models that offer more intimate knowledge and consistent management of an individual's care needs, in addition to targeted training of disability support workers

Equipment and Consumables

ISSUE

- 52% of participants utilise 5 or more items of specialised equipment
- Many people require custom made equipment to minimise health risks and maximise participation - some do not have this equipment because people in RAC are not eligible for funding via the Victorian Aids and Equipment program
- 30% of participants utilise 5 or more types of consumables on a daily basis
- The cost of consumables are currently met by RAC facilities but may be a significant expense for people in community settings

Ninety-three percent of this group received a Disability Support Pension, most of which was utilised to pay RAC accommodation costs. The equipment and consumable needs of this group were generally high, will be life long and may increase, particularly in the case of degenerative conditions. These costs will be difficult for the target group to meet given their limited income. Customised equipment is expensive to purchase and maintain. Expertise is required for the prescription of equipment and ongoing modification for those people with changing needs. Some people were severely restricted because they did not have access to suitable equipment. For example, in some cases, pressure care and comfort was compromised because the person could not afford appropriate pressure care mattresses or overlays. Others were restricted to the facility or, for some, even bed because they did not have access to customised supported seating or a suitable wheelchair. Although RAC facilities are technically responsible for the provision of equipment in RAC, they do not generally provide customised wheelchairs or other expensive equipment that is specifically for the use of one resident.

Given the significant ongoing cost of consumables and equipment maintenance, careful consideration needs to be given to the expense of these items when a person moves to an alternative accommodation option. Existing subsidies (e.g. the Continence Aids Assistance scheme) do not meet the considerable costs incurred and there is a significant risk that these expenses will exceed the person’s limited disposable income and further reduce their already restricted opportunities for community access and recreation.

EQUIPMENT AND CONSUMABLES: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- Specialised prescription, supply and maintenance of customised equipment would assist people to stay at home longer and significantly enhance the health and well-being of some younger people living in RAC, in addition to reducing secondary health complications in the target group
- Funding for transition planning will need to include resources for the assessment and provision of specialised equipment
- An increase in funding for aids and equipment and expansion of the eligibility criteria to include younger people in RAC is required
- The development of alternative accommodation options will require adequate space for use and storage of required equipment and consumables
- Planners need to consider the ongoing cost and supply of equipment and consumables when arranging transitions to alternative accommodation options

Nutrition, Swallowing & Communication

ISSUE

- 42% of participants had problems swallowing, increasing their risk of aspiration and chest infections
- 18% of participants had a chest infection in the previous 12 months
- 33% of people had special dietary needs including PEG feeding
- 48% of participants had trouble communicating their basic needs

Many of the participants in this study had very specialised requirements for nutritional intake. Swallowing difficulties were common and associated with significant risks (e.g. chest infections and choking). The acute hospital management of people with catastrophic injuries often involves a surgical procedure to enable PEG feeding so many of the participants discharged to RAC have PEGs in-situ, including 16 people in the *Very High Care Needs* Group.

Management of PEG feeding is complex and specialised both in terms of maintaining the PEG site and ensuring an appropriate feeding regime. In addition to nursing care, input is required from a speech pathologist and dietician. Regular swallowing reviews are also required and, at the right time, the opportunity to transition people from PEG to oral feeding (e.g. establishing the required consistency of food and drinks) needs to be provided. Again, this is a complex process that requires skilled management.

Positioning during meal times is another critical element in ensuring oral or enteral intake is conducted safely. Staff require knowledge of correct positioning as well as access to the right equipment (e.g. customised seating) to enable the person to achieve and maintain an upright position. As previously described, these fundamentals were often lacking in RAC settings and it was therefore not surprising that weight problems were prevalent and PEG-related medical issues and chest infections accounted for a large proportion of acute hospital re-admissions. The data suggests that hospital admissions could be significantly reduced with appropriate meal time assistance routines, specialist guidelines and training, and equipment to ensure nutritional intake is conducted safely. The individual's participation during meals is maximised by allowing enough time to process sensory information and respond. Not only does this support safety but also enables opportunities for expression of choice, such as the type of food consumed.

Providing routine opportunities for choice making throughout the day is crucial for mental health and for opportunities to communicate. Choice helps people have a sense of control and meet needs that may otherwise be triggers for challenging behaviours. An understanding of the individual's level of awareness, their receptive language skills and capacity to express themselves is required and leads to the shaping of a positive communication environment. In order to enhance social connections, everyone who communicates with the individual should be supported to learn new styles of interaction and to establish concrete supports to serve as a reference for conversation, especially with those who are non-verbal. Strategies and communication aids to maximise receptive and expressive communication and facilitate choice making can also be guided by speech pathologists.

NUTRITION, SWALLOWING & COMMUNICATION: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- People with identified swallowing difficulties require speech pathology assessment and regular review. Mealtime assistance regimes with written and pictorial guidelines for staff should be developed
- Advice for people in the target group, support staff and primary carers on positioning
- The prescription and purchase of necessary equipment for positioning and communication
- Education and communication between speech pathologists, nurses and those preparing meals is required
- The need for PEG feeding should be reviewed on an annual basis and the person should be provided with the opportunity to transition to oral feeding. Such a program would be set up and monitored by a speech pathologist
- Specialised input by a dietician is required to prescribe and review the dietary needs of people, especially those with PEGs, medical conditions such as diabetes and weight issues
- Training of support staff is required to ensure they have the skills to support each individual to make sense of their environment and to communicate their needs and choices

Behaviour

ISSUE

- 78% of younger people in residential aged care display challenging behaviour
- 56% of people have more than one type of challenging behaviour
- Challenging behaviour is often exacerbated by boredom, loneliness, impaired communication, lack of choice and control as well as mental health issues

The consequences of challenging behaviours are immense for the individual as they contribute to the depletion of natural support networks and the loss of access to valued activities, as well as creating significant occupational health and safety risks for carers.

The Overt Behaviour Scale enabled the following behaviours to be recorded: aggression, inappropriate social or sexual behaviour, repetitive behaviour, wandering or absconding and adynamia or lack of initiative. The level of challenging behaviour found in participants (78%) may be related to the high number of people with acquired brain injury and other neurological disorders who participated in the planning process. Injury to the areas of the brain that control and regulate behavioural responses is the primary reason people display challenging behaviours. However, the day to day levels of challenging behaviour exhibited by an individual are highly influenced by factors in the person's environment.

For young people in residential aged care, lack of participation in meaningful occupation may lead to boredom and social isolation, exacerbating challenging behaviours. Further, overt behaviours often result from an inability to communicate one's needs, with the study finding that 48% of people had trouble communicating basic needs and choices. In the absence of adequate time and staff support to enable a person to communicate, their needs will often be expressed though behavioural responses. For some people, higher levels of challenging behaviour were also found to co-exist with mental health problems. The distress and sense of hopelessness that characterises depression (prevalence of 65%) was a likely factor underlying challenging behaviour and, for those people, increases the complexity of developing effective strategies.

A holistic approach to managing behaviour that provides an understanding of the role of the neurological impairment, coupled with an understanding of environmental triggers and other contributing factors, is vital. This understanding forms the basis of the development of a behavioural plan for the individual. The approach needs to be developed in a timely manner to prevent escalation and entrenchment of behaviours.

Multi-disciplinary input for the target group enables a co-ordinated effort that combines communication and independent living skill development with structured and proactive management of behavioural triggers. Long term effectiveness relies on building the individual's skills and strengths and supporting the person to engage in meaningful social and recreational occupation. It is vital the behavioural plan is implemented consistently by carers who are trained and well supported. Such training also assists to reduce burn-out and turn-over of workers.

BEHAVIOUR: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- Multi-disciplinary approach to develop a behaviour plan for all people displaying evidence of challenging behaviour
- Behaviour plans to address the various background factors to challenging behaviour and emphasise the person's strengths and skill building as well as engagement in meaningful occupation. Flexible funding to enable participation in these additional activities
- Communication assessment and guidelines provided for all residents to enable needs to be expressed through more adaptive means and to maximise participation in day to day decision making
- Comprehensive training in the understanding of brain injury and principles of behaviour management for disability support workers to be included in relevant Certificate training courses. Mandatory agency training provided to workers engaged with individuals with ABI and other neurological disorders. Funding for ongoing training built into packages
- Accommodation environments designed to provide adequate personal space and privacy and located to maximise opportunities for community and social inclusion
- Staff cultures of inclusion and respect encouraged and supported

Role Participation

ISSUE

- 30% of younger people participated in recreation activities organised by the RAC facility less often than once per month
- 45% seldom or never participate in community based leisure activities
- Very few people participated in paid worker (1 person) or volunteer (5 people) roles
- RAC severely limits the capacity for involvement in homemaker roles

Given the impact of the complex care needs of this group, in addition to the social and physical environment of RAC, younger people are often deprived of opportunities for participation in valued life roles. The permanent loss of age-appropriate roles for many people in this group, most notably paid worker or primary caregiver, points to the need for expansion of other valued roles, such as participant in organisations or hobbyist, to fill the void. In addition, accommodation settings should offer opportunities for involvement in homemaking roles if desired by the individual. Wherever possible, family and friendship roles should be supported and nurtured.

Issues associated with life role choice and participation for this group are multi-faceted and may include:

- The level of physical, social communication or cognitive behavioural ability of the individual
- The lack of opportunity afforded within the RAC environment
- Complex care routines (e.g. multiple daily requirements for intramuscular insulin administration) and the impact of these on the timing of other chosen activities
- The availability of the support of another person or adaptive equipment to access the community or engage in roles
- Accessible or supported transport options
- Availability of financial resources to meet the costs associated with participation in activities.

Recreational participation provides an important opportunity for socialisation and meaningful use of time. Some participants had RAC-based recreational programs available to them; however, these were typically identified as not being age appropriate or of personal interest. Individualised planning consistently highlighted goals around enhancement of recreation, community access and leisure role participation. For people who choose to remain living in RAC, and those who move to an alternative accommodation and support option assistance is required to identify, find and participate in personally valued home and community based leisure activities.

Recreational services that offer skilled assessment of the person's capacity for leisure, and advice regarding specialist recreational equipment to aid participation are important components of engagement. Home based recreation for this group may require the prescription and training on the use of augmentative communication devices, environmental control units, or adaptive equipment. It may also involve training staff or the primary support network on positioning or communication techniques to maximise participation. This may also require secondary consultation from allied health services. Flexible packages of support to meet this range of needs, in addition to transport requirements, are necessary.

Community based role participation may be undertaken in mainstream (e.g. local club or church) or supported (e.g. disability-specific program) settings. Either way, in order to enhance social connections, training and ongoing support of community members or group facilitators regarding the individual strengths and support needs of each person is required. Where possible, graded or background support (e.g. disability support workers) should facilitate the development of natural supports and links to sustain participation and foster inclusion of the individual over time. People in the target group also require information about relevant resources (e.g. Talking Book Library) or referral to relevant services (e.g. Visiting Pets Program).

Innovative supported employment models will be required to facilitate the involvement of people in the target group in paid or voluntary work roles. A number of individuals expressed limited desire to engage in existing or traditional models of supported employment (e.g. sheltered workshop). Occupational therapy input would be of benefit to identify and assist the person to successfully negotiate a position within their area of interest, grade tasks to ensure success, and thus integrate into a voluntary, supported or paid work role. There is also an opportunity to partner with disability government organisations (e.g. the Transport Accident Commission) who are already involved in forging new opportunities for people with disabilities to secure work.

ROLE PARTICIPATION: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- Targeted allied health input to assist people to identify and participate in both home and community based life roles
- Individual packages and community resourcing to support people to access and participate in valued occupations
- Partnership with, and learning from, other government organisations to offer innovative solutions to meet complex care needs within recreation or employment roles
- Participation in community-based social activity programs should be supported by social communication skills training on an individual or group basis
- Opportunities to build domestic activities or home maintenance participation and choices into accommodation settings, if desired by the individual

Community Inclusion

ISSUE

- 23% of participants travel out of the RAC less than once per month
- 47% of participants in RAC seldom or never go shopping
- 56% of participants in RAC seldom or never visit relatives in their home

A large number of people in this study are virtually excluded from participation in community life. Barriers to community access include:

- Limited funding for individual support to assist the person to access the community
- The limited availability of affordable and accessible transport
- Limited personal finances – 93% of participants are on the Disability Support Pension
- Some people live a long way from friends, family and familiar community facilities.

Although disability support workers can assist some people to access their local community, physical placement in the community and accessing community facilities are only the first steps in community inclusion. Being present in the community is not the same as being included in the community. Being included in the community means having the opportunity to interact and form relationships with other community members (Bogdan & Taylor 1991). Assisting people with high care and complex needs to become part of community life is a challenging area of work that requires tenacity because relationships are not always spontaneously formed (Bogdan & Taylor, 1991; McKnight, 1995). Disability support workers need to be trained and supported by relevant members of a multi-disciplinary team to foster the community inclusion of people in the target group.

The primary goal for community inclusion is to integrate people into mainstream recreation, however some people in this population have limited success in integrating into the existing interest groups or recreation facilities in their local community. In response, the M.S. Society has developed the Confident Living Program for people with neurodegenerative conditions enabling some people in the target group to access recreation activities and socialise at venues in their local community.

A number of other services in Melbourne have partnered with mainstream recreation-based community organisations to develop groups for people with very severe brain injury who share a common interest (Eastern Access Community Health, 2007; Wesley Mission Melbourne, 2007). Transport costs and funding support are shared and experts in the specific activity (e.g. bowling instructor) can be trained on individuals' support needs in order to facilitate participation. There is an opportunity to expand this model of recreational support to include people with a range of disabilities living both in RAC and in community-based accommodation.

COMMUNITY INCLUSION: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- Skilled input to assist and support people to find and participate in meaningful roles and activities in their local community (e.g. volunteer worker, member of a service organisation)
- Flexible funding packages to support the costs of transport and 1:1 assistance in a range of community activities
- Access to accommodation as close to a familiar, local community as possible
- Based on existing models, the development and expansion of supported community based interest groups for people with high care and complex needs, both for people who remain in RAC and people who move

Social & Family Relationships

ISSUE

- Younger people in RAC are isolated from peers with 42% never receiving a visit from a friend
- Family members are often the only visitors the person receives, magnifying the importance of this contact and increasing the burden of care
- 28 people in the sample were parents of children under the age of 17 years

Many people in the target group are socially isolated from peers. The frequency of visiting family or friends by the individual was extremely low with 56% seldom or never visiting relatives in their own home and 82% seldom or never visiting friends. The responsibility was largely on the relative or friend to visit in the RAC.

However, family members reported that some relatives and friends find it very difficult to visit the person living in RAC. Barriers to visiting include: lack of privacy, visitors not knowing what to do or say and the distance and costs of travel. Further, a range of very strong and uncomfortable emotions created obstacles, particularly intense grief at witnessing the plight of the young person and despair at their living conditions.

As a consequence of these factors, the social networks of younger people living in RAC tend to contract over time. Social networks were often depleted to the point where parents or immediate family members were the only visitors the person received. There were a significant number of family members who reported feeling compelled to visit at least once per day, often for many hours at a time, to complement paid staffing support or compensate for the lack of social stimulation provided in the RAC environment. The burden of care experienced by these family members appeared to be high.

Some younger people in RAC are parents and informants reported that small children and teenagers find it particularly difficult to visit their mother or father in RAC. These parent-child relationships were severely disrupted and the responsibility for rearing often fell to the non-disabled sole parent or to grandparents.

SOCIAL & FAMILY RELATIONSHIPS: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- Early intervention is required in the acute and rehabilitation hospitals to support friends and extended families when they visit and assist them to remain engaged
- The development of a practical guide containing strategies designed to support social relationships, which is made available to families and friends in acute hospitals and available on the Internet
- Location of alternative accommodation options as close to family and friends as possible and near accessible community facilities and transport
- Accommodation designed to facilitate privacy and support positive interactions with visitors of all ages
- Development of a positive staff-resident culture in community based settings is vital to create an environment of appropriate social communication, behaviour and valued relationships
- Participation in community-based social activity programs should be supported by social communication skills training on an individual or group basis
- Provision for small modifications to be undertaken (e.g. handrail in toilet) or purchase of items of equipment (e.g. portable ramp for front entrance) to enable people to visit relatives and friends in their own homes
- Expansion of existing family counselling services for family and friends
- Planning to include the development of strategies to support the children of people in the target group to maintain or re-establish regular contact with their parent

Systemic Issues and Solutions

Four key systemic themes underpinning the development of an effective service system were identified: workforce issues; rural and regional areas; information; and resource allocation and outcomes.

Workforce Issues

Some of the people currently in RAC are likely to have different or more complex care needs than people with disabilities currently supported in the community. Successful transition into community settings is achievable for this group, but will require substantial adjustments in the workforce. Implementation of the *my future my choice* initiative will therefore result in the need for a greater number of skilled disability support staff, case managers and allied health professionals.

Currently, there are a small number of case managers and allied health professionals who have experience in facilitating the transition or managing the ongoing complex care needs of younger people in the community. The disability service sector needs to identify and harness this existing expertise, and utilise it to develop a workforce equipped to support the target group. These personnel could form the nucleus of specialist, multi-disciplinary community teams.

Community teams could provide individualised assessments of individuals, followed by training and ongoing mentoring of both regional and generic service and accommodation providers. Examples of such consultancy includes speech pathologists specialising in augmentative communication for people with multi-sensory disabilities; physiotherapists experienced in complex seating prescription, and neuropsychologists experienced in managing challenging behaviours in community settings. Outreach and secondary consultation services will ensure that knowledge regarding service and support planning for people with specific disabilities or complex care needs is shared and workforce capacity is built.

As previously noted, medical outreach teams attached to acute hospitals could also be utilised to ensure that staff are skilled to provide appropriate nursing and medical input. They would also be able to suggest and refer to existing services (e.g. PEG support, dietetics, continence advisors). These existing services would need to be expanded to manage additional demand.

In the current system, it is a constant challenge to find, train and keep quality disability support workers for the existing group of people with disabilities living in the community. The constant turnover and retraining of workers compromises the quality of support provided to people with disabilities living in the community. The *my future my choice* initiative will result in a vulnerable group of people with complex needs moving into the community, and disability support workers will need to develop the skills required to meet their specific needs. The target group require very consistent daily care and support workers who understand potential health risks and early warning signs.

Support staff will need to have links to a multi-disciplinary and medical outreach team that can be consulted proactively as issues arise in order to minimise secondary complications and acute hospital admissions. Disability support workers will require training specific to each individual's needs in addition to ongoing support from case managers and health care professionals

WORKFORCE ISSUES: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- Identification of expertise specific to the needs of this population currently available in the health, rehabilitation and disability sector and the harnessing of this expertise to develop community support teams
- Expansion and use of a specialist approach to assess and review people with complex support needs in RAC, at risk of RAC placement or supported in the community
- Partnering with agencies and individuals with expertise in working with this population to provide training and build the capacity of the health, rehabilitation and disability sector
- Maximise the quality of support provided to this population through client and facility specific training and ongoing support and training for disability support workers
- Research to explore the health and cost-benefits of reducing the turnover of disability support workers

Rural and Regional Areas

Approximately one third of participants in this study are from rural and regional Victoria so it is essential that alternative accommodation and support options and outreach services are developed statewide. Considering 85% of the whole sample stated that it is important to live close by to family and friends it is likely that many people may choose to stay in the RAC in their rural area rather than move to a larger town that may offer an alternative accommodation option. Flexible funding packages should be made available to enable this group to fulfil valued life roles and participate in the life of their local community.

Due to the lower numbers of people living in rural areas, more small scale and individualised accommodation and support solutions will be required and should be provided in a flexible way to cater for a diverse range of abililities and support needs. This includes people with degenerative conditions who may require graded, increasing support over time, as well as people with the potential for skill development or more independent living who may require transitional accommodation combined with slow stream community based rehabilitation. Further, partnerships with other funding bodies (e.g. Transort Accident Commission, Senior Master's Office) may assist to identify other people in rural areas who have similar needs, enabling the development of viable shared accommodation and support options.

Planners reported that rural and regional areas offer a range of benefits, as well as posing challenges and this should be considered in service planning. In some cases, community spirit and natural supports were more easily harnessed to facilitate role participation (e.g. voluntary support from local football club members to provide supervision and assistance to an individual to attend the weekly game). However, transport and community mobility may be challenging for this group, given large distances and the limited availability of accessible community transport or environments (e.g. sealed footpaths). The choice of supported activity programs in rural areas is much more limited compared with metropolitan regions. The programs available in rural areas tended to be developed for people with congenital disabilities and some people in the target group did not want to attend these groups.

Allocated support packages in rural areas need to be flexible to enable participation and should recognise the additional travel costs incurred in rural areas, in addition to the reduced opportunities to share support and activity costs. Providing outreach services and secondary consultation to people in the target group who live in rural areas is essential. These services could be provided in a range of ways including phone contact, email, the use of web-cams for reviews as well as some face to face contact. These services would also provide professional support and work collaboratively with local generic allied health staff to build their capacity to provide services to people in the target group.

RURAL & REGIONAL: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- Substantial individual packages to enable people in rural regions to live at home and access the community, where shared supported solutions are not viable
- Enhancement packages for people where RAC is the only option
- The development of partnerships and flexible models of accommodation and support in regional areas that cater for a wide range of needs
- The expansion of existing outreach services (via regional visits, phone contact and internet-based consultation)
- Professional support and collaborative work with local generic allied health staff

Information

There is significant variation in the amount of additional supports or resources that are accessed and utilised by younger people in RAC. Some families had no knowledge of any services outside the RAC facility, while others were proactive in seeking and applying for additional services. Approximately 23% of participants received Slow to Recover funding; in contrast, one third of people received no additional support. Further, a number of younger people had limited or no advocacy (informal or formal) support available to them. As acknowledged in the Method section, it is likely that our sample was biased towards people who had some form of advocacy and that the total numbers of people without such support living in RAC are higher than indicated in this report. The need for long term, episodic case management was a consistent theme identified by the planners.

Some RAC facilities appeared to have little understanding or knowledge of the complex support needs associated with some disability types or how to access potential sources of information and expertise that could assist them in meeting the needs of these people. Variation in the level of interest and input provided by general practitioners was also apparent.

Some discharge planners at acute and rehabilitation facilities also have limited knowledge about relevant services, sources of information and support for younger people in RAC and their families. It was apparent that some younger people had been transferred from acute or rehabilitation hospitals without any referrals to relevant disability services, specialist services or advocacy organisations.

INFORMATION: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- An audit of the eligibility criteria for the range of existing services and resources that are relevant to the target population
- Identify and remedy gaps and anomalies in the existing service system
- Development of partnerships with existing providers to extend their services to meet the needs of this population
- Identification of gaps in the service system where existing services cannot be modified or extended and new services need to be developed
- Provision of accessible information about existing services and resources relevant to the target group, their support networks, RAC facilities and the health, rehabilitation and disability sector on one website with links to other relevant sites
- Development of resource kit for younger people who are living in RAC or who are at risk of admission in the future
- Development of a resource kit for RAC facilities with younger residents
- Development of a resource kit for discharge planners and social workers at acute and rehabilitation hospitals

Resource Allocation and Outcomes

This report has identified a wide range of unmet needs and systemic issues that impact on the health and well-being of younger people living in RAC. Adequate funding is required to meet these areas of need if the outcomes for this group are to be improved. It is essential that the cost-benefits of the resources allocated to address the issues in this population are examined both on an individual basis and at a systemic level. Further advances in provision of support will depend upon better efficacy and cost-benefit studies which must then be translated into specific evidence based guidelines of care, care quality measures and reporting mechanisms to allow proper auditing (Cope, Mayer, & Cervelli, 2005).

This study has demonstrated a range of methods for measuring the life circumstances of this population. Some of these methods will be useful in measuring the individual outcomes of interventions and additional supports funded through the *my future my choice* initiative. The process of setting measurable, individualised goals and monitoring outcomes is essential if support services and interventions are to be improved in the longer term.

In addition to measuring the outcomes on a case-by-case basis, it is imperative that the impact of the *my future my choice* initiative be examined for the whole group. In order to learn from the initiative and plan future services, we need to determine if the resources spent make a significant difference to the health and well-being of people who remain in RAC, as well as those who move to alternative accommodation and support options.

Finally, dissemination of outcome information will equip the wider disability service system to better meet the needs of this group.

OUTCOMES: OPPORTUNITIES AND POTENTIAL SOLUTIONS

- **Planners develop measurable, individualised goals to determine the benefit of any additional supports or interventions**
- **Systematic review of the health and well-being outcomes of people who participated in the *my future my choice* initiative – including both those people who move and those who chose to stay in RAC**
- **Publication of the results, both aggregate data and individual stories via the mfmc newsletter, DHS website, conference presentation and peer reviewed journals**

Conclusion

It is our understanding that 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 solutions to 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 is an opportunity 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, the numbers of younger people living in RAC can be significantly reduced.

The $60.2 million in joint funding for Victoria over five years is a tremendous start to resolving the issue of younger people living in aged care, however further resources will be required to fully address the level of unmet need identified in this report. The *my future my choice* initiative is an opportunity to demonstrate pragmatic alternatives to younger people living in RAC and develop innovative services that address the needs identified.

Outcome studies, which examine the efficacy of these services and document the changes in the health and well-being of the target group will provide an evidence base to justify the next investment of funds to address this issue. Indeed, over the next decade, there is a once in a generation opportunity to resolve the issue of younger people in aged care in Victoria.

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Appendix A:

Organisations and Individuals Consulted in Relation to this Report

my future my choice team Department of Human Services

Francene McCartin

Heather Thompson

Kylie Franklin

Helen Garner

Planners and Agencies Involved in Data Collection

William Crisp (Annecto)

Lee Wilkinson (Care Connect)

Vicki Koller (Care Connect)

Megan Parsons (Karingal)

Jacqui Pierce (Karingal)

Deb Sytema (Karingal)

Victoria Chipperfield (Melbourne City Mission)

Helen Parker (Melbourne City Mission)

Maria Bowman (Moreland Community Health Service)

Duane Bell (Moreland Community Health Service)

Warren Featherstone (Moreland Community Health Service)

Arlene Tan (Multiple Sclerosis Society Victoria)

Coral Price (Multiple Sclerosis Society Victoria)

Kylie Morgan (Multiple Sclerosis Society Victoria)

Janet Francis (Multiple Sclerosis Society Victoria)

Joanne Airey (Multiple Sclerosis Society Victoria)

Andrea Salmon (Multiple Sclerosis Society Victoria)

Tracey Appleby (Ovens and King Community Health Service)

Neroli Raff (Ovens and King Community Health Service)

my future my choice advisory committee

Jason Anderson (Person at risk of entry to RAC)

Alan Blackwood (Multiple Sclerosis Society Victoria)

Jennifer Boulton (VCASP)

Paul Butler (Paraquad)

Merrilee Cox (Headway)

Glen Mahoney (Parkinson's Victoria)

Bronwyn Morkham (YPINH Alliance)

Mary Nolan (Carer/Family Member)

Irene O'Brien (Carer/Family Member)

Margaret Summers (Aged Care Branch, DHS)

George Taleporos (Youth Disability Advocacy Service)

Joint Solutions

Bart Ruyter (Kilmore & District Hospital)

Tess Veitz (Transport Accident Commission)

Kem Mayberry

Trish Blundell (Supreme Court Senior Master's Office)

Barb Lloyd (Ashcare Inc.)

Victorian Brain Injury Recovery Association Inc (VBIRA)

Dr Jacinta Douglas (La Trobe University)

Paul Ellis (Marg Darcy & Associates)

Meg Irwin (Austin Health)

Michelle French (Michelle French & Associates)

Rosalie Hudson (University of Melbourne)

Sue Vincent (Neuro Rehabilitation Group)

Mary Galea (University of Melbourne)

Dr Joan Tierney (Brain Disorders Unit - Austin Health)

Dr Barry Rawicki (Southern Health)

Allen Martin (VBIRA)

Other Individuals

Jan Mackey (Applied Communication Skills)

Grahame Simpson (Brain Injury Rehabilitation Unit, Liverpool Health Service)

Denise West (Communication Resource Centre, SCOPE)

Susan Lett (Neuroskills Gippsland)

Appendix B:

Division of Sample into Sub-groups

Cluster analysis was used to divide the whole sample into sub-groups. Cluster analysis identifies clusters of participants with respect to some pre-determined selection criteria. The current study utilised two measures of support needs, the RCS and the CANS, as variables for the cluster variate because they relate directly to the objectives of the cluster analysis and characterised the objects being clustered (Hair, Anderson, Tatham, & Black, 1995). The distributions of the RCS and the CANS were examined to determine if they were relatively normal. The quick cluster function on SPSS (SPSS, 2005) was used to divide the sample into smaller homogenous groups.

Differences between groups derived from cluster analysis was then examined using the Pearson's Chi-Square test (SPSS, 2005). Seventeen categorical variables were examined to determine if there was a significant difference between the four clusters. This analysis found that there was a significant difference between the four groups on the following twelve variables:

- Presence of swallowing difficulties
- Recurrent chest infections
- Contractures
- Critical to ensure that the resident is positioned correctly
- Able to get around inside the place they live without help
- Able to get around the local community without difficulty
- Able to get in and out of the place they live without help
- Nasogastric/PEG feeding (CANS)
- Bed mobility (e.g. turning)
- Transfers/mobility (CANS)
- Language impairments (CANS)
- Continence (CANS)

There was no significant difference between the groups on the following variables:

- Wanders/gets lost
- Exhibits behaviours that have the potential to cause harm to self or others

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