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 were 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)

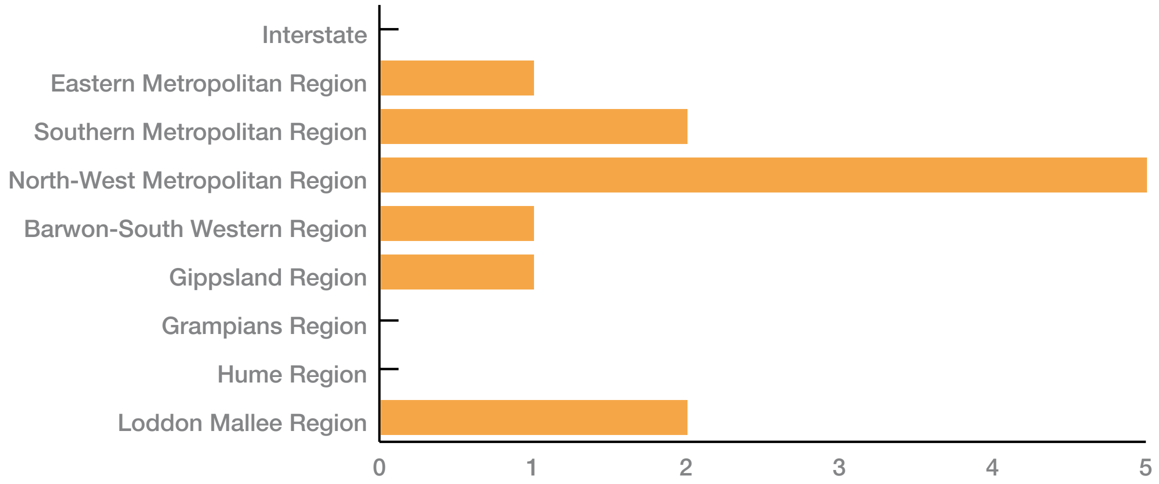
Consumables and Equipment	n	%
Absorbent bed sheets	2	13%
Pads or Pull-ups	1	6%
Topicals	1	6%
Shower chairs	3	19%
Wheelchairs	3	19%
Pressure care mattresses and overlays	1	6%

Nine 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.

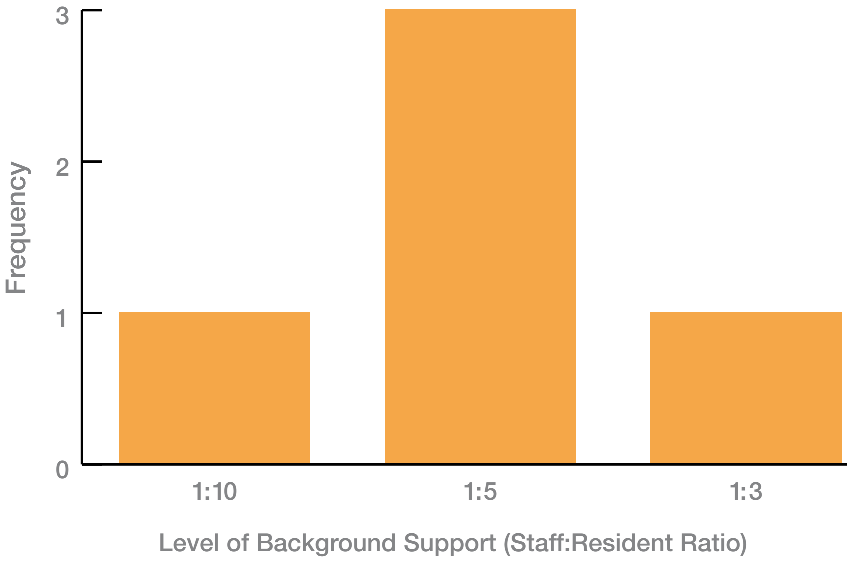
Figure 3.6 - *Moderate Care Needs* group original DHS location



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, involving 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), therapy and advisory services (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 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

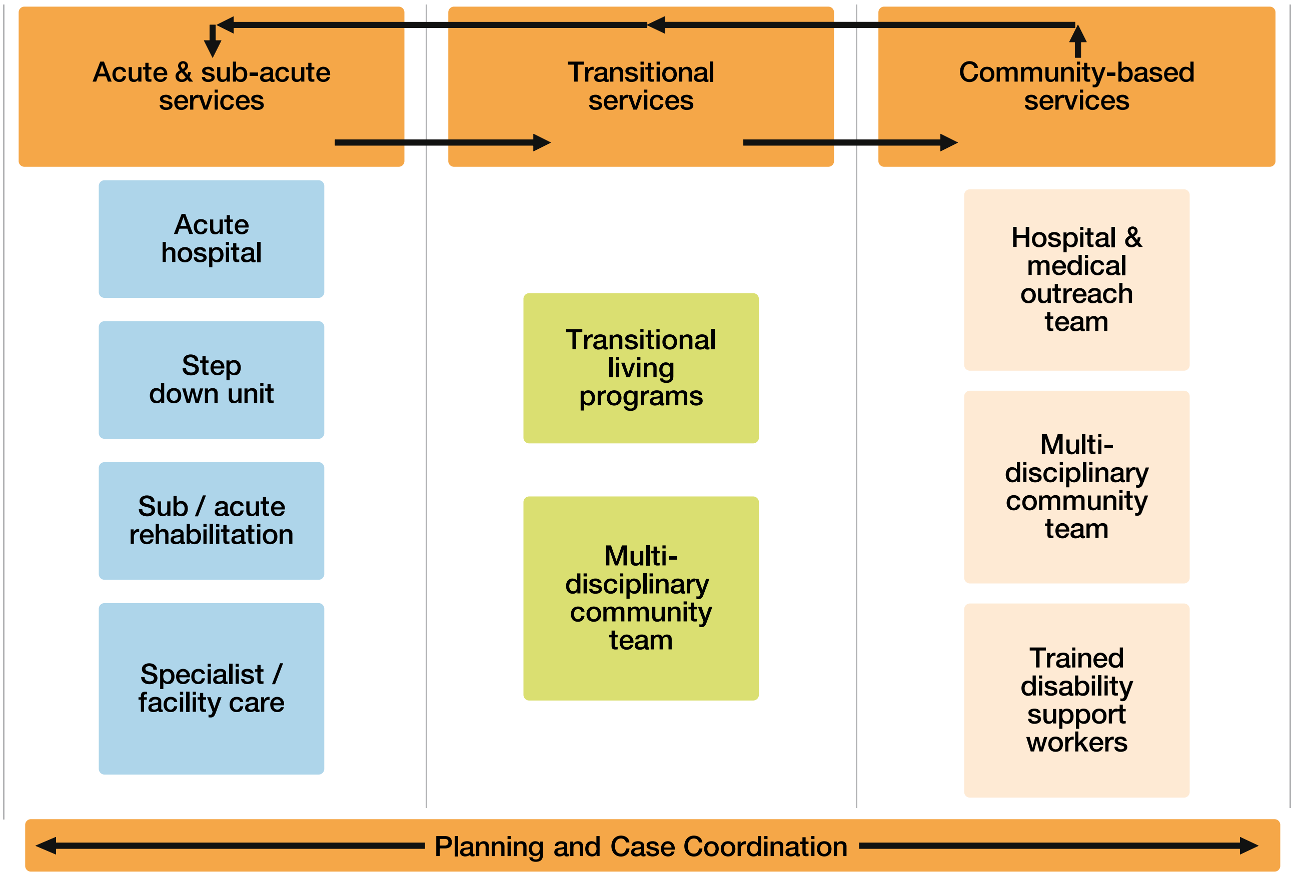


Figure 4.1 depicts an integrated service system designed to assist people with complex care needs to achieve and sustain community living as an alternative to RAC placement. There are three phases to this continuum of care: acute/sub-acute health services, transitional services, and community-based services. Within each of these service system phases, there are critical elements. The arrows demonstrate that people can move 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. They 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, severe 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 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 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, keeping staff and developing a positive staff-resident culture.

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

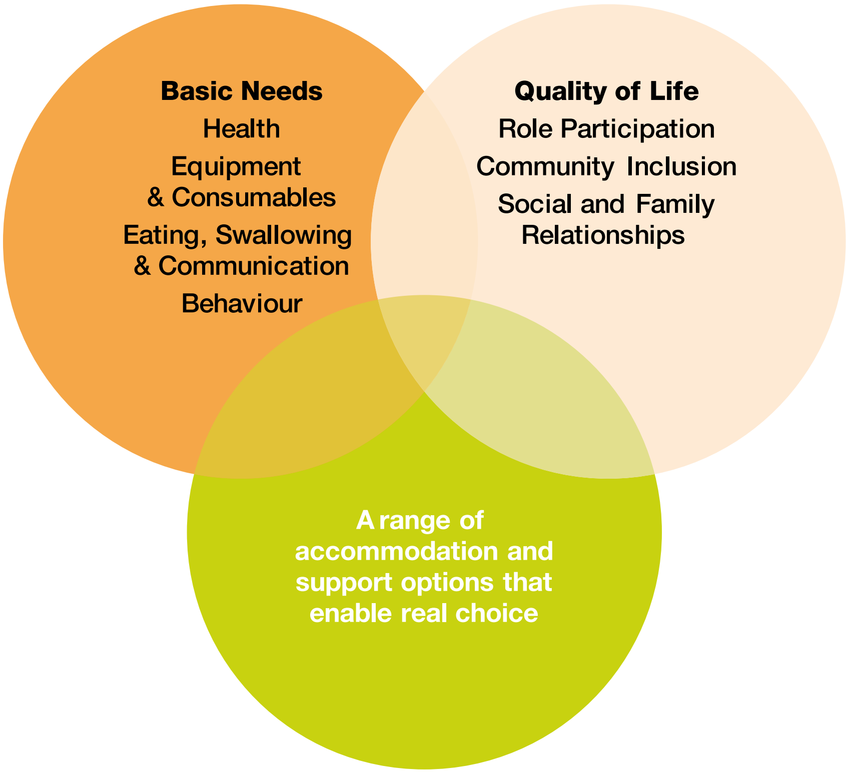


Figure 4.2 shows the three key elements to achieve successful accommodation and support options for people with complex care needs. These elements are:

- 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 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

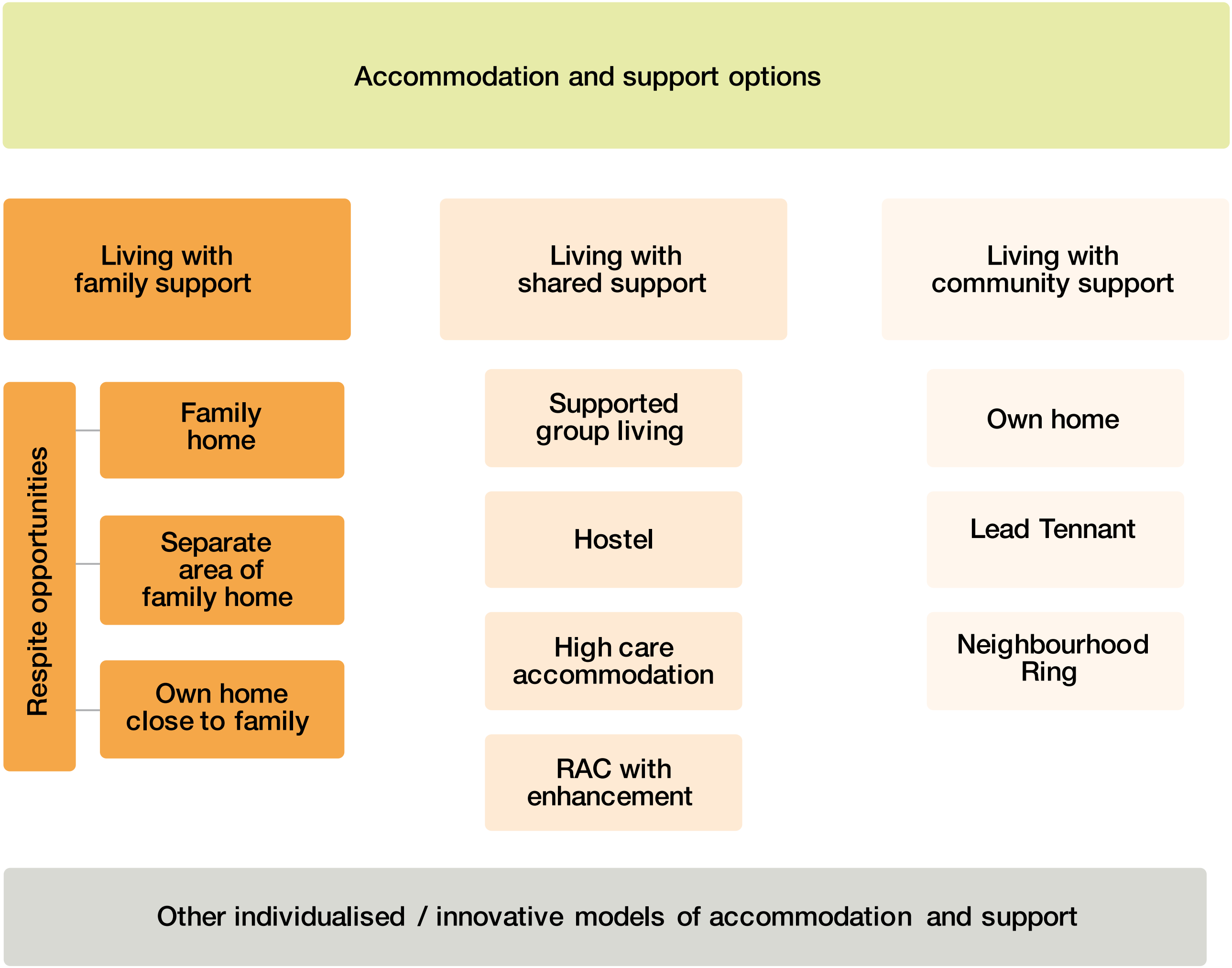
Very High Care Needs **Group**	***High Care Needs*** **Group**	***Moderate Care Needs*** **Group**
24-hour care and support, 7 days per week: • Minimum of 1:1 support for almost all daily living tasks, with additional 2:1 support for specific tasks • Overnight support of 1 to 2 people awake and available	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 report, 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 in an outreach model from a community organisation 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 of experts with a 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**
- **44% 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 outreach teams in specified regions 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 option

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 to develop 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 input provided by a community-based team 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 support 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,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 fees, 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 (e.g. Bouverie Family Counselling Centre) 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 specialist services 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 by providing ongoing support and training and increasing their remuneration based on key performance indicators

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 relevant 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 implementing those aspects of systematic care that are understood 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

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Planners and Agencies Involved in Data Collection

William Crisp (Annecto)

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Maria Bowman (Moreland Community Health Service)

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Kylie Morgan (Multiple Sclerosis Society Victoria)

Janet Francis (Multiple Sclerosis Society Victoria)

Joanne Airey (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)

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 are 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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