The Victorian Younger People in Residential Aged Care Initiative

Evaluation of quality of life outcomes for participants

my future my choice

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List of Abbreviations

ABI	Acquired brain injury
CANS	Care and Needs Scale
CIQ	Community Integration Questionnaire
COAG	Council of Australian Governments
CSO	Community Service Organisation
DHS	Department of Human Services
FaHCSIA	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
HoNOS	Health of the Nation Outcome Scale
HoNOS-ABI	Health of the Nation Outcome Scale – Acquired Brain Injury Version
ISP	Individual Support Package
OBS	Overt Behaviour Scale
PEG	Percutaneous endoscopic gastrostomy
RAC	Residential Aged Care
RC	Roles Checklist
SCI	Spinal Cord Injury
SPSS	Statistical Package for the Social Sciences
SSA	Shared Supported Accommodation
YPIRAC	Younger People in Residential Aged Care

Executive Summary

The Victorian Younger People in Residential Aged Care (YPIRAC) Initiative

In February 2006 the Council of Australian Governments (COAG) agreed that the Australian Government, states and territories would, from July 2006, work together to reduce the number of younger people with disabilities living in residential aged care (RAC). Governments jointly established and funded a five-year YPIRAC program, providing $244 million, with the initial priority being people aged less than 50 years. The $60.4 million Victorian initiative, called *my future my choice*, aimed to provide better living options for young people in, or at risk of entry to, RAC.

At the commencement of the Victorian YPIRAC initiative in 2006 there were 221 people under 50 years living in RAC in Victoria (Australian Institute of Health and Welfare, 2010). The three main objectives of the initiative were to provide alternative accommodation and support options; enhance disability supports for those people who remain living in RAC; and divert future admissions of younger people with a disability who are at risk of admission to RAC.

In Victoria, between July 2010 and June 2011 there were 284 Victorian YPIRAC service users. In 2010-11 participants in the Victorian YPIRAC initiative received the following services:

RAC Exit Group: 58 people who had previously lived in RAC received support to live in an alternative accommodation option. Most of these people were supported to move to one of the 22 new disability Shared Supported Accommodation (SSA) services developed across Victoria for 104 people.

Diversion Group: 57 people received support to prevent them from entering RAC and reside instead in either their family home or an alternative accommodation setting.

Enhancement Group: 72 people living in RAC received additional supports through an individual support package (ISP). These ISPs included recurrent funding (mean $10,000) for community access, therapy, transport, recreation and leisure.

Equipment: 114 of the 2010-2011 YPIRAC service users received much-needed adaptive equipment such as wheelchairs, supported seating and communication devices.

In June 2011 there were 133 people under 50 living in RAC in Victoria. The Victorian YPIRAC initiative has achieved a net reduction of 88 people (40%) since June 2006.

CHAPTER 1: INTRODUCTION

Literature Review

The Victorian YPIRAC Initiative

This evaluation of quality of life outcomes for Victorian YPIRAC participants demonstrated improvements in quality of life for the majority of service users as well as their family members. This evaluation involved interviews with 68 people with disabilities who had received YPIRAC services. It included 34 people who moved, 11 people who were diverted and 28 people who received enhancements. Some people were interviewed when they were in RAC receiving enhancements and again after they had moved.

CHAPTER 2: METHODOLOGY

Quality of Life Outcomes

For the RAC Exit Group, the initiative has demonstrated that not only can people with high disability support needs be successfully supported to live in community settings, but that also their lives are enriched when placed in more normalised, age-appropriate environments with person-centred supports. The RAC Exit Group had more frequent community access and was provided with more opportunities to make everyday choices. There was also an increase in its frequency of social contact. Group members spent fewer hours in bed, and went outside more often. A more home-like environment and additional supports enabled some people who moved to demonstrate their potential for increasing their independence in a range of personal and domestic tasks.

The Diversion Group was typically earlier post-injury or diagnosis than those people in the RAC Exit Group and Enhancement Group. Thus, many of these people had retained social and community links and held expectations of a return to age-appropriate life participation. In addition, to date they had avoided developing the range of secondary health conditions experienced by some people living with profound disability for longer periods of time. The Diversion Group was more likely to return to live in the family home, having the opportunity to harness informal supports and resume existing or modified life roles that younger people who had been living in RAC for many years did not.

CHAPTER 3: RESULTS — ALL PARTICIPANTS

The supports and equipment received by the Enhancement Group made a valuable difference to their daily lives through the receipt of an item of disability equipment to enhance comfort, communication or independence, or via the provision of individual support for weekly outings to engage in a community-based leisure activity. The provision of enhancements enabled people to participate in community-based leisure activities and increased their opportunities to make everyday choices. These enhancements, particularly the one-to-one support of a disability support worker, also provided reassurance to the families of young people living in RAC that there were other people visiting their family member on a regular basis and monitoring their health and well-being.

In the context of the range of positive findings from the quality of life evaluation, it is important to note that the improvement in quality of life came from a very low base where many participants in aged care led lives impoverished in the extreme. Prior to the receipt of supports through the initiative, participants did not have the opportunity to make the everyday choices that most of us take for granted. They were effectively excluded from community life. They also had limited access to adaptive equipment. One man spent two years without a communication device which, once supplied through an enhancement package, now enables him to express his thoughts and needs. Others were unable to sit out of bed comfortably because prior to the initiative they did not have a suitable wheelchair with customised seating. Although the lives of people involved in the Victorian YPIRAC initiative have improved, many of them are not yet leading rich, fulfilling and meaningful lives. More needs to be done to build on the initial gains made and support the YPIRAC target group to participate in valued life roles and engage in their local community.

This evaluation found that community inclusion for people with severe disabilities did not happen spontaneously when people moved from RAC to shared supported accommodation. Once people had settled into their new accommodation, this target group required assistance to reintegrate more fully into community life, increase their independence in daily tasks and rebuild valued life role participation that offered social connectedness. Supporting people with high care and complex needs to become part of their local community requires individualised support and skilled workers and takes time and tenacity.

CHAPTER 4: RESULTS — RAC EXIT GROUP

Characteristics
Participation
Choice
Quality of Life
Family Support
Shared Supported Accommodation living – the Advantages
Shared Supported Accommodation living – the Challenges

CHAPTER 5: RESULTS — DIVERSION GROUP

Characteristics
Participation
Choice
Quality of Life
Family Support
Being as independent as I can
Remaining in my community
It has made a huge difference

CHAPTER 6: RESULTS — ENHANCEMENT GROUP

Characteristics
Participation
Choice
Quality of Life
Family Support
I can go places
They’re all looking out for him as well
More opportunities and choices

Critical Success Factors

The key critical success factors that promoted improved quality of life outcomes for the RAC Exit Group included staff ratios, attitudes and training and the small scale and physical design of the shared supported accommodation services developed.

The critical success factors that promoted improved quality of life outcomes for people who received diversion packages related to having an accessible home environment, support that fostered independence and returning to live in their previous home and familiar community.

This evaluation identified three critical success factors that promoted improved quality of life outcomes for people who received enhancements: individualised and flexible funding, consistent disability support workers and ongoing monitoring of enhancement package implementation.

Recommendations

This evaluation provides clear direction to inform the Department of Human Services (DHS) regarding future decision making and service responses for the target population of the Victorian YIPRAC initiative. These recommendations are also highly relevant to the implementation of a proposed National Disability Insurance Scheme.

There are eight key recommendations stemming from this evaluation. The final chapter outlines strategies for the implementation of each recommendation.

1. Disability services, health and aged care services to continue to collaborate to develop the services and systemic change required to create pathways back to community living and prevent new admissions of young people to RAC.
2. Increase the range and number of alternatives to young people with high and complex care needs living in or at risk of admission to RAC.
3. Proactive intervention to reduce the lifetime care costs of younger people with complex care needs by providing the services required to reduce secondary health conditions and maximise independence.

4. Provide young people living in RAC with timely access to skilled prescription, training and funding for customised equipment and its maintenance.

5. Provide dedicated resources and skilled, flexible support to maximise the autonomy and home and community integration of people with high care and complex needs.

6. Develop a disability workforce that has the scale and capacity required to support people with high care and complex needs to live meaningful lives in the community.

7. Engage and sustain informal care and support though the provision of timely information and support services that work in partnership with families.

8. Provide support and regularly review the specific needs and preferences of people who remain living in RAC.

CHAPTER 9: RECOMMENDATIONS

Prevent new admissions of young people to aged care

Increase the range and number of alternatives to RAC

Proactive intervention to reduce the lifetime care costs of young people with complex care needs

Provide timely access to assistive technology and customised equipment

Maximise autonomy and home and community integration

Develop disability workforce capacity

Promote engagement and inclusion of informal support and relationships

Support People who remain living in RAC.

The COAG agreement regarding the YPIRAC initiative finished in June 2011 and the packages and accommodation places funded through this agreement are now fully utilised. Twenty-two new supported accommodation services were developed through the initiative, and all places within these services have now been allocated to individuals. So, without continued investment, a new group of young people with high support needs will again be entering RAC.

CHAPTER 10: CONCLUSION

From the implementation of the YPIRAC initiative as well as this evaluation, we now understand this group's complex support needs and preferences and are aware of the inappropriateness of RAC placement and its impact on quality of life outcomes for younger people. The Victorian YPIRAC initiative has raised awareness in the health and aged care sectors and expectations that Disability Services will provide more appropriate accommodation and support for this target group. However, the pressure remains for health services to discharge people who are medically stable and free up hospital beds. Without additional investment in services and alternative accommodation options, the main option for this group of people will once again be Residential Aged Care.

Chapter 1: Introduction

As the name suggests, Residential Aged Care (RAC) is designed to meet the needs of elderly people who are unable to live independently by providing nursing care, supervision, meals and personal care as required. There is, however, no age restriction for entry to RAC and, historically, younger people requiring high level care (often arising from injury or neurological illness) may be admitted to RAC. In this report we define younger people as those aged less than 50 years (unless stated otherwise).

Literature Review

Prior to the national Younger People in Residential Aged Care (YPIRAC) initiative, which commenced in 2006, apart from annual publication of basic demographics by the Australian Institute of Health and Welfare (AIHW), little empirical evidence was available about the specific support needs and preferences of younger people living in RAC in Australia. Although there were a range of government and non-government reports, rigorous empirical data and peer reviewed research studies regarding young people in RAC were scarce.

The following literature review starts by outlining the findings of these pre-2006 government reports and studies. Following this, a review of literature on young people in RAC published throughout the five-year national initiative will be detailed.

In Australia, prior to 2006, two postal surveys of young people in RAC had been conducted: one national survey (Moylan, Dey, & McAlpine, 1995) and one specific to people with acquired brain injury (ABI) in Queensland (Cameron, Pirozzo, & Tooth, 2001). Other reports had largely relied on qualitative data and anecdotal evidence to outline the problems and offer some potential solutions to the issue of younger people in RAC (Fyffe, McCubbery, & Honey, 2003; Strettles, Bush, Simpson, & Gillet, 2005; Stringer, 1999). Some of these reports provide a critique of specific existing projects developed as alternatives to younger people living in RAC (Cox, 2003; Gallop, 2001; Jones & Lawn, 1999a, 1999c). The following is a summary of the key findings of this literature.

In a national survey, Moylan (1995) obtained the characteristics of 1,515 people under 60 years of age living in 811 RAC facilities across Australia. The survey included three sections. The first section gathered information about the RAC service and number of residents under 60 years of age. The second part obtained non-identifying data about residents under 60 years of age. The last section obtained non-identifying individual data regarding former residents under 60 years of age who had relocated to community-based accommodation in the previous 12 months.

The Moylan study found that the most common disability types of younger people in RAC were ABI (31%), neurological disability (21%) and intellectual disability (20%). Of 76 former residents under 60 who had been relocated to community-based residential options in the previous 12 months, 47% went to their own home, 12% to hostels, 3% to other nursing homes and 38% to “other” (Moylan et al., 1995). The “other” category included people who were deceased.

The Moylan et al. (1995) study highlighted the complexities of studying younger people in RAC. This population can be difficult to locate and access for research because there are often only one or two younger people in each RAC facility and they may have difficulty responding due to their level of disability. The study method used involved a survey of the managers of RAC facilities to obtain information about young people in RAC. Given the response rate of 68%, the study method used is considered very effective. This method has been utilised in subsequent studies of this population (Australian Health Care Associates, 2007; Cameron et al., 2001; Winkler, Farnworth, & Sloan, 2006).

A survey of managers of RAC facilities in Queensland in 2000 had a 75% response rate and found that there were 97 RAC facilities providing care for 209 people under 65 (Cameron et al., 2001). The aims of this study were to identify the number of people under 65 residing in RAC in Queensland and to assess the appropriateness of this accommodation and support option for this population of younger people. Managers of RAC services were asked to identify residents with ABI under 65 years of age and to comment on various issues related to client care, support needs and barriers to meeting these needs. This study found that younger residents were in the minority. They were isolated from peers, often with limited space and privacy, and were reported to experience restricted or no access to the community, counselling or rehabilitation services. RAC managers reported that inadequate training and staffing levels, and limited resources, were significant barriers to RAC facilities being able to meet the social, cognitive and rehabilitation needs of younger people with ABI. Although other reports concluded that the placement of younger people with ABI in RAC was inappropriate (Honey, 1995; Jones & Lawn, 1999b; McNeill & McNamara, 1996; Ministerial Implementation Committee on Head Injury, 1994; Stringer, 1999), the Queensland study was the first to support this view with empirical evidence.

In one of the first Victorian reports specific to young people in RAC, Stringer (1999) concluded that RAC facilities are not appropriate for young people because they do not provide age-appropriate activities and offer few opportunities for interaction with peers. This report was based on two detailed case studies, coupled with consultation with a range of stakeholders.

In 2000, Wales and Bernhardt published a single case report that documented the physical recovery of a 24 year-old man who was initially discharged to RAC in a minimally responsive state and received rehabilitation through the Victorian-based Acquired Brain Injury Slow to Recover program (Wales & Bernhardt, 2000). After two and a half years he was discharged home. At three and a half years he was walking with a gutter frame, had good use of his right hand and, having previously been PEG fed, was starting a modified oral diet.

This article demonstrated the potential that some people with severe ABI living in RAC have for slow but significant recovery.

Reynolds (2002) investigated the difficulties of supporting younger people with high-cost care needs, who were not eligible for any financial compensation, in the community in rural and metropolitan Victoria. This project involved sending a brief questionnaire to 13 Community Care Issues Network (CCIN) agencies, a network of managers of multiple case-management community care programs. The questionnaire sought information on the nature of clients' disability and support needs, their living and support arrangements, services received and the cost of these services. Information was gathered on 135 people, the report of which also included six detailed case studies to provide further insights into possible ways to improve the delivery and funding of support to people with high care needs. Additionally, interviews with 11 organisations with an interest in working with people with high-cost care needs were conducted, as well as a workshop with eight service providers and agencies (Reynolds, 2002). This report identified the need to collaborate across government departments and consult with people with disabilities, their families and service providers. Reynolds (2002) recommended cross-program research, planning and program development for this target group across the Home and Community Care, Disability, Health and Housing areas of the Department of Human Services and between the State and Federal governments. Population and disability trends indicated that the needs and demands for support of people with high-cost care needs would continue to increase. Reynolds also suggested that a comprehensive system-wide strategy was required to develop an effective, practical and sustainable approach to supporting people with long-term high-cost care needs.

Although not published in a peer-reviewed journal, a Victorian study by Storace (2002) surveyed the differences between 35 people with ABI living in RAC and 35 people with ABI living in a home environment with at least one primary carer. Respondents ranged in age from 21 to 59 years. This study found that there were significant differences between the two groups, with the group in RAC reporting a lower quality of life, lower levels of perceived social support and lower levels of psychological well-being compared to the group living in the community (Storace, 2002).

A qualitative study conducted in South Australia in 2004 involved semi-structured interviews with four men and four women aged 40 to 57 years who were living in RAC (Smith, 2004). Participants perceived that they had no alternative to their current living situation. While six of the participants could identify some positive aspects of residing in RAC, two participants could not identify anything positive about their living arrangement. Two participants reported that lack of intimacy with a partner was also a significant issue. Key themes that emerged during these interviews included feelings of depression, limited contact with children, spouses and siblings, and limited opportunities for recreation.

The inappropriate placement of young people living in RAC is not unique to Australia. Several studies conducted in the United States of America describe the characteristics of various diagnostic groups of people living in RAC, including acquired brain injury (ABI) (Buchanan, Wang, & Huang, 2003), Multiple Sclerosis (MS) (Buchanan, Martin, Wang, & Hyunsu, 2004) and Spinal Cord Injury (SCI) (De Vivo, 1999; Putzke & Richards, 2001). Buchanan et al. (2003) found that people living in RAC with ABI in the United States were overwhelmingly male and averaged 53 years of age at admission, with approximately 50% (6,034 people) aged 50 years or younger. This study found that providing care for residents with ABI presented major challenges for staff in RAC. Staff who usually provide care to elderly residents may not have the expertise required to meet the needs of younger residents with ABI who have severe physical and cognitive disabilities.

Buchanan et al. (2004) reported that, in the United States, about one third (430 people) of longer-stay residents with MS in RAC were aged 50 years or younger at admission. Another United States study found that 4.3% of people with a spinal cord injury were discharged to a nursing home (De Vivo, 1999). A study by Putzke et al. (2001) compared the quality of life of individuals with SCI living in a nursing home with that of those living in the community. The average age of the nursing home cohort was 46.6 (SD ± 16.1) years. Quality of life was measured using the Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992) and the Satisfaction With Life Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1985). This study found that despite matching numerous variables for these two groups, the individuals with SCI residing in nursing homes demonstrated significantly lower quality of life across multiple domains compared to their counterparts dwelling in the community.

Another United States study, conducted by Heller, Miller and Factor (1998), examined whether the characteristics of the RAC environment and community-based residential settings were associated with adaptive behaviour and the health and community integration of adults with intellectual disabilities living in those two settings. This study included 50 people who had moved to community-based facilities and 199 people who remained in RAC. They found that, compared to residents living in RAC, people residing in community-based settings had better health (measured by Multi-Level Assessment Instrument (Lawton, Moss, Fulcomer, & Kleban, 1982)), greater levels of community integration (measured by the Community Integration Scale (Heller, Factor, & Hahn, 1999)) and greater adaptive behaviour (measured by the Inventory for Client and Ageing Planning (Bruininks, Hill, Weatherman, & Woodcock, 1986)).

LIVING IN THE COMMUNITY

Compared to residents living in RAC, people residing in community-based settings had better health, greater levels of community integration and greater adaptive behaviour.

A telephone survey of 75 RAC facilities in Greater Glasgow, Scotland, described the characteristics, level of disability and services received by 92 people with ABI under 65 years of age (McMillan & Laurie, 2004). McMillan & Laurie found that 35% of younger people with ABI in RAC exhibited challenging behaviour defined as “behaviour which staff found difficult to manage and adversely affected the comfort of other residents” (p. 135). Nine of these residents were described as physically violent. Most (94%) of this group had received behavioural intervention since admission, with some people prescribed medication (56%) and only 6% receiving behaviour modification supervised by a clinical psychologist. For 86 of the younger RAC residents with ABI, siblings visited most frequently (42%), followed by parents (28%), other relatives or friends (19%) and spouses (12%). Visits tended to be more frequent if residents were more severely disabled. Daily or weekly visits were common (66%) and 15% of younger residents had visits less than monthly or never.

McMillan and Laurie’s study (2004) raised concerns that medication prescribed during an acute hospital stay was not reconsidered after discharge to RAC. For example, they found 42% of younger people with ABI were prescribed anti-convulsant medication without a diagnosis of epilepsy. They also found a high incidence of psychotropic drugs prescribed without a clear rationale documented in the RAC facility records. Given the potential of people with ABI to recover slowly and the fact that their life expectancy is similar to the general population (Baguley, Slewa-Younan, Lazarus, & Green, 2000; Brown et al., 2004; Harrison-Felix, Whiteneck, DeVivo, Hammond, & Jha, 2004; Ratcliff, Colantonio, Escobar, Chase, & Vernich, 2005), the authors advocated routine medical reviews and the provision of rehabilitation. They argued that investment in rehabilitation had the potential to significantly reduce the lifetime care costs of young people residing in RAC and concluded more research was required to examine the needs of young people with ABI living in RAC. Although previous reports and articles had made similar statements, this study provided significant empirical evidence to support the assumption that RAC placement is inappropriate for some younger people.

In Australia, many reports by non-government organisations have advocated for the movement of young people from RAC to community accommodation, based on anecdotal evidence (BIAQ, 2003; Connellan, 2001; Fyffe et al., 2003; Macneill & McNamara, 1996; O'Reilly & Pryor, 2002; Smith, 2004; Stringer, 1999; Young People in Nursing Homes, 2002). However, at the commencement of the five-year Younger People in Residential Aged Care initiative (Australian Government Department of Families Housing Community Services and Indigenous Affairs, 2010b) in 2006, there was a lack of rigorous research that detailed the specific characteristics, participation and support needs of this target group in Australia. There was also limited research about the experience of younger people in RAC. This gap in research knowledge was a barrier to the development of evidence-based interventions to optimise the social inclusion of this target group.

Annually, the Australian Institute of Health and Welfare provides data about young people in RAC including age, location and length of stay (Australian Institute of Health and Welfare, 2005, 2006, 2008). Although limited, this data indicates the scope of the issue of young people in RAC and tracks overall trends on a national and state/territory level. From this data we know that the majority of people under 50 in RAC are aged between 40 and 49 years and that, prior to the five-year national YPIRAC initiative, there were 1,007 people aged under 50 living in RAC in Australia in June 2006 (Australian Institute of Health and Welfare, 2011b).

In 2005, two significant reports focusing on the issue of young people in RAC were released. One presented the findings of a mixed methods study in New South Wales (Strettles et al., 2005) and the other was released by DHS in Victoria (Department of Human Services, 2005). Strettles et al. (2005) reviewed 178 first-time admissions to the Brain Injury Rehabilitation Unit at Liverpool, Australia. They found that 5.6% of people admitted to the unit were discharged to RAC. This study involved interviews regarding the outcomes for 39 people with ABI with complex high care needs. Nine participants had been discharged to RAC and 30 discharged to the community, primarily to the family home. Semi-structured interviews were conducted with the person with ABI (if cognitively and physically able), a relative and staff members associated with original discharge, as well as those involved in the individual's current management (Strettles et al., 2005).

None of the participants in the RAC group thought that living with older residents met their social needs. However, some people with disabilities in the home discharge group also reported social isolation from peers and an over-reliance on key family members for social relationships. Families within both groups reported that having a family member with an ABI impacted on family life in a range of ways, including the impact of the specific injury sequelae; loss of privacy; changed roles; impact on health and well-being; financial impact and the burden of providing support (Strettles et al., 2005).

Strettles et al. (2005) identified four systemic barriers to the community participation of people with ABI and complex care needs living in RAC. Firstly, people in this target group were generally not eligible for community-based services and programs because they resided in aged care services. Secondly, they did not have the equipment and resources for modifications to access the community or visit family. Thirdly, they did not have access to long-term rehabilitation services. Finally, residents of aged care were limited in the number of nights they could spend away from the RAC facility (e.g. in the family home) each year because of legislation (Strettles et al., 2005).

Although technically eligible for a range of services, people living at home in the Strettles et al. (2005) study still had great difficulty accessing sufficient levels and types of services and transport. Themes common to both groups included feelings of distress associated with not being in control, not living with people the person with disability liked or not being able to choose who they lived with, and not doing what they wanted (Strettles et al., 2005). Some families from the RAC group felt a sense of security because the RAC facility was able to provide care for their relative into the future (Strettles et al., 2005).

This study found that the core factor that determined an individual's discharge destination was the willingness of the family to undertake the role of providing the individual's care and support. Strettles et al. (2005) concluded that the inappropriate placement of younger people with complex high-support needs after ABI into aged care services is unsatisfactory to all parties involved. They found that people were admitted to RAC because of a lack of any viable alternative. This finding supported a prior conclusion drawn by O'Reilly & Pryor (2002) that, when overwhelmed by the possibility of taking their family member home, some people saw RAC as their only option (O'Reilly & Pryor, 2002).

In 2003 and 2004, the Victorian State Government demonstrated increasing commitment to address the needs of young people in RAC by initiating two projects specifically looking at the needs of younger people in Victoria's Residential Aged Care facilities. The subsequent reports were authored by Fyffe et al. (2003) and Department of Human Services (2005).

The DHS (2005) report was titled "Creating New Opportunities: Responding to the need of younger people in Victoria's residential aged care services" and was based on a retrospective analysis of data made available to the Victorian Government by the AIHW and Department of Human Services (Department of Human Services, 2005). This report stated that, although there was a relatively stable number (mean 219, SD ± 4.5) of people under 50 years living in RAC between 2001 and 2005 in Victoria, there were 70 to 80 new admissions each year. Between 38 and 54 people under 50 were discharged from RAC each year. Reasons for permanent discharges included death, returning to live at home or with family, admission to hospital or transfer to alternative accommodation. Between July 1999 and June 2005, 150 people under 50 living in RAC died, with an average of 21.4 deaths per year. During the same time, a further 101 people had "other reasons" for permanent discharge, including discharge to an acute hospital. It is probable that death was the outcome of some of these other permanent discharges. The majority of deaths occurred within two years of admission to RAC services (Department of Human Services, 2005).

The Creating New Opportunities report (Department of Human Services, 2005) demonstrated that younger people living in RAC are not a static population. The specific AIHW data and the costs of alternative accommodation presented in the 2005 report were not previously available to the public. The review of relevant services, costs and challenges to service delivery and developments for young people in RAC in the 2005 report provided a timely evidence base for the national YPIRAC program (Australian Government Department of Families Housing Community Services and Indigenous Affairs, 2010b).

SOCIAL ISOLATION

Early reports identified social isolation from peers and lack of appropriate leisure activities as significant issues for younger people living in RAC.

In 2006, Winkler et al. (2006) conducted a survey to obtain data about the characteristics and participation of young people in RAC in Victoria. This survey described the characteristics of 330 people under 60 years with high clinical needs residing in RAC and met the need identified earlier (Fyffe et al., 2003; O'Reilly & Pryor, 2002) for reliable data about the characteristics of young people in RAC. The mean length of stay in RAC for participants in Winkler's study was nearly four years with one person residing in an aged care facility for 23 years. Acquired brain injury was the most common disability type (37%): others included Multiple Sclerosis (17%); intellectual disability (15%); and Huntington's disease (7%). These figures are broadly consistent with the proportion of disability types reported elsewhere (Moylan et al., 1995; Australian Health Care Associates, 2007). Thirty-eight per cent of the sample had more than one disability. The five most common complex care needs identified were: managing challenging behaviour (63%); pressure sore prevention/management (52%); epilepsy management (20%); percutaneous endoscopic gastrostomy (PEG) tube feeding (18%); catheter care (16%); and diabetes management (13%). Consistent with previous studies (Australian Health Care Associates, 2007; Moylan et al., 1995), Winkler et al. (2006) found that young people in RAC in Victoria were a heterogeneous group.

Early reports identified social isolation from peers (O'Reilly & Pryor, 2002; Senate Community Affairs References Committee, 2005; Stringer, 1999) and lack of appropriate leisure activities (Cameron et al., 2001; Senate Community Affairs References Committee, 2005; Stringer, 1999) as significant issues for younger people living in RAC. One international study had previously documented the social isolation experienced by this group (McMillan & Laurie, 2004). It reported the frequency of visitors to young people in RAC and found that 15% of younger RAC residents received a visitor less than monthly or never. Winkler et al. (2006), and other studies by Winkler and colleagues, have qualified the relationships of visitors (i.e. friend or relative) (Winkler, Farnworth et al., 2006; Winkler, Farnworth, Sloan, Brown, & Callaway, 2010; Winkler, Sloan, & Callaway, 2007b, 2010). In the first study to quantify peer isolation of younger people living in RAC, Winkler et al. (2006) reported that 44% of this group received a visit from a friend less often than once per year.

In addition to quantifying peer isolation, Winkler et al. (2006) offered the first study to quantify other participation restrictions experienced by young people in RAC, such as frequency of participation in recreation activities, frequency of going outside and frequency of participating in community-based activities such as shopping, leisure or visiting friends and family. It was reported that 34% of the sample of 330 people living in RAC almost never participated in any community-based activities such as shopping, leisure or visiting friends and family (Winkler et al., 2006).

The Victorian YPIRAC Initiative

In February 2006, the Council of Australian Governments (COAG) agreed that the Australian Government, states and territories would, from July 2006, work together to reduce the number of younger people with disabilities living in RAC. Governments jointly established and funded a five-year YPIRAC program, providing $244 million, with the initial priority being people aged less than 50 years. The Victorian initiative, called *my future my choice*, aimed to provide better living options for young people in, or at risk of entry to, RAC.

At the commencement of Victorian YPIRAC in 2006 there were 221 people under 50 years living in RAC in Victoria (Australian Institute of Health and Welfare, 2010). The three main objectives of the initiative were to provide alternative accommodation and support options, enhance disability supports for those people who remain living in RAC and minimise subsequent admissions to RAC for younger people with a disability.

Planning and Assessment Process

In 2006, the Summer Foundation was appointed by the Victorian Government Department of Human Services to develop a planning and assessment framework (Winkler et al., 2007b) to support the implementation of the Victorian YPIRAC initiative. Eight community service organisations (CSOs) were appointed by DHS to complete the assessment and planning process with consenting younger people with disabilities living in RAC in Victoria who were deemed eligible for the initiative. Following the development of the planning and assessment framework, the Summer Foundation trained planners from the eight CSOs on its use and supported them during the data-gathering phase. The Summer Foundation was also responsible for aggregating all of the group data obtained from the assessments in order to provide an evidence base for future service planning and development to DHS.

The individualised planning and assessment process had three key objectives:

1. Assessment of current situation: Planners gathered very detailed information about the issues faced by each individual including their care and support needs.

2. Individualised planning for the future: Based on the discussions with the individual and their support network, planners assisted them to develop a plan for the future outlining aspirations, goals, preferred options and strategies to achieve these. It also included some immediate actions towards achieving these goals.

3. Inform new service development: The planner collected data on each individual that could be aggregated to provide direction for future service planning and development on a regional and statewide basis.

In 2007, the Summer Foundation published a report that summarised the characteristics, support needs and preferences of the first 105 people involved in the assessment and planning process (Winkler et al., 2007b). This data further quantified the impoverished lives experienced by this group (13% seldom or never went outside), as well as demonstrating their reduced community access and inclusion (23% seldom or never travelled into the community, 47% seldom or never went shopping, and 45% seldom or never participated in community-based leisure activities). This data provided a baseline prior to the implementation of the YPIRAC initiative in Victoria. Some of this data has been used as baseline data for comparison to the results of the current evaluation of the five-year Victorian YPIRAC initiative.

Victorian YPIRAC Implementation

In Victoria, there were 284 YPIRAC service users between 2010 and 2011. The participants were categorised in the following groups:

RAC Exit Group: People who have moved, or are going to move, from RAC to shared supported accommodation services.

Diversion Group: People who have received supports through an individual support package to be diverted from entering RAC to reside instead in their family home or an alternative accommodation setting.

Enhancement Group: People who received additional supports through an individual support package (ISP) whilst remaining in RAC.

RAC Exits

Of the 136 people in RAC, 69 people (51%) expressed an interest in exploring alternative living options to RAC. In 2010-11, 58 people who had lived in RAC were assisted to live in an alternative accommodation option. In June 2011, most (56 people) had moved to shared supported accommodation, with one person moving to their own home with supports and another living in private accommodation.

Through the initiative, a total of 22 new disability Shared Supported Accommodation (SSA) services for 104 people were developed across a range of regions and sites in Victoria. With most of these services operational, the recurrent cost of these services is estimated to be $15 million per annum statewide.

Diversions

In 2010-11, 57 people at risk of admission to RAC received funding to be diverted from such placement through the Victorian YPIRAC initiative. This included people diverted from acute hospitals, living at home with informal family support, and from rehabilitation units. In June 2011, 27 people who had been diverted from RAC were living in a private home, 23 people were funded to live in shared supported accommodation, and the remaining were funded to live in supported residential services or hospital. Note that none had reverted back to RAC.

People diverted from RAC have had a range of disability types including ABI, degenerative neurological conditions, physical disabilities and spinal cord injuries.

Enhancements

In 2010-11, 72 young people were living in RAC and receiving enhancement packages aimed at improving their quality of life. These packages funded services such as therapy or supports to access the community or to undertake recreation and leisure pursuits. The average amount of funding received per individual for a recurrent enhancement package amount was $10,000 per annum.

Equipment

One hundred and fourteen (40%) of the 2010-11 YPIRAC service users received non-recurrent funding for assistive products and technology. Equipment funded included wheelchairs and accessories, walking frames, slide sheets, hoists cushions, commodes, beds, mattresses, overlays, recliner lounge chairs, over-bed tables, portable ramps, bariatric equipment, slings, communication devices, computers, call buzzers and adaptive switches. The Victorian YPIRAC initiative funded over $1.4 million for the supply of assistive technology and equipment, including associated administration, repairs and maintenance.

Continuous Care Pilot Project

Multiple Sclerosis Australia also received DHS funding to implement a Continuous Care pilot project (Multiple Sclerosis Australia & Bethlehem, 2009). This project aimed to identify better options to support younger people with neurological conditions to avoid their admission into RAC. Multiple Sclerosis Australia undertook an evaluation of this project, the report of which is available (Multiple Sclerosis Australia & Bethlehem, 2009).

Mid-term Evaluations of the National Initiative

In 2010, the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaCHSIA) released a mid-term evaluation of the national YPIRAC initiative. This evaluation was conducted by Urbis (Ryan, Lopata, & Yeomans, 2010) and found that mid-way through the five-year program, the national YPIRAC initiative had a positive impact on a large number of young people in RAC. The Urbis report (Ryan et al., 2010) was based on in-depth telephone interviews with the Program Managers from respective Commonwealth, state and territory governments implementing the COAG initiative.

Winkler and colleagues also completed a mid-term evaluation of the national YPIRAC initiative (Winkler, Farnworth, Sloan, & Brown, 2011). This evaluation involved interviews with 36 health professionals, disability workers and advocacy organisations in addition to public servants. A range of authors (Fyffe et al., 2003; Jones & Lawn, 1999b; Ryan et al., 2010; Stringer, 1999) had previously identified that a significant barrier to the development of services for this group was the lack of collaboration between the housing, health and disability sectors and the need to develop partnerships. Winkler et al. (2011) concluded that, without an increased focus on systemic change to prevent new admissions, the national YPIRAC program would not result in a long-term reduction in the number of young people in RAC. Ryan et al. (2010) reported that, while the program was likely to meet its targets, many younger people living in RAC would continue to have significant needs that could not be met within the current funding allocations. Similarly, Winkler et al. (2011) concluded that, without sustained investment in developing alternative accommodation options and systemic change to prevent RAC admissions, the accommodation options being developed during the five-year initiative would be full to capacity and approximately 200 people under 50 would likely be admitted to RAC each year in Australia. The Urbis report (Ryan et al., 2010) recommended three specific areas of research related to the current YPIRAC program: quality of life outcomes, cost-benefit analysis, and likely future demand for these services.

Measuring Quality of Life

The objective of the national YPIRAC program was to provide long-term accommodation and support services “leading to an improved quality of life”. The focus of the current evaluation is quality of life outcomes. The World Health Organisation (WHO) defines quality of life as an “…individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (World Health Organisation Quality of Life Group, 1998, p. 551-552). Quality of life includes both subjective and objective indicators. Subjective measures indicate a person’s level of satisfaction with particular areas of their life. Objective measures explore material circumstances and environment. While both areas are important, there is poor correlation between objective and subjective measures (Abello & Muir, 2008). Objective measures cannot predict subjective responses and vice versa (Cummins, 2004).

When considering subjective quality of life outcomes for young people in RAC there are two major limitations. Firstly, most of the research group are not able to provide their individual perceptions due to cognitive and communication impairments they experience. Many (48%) have difficulty communicating their everyday needs let alone being able to convey their perception of their position in life in relation to their goals, expectations, standards and concerns (Winkler, Sloan, & Callaway, 2007a). Secondly, it is reported that subjective quality of life is not a measure that is highly sensitive to change. That is, subjective ratings of quality of life are relatively static and are not often reflective of changes to one's circumstances (Abello & Muir, 2008; Cummins, 2004). The self-assessed subjective quality of life is durable and largely fixed over time despite significant life changes.

While it is vital to obtain the perceptions of young people in RAC who can inform us about their quality of life, the reliance solely on standardised, subjective quality of life instruments would result in too much missing data. An individual's quality of life is influenced by a number of areas or domains. These include material/financial well-being, health, personal relationships and social interaction, feelings of safety, and socio/economic factors including social/leisure, workforce and educational participation (Abello & Muir, 2008; Cummins, 1997; World Health Organisation Quality of Life Group, 1998). The opportunities to make choices and have some control over aspects of life are considered to be important elements in determining people's well-being and quality of life (Abello & Muir, 2008). These domains are important to people with and without disability and can be more easily measured in the young people in the RAC target group than more subjective measures of quality of life. Previous studies with young people in RAC have used a range of measures that do not specifically measure quality of life but do provide indicators of health and well-being such as frequency of social contact, community-based leisure activities and going outside, opportunities for choice and the number of health conditions (Winkler, Farnworth et al., 2006; Winkler et al., 2007b).

Victorian YPIRAC Quality of Life Evaluation

In May 2010, the Summer Foundation was appointed by the Department of Human Services to develop a framework and conduct an evaluation of quality of life outcomes for Victorian YPIRAC participants. The evaluation aimed to assess whether there has been an improvement in the quality of life of people supported through the Victorian YPIRAC initiative, and examine factors that fostered or impeded successful outcomes, in order to inform future service delivery.

In June 2010, the Summer Foundation appointed a research coordinator for the evaluation. Data was collected by the research coordinator and three other appointed researchers from the Summer Foundation from August 2010 to August 2011. This data was collected via a series of in-depth interviews with the participants, family members, guardians and service managers. Additionally, a range of customised and published measures of physical health, behaviours of concern, mental health, choice opportunities, role participation, community integration and quality of life were completed with participants or, where appropriate or necessary, their nominated next of kin. Refer to Table 2.1 for details of measures used.

Aims

The Victorian YPIRAC evaluation of quality of life outcomes for participants aimed to:

1. Develop and implement a framework for evaluation of the quality of life outcomes offered to people receiving supports under the Victorian YPIRAC initiative, utilising relevant quantitative and qualitative methods and data analysis.
2. Measure changes in the health, independence, and community inclusion of people in each of the three sub-groups (RAC Exit, Diversion and Enhancement) assisted through the Victorian YPIRAC initiative.
3. Provide comparison of the quality of life outcomes of people assisted through the initiative with the quality of life of young people with disabilities living, or previously living, in RAC without YPIRAC support.
4. Identify the differences and similarities between the three sub-groups of people assisted through the Victorian YPIRAC initiative.
5. Identify critical success factors that promote improved quality outcomes in each of the sub-groups of people who received support through the Victorian YPIRAC initiative.
6. Provide an evidence base to inform the Department of Human Services regarding future decision making and service responses for the target population of the initiative.
7. Make recommendations to improve outcomes for individuals receiving disability services into the future.
8. Provide a written report to DHS on the above findings.

Chapter 2: Methodology

Participants

Identification of Participants

People were eligible for inclusion in the evaluation if they were receiving supports funded through the Victorian YPIRAC initiative within the data collection period of August 2010 to August 2011. These participants were identified by the Department of Human Services (DHS) and were recruited initially through written invitation from DHS.

Participants in the evaluation were categorised into three sub-groups. These groups related to the type of supports the person received through the YPIRAC initiative.

RAC Exit Group: People who have moved, or are going to move, from RAC to shared supported accommodation services.

Diversion Group: People who have received supports through an individual support package (ISP) to be diverted from entering RAC to reside instead in their family home or an alternative accommodation setting.

Enhancement Group: People who have received additional supports through an individual support package (ISP) whilst remaining in RAC.

Recruitment Process

Ethics approval for this evaluation was obtained in July 2010 from the Victorian Government Department of Health Human Research Ethics Committee. In August 2010, DHS commenced sending letters to people in Victoria who were receiving current YPIRAC supports inviting them to take part in the evaluation. Letters were sent to 187 eligible participants. Enclosed with the DHS invitation was a letter from the Summer Foundation introducing the researchers and providing each participant with a permission slip and stamped addressed envelope to respond to the invitation. People interested in taking part in the evaluation sent their contact details to the Summer Foundation using this permission slip. Prior to contacting the individual, the researchers contacted DHS to confirm that the individual was in receipt of services funded through the YPIRAC initiative.

Letters were also sent by DHS to 64 residential aged care managers and 16 shared supported accommodation service managers (CSOs and private providers) who were currently providing accommodation and support to YPIRAC participants. This aimed to raise the services' awareness that the evaluation was taking place so they could support potential participants to respond to the invitation being sent to each individual. Additional letters were sent to new YPIRAC recipients up until 31 July 2011. The final date for data collection was 31 August 2011.

Communication Strategy

Many YPIRAC participants had severe communication or cognitive impairments or were unable to make an informed choice about participating in the evaluation without support from another person. Therefore, in an attempt to engage disability and aged care sector services to maximise the participation rate in the evaluation, a comprehensive communication strategy was developed by the Summer Foundation and implemented. This strategy used relevant websites, professional emailing list servers, direct emails to allied health professionals and case managers, and newsletters. In addition, one of the project directors or the researcher coordinator from the Summer Foundation also attended provider and disability network meetings.

The aims of the communication strategy were to:

- ensure all people invited to participate were given adequate information to make an informed choice regarding involvement in the evaluation
- ensure key family members and paid carers supporting potential participants were made aware of the evaluation and were provided with adequate information
- maximise the dissemination of information to the disability and aged care sector stakeholders. This aimed to ensure that as many workers as possible were provided with adequate information to support the invited person to make an informed choice regarding participation
- ensure stakeholders and participants were kept informed of the progress of the evaluation, in conjunction with the DHS project team.

Data Gathering

Once the invited participants sent their permission slip to the Summer Foundation, and their participation in the YPIRAC initiative had been confirmed by DHS, the researchers telephoned the participant and/or family member or significant other (e.g. advocate/guardian) to explain the evaluation process and make a time to conduct the interview. If the participant or family member needed more information prior to the interview, the researchers would arrange a time to discuss the evaluation further. The interviews commenced in August 2010. Interviews were conducted at a preferred location for the participant, family member or service manager. These ranged from participants' bedrooms and lounge rooms to management offices, boardrooms, local cafes and family homes. The researcher provided a copy of the participant explanatory statement and consent form, and explained the interview process in detail. Consent to participate was then obtained from the participant or their authorised representative. Data was gathered within this face-to-face meeting with the participant and, where appropriate or relevant, their family member or authorised representative. If the participant lived in RAC or SSA, the service manager was also interviewed.

The different methodological approaches for collecting and analysing the qualitative and quantitative data from participants are outlined in separate sections below.

Quantitative Data

In a semi-structured interview, the researchers asked the participant structured questions from the selected assessment tools listed in Table 2.1. Many of these questions required a yes/no or short answer.

Measures

Table 2.1 Summary of the tools used in the evaluation

Measures	
Quality of Life	
Subjective Measure	Personal Well-being Index (PWI) (Cummins & Lau, 2005)
Objective Measure	5 questions from ComQol-15 (Objective Component) (Cummins, 1997)
Community Integration	
Community Integration	Community Integration Questionnaire (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1994)
Social Inclusion	1 item from Summer Foundation Planning and Assessment Tool (Winkler et al., 2007a)
Community Activities	1 item from Summer Foundation Planning and Assessment Tool (Winkler et al., 2007a)
Frequency of Going Outside	1 item from Summer Foundation Planning and Assessment Tool (Winkler et al., 2007a)
Life Roles	Life roles checklist (part 1) (Oakley, Kielhofner, Barris, & Reichler, 1986)
Choice	
Choice	Resident Choice Scale (13 items) (Hatton et al., 2004)
Health	
Complex Care Needs	Simplified checklist of health issues section on Summer Foundation Planning and Assessment Tool
Neuropsychiatric Sequalae	Items from the Health of the Nation Outcome Scale-ABI (Fleminger et al., 2005)
Behaviours of Concern	Items from the Overt Behaviour Scale (Kelly, Todd, Simpson, Kremer, & Martin, 2006)
Movement and Mobility	1 item from Summer Foundation Planning and Assessment Tool
Other Factors	
Demographic and Background Information	Semi-structured interview
Level of Awareness	Rating by observation and reporting
Additional Services Received	Semi-structured interview
Current and Past Living Situation	Semi-structured interview
Support Needs	Care and Needs Scale (Soo et al., 2007) & semi structured interview
Families	
Impact of injury or illness on family	Family Outcome Measure (FOM) (Simpson & Winstanley, 2009)
Service provider interviews	
Changes observed as a result of move or ISP or any ongoing issues or concerns	Semi-structured interview
Number of staff providing direct support, staff turnover, additional services received	Semi-structured interview

The quality of life evaluation of the YPIRAC initiative used a selection of questions from the Summer Foundation Planning and Assessment Tool (Winkler et al., 2007a). The Summer Foundation planning and assessment tool, developed for the Victorian YPIRAC Initiative planning process, is a customised battery of measures drawing on published instruments supplemented with targeted questions and functional assessments. It aims to capture key information pertinent to individualised accommodation and support planning with people with complex needs.

Health

Younger people are often placed in RAC because there are a limited number of established community-based service models to meet high levels of health and clinical care needs (Department of Human Services, 2005). As part of the evaluation of quality of life outcomes, it was essential to identify the specific health issues experienced by the target group to inform service development.

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

Mental health

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

We only used the five items from the HoNOS-ABI that related directly to mental health. For example, items regarding physical illness or disability, living conditions and cognitive problems were not administered.

Behaviours of concern

The Overt Behaviour Scale (OBS) (Kelly et al., 2006) was used in this study to measure the range of challenging behaviours or behaviours of concern frequently observed following neurological conditions.

These behaviours include:

- Verbal aggression
- Physical aggression against objects
- Physical acts against self
- Physical aggression against other people
- Inappropriate social behaviour
- Perseveration (repetitive behaviour)
- Wandering or absconding
- Inappropriate sexual behaviour
- Lack of initiation.

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

Resident choice

One of the key limitations of institutional living is the limited opportunity to make everyday choices. The Resident Choice Scale (RCS) (Hatton et al., 2004) was designed for use with people with intellectual disabilities to assess service practices for promoting choice. This scale has 26 items and is administered by interview with a key informant. This study reports on the 11 items most relevant to younger people living in RAC.

Role participation

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

Community inclusion

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

Social integration

In addition to obtaining information from the social integration subscale of the CIQ, this evaluation also used the social integration subscale of the Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck et al., 1992). The CHART was designed to provide a simple, objective measure of the degree to which impairments and disabilities result in handicaps (participation restrictions). The social integration subscale measures the person's ability to participate in and maintain customary social relationships.

Support needs

The Care and Needs Scale (CANS) is an eight-category scale, which measures the type and extent of support needed in daily life and was developed specifically for application with people with ABI in the post-acute rehabilitation stage (Soo et al., 2007; Tate, 2004). The CANS was used in this evaluation to measure the support needs of participants.

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

Section Two of the CANS indicates the level of support needed ranging from a very high level of care and support (i.e. Level 7 – 'cannot be left alone') to very low levels (i.e. Level 1 – 'can be left alone for more than a week' or Level 0 – 'can live in the community, totally independently'). Responses within the activity checklist in Section One of the CANS are used as the basis upon which to determine, using clinical judgement, the length of time that the person can be left alone and, therefore, the level of support required.

Level of awareness

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

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

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

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

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

This distinction was made through:

- The reported observations of staff and family members
- Questions and answers (e.g. relating to knowledge of time, place and person) and if the individual was able to communicate (verbally or via assisted means)
- Behavioural indicators of awareness and orientation (e.g. wandering, agitation and social behaviours).

Quality of life

In the brief for the current evaluation, the Department of Human Services stipulated the use of two tools to capture both subjective and objective quality of life – the Personal Well-being Index (PWI) (International Well Being Group, 2006) and the ComQol-15 (Objective Component) (Cummins, 1997). These tools were recommended by the Social Policy Research Centre (Abello & Muir, 2008), who conducted a review on relevant quality of life tools for use with the YPIRAC target group and determined the Personal Well-being Index and objective component of the Comprehensive Quality of Life Scale to be relevant, appropriate and effective tools to measure these quality of life changes for young people living in residential aged care (Abello & Muir, 2008).

Objective Measure of Quality of Life

The Comprehensive Quality of Life Scale (ComQol-15) comprises both an objective and subjective measure of life quality. Details of the development of this test have been published (Cummins, 1991; Cummins, McCabe, & Romeo, 1994; Gullone & Cummins, 1999; Marriage & Cummins, 2004).

In 2001, the ComQol was abandoned by its authors due to major flaws including that the objective scale never factored into seven non-complex domains as intended and that domain importance and domain satisfaction were multiplied. The detailed rationale for this action is available in Cummins (2002). A seminal article by Trauer and Mackinnon (2001) convincingly outlined the limitations of the ComQol. However, the DHS tender brief for this evaluation stipulated the use of the ComQol.

Given the recommendations in the Social Research Policy Centre report (Abello & Muir, 2008), five questions from the ComQol were used in the Victorian YPIRAC initiative evaluation, which were relevant to quality of life outcomes for receiving supports through the initiative. These were:

- In your spare time, how often do you have nothing much to do?
- Do you watch TV, how much TV do you watch?
- Do you sleep well? How often?
- Are you safe where you life? How often do you feel safe?
- Are you ever worried or anxious during the day? How often?

Subjective measure of Quality of Life

The Personal Well-being Index and Satisfaction with Life as a Whole (International Well Being Group, 2006) was created from the ComQol (Cummins, McCabe, Romeo, & Gullone, 1994). The PWI scale contains eight items of satisfaction, each one corresponding to a quality of life domain: standard of living, health, achieving in life, relationships, safety, community-connectedness, future security, and spirituality/religion. These eight domains are theoretically embedded, as representing the first level deconstruction of the global question: How satisfied are you with your life as a whole? Data derived on the Personal Well-being Index scale may be used either at the level of individual domains, or the domain scores may be aggregated and averaged to form the Personal Well-being Index (PWI). The item Satisfaction with Life as a Whole is not a component of the PWI. Hence, it was analysed as a separate variable per the authors' guidelines (International Well Being Group, 2006). Only participants themselves could directly respond to these questions, not proxies.

Impact of injury or illness on family

To assess the impact of the injury on family, where available, a nominated next of kin of each participant completed the Family Outcome Measure (Simpson & Winstanley, 2009) with the researcher.

The Family Outcome Measure (FOM) is a self-report measure that aims to capture data on the reactions, responses and experiences of families along several dimensions following an acquired disability of a relative. It documents the current state of the family system in long-term settings. The FOM comprises 42 items, organised into seven subscales: family member coping (8 items); family cohesion (6 items); support demands (burden) (8 items); relative adjustment (5 items); adequacy of service support (5 items); family member resilience (5 items); and sustainability of family support (5 items). Each item is rated on a four-point scale with response options of Strongly Agree, Agree, Disagree, or Strongly Disagree. The FOM produces seven scores (totals for each subscale derived by adding the scores for the relevant items) – there is not a single global FOM score. For each subscale, increasing scores represent improved well-being, family cohesion, coping and support.

Quantitative Data Analysis

The data from published measures was entered into the Statistical Package for Social Sciences software package version 19 (SPSS, 2010), which was used to produce descriptive statistics to summarise the characteristics and outcomes for participants in the Victorian YPIRAC initiative evaluation.

Sub-groups of participants of the Victorian YPIRAC initiative were also compared with each other and with the group of participants summarised in the 2007 report from the assessment and planning process, all of whom were yet to receive services through the YPIRAC initiative (Winkler et al., 2007b). The categorical data that obtained information about the frequency of social contact and community participation was converted to continuous data (i.e. times per year). Group differences in continuous data were assessed with Mann-Whitney's U-Test because some of the results were not normally distributed. The Wilcoxon signed ranks test (non-parametric) was used for difference in paired samples.

Qualitative Data

Due to cognitive or communication impairments, not all eligible participants in the evaluation were able to fully participate in the semi-structured interviews. To determine whether the person was able to participate, the researchers initially made contact with the person whose name was recorded on the permission slip and discussed the level of communication skills required for a person to participate in the qualitative interview. The requirement was that the person was able to express responses that were broader than "yes" or "no".

Where the person was unable to participate, consent was obtained from the participant's authorised representative for the researcher to make contact with an alternative person, usually a family member. However, where possible, the researchers made accommodations for the person with the disability to be supported to fully or partially participate in the interviews.

Interview Process

Given the mixed methods design of the evaluation, there was a capacity for the researchers to flexibly decide whether to initially introduce the interview or published measures. In most cases, rapport was built with the participants during the interview phase; therefore this formed the initial stage of the interview, followed by the completion of the quantitative published measures. Some participants asked for interview questions to be sent in advance so they could prepare responses on their computers or communication aides.

The interviews were semi-structured and audio taped for transcription and analysis. The semi-structured format allowed the researcher to flexibly modify the interview if the participant had cognitive or communication impairments. Additional prompting was provided to support the participant to elaborate on their responses where possible. Some participants provided their answers using an augmentative communication device (e.g. a Lightwriter or computer).

Refer to Appendix 1 for the outline of the interview questions.

Reflective Journal of Researchers

Researchers used a reflective journal of field notes that were completed immediately after each interview. The journal consisted of brief notes and observations and made comment on observations regarding the environment, the interviewee's presentation or emotional state, or particular issues that may not have been made apparent through the interview transcripts. As themes emerged and were consolidated over a number of interviews, these themes were subsequently explored with new interviewees to check their relevance.

The researcher coordinator met on a monthly basis with the research team to discuss the interview and data gathering process, review emerging themes and discuss any methodological issues regarding the qualitative data gathering.

In addition, the research coordinator provided over the phone and/or face-to-face supervision to the other researchers during the data gathering phase.

Qualitative Data Analysis

Interviews were audio-taped, transcribed verbatim, and then analysed using NVivo 8 (QSR International Pty Ltd, 2008), in conjunction with field notes from the reflective journals of the researchers. This ensured triangulation and in-depth understanding of interview data gathered.

A qualitative comparative method of thematic analysis was used to analyse the qualitative data (Braun & Clarke, 2006; Corbin & Strauss, 2008). Thematic analysis was used for a number of reasons, including that it can be applied across a range of theoretical and epistemological approaches; it offers a rich and detailed account of qualitative data; and it allows a contextualist method where exploration of individual experiences is examined and understood within the context of environmental and societal impacts (Braun & Clarke, 2006). Using an inductive approach, where the themes identified are strongly linked to the data themselves (Patton, 2002) and coding of data was undertaken without trying to fit it into a pre-existing coding frame (Braun & Clarke, 2006), six phases of thematic analysis were undertaken:

1. Familiarisation with the data

The written interview transcript was read through by the researcher before coding began. Transcripts were checked for accuracy against the original audio recordings.

Interview transcripts were sorted into one of three groups: RAC Exit, Diversion or Enhancement. They were then sorted into one of three sub groups within each group: participant interview, family interview, and service provider interview.

The researcher noted down initial ideas about interesting elements of the data while reading transcripts.

2. Generating initial codes

The initial ideas documented, as well as additional emerging patterns in the data, were used to develop thematic categories using NVivo, with selections of transcribed interview data saved under each category.

Due to the vast amount of qualitative data (over 124 interviews), the data was initially sorted into the following groups:

- Experiences of living in RAC
- Decision to stay or move from RAC
- RAC exits positive experiences
- RAC exits challenging experiences
- Diversion from RAC
- Enhancements
- Victorian YPIRAC Initiative – general process.

Categories of emerging themes were then identified via analysis of data within each of these groups. Themes identified were vast to begin with so as not to narrow coding as additional interviews were read.

The entire data set was read and analysed using this method and the data extracted was collated under the themes developed.

3. Searching for themes

When new patterns and codes were developed later in the analysis, previous interviews were re-read to determine whether they contained any additional data extracts to add to a particular theme.

Once all data was coded, the researcher then began collating all the relevant coded data extracts into broader themes.

Via ongoing analysis and comparison, it became clear that some of the coding categories could be combined due to their similarity. (QSR International Pty Ltd, 2008).

4. Reviewing themes developed

Each category of data was read to determine if the data extracts were correctly themed. If in doubt, the researcher returned to the original transcript to check the content of the data extract.

Decisions needed to be made as to whether data extracts that did not fit within a theme fitted into another category or should be discarded. Some categories were discarded as they were not strongly represented across a number of interviews.

To ensure that there were clear and identifiable differences between the themes, some themes were collapsed together while others were expanded or coded on (due to the broad range of data that was collected under this theme). For example, the original themes of ‘opportunities to go places’ and ‘choices’ were collapsed into ‘freedom and choices’.

After the above process was completed, final review and refinement of the themes were required. This was to ensure that the finalised themes reflected the meanings from the data set as a whole.

5. Naming themes

To name the themes, where possible, a short, direct or paraphrased quote from a participant or family member was chosen that best represented to the reader the meaning of the theme.

6. Reporting on themes

A report on the qualitative data was developed. Where possible, themes identified were used as sub-headings containing direct quotes from participants and including a narrative about the theme.

When writing the narrative the researcher considered a range of questions, including what the theme meant; what the assumptions underpinning it were; the implications of the theme identified; the conditions likely to give rise to it; and the overall story the different themes revealed about the topic (Braun & Clarke, 2006).

A total of thirty-nine themes were identified through the qualitative data analysis and placed under nine sub-headings as outlined below:

Living in RAC – Advantages

Celebrity status

Have fun with staff

Safety and medical care

Living in RAC – Challenges

It's geared towards dying well not living well

Just existing

Institutionalised

It's all with the oldies

They don't have time for his individual needs

Making the decision to move from RAC

Taking a risk

I want him to have choices

Promise of better care

It'll be nice to be with younger people

Deciding to stay in RAC

Better the devil you know

The change is huge

Too far away

Who will they be living with?

RAC Exit and Shared Supported Accommodation Living – Advantages

Freedom and choices

Better quality of life

It has relieved the pressure on the family

It's a home of ours

I've got my independence

It's so roomy and it's got everything

He's in good hands

RAC Exit and Shared Supported Accommodation Living – Challenges

Giving up funding

Staffing concerns

It's not a home it's a facility

Missing RAC staff and routines

Resident compatibility

Diversion

Being as independent as I can

Remaining in my community

It has made a huge difference

Enhancement

I can go to places

They're looking out for him as well

More opportunities and choice

The Victorian YPIRAC Initiative Process

Starting out

The process dragged on

Lack of ongoing monitoring and flexibility of funding

Rural issues

No other offers

Project Rigor

A number of strategies were used to ensure the rigor or trustworthiness of the qualitative data gathering and the analysis undertaken (Braun & Clarke, 2006).

Reflexivity

Reflexive work is used in qualitative research to ensure that there is regular reflection on emerging themes and personal critique by the researcher to assess the influence of that person on the research process. This is completed via the development of daily schedules, logistics of the study, a methods log and/or a reflective journal. As part of this study, a field journal (including daily schedule and logistics of the study; and reflections on the researcher's thoughts, feelings, ideas and developing propositions) was kept and used to feed back emerging themes to participants throughout the study. This journal included the researcher's subjective thoughts and feelings as well as observations within, and reflections upon, the interview process and associated findings.

Member checking

Member checking involves the researcher feeding back, and exploring further, emergent themes with research participants. Emergent themes from initial data analysis were identified and fed back to individuals within this study, and underwent member checking with each research participant within the interview process.

Peer examination

Peer examination requires the researcher to gain support, advice and methodological input during the research process from someone experienced in their chosen field of research. The three project directors (Winkler, Callaway and Sloan) provided peer examination to the researchers during data gathering. In addition, the preliminary results of this study were presented to a DHS reference group at the mid-way point of the evaluation, as well the conclusion of drafting the results. The researchers also undertook informal thematic analysis and discussed preliminary study findings with co-researchers involved in data collection, as well as other colleagues who work in community practice with people with severe ABI.

Triangulation

Triangulation is the use of strategies to ensure that a study's findings are not the result of a single source (Krefting, 1991).

Triangulation of data methods: Triangulation of methodology occurred by utilising mixed qualitative and quantitative data methods in an effort to ensure the rigor of the research findings.

Triangulation of data sources: Triangulation of data sources is completed because the data may vary depending on other external or internal influences on research participants (e.g. how a participant feels from day-to-day or at different times of the day; other events which occurred during the day; the participants' willingness to discuss particular research areas). By gathering data from a number of sources, the risk of data being influenced by other aspects of the person's life is minimised. Triangulation of data sources occurred by the completion of an interview with each participant, as well as service providers and family members where possible, in addition to completion of the quantitative measures and the Personal Well-being Index, which offers a subjective measure of life satisfaction and well-being.

Theoretical triangulation: Occupational therapy, occupational science, neurology and neuropsychology, sociology, and psychology literature has been drawn upon during the research process, to broaden the scope of how the researchers understood the topic under discussion and to help ensure theoretical triangulation.

Chapter 3: Results — All Participants

Chapters 3-7 present both the quantitative and qualitative results for the evaluation. This chapter (Chapter 3) starts by providing an overview of the results of this evaluation and then summarises data for all participants. This includes some demographic data and outcome data related to community integration, quality of life and outcomes for families. The final section of Chapter 3 summarises the perspectives of people with disabilities and their families on living in RAC, making the decision to move or stay and the process of planning and receiving services.

Chapters 4-6 present the results for each of the three sub-groups: RAC Exits, Diversions and Enhancements. For each sub-group, quantitative data that summarises the demographics and outcomes for each sub-group is followed by qualitative data that provides the perspective of participants in each sub-group.

Finally, Chapter 7 outlines a range of comparisons made between the sub-groups of participants and the data collected during the assessment and planning process in 2007.

Missing data accounts for some tables displaying a smaller sample size. The percentages in the tables have been rounded so that some columns may not add up to exactly one hundred per cent.

Overview of Results

This evaluation includes data from three time points (Figure 3.1). Baseline data was available from the Victorian YPIRAC assessment and planning process in 2007 for 105 people prior to them receiving services from the YPIRAC initiative (Winkler et al. 2007). In Figure 3.1, this is referred to as 2007 baseline data. We also interviewed young people living in RAC, most of whom were receiving enhancements services. Some of the people living in RAC subsequently moved out so we interviewed them again to examine the outcomes of the move. We also interviewed some people who had moved out prior to the evaluation commencing. Finally we interviewed 11 people in the Diversion Group who were at risk of admission to RAC and were diverted.

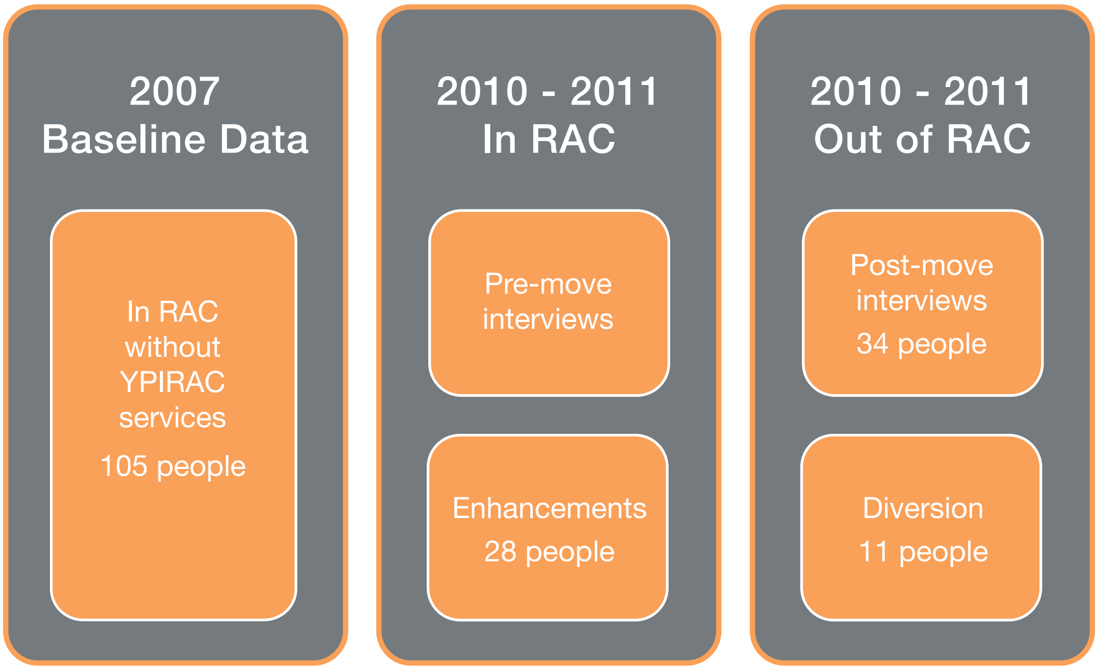


Figure 3.1 The data in this evaluation was obtained at three time points – 2007 baseline data, in RAC and out of RAC.

Differences between groups

The Enhancement Group contained more people with neurological conditions than either of the other groups. Neurological conditions included Multiple Sclerosis and Huntington's disease. There were more people in the RAC Exit Group with an acquired brain injury than in either the Enhancement or Diversion groups.

The RAC Exit Group was significantly younger (range 21-53 years, mean 40 SD ±10.13) than the Enhancement Group. The RAC Exit Group was also younger than the total population who received services through the Victorian YPIRAC initiative.

The Enhancement Group had an overall lower level of awareness than the other groups. The Diversion Group had a higher level of awareness than both the RAC Exit Group and the Enhancement Group.

A series of group comparisons was conducted. Overall this series of group comparisons found that the provision of enhancement services improves the quality of life of young people in RAC. The provision of enhancements enabled people to participate in community-based leisure activities and some increase in their opportunities to make everyday choices.

The RAC Exit Group had better outcomes than the Enhancement Group, including more frequent community access and being provided with more opportunities for making everyday choices. This group had positive outcomes on a range of outcome measures. There was an increase in their frequency of social contact, they spent fewer hours in bed, went outside more often and were able to be left for longer periods of time after they moved out of RAC. The RAC Exit Group was also more involved in meal preparation and household shopping and participated in more life roles after they moved.

No Enhancements v. Enhancements in RAC

The 28 people in the Enhancement Group were compared with a group of people living in RAC without enhancement services (2007 Baseline data) on 41 outcome variables related to mobility, independence, health, behaviours of concern, community integration, social contact and choice. Overall there was little difference between these two groups on these outcome measures except for a few items related to community access and choice. The group who received enhancements participated more frequently in community-based leisure activities (e.g. movies, sport and restaurants). There was also a significant increase in the opportunities for making everyday choices in three out of the 11 areas examined. These three specific areas were the content and timing of their evening meal and the furnishings of their room. Young people living in RAC receiving enhancements still had very limited opportunity to make the everyday choices that most of us take for granted. Many people had no choice in the timing (79%) or content (68%) of their evening meal or the amount of time they spent in the bath or shower (71%).

No Enhancements v. RAC Exit Group

The 34 people in the RAC Exit Group were also compared with the group of people living in RAC without enhancement services (2007 Baseline data) on the same 41 outcome variables related to mobility, independence, health, behaviours of concern, community integration, social contact and choice. There were significant differences between these two groups on a range of variables related to social contact, community integration and choice. The RAC Exit Group went outside more often, travelled into the community more often and participated in shopping and community-based leisure more often than the 2007 Baseline Data Group. The RAC Exit Group also visited relatives more often and was more involved in household shopping and meal preparation.

The RAC Exit Group had more opportunity for everyday choices in 10 out of the 11 areas examined. The only area of life where there was no increased opportunity to make a choice was the involvement of intimate partners.

Outcomes of Individuals with Pre and Post-move Data

Of the 34 people in the RAC Exit Group, 13 of them also had pre-move data. An analysis of matched pairs examined the outcomes for this group on the same 41 outcome variables. There was a significant difference on a range of outcome variables related to mobility, independence, social contact, community integration, everyday choices and role participation. This group spent fewer hours in bed, went outside more often and were able to be left for longer periods of time after they moved out of RAC. This group was more involved in meal preparation and household shopping and participated in more life roles after they moved. They also travelled outside their home and participated in community-based leisure activities more often after they moved. They had more opportunity for everyday choices in 10 out of 11 areas after they moved. The only area of life where there was no increased opportunity to make a choice was the involvement of intimate partners.

Health

The Enhancement Group had up to 11 health conditions. They had significantly more health conditions than the 2007 group who were not receiving enhancements. There was no significant difference between the number of health conditions in the 2007 group who were not receiving enhancements and the RAC Exit Group. The RAC Exit Group tended to have fewer health conditions than the Enhancement Group. The Diversion Group had the least number of health conditions of all the groups.

For example, 77% of the Enhancement Group had swallowing difficulties, 65% of the RAC Exit Group had swallowing difficulties and only 27% of the Diversion Group had swallowing difficulties.

Thirty-two per cent of the Enhancement Group had health conditions related to breathing such as recurrent chest infections or difficulty coughing, 15% of the RAC Exit Group had breathing difficulties and only 9% of the Diversion Group had breathing difficulties.

Sixty-four per cent of the Enhancement Group had skin problems such as pressure areas or rashes, 27% of the RAC Exit Group had skin problems and 27% of the Diversion Group had skin problems.

Support needs

There was no statistically significant difference in the support needs of the group of people who moved from RAC and the group who remained in RAC and received enhancements. Both groups had high support needs. However, overall, there was a trend across a range of variables with Enhancement Group requiring the most support and the Diversion Group requiring the least support. For example, 29% of the Enhancement Group required 24-hour assistance or supervision, 15% of the RAC Exit Group required 24-hour support and only 9% of the Diversion Group required 24-hour support.

Many of the health problems experienced by this target group were exacerbated by lack of movement, opportunities to sit upright and appropriate supported seating and positioning (Diab & Johnston, 2004; Mackay, Morgan, & Bernstein, 1999). For example, on average the Enhancement Group spent the most time in bed (mean 14 hours) followed by the RAC Exit Group (mean 12 hours) with the Diversion Group spending the least number of hours per day in bed (mean 10 hours). Sixty-one per cent of the Enhancement Group needed assistance with bed mobility and turning and 89% of the Enhancement Group required assistance with transfers and mobility. Again, there was a trend, with the Enhancement Group being less mobile (in bed and on the ground) than the RAC Exit Group and the Diversion Group being the most mobile.

Life roles

A role is defined as the expected pattern of behaviour associated with occupation of a distinctive position in society (Heard, 1977). Adult occupational, family, avocational and social roles allow people to participate in society and satisfy human needs (Oakley et al., 1986). The overall trend was that the Diversion Group was most involved in life roles (mean 3.8) followed by the RAC Exit Group (mean 2.5) and the Enhancement Group (mean 1.92). The roles most often preserved were family member and friend. Twenty-five per cent of people in the Enhancement Group were parents of school-age children and 9% of the RAC Exit Group were parents of school-age children. None of them was actively participating in this role; i.e. they did not have responsibility at least once a month for the care their child.

Behaviours of concern

Both the Enhancement and RAC Exit Groups had fewer behaviours of concern than the 2007 group who had not received enhancement services. The most common behaviours of concern were lack of initiation and verbal or physical aggression.

Mental health

Depression was the most common mental health issue identified in all groups. The participants in this evaluation displayed less evidence of mental health issues than the 2007 group who had not received enhancements. For example, 71% of the 2007 group displayed symptoms of depression of varying severity in the two-week period preceding the assessment. In the current evaluation, symptoms of depression were reported for 47% of the Enhancement Group, 37% of the RAC Exit Group and 50% of the Diversion Group.

Community integration

The Enhancement Group was the least integrated into the community. The RAC Exit Group had much higher levels of participation on home integration tasks than the Enhancement Group. While none of the Enhancement Group were involved in household shopping, meal preparation or housework, some people in the RAC Exit Group were participating in these tasks. The RAC Exit Group was also more actively involved in planning social occasions and looking after their personal finances than the Enhancement Group.

The Diversion Group was the most integrated into the community. However, even the Diversion Group had poor community integration outcomes compared to other groups of people with disabilities (Colantonio, Dawson, & McLellan, 1998; Corrigan & Deming, 1995; Corrigan, Smith-Knapp, & Granger, 1998; Fleming, Tooth, Hassell, & Chan, 1999; Sander et al., 1999; Sander et al., 1997; Schmidt, Garvin, Heinemann, & Kelly, 1995; Willer et al., 1993; Winkler, Unsworth, & Sloan, 2006), let alone the general population.

Families

There was a wide range of outcomes for families of participants in the Victorian YPIRAC initiative. Twenty-nine per cent of people receiving enhancement services were visited by a relative on most days. This is likely to reflect the significant burden of care experienced by some families of people in the Enhancement Group. Families tended to visit the RAC Exit Group less than the people in the Enhancement Group. Overall, the families of young people living in RAC with enhancements had poorer outcomes than the families of the other sub-groups. The families of the RAC Exit Group tended to have better outcomes than the families of the Diversion Group.

The data collected from all of the participants in the evaluation will now be summarised. These participants were from all three YPIRAC sub-groups and had a broad range of supports or equipment provided through the initiative.

Quantitative Data

Participants

A total of 68 participants consented to being contacted by the researchers and 17 people declined to be contacted. The participation rate of those people receiving supports through YPIRAC was 36%.

The Victorian Government Department of Human Services delivers services through its eight geographical regions. There are three metropolitan regions and five rural regions.

Table 3.1 Number of participants from each Victorian DHS region (n=68)

Region	Participants
North Western Metropolitan	17
Eastern Metropolitan	12
Southern Metropolitan	12
Barwon South Western	8
Loddon Mallee	6
Gippsland	5
Hume	4
Grampians	4
Total participants	68

People who participated in the current evaluation came from a range of regional areas. Although the evaluation included people from all DHS regions, some regions (e.g. Loddon Mallee) had greater representation than others (e.g. North Western Metro Region) given the total number of people who were receiving YPIRAC funded services in each region. The representation of regional and rural people (40%) in the current evaluation was higher than expected given that 28% of the total population of YPIRAC participants were from rural and regional areas. The people who participated in the current evaluation were representative of the wider population in terms of the services received.

Demographics

The age of the participants in the current evaluation ranged between 20 and 54 years with the mean being 44 years of age. The people who participated in the current evaluation were significantly younger than the population who received services through YPIRAC. Prior to the onset of their illness or acquired disability, 37 (54%) participants were employed full- or part-time. There was a greater representation of males (62%) in the current evaluation than in the total population of Victorian YPIRAC participants (56% males).

Table 3.2 Demographics

Demographics	n	%
Language (n=67)		
English speaking background	63	94%
Non-English speaking background	5	7%
Marital Status (n=67)		
Never married	38	57%
De facto	4	6%
Married	10	15%
Separated but not divorced	4	6%
Divorced	13	19%
Living Situation (n=68) §		
Residential aged care	36	53%
Disability shared supported accommodation (SSA) †	26	38%
Lives with family	4	6%
Lives alone	2	3%
Disability Support Pension (n=59)		
Yes	55	93%
No	4	7%

§ Living situation when first interviewed

† This includes people who have moved to existing shared supported accommodation services (SSA) and new SSA services developed as part of the YPIRAC initiative.

Disability Types

Table 3.3 Disability Types (n=68)

Disability Types	Primary Disability n	Primary Disability %	Secondary Disability n	Secondary Disability %
Acquired brain injury	37	54%	0	–
Multiple Sclerosis	13	19%	0	–
Huntington's disease	6	9%	0	–
Other neurological	5	7%	0	–
Other	2	3%	5	7%
Cerebral palsy	2	3%	2	3%
Intellectual disability	1	1%	2	3%
Quadriplegia	1	1%	1	1%
Paraplegia	1	1%	0	–
Spina bifida	1	1%	0	–
Vision impairment	0	–	3	4%
Parkinsons	0	–	1	1%

Primary disability is the disability causing the most difficulty to the person (overall difficulty in daily life, not just within the context of the support offered by the service). Secondary disability is a disability that also clearly expresses the experience of disability by a person and/or the cause of difficulty for the person (Australian Institute of Health and Welfare, 2011a).

Compared to the whole population of people who received services through YPIRAC in Victoria, there were more people with ABI and fewer people with intellectual disability who participated in the evaluation. The representation of people with neurological and physical disabilities in the evaluation was similar to the percentage in the whole population.

Table 3.4 Comparison of Primary Disability Types Across Groups

Disability Types	RAC Exit n=34 %	Diversion n=11 %	Enhancement n=28 %	Evaluation n=68 %	All Victorian YPIRAC Participants %
Acquired brain injury	65	45	43	54	45
Neurological	26	36	43	35	36
Intellectual disability	0	9	0	1	10
Physical	9	9	14	9	9

The primary disability types outlined in Table 3.4 use the definitions provided by the Australian Institute of Health and Welfare (Australian Institute of Health and Welfare, 2011a). The Enhancement Group contained more people with neurological conditions than the RAC Exit Group and the Diversion Group. Neurological conditions included Multiple Sclerosis and Huntington's disease. There were more people in the RAC Exit Group with an acquired brain injury than either the Enhancement or Diversion groups. The Diversion group had more people with an intellectual disability than the other groups.

Communication

Where possible, all participants were given the opportunity to participate in the evaluation through either providing verbal answers or through using a communication device. In many cases the interviews were conducted with the participants and their nominated support person. The support person (usually a family member) would help prompt the participant if required, or assist the researcher to modify the questions to best support their participation.

Ten (15%) participants responded to questions using a communication device. Twenty (29%) of the participants were able to fully participate in the interview; i.e. answer all questions independently. Twenty-eight (41%) participants were able to partially participate; i.e. they were able to answer some direct questions but generally relied on their nominated informants to answer in more detail on their behalf. Twenty-one (30%) participants were unable to participate in the interview, therefore their informants were interviewed.

Table 3.5 Levels of Awareness (n=68)

Level of Awareness	RAC Exit Group %	Diversion Group %	Enhancement Group %	All Participants %
Fully aware: Alert and orientated to time, place and person	45	64	43	46
Partially aware: Awake but had profound memory difficulties and had significant levels of confusion	45	36	46	46
Minimally aware: Minimally conscious state, vegetative state or coma	9	0	11	9

The group of people who were in RAC and received enhancements had an overall lower level of awareness than the other groups. The group of people who were diverted from RAC had a higher level of awareness than people who received enhancements and people who moved out of RAC.

Table 3.6 Community Integration Questionnaire (CIQ) Total Scores and Subscale Scores for Each Group

Variable	2007 Baseline Data Mean (SD)	RAC Exit Mean (SD)	Diversion Mean (SD)	Enhancement Mean (SD)
Home integration subscale	0.94 (±1.03)	1.56 (±1.88)	2.95 (±2.33)	1.11 (±.69)
Social integration subscale	2.38 (±1.77)	4.12 (±2.07)	6.27 (±2.83)	3.32 (±1.70)
Productivity subscale	1.59 (±1.18)	1.52 (±.89)	2.63 (±1.77)	1.25 (±1.00)
CIQ total score	4.92 (±3.00)	6.21 (±3.75)	9.23 (±4.54)	5.68 (±2.60)

Community Integration Questionnaire (Willer et al., 1993)

The scores on the Community Integration Questionnaire (CIQ) (Table 3.6) show that, compared to other groups of people with disabilities, all of these groups were effectively excluded from participation in the community. It is difficult to find a comparison group to assist in the interpretation of these scores. To date, most previous studies have only included people with ABI. The mean CIQ total score for this sample of young people living in RAC is much lower than the CIQ total means scores for any samples from previous studies, which range from 13.02 to 19 (Colantonio, Dawson, & McLellan, 1998; Corrigan & Deming, 1995; Corrigan, Smith-Knapp, & Granger, 1998; Fleming, Tooth, Hassell, & Chan, 1999; Sander et al., 1999; Sander et al., 1997; Schmidt, Garvin, Heinemann, & Kelly, 1995; Willer et al., 1993; Winkler, Unsworth, & Sloan, 2006). All of these samples included people with severe acquired brain injury more than one year post-injury.

All three sub-groups tended to have higher levels of community integration than the 2007 group living in RAC without Enhancements. Of the three sub-groups, the Enhancement Group had an overall lower level of awareness than the other groups. The Diversion Group had a higher level of awareness than the Enhancement and RAC Exit groups

Quality of Life

The Personal Well-being Index (PWI) scale contains eight items of satisfaction, each one corresponding to a quality of life domain: standard of living, health, achieving in life, relationships, safety, community-connectedness, future security, and spirituality/religion.

Participants were asked how satisfied they feel on a range of questions, on a scale of zero to ten. Zero means ‘Completely Dissatisfied’, and 10 means ‘Completely Satisfied’.

Table 3.7 Three Sub-groups – Personal Well-being Index

How Satisfied Are You With...	RAC Exit Mean (SD) n=14	Diversion Mean (SD) n=7	Enhancement Mean (SD) n=10	Australian Normative Mean (SD)
Your life as a whole?	7.6 (± 2.4)	6.5 (± 1.9)	7.1 (± 2.4)	7.1 (± 2.4)
Your standard of living?	6.8 (± 2.8)	7.3 (± 2.5)	5.6 (± 3.7)	7.7 (± 1.1)
Your health?	7.4 (± 2.4)	6.0 (± 3.2)	5.5 (± 3.0)	7.5 (± 0.6)
What you are achieving in life?	6.9 (± 2.3)	6.0 (± 2.1)	6.0 (± 2.9)	7.4 (± 0.8)
Your personal relationships?	7.5 (± 2.2)	7.4 (± 1.7)	7.1 (± 2.4)	8.0 (± 1.0)
How safe you feel?	8.2 (± 2.1)	8.9 (± 1.2)	8.6 (± 1.9)	7.8 (± 1.6)
Feeling part of your community?	5.6 (± 2.5)	7.7 (± 1.3)	7.0 (± 2.8)	7.1 (± .97)
Your future security?	7.9 (± 2.7)	6.9 (± 1.6)	6.8 (± 3.2)	7.1 (± 1.3)

Personal Wellbeing Index (International Well Being Group, 2006)

There was surprisingly little difference in the scores between the three sub-groups and the normative data on the PWI. However, this data should be interpreted with caution because of the small sample sizes. Many of the participants did not have the cognitive and/or communication abilities to provide their perspective on their quality of life.

Table 3.8 Comparison of the three groups and normative data on the ComQol

ComQol Question	RAC Exit Group Mean (SD) n=29	Diversion Group Mean (SD) n=22	Enhancement Group Mean (SD) n=22	Normative data Mean (SD)
Time use	3.10 (± 1.04)	4.1 (± 1.37)	1.91 (± 1.06)	4.13 (± 1.00)
Sleep	4.20 (± 0.96)	3.90 (± 1.10)	3.81 (± 1.26)	3.96 (± 1.07)
Safety	4.83 (± 0.66)	4.70 (± 0.48)	4.18 (± 1.18)	4.76 (± 0.56)
Worry	2.10 (± 1.37)	1.90 (± 0.99)	2.20 (± 1.06)	3.62 (± 1.05)
Television	3.0 (± 1.16)	3.2 (± 1.40)	2.43 (± 1.34)	2.88 (± 1.50)

ComQol -15 (Cummins, 1997)

Higher scores represent higher subjective quality of life. The Diversion Group tended to have the best outcomes followed by the RAC Exit Group and then the Enhancement Group. Having nothing to do appeared to be an issue for the Enhancement Group.

Table 3.9 Three sub-groups – Family Outcome Measure Subscales

Family Outcome Measure Subscale	RAC Exit Mean (SD) (n=33)	Diversion Mean (SD) (n=6)	Enhancement Mean (SD) (n=14)	Score Range	Higher scores Represent
Family member coping	14.4 (± 4.2)	12.0 (± 3.9)	9.43 (± 5.6)	0-24	Increased coping
Family cohesion	10.0 (± 3.0)	12.4 (± 6.2)	9.57 (± 3.3)	0-18	Increased closeness
Support demands (burden)	11.9 (± 4.4)	8.0 (± 6.9)	6.36 (± 5.7)	0-24	Reduced support demands
Relative adjustment	8.1 (± 2.6)	6.2 (± 2.9)	6.21 (± 3.3)	0-15	Improved adjustment
Adequacy of service support	10.0 (± 3.4)	8.2 (± 4.2)	8.79 (± 4.1)	0-15	Improved service support
Family member resilience	10.8 (± 2.4)	10.8 (± 3.4)	9.21 (± 5.6)	0-15	Increased resilience
Sustainability of family support	10.7 (± 2.6)	9.5 (± 3.0)	9.43 (± 3.4)	0-15	Increased likelihood long-term support sustainable

Family Outcome Measure (Simpson & Winstanley, 2009)

The scores on the FOM indicate that there was a wide range of outcomes across all scales for families of participants in the YPIRAC initiative. Some families of young people living in RAC still experience a significant burden of care. Overall, the families of young people living in RAC with enhancements had poorer outcomes than the families of the other sub-groups. The families of the RAC Exit Group tended to have better outcomes than the Diversion Group on most of the FOM subscales.

Qualitative Data

Living in RAC – Challenges

Participants and families wanted to share with the researchers some of the challenges of being a younger person with a disability living in RAC. The overwhelming majority of people interviewed advised living in RAC was inappropriate for their needs and they found the experience distressing. However fears regarding the unknown of alternative SSA services, or the potential risks associated with change, meant that many people chose to stay in RAC, even given their distress.

The following five themes highlight the issues the younger person and their family faced, or continue to face, while living in RAC.

It's geared towards dying well…not living well

A number of participants and their families reported that the structured routines, physical and social environment and recreational programs within RAC were inappropriate for younger people with disabilities. Families reported that the services were established to support people comfortably at the end stages of life; however, when faced with a younger resident with different interests, needs and perhaps even rehabilitation goals, the service was often unable to help. A manager of one aged care service explained the challenge of supporting a younger resident:

> “When a younger person comes in we are at a loss. They don't want to play bingo, they don't want to do indoor bowls…we're just not geared for younger people.” RAC MANAGER

Participants reported that they wanted to be with peers.

> “It would be nicer to be able to be with people more my age in general. I feel that would help a lot.” BARB, PARTICIPANT

Many participants reported that their basic health and support needs were usually met, but little else. Support to maintain and develop new friendships and to access and be included in the community was limited. A participant commented:

> “They feed me and they dress me…but they don't help me with anything else.” BELINDA, PARTICIPANT

Even families who thought the level of care and support provided by the service and staff was adequate still reported finding the accommodation setting inappropriate for their younger family member.

> “The staff are good. The conditions are good. The place itself is good. But it’s not for bloody young people. That’s why we want him out of there.” MARTY’S FATHER

Some participants reported withdrawing from the activities designed for older people that in turn reduced their opportunities for social interaction. Some reported that this led to feelings of despair or depression, which sometimes went untreated.

> “He was very depressed. He just hated it there and you could tell he hated it, even though the nurses… there were a lot of nurses there that were fantastic.” SHAUN’S MOTHER

> “All she ever did was stay in bed. She just got to the stage where she just couldn’t be bothered getting out of bed. So there was nothing for her to do.” PATRICIA’S SISTER

Family members reported high levels of distress when they walked through the doors of an aged care facility to visit their family member.

> “We feel like he’s suffering, we’re suffering and there’s no end to it. It’s like a bloody worst nightmare that anyone can endure because it doesn’t end.” HARRY’S SISTER

They often felt obliged to spend long hours at the service to provide the participant with company and check they were receiving adequate care.

> “He’s treated like probably one of the elderly people… But he’s 20 something… I hate it. I hate it. I hate coming here. But Tom’s here… I mean, people come here to die, that’s what they are. Like, someone died yesterday. So it’s geared towards dying well, I guess. It’s not geared towards living well. But Tom’s still got his whole life in front of him.” TOM’S MOTHER

A particularly difficult issue for the participants is that they often would outlive their co-residents. In particular, participants with non-progressive disabilities such as acquired brain injuries do not necessarily have a shorter life expectancy due to their disability. Therefore many expressed the difficulty of watching their co-residents die.

> “It’s very saddening because at one stage we were losing three or four a week. So…you’re talking and joking with these people and then all of a sudden they weren’t there any more.”
> CALLUM, PARTICIPANT

One participant, Sally, described the pain of living in a six-bed room and watching the five other residents die one by one and then being replaced by new residents. She described developing valued relationships with the older residents who would then pass away:

> “Being in an old-people, home no one knows deep down what it’s like. The thing that I’m pointing out is that you get to know them and then they pass away. It was like losing one of your family.” SALLY, PARTICIPANT

Many stories emerged through the interviews about how many participants’ children, spouses, siblings and friends would find it too difficult to visit the participants in aged care.

> “Well the children were shocked to see their father amongst elderly people… it was just not a home environment. In some ways they were a little bit embarrassed for their Dad. Just very, very unpleasant.” RAC MANAGER

Just existing

A high number of respondents discussed the issues involved with the lack of age-appropriate, meaningful activities available for younger residents living in RAC. Many family members expressed frustration that even when group activities were not available or appropriate, staff did not set up passive recreation activities for the participant, such as age-appropriate television viewing, music, being read to or just spending some time talking. As one mother explained:

> “He loves music – and that’s not always (on)…so he can be left with nothing…just sitting there like a little old man.”
> CRAIG’S MOTHER

Many family members reported high levels of distress at seeing the participant sit in their room all day. Further fuelling the family’s distress was that the participant would often be left in bed all day, even when they weren’t unwell. Some family members felt this was due to the additional effort required to hoist, change and manage continence issues for participants with complex needs.

One mother reported:

> “I think they forget that Ned is a young man…. He doesn’t need to be in bed all day…he’s not elderly and he’s not sick.”
> NED’S MOTHER

Some families thought the participant was not included as much as the older residents, even for basic activities.

> “They don’t even remove him from his room for meals like they do with every other person.” HARRY’S SISTER

One participant spoke of only leaving her room when her elderly parents would take her out. She received all of her PEG feeds in her room, not in the main dining room with other residents. This was primarily by her choice, as she did not wish to socialise with the older residents. She reported via her communication device that staying in her room was:

> “Lonely but it was better than being out with everyone else.”
> KRISTY, PARTICIPANT

Another participant made the choice of staying in her room:

> “I spent 99.5 per cent of the time in my room; hide in my room.”
> CAROLINE, PARTICIPANT

Some participants used the words ‘lonely’ and ‘isolated’ as a way to describe their life in RAC and therefore placed high importance on being involved in the community:

> “To be honest, I don’t like living here because of the loneliness mainly…that’s why I’m involved in a lot of things or projects which keep me out of here at times.” VIC, PARTICIPANT

However, many participants felt the numbers of community access opportunities were reducing over the years they spent in RAC. This was usually due to their high physical support needs making transport difficult in the community. Some reported the service’s single vehicle available for community access could only accommodate one wheelchair, thus limiting their access to it. Others reported cut-backs in staffing impacting on their access to support for community outings. Many felt that the participant’s limited mobility or complex needs made the staff less likely to choose them for an outing:

> “They couldn’t take her out unless they had extra volunteers, or extra carers.” PATRICIA’S SISTER

One family member expressed frustration that the participant had been on one outing in four years. Generally, it was found by the researchers that unless the participant had funding for attendant care support, or had family members living nearby, they would rarely leave the RAC facility.

Institutionalised

Many participants and families often referred to institutional elements of RAC such as rigid routines revolving around the needs of staff rather than individual residents. Participants described feeling part of a regimented system where it was difficult to express choice or find freedom in their daily lives.

> “Everything was by the clock…just everything had to work on time. It was 110 people and it wasn’t personal. I was known as G10. So if they were speaking about me…they would call me G10.” CAROLINE, PARTICIPANT

Another parent highlighted that inflexible routines were an issue:

> “He gets fed in bed. I don’t feed him in bed. I always get him in the armchair or wheelchair to feed him. But 25 year-old men don’t usually get fed in bed and that really irritates me. Having said that, I understand why. Their routine is that at four o’clock at night they’re putting everyone in their pyjamas. To get him out of bed, feed him and put him back to bed is out of that routine.”
>
> CRAIG’S MOTHER

One family described watching their son’s opportunities and motivation to practice daily living skills reduce as the years passed. They noticed that even though he could feed himself with a spoon, he’d often cross his arms and the staff would spoon-feed him instead, rather than taking the time to encourage him to feed himself.

> “Because most of the patients there had to be fed, he decided… right well if they can get fed, I can get fed. Cross your arms and sooner or later, somebody will come along with a spoon.”
>
> MARTY’S FATHER

Many participants discussed their frustration at the lack of choice and freedom they experienced in RAC, often through the presence of security codes, locked doors and visitor sign-in books as well as inflexible routines for bathing, meals and going to bed. Additionally, a big issue raised was lack of privacy, including having to entertain friends and family in a shared room. One participant reflected after moving out that she appreciated the new staff now shutting the door when they assisted her to shower, as this was not common practice at her RAC facility.

Another very common complaint relating to the institutionalised nature of the setting was the perception of the poor quality of the food provided in the RAC facility. Participants were distressed when discussing the lack of choice and taste in the food provided. Words such as ‘mush’, ‘slush’, ‘revolting’ and ‘disgusting’ were used to describe the food received. For many, this was a key reason for wanting to move out.

> “Sometimes they’d bring his meal and I’d lift the lid and think ‘Oh my god, I couldn’t even eat that’. ” GREG’S MOTHER

However, although many participants detested the inflexible and regimented routines of RAC, it was clear that to some participants the thought of moving out of the RAC facility was terrifying and they found it difficult to imagine any other way of living. Some spoke of skills that had deteriorated since living in aged care, such as social, physical and domestic skills.

> “I’m very isolated, very isolated to a point where it’s going to be a challenge actually talking to normal people again and living a normal life because I speak to some nurses and that but it’s all about people here or sickness…it’s not, what do you think we’ll get up to this weekend, got any plans?”
> CAROLINE, PARTICIPANT

While other family members were able to identify that the participant had actually become institutionalised:

> “It would be nice to see him doing some useful things. Because you get into that mindset after a while that you just want to sit and watch television and have your meals and that’s it.”
> ADRIAN’S MOTHER

It’s all with the oldies

Nearly all of the participants spoke of the challenge of living with people who were born one or two generations before them. Many reported that even though they liked older people, they just found they had vastly different interests to them.

> “They were brought up in a different world than I was.”
> KARL, PARTICIPANT

Family members reported finding it difficult to visit when the participant shared a room with an older co-resident:

> “You’d have to sort of creep in….because they were elderly and they needed you to be quiet…you’d have to whisper and try and be nice and quiet.” NED’S MOTHER

Many spoke of the frustrations with the RAC recreational programs that only catered for the elderly, such as bingo, craft or concerts. As these parents explained:

> “They’re older and you’ve got this generational gap…when they bring the fellow in to play the piano, that’s terrific for the oldies but for Wal he doesn’t like that stuff. He’d rather his own music; U2 and all that sort of stuff.” WAL’S FATHER

> “Matthew had his AC/DC discs in there but all he could hear was the golden oldies from World War I and World War II; so entirely inappropriate for him.” MATTHEW’S MOTHER

Some parents of residents also reported their ongoing concern that the participant was living with people with dementia. They often worried that a wandering resident would injure their family member, who, due to physical or communication impairments, may be unable to seek help or defend themselves. One mother said:

> “They wander, I don’t know if they wander into Tom’s room or not. He can’t call out…and because he’s not vocal it can be very out-of-sight out-of-mind…because he’s just in his room.”
> TOM’S MOTHER

Many participants described finding it hard to interact with their older co-residents, mainly because the older residents needed more rest or they had hearing loss.

> “I’ve become very friendly with one lady but most of the residents sleep a lot.” SALLY, PARTICIPANT

Families also found it hard to see their relative with older residents.

> “He’s sitting there with old ladies in chairs who don’t talk and he’s the only young one that might be sitting amongst them.”
> ADRIAN’S MOTHER

Some family members described how their family member, who had cognitive impairment, was confused as to why they lived with older people. A spouse described the distress her husband, who had an acquired brain injury, experienced when a co-resident died:

> “The first time one of the residents died he was having a sleep; he came out white as a ghost …and he said, “there’s been robbers in here and they’ve killed a man.” CLINT’S PARTNER

Some participants would forget their individual skills and abilities, and would often copy the other residents' behaviour:

> "They've been there so long and they've got nothing to do… they end up imitating the old people. Like, she used to shuffle along and do what the old people did. I used to say to her, 'Stop doing that, you're not that old.'" PATRICIA'S SISTER

They don't have time for his individual needs

Many participants and their families were disappointed with the lack of individualised support provided by the aged care facility. As such, some family members felt that they needed to visit as often as possible to provide additional support to ensure the younger person's health and well-being was maintained. This placed a high amount of stress on family members. They often felt that the participant's basic medical needs weren't being met; an issue that many families felt was related to the inadequate staffing ratios in RAC.

> "I don't like the size of it – it's too big…too many staff who are never going to learn his idiosyncrasies and his individual needs...because he can't communicate himself. So he can't ring a bell like most other clients. So it's valuable if they could pick up on these signs…sometimes he can be really grizzling and refusing food when in fact he's actually really hungry."
> CRAIG'S MOTHER

Many participants and their family members became angry and distressed in the interview when they described the neglect experienced and the inability of RAC staff to meet basic needs. Some of the examples included participants waiting on the toilet for over two hours, no response to a person's call bell being activated, not being showered for a number of days, lack of teeth brushing or other hygiene tasks, and lack of understanding of behavioural issues.

One participant living in RAC stated:

> "We're still human beings, we've just got a disability and we need a bit of help at times. They decided to take up a career in nursing. Well, if that's the case, you do it properly."
> VIC, PARTICIPANT

Family members were concerned that staff were not trained to deal with the complexities of working with someone with a brain injury, or even understand the needs of the disabled compared to the elderly. One mother explained the lack of understanding of her son's behaviour:

> “Because of his brain injury, he would call out. Then, he would become fixated and he would call and call and call. When that got nowhere, that was when he started to lose his voice and from there, he progressed to clapping. So, Matthew was seen as a troublesome resident. It was just that Matthew couldn’t get attention.” MATTHEW’S MOTHER

Another family member described needing to train the nursing staff on how to provide a PEG feed to her son as no one had any experience in enteral feeding. Some family members reported that the participants had limited opportunity to practice everyday tasks in RAC, which led to a deterioration in living skills such as continence, self-feeding and mobility. Families reported that staff in RAC either did not have the time or did not see the provision of opportunities and support to maintain everyday living skills as a priority.

> “Yes, he’s got the ability to do it [feed himself] but they just don’t have the time. It’s easier for them to come along if he’s not eating, to get a spoon and go glump, glump like that. Like an aged person.” MARTY’S MOTHER

A sibling also highlighted the facility’s inability to maintain her brother’s mobility, which resulted in health issues and reduced skills:

> “When the mobility got worse they realised that he couldn’t get to the toilet on his own. So rather than assist him when he presses the buzzer, they wanted him in aids – incontinence aids – to make their world easier…they would let him sit there all day in his aids so they can save a penny or two. Every time my mother goes in there, he’s wet.” HARRY’S SISTER

Living in RAC – The Advantages

Although the overwhelming majority of participants and their families found living in RAC a negative and very challenging experience, some were able to identify some positive aspects to it.

Celebrity status

A few of participants and their families used the term ‘celebrity status’ when describing the experience of being the youngest person in an aged care facility. This often would mean receiving a bit more special attention from the staff.

> “If I don’t like something they’re serving up for tea I can speak to one of the kitchen ladies and they’ll bring me something different…I’ve got the run of the place now.” CALLUM, PARTICIPANT

Some of the participants spoke fondly of special tasks they would do in the aged care facility, such as being Santa each year, or helping with the bingo. One family member describes the advantage of being the youngest resident:

> “She’s a bit blessed in the way that, I guess, because she’s unique, she’s not like Bill and Bob and Annie and all that sort of thing.” TAMMY’S FATHER

Have fun with staff

For some participants, their long stay in aged care meant valuable relationships were developed over many years with regular staff.

> “I made a lot of friends with the staff and their families.”
> POLLY, PARTICIPANT

Often, these relationships with staff who were of similar age seemed to make up with lack of connection with the older residents.

> “The other thing I like is the staff are around my age, because the residents aren’t – most of them are way old for me. But I get on well with the staff, we like stirring each other up.”
> OWEN, PARTICIPANT

The busy, bustling environment of larger facilities had high numbers of staff, residents and visitors around each day. For some participants and their families this meant it was a place full of energy and movement.

> “There’s always something happening.” TAMMY’S FATHER

Safety and medical care

The availability of nursing care 24 hours a day was very important to some family members. They felt the nursing staff could manage any critical health issues.

> “If he is ever really crook or there’s something wrong, which fortunately doesn’t happen too much, they just ring up and he’s in straight away. The ambulance is here and he’s in.” WAL’S FATHER

For some family members, this level of support and medical care was reassuring:

> “It’s a weight off my mind knowing she is safe here.” MARY’S PARTNER

Some participants with progressive neurological conditions and their families felt it was best remaining in aged care services where they could receive high-level care as their needs change.

> “I wanted to go to [SSA where participant had stayed previously for respite] and I used to like it there but because of my condition worsening they wouldn’t (have me)…I needed high level care.” VIC, PARTICIPANT

Some RAC staff expressed concern and doubt in regards to how the staff at the new service would be able to support the participant’s high care needs:

> “That would be my concern, and if they don’t have upstanding staff at night…he is bedbound and things like that, pressure area care, those sorts of things, people can brush over that.” RAC MANAGER

Making the decision to move from RAC

The decision to move out of residential aged care (RAC) facilities during the YPIRAC initiative was described by participants and their families as an incredibly difficult one. Despite welcoming the offer of an alternative, often purpose-built, accommodation that included the opportunity for their family member to live with younger co-residents, they still spoke of their apprehension in accepting the offer. This apprehension was primarily due to the many unknown factors that may adversely affect their family member’s experience of, or safety within, community living.

The following four themes that emerged from the analysis of the interviews highlight the reasons why participants decided to accept the offer and move from their current aged care facility to alternate accommodation.

Taking a risk

Even for those participants and families who were dissatisfied with the quality of the care and support they received through the aged care facility, making the decision to move out was still described as ‘taking a risk’. Many perceived that the proposed care and support at the new shared supported accommodation (SSA) sounded better than the current model of care within RAC, but also doubted whether it would live up to the promise.

> “So everything I’d heard about the house, given the staffing levels, given the type of environment it would be, all sounded absolutely wonderful to me. So, I guess I was a little hesitant as well thinking, ‘Will it really be that good?’” MATTHEW’S SISTER

During the interviews, some families reported that, at that time, many questions remained unanswered about the new service and support model. Common questions that were unanswered were; ‘Who will the other residents be, and what are their needs? What individualised funding will the person lose or gain? Will the staff be well trained? Will they still be supported to do the activities they enjoy? When will they move?’

Some family members described the difficulty in making a decision given the lack of information provided:

> “They didn’t give me any information about it; they just said there’s a group home. They didn’t tell me it was younger people, but because I didn’t know enough about it I had to judge whether I was putting her in a worse situation than what she’s in or a better one…then when I found out all about it and went, ‘Oh no that’ll be really great for her’…I think I would’ve said yes in the beginning if they’d given me the information.”
>
> PATRICIA’S SISTER

> “I had been offered a place at [new SSA]…and I think that was sort of still in the building process and they wanted me to say yes before they’d even built it and put things in place and I just couldn’t do that.” HARRISON’S MOTHER

Another concern for some families was whether the person with a disability would be safe within a SSA, which may be less secure than their current RAC.

> “I wouldn’t be surprised if he tries to escape out there…they’re not going to lock him in. That just makes me a bit nervous.”
>
> HARRISON’S MOTHER

A particular concern for many family members was that after many years, the participant has finally settled into a predictable routine and lifestyle at the aged care facility. Families worried that the disruption of moving would negatively impact on the participant's health, both physical and emotional. Furthermore, many worried that if the alternate accommodation didn't work, the participant may be unable to return to the previous RAC.

> “She's well cared for, she is safe. That's really all…so what's the new place going to be like? Is it fair to put her through all this trauma of shifting when she has settled finally? Would I be doing it because it's going to make me feel better or is it really for her?” JAYNE'S FATHER

In situations where the participant was unable to make a decision regarding their accommodation, family members involved in making the final decision discussed weighing up the risks and then questioning whether their decision would negatively impact on the person's life.

> “I laid awake for weeks prior to him moving 'cause I was worried that…was it going to be the right thing, the wrong thing? It was further away from home.” GREG'S MOTHER

Overall, what generally helped the family's decision to accept the offer of alternate accommodation was when staff from the new SSA provided written and verbal information about the new service.

> “I thought about it and thought about it and I asked a lot of questions and then I thought…well you're answering them all, what I want to know and yes, we will take the place, because it's better care for her.” PATRICIA'S SISTER

One SSA manager also discussed the importance of spending time with the new residents in their current RAC environment as part of transition planning before the person moved:

> “The staff here went and did shifts at the nursing home… to find out what his routine was and everything…so we weren't changing it and it wouldn't be so frightening for him.”
> SSA MANAGER

Many families and participants interviewed who were offered a place decided that it was worth taking the risk despite some unknown factors, particularly as they were unsure whether the opportunity would be offered again.

> “Above all, it was an opportunity that…I just couldn't let slide.”
> MATTHEW'S SISTER

I want him to have choices

Family members reported that a significant factor influencing their decision to accept the offer of new accommodation, as an alternative to RAC, was the possibility that the new SSA could provide more activity options and everyday choices for participants. They wanted to see their family members given opportunities to make everyday choices regarding age appropriate activities, clothing, and meals, and they felt that these choices were restricted in RAC and would be more readily available in the new service.

> “It would be nice for him to have the choice. If he doesn’t feel like movies one day or whatever, just stay at home or whatever he wants to do.” HARRISON’S MOTHER

A number of family members confirmed that they left the final decision on whether to accept the offer to the participant.

> “It was her choice. It’s her future and it’s what she wants.” JAYNE’S FATHER

> “So in the end it was basically – well it was his decision. I wasn’t going to force him one way or the other.” GREG’S MOTHER

Promise of better care

Ultimately, the promise of the participant receiving better care than they did in the aged care facility was a strong reason for moving out. Participants were seeking individualised care, where staff understood their unique needs and proactively managed their health.

> “The more we sort of developed, I thought, yeah, this is going to be good; if it works, this is going to be brilliant.” JAYNE’S FATHER

> “We wanted people who knew how to work with brain-injured people. Now, all the people in the aged care facility know how to care for aged care people. They do that to varying degrees. But we wanted people to have an awareness and a capacity to work productively with him and make the most out of his life.” NEIL’S FATHER

Participants and their families were also seeking input from support staff that focused not only on the resident's basic care and health needs, but also looked to improve the person's well-being and participation in the community.

> "I guess it was an unknown, something that I didn't really know what it would be like, but I just knew that it had to be better than where he was." MICHAEL'S SISTER

For one family, they felt that the effort involved in helping set up the new SSA would assist future residents of the service, who may have otherwise faced RAC placement, to receive good care within the new accommodation setting.

> "It's great to think that as a family we've been at the start of something that's going to carry on for others families, they won't have to go through what we've been through, you know."
> JAYNE'S FATHER

It'll be nice to be with younger people

Nearly all participants who lived in aged care facilities expressed their desire to live with people of a similar age.

> "It'll be good. It'll be nice to be with younger people…just people my own age." SALLY, PARTICIPANT

Only a few participants spoke of their hope of making new friends with the people they would live with. Rather, most participants just wanted to regularly interact with others who were a similar age and had some common interests.

> "There will be more of a talking point round about the same age and our lives and where we've come from and what we've done. So that'll be different, exciting, really." CALLUM, PARTICIPANT

A few participants were concerned their social and communication skills had reduced since living in aged care, where they had less interaction with others. In the new SSA they felt they would have to push themselves to try new things and interact with others.

> "I'm going to have to really push myself to try and open myself up to new feelings, new emotions and what not. I won't be able to just hide in my room as I have done here for two and a half years." CAROLINE, PARTICIPANT

One participant commented that she wanted to have fun with future co-residents at the service she was moving to. When asked by the researcher to elaborate on what they would do to have fun, she replied:

> “Gee I don’t know, it’s been a long time since I’ve had fun with young people.” FAYE, PARTICIPANT

Considering the average length of time participants lived in aged care prior to moving out was four years, it is understandable that they were concerned about how they would manage interacting and living with people of similar age, and returning to a community setting.

Deciding to stay in RAC

Some participants and family members chose for the person with a disability to remain living in aged care rather than nominating to move to a new YPIRAC funded service either during the initiative’s planning process or when offered alternative accommodation. Below are the themes that summarise the reasons behind this decision.

Better the devil you know

Many participants were clear that despite being unhappy with the lack of individualised care they received in RAC, they decided to stay to avoid any potential risks associated with moving into a brand new service.

> “The devil you know is better than the devil you don’t.” KYLIE’S MOTHER

Some felt unsure whether the new support model would provide the same or better care for their family member, especially when they learnt that the new services did not have 24-hour nursing staff available.

> “We didn’t want him to go into one of those homes, well it’s a house, just an ordinary house…a sister is not on at night time and [if] something happens you’d never forgive yourself and he’s been through enough now.” WILL’S MOTHER

> “We can’t see any reason why he would [move to SSA]…in his present health he would find it hard, he’s virtually bedridden 24 hours a day. He’s being looked after 24 hours a day and would he get this in a place like that?” BARRY’S FATHER

The perceived safety of having 24-hour nursing support within a familiar setting of the RAC was a common reason why some families decided the participants should stay living in RAC.

> “They all have rooms of their own and they have nurses.”
> WILL’S MOTHER

The change is huge

The families of participants who had complex care needs or progressive neurological conditions were concerned that the stress and demands involved in moving could cause unwanted secondary health issues. These families reported that the changes required as part of moving out were just too great for the person with disability to manage.

> “He would have had to have change doctors. He would have had to changed adult training centres. People need to be aware of that…change for the disabled is huge.” CRAIG’S MOTHER

> “To uproot…and move him now would be more distressing and there would possibly be a greater deterioration suddenly which is part of it. So this is home for him now.” BARRY’S FATHER

Other families felt that the participant’s awareness of their surroundings had reduced, so they would be less able to notice or enjoy their changed environment.

> “We recommended against it because… it would be depriving someone more needy, someone who can interact…had it been there five, say, or eight years ago it would have been fantastic.” RON’S FATHER

Some families seemed unclear on the model of support the new service could provide, and whether this support model could adapt if the participant’s needs increase.

> “So you feel like here, if he needs more support, then they’re able to provide that whereas if he moved somewhere else you’re not sure whether that would have been able to be met.”
> BARRY’S FATHER

Too far away

For some families, the fact that the new SSA was further away than the RAC from where the participant’s family lived was an issue that caused them to decline the offer to move. Families were concerned that they wouldn’t be able to visit as often, and the participant would be further away from their familiar community and activities. This was particularly relevant to people living in rural communities, who found the new SSA services were being built in another town, which meant a much greater distance to travel than was required to visit at the RAC located in the same town.

> “I'm getting old and I'm there every day from half past nine in the morning til half past five, quarter to six, every day, from Monday to Sunday, every day. So I want it [the accommodation] to be close to me.” FREDDY'S FATHER

Who will they be living with?

A common issue that impacted on families and participants' decision to stay in RAC was that they knew very little about the other potential residents at the new SSA. Some were concerned that the participant may be living with people with high levels of cognitive or behavioural impairments that might compromise the individual's safety. Other family members relayed stories about other services that housed young people who displayed behaviours of concern (e.g. aggression) and decided that it would be better to remain in RAC, where these issues were less apparent for them.

> “There was a boy in [service name]. Now he was having high care, he had a motorbike accident but he used to belt the carers up and hit them and scream and yell. I mean I wouldn't like him to be with someone like that when he couldn't look after himself and defend himself.” WILL'S MOTHER

Families placed high importance on the participants being able to communicate and interact with the other residents, even if these other residents were older.

> “I wanted him to be with people that had a similar disability so that he could at least converse with someone.” GREG'S MOTHER

The Victorian YPIRAC Initiative – the Process

Starting out

Participants and their families had varied stories to tell regarding how they learned about the initiative and the people who supported them to make their initial application. A few participants reported that their family members discovered the YPIRAC initiative through researching on the internet.

> “After my stroke…I'd be going home – nobody there. My eldest daughter checked it out and found this package on the internet. We spoke to the social worker and [they] got it done for me.” LARA, PARTICIPANT

Some reported that their medical or rehabilitation teams were unaware of the initiative or had inaccurate information regarding it.

> “We were basically told the wrong information, because the social worker didn’t know, didn’t have a copy of *my future my choice*. We weren’t told we could get a copy of *my future my choice* guidelines.” PHILLIP, PARTICIPANT

Cara’s mother found out about the Victorian YPIRAC initiative through her local Member of Parliament.

> “I took [participant name] into the local office. I think it was the Federal MP first and they handballed me, they said ‘Health is a state issue’, so then we got the state. They mentioned *my future my choice*, the local MP, they said it was just a new thing coming round then. I didn’t know anything about it.”
> CARA’S MOTHER

Many family members felt that spending time researching the initiative and advocating on behalf of the participant was crucial in ensuring they got the supports they required.

> “I know there’s paper work and there’s red tape and everything. I know these processes are going to take a long time. Yeah, so I sort of stood up and got this thing moving.” VERA’S MOTHER

> “Yeah, I think the whole system, yeah...you’ve got to be proactive and you’ve got to be really involved and allow a lot more time than they tell you.” ELIZABETH’S PARTNER

The mother of one participant discussed that she decided that she and her daughter would not participate in the original planning and assessment process as she thought nothing would come of it. However, she was encouraged by another family receiving YPIRAC supports in RAC to reconsider and thus went ahead with the assessment process.

> “A lot of people I think thought about *my future my choice* that they had never been able to get anything through DHS and this was just another thing. So they wouldn’t bother to do it.”
> KYLIE’S MOTHER

Another mother reported that she wrote a letter to the Prime Minister’s office asking for assistance, as she was unable to keep caring for her son at home. She was surprised when a few months later her case manager mentioned the letter.

> It [the letter] went all the way back to the case manager. She had to answer to make sure that all the facts were correct and everything. Then it went all the way back up the tree. Then we got a response. Then a few months later, we got a place.”
> HENRY’S MOTHER

Elizabeth’s partner highlighted that he found the process of starting to plan a diversion ISP, and the hours allocated to attendant care support, were particularly difficult.

> There’s no formula. There’s no process on this. Yeah, work it out yourself. I mean I had help from the OTs and whatever. But there‘s no guidelines on this. I think that was the hardest part. Because, actually, I’ve probably fallen short now on my hours.” ELIZABETH’S PARTNER

The process dragged on

Many participants and their families reported their frustration that the processes required during the initiative were time consuming.

> The process has taken way longer than we anticipated.”
> ELIZABETH’S PARTNER

> We actually had to wait for a while and we actually had to remind them. I think some of the services took a long time to get into place.” CRAIG’S MOTHER

One participant living in RAC reported a high level of complication and frustration with regard to the yearly review of his enhancement ISP.

> There is always a delay.” VIC, PARTICIPANT

Other family members found the time between accepting the offer to move into a new service and actually moving in to be a long, frustrating time for the participant.

> So lots of delays which was a bit heartbreaking, but I said to him ‘Look, you will get there mate, it’s just that we’ve got to have patience and wait’.” SHAUN’S MOTHER

Additionally, many families reported they found the paperwork and bureaucratic processes laborious, and they needed to manage these closely.

> “I’ve been treated well and we’ve got pretty much what we asked for, but it’s just the process and passing the buck, with services, you go around in a circle and you’ve got to really be on top of it or you end up with nothing.” ELIZABETH’S PARTNER

> “So the thing is, with DHS I find they’re very slow and by the time one thing gets accepted you’ve got to put in another application for the next lot and that’s what the problem is.”
> VIC, PARTICIPANT

> “All the people that I’ve had to deal with from nurses up to social workers and psychologists and all that have been great…it’s just the paper trail, the red tape, that I’ve had to deal with…you’ve really got to spend a lot of time looking.”
> ELIZABETH’S PARTNER

This difficulty was recognised by SSA staff who were transitioning the participant to their new home.

> “Getting information from the facilities and different places that we needed was really, really challenging…I don’t think the transitions here... were as smooth as they could have been and I think they were really anxiety—provoking for families and for us.” SSA MANAGER

Lack of ongoing monitoring and flexibility of funding

A number of family members reported difficulty in determining how to apply for variations in funding, as they didn’t have a direct worker at DHS to contact to discuss their needs.

> “The thing I find disappointing is we don’t know where the budget is standing, we don’t know what we can apply for him…we don’t have direct contact to a caseworker or to the financial manager…it’s sort of, we get told once a year what we can do, and that’s it.” BARRY’S FATHER

Some family members and participants reported a frustration that many of the participants who remained living in RAC had ISPs that were not monitored closely once they were established. These people felt that the funds were not adequately utilised, as often the RAC facilities were left responsible for the ISP implementation.

> “She had a communication assessment funded…and they recommended that she have a communication board so that she could communicate more effectively with staff…when I visited [months later] there was no board and nursing staff didn’t know anything about the board.” EMMA’S GUARDIAN

Other issues of funding issues were reported:

> “They won’t even recognise past funding that’s not been utilised. Every year that it’s not utilised it gets scrapped. The reason it hasn’t been utilised is mismanagement through case managers of the past…and then we have to go begging to DHS.” HARRY’S SISTER

A number of family members were frustrated that the initiative didn’t flexibly adapt to the changing support needs and goals of the participant.

> “[it needs to have] the flexibility to meet the needs of the person as they change and being responsive to that change.”
> RON’S FATHER

Ian’s partner discussed how Ian was unable to change his diversion package to allow him to access the community more as he gained independence.

> “The challenge for us with that was that was done at a very early stage so that didn’t really take into account what our life is like now or what we need now. It was great because it got us home, but that’s all it did. They’ve always been a closed show so it’s never been anything we could go back and adjust since then…it didn’t adapt to what he needed.” IAN’S PARTNER

Many family members and service providers didn’t have accurate information regarding what would happen to the participants’ supports in the future, once they were aged over 50.

> “I think because he’s reaching 50 there’s anxiety for him… there’s never assurance that the funding will keep going and I think that’s the biggest worry and what will he do when it stops.” SSA MANAGER

Rural issues

A few families living in rural areas felt that the funding for support did not allow for the amount of time required for workers to travel the long distances, therefore much of the funding was spent on travel expenses.

> “The carers mainly came from [town name]…three quarters of an hour drive to [participant’s town] and then three quarters of an hour to drive to come back. So that was included in his outing.” BRAD’S FATHER

Another issue that was identified was the difficulty in trying to set up a therapy program at home for a participant who was being discharged from hospital. The recruitment of appropriate therapists and supports in her rural town location was difficult.

> “There’s not those sort of professionals in this area.” ELIZABETH, PARTNER

No other offers

Many participants reported that they were only offered the one option for a new accommodation setting, and therefore felt pressured to accept it in case no other offers arose and thus they missed out altogether.

> “Not in so many words but we were pretty much told that ‘if you don’t take a placement if it’s offered then you’re going to [be] waiting a very long time before you get offered another one’.” HENRY’S MOTHER

> “I had to move somewhere and it was available.” BELINDA, PARTICIPANT

Other participants who had requested to move but were still living in aged care with enhancement support felt that their request to move out of RAC had been forgotten.

> “The plan they drew up, I never got to see it. They came here and they just left with their briefcases and that was the end of it.” MARY’S PARTNER

Each of the three groups (RAC Exits, Diversions and Enhancements) will now each be considered in turn. The demographic, characteristics and outcomes for each sub-group will be presented prior to a summary of the perspective of participants and families from each group with verbatim quotes from the semi-structured interviews.

Chapter 4: Results — RAC Exit Group

Quantitative Data

Demographics

There were 34 people who moved out of RAC through the YPIRAC in Victoria and most (65%) were male. Most people moved to a shared supported accommodation service. One person moved out of RAC to live alone and another to live with family. Two people moved to an interim accommodation service in between living in RAC and their current accommodation. The people who moved out of RAC were significantly younger (range 21-53 years, mean 40 years, SD ±10.13) than the people who remained in RAC and received enhancements and the total population who received services through the Victorian YPIRAC initiative.

Disability Types

Table 4.1 RAC Exit Group – Disability Types (n=34)

Disability Types	n	%
Acquired brain injury	24	71%
Huntington's disease	3	9%
Multiple Sclerosis	2	6%
Other neurological	4	12%
Cerebral palsy	2	6%
Intellectual disability	1	3%
Quadriplegia	1	3%
Spina bifida	1	3%
Other	2	6%

N.B. One person may have more than one disability type

In contrast to the Enhancement Group, a large percentage of participants who moved from RAC had sustained an ABI.

Communication

Most people who moved out of RAC were fully aware (45%) or partially aware (45%) (Table 3.6). Seven people were able to fully participate in an interview, 17 were partially involved in an interview and ten people were not able to participate in an interview. Twelve people used a communication device to participate.

Table 4.2 RAC Exit Group – Health Issues Identified (n=34)

Health Issue	% Total Respondents	n
Hearing, Seeing and Feeling	**53%**	**18**
Hearing impairment		3
Vision impairment		12
Hypersensitivity to sensory stimuli		10
Heart and Circulation	**27%**	**9**
Heart or blood pressure problems		7
Postural hypertension		1
Limb swelling		3
Swallowing, Eating or Drinking	**65%**	**22**
Swallowing difficulties		21
Saliva management		9
Special dietary needs		9
PEG feeds		7
Weight problems (under or over)		4
Problems with appetite regulation		4
Reflux		3
Breathing (n=33)	**15%**	**5**
Recurrent chest infections		2
Difficulty coughing or clearing sputum		1
Asthma		4
Sleep apnoea		0
Tracheotomy		0
Muscles and Bones	**94%**	**32**
Altered muscle tone, spasticity or muscle spasm		27
Contractures		13
Involuntary movements		7
Paralysis, loss of movement of arms or legs		12
Chronic pain		5
Fatigue		16
Osteoporosis		3
Reduced physical fitness or conditioning		14
Skin Problems	**27%**	**9**
Pressure areas, or pressure care		4
Loss of sensation		0
Skin rashes		7
Bladder	**71%**	**24**
Urinary incontinence		18
Urinary tract infections		3
Bowel	**82%**	**18**
Faecal incontinence		17
Diarrhoea or Colitis		1
Constipation		5

Health Issue	% Total Respondents	n
Other		
Epilepsy	41%	14
Diabetes – Type 1	6%	2

N.B. Participants can have more than one problem in each category

On average each participant interviewed who had moved from RAC had four health conditions.

Mental Health

Table 4.3 RAC Exit Group – Mental Health Problems (in last two weeks) (n=34)

Mental Health Symptoms	None	Minor	Mild	Moderate	Severe	Not known
Depressive symptoms	19	5	5	1		4
Self-directed injury	31					3
Problems associated with hallucinations/ delusions/ confabulations	30					4
Problem drinking or drug use	31					3
Anxiety or stress	26	3	1	1		3

Health of the Nation Outcome Scale (HoNOS) (Fleminger et al., 2005)

Scores on the HoNOS-ABI provide descriptive indicators of mental health issues rather than specific diagnoses. Thirty-two per cent of participants in the RAC Exit Group had symptoms of depression in the previous two weeks. The only other mental health issues related to anxiety or stress (15%).

Behaviours of concern

Table 4.4 RAC Exit Group – Behaviours of Concern (n=34)

Overt Behaviour	n	% Respondents
Lack of initiation	9	27%
Verbal aggression	12	35%
Inappropriate social behaviour	3	9%
Perseveration/repetitive behaviour	8	24%
Inappropriate sexual behaviour	5	15%
Physical aggression	6	18%
Wandering/absconding	4	12%

Overt Behaviour Scale (OBS) (Kelly et al., 2006)

People who exited RAC had an average of 1.41 (SD ±1.73) behaviours of concern. More than 50% had displayed verbal and/or physical aggression in the past three months. Previous studies of younger people in RAC have found that behaviours of concern were the most common complex care need identified (Strettles et al., 2005; Winkler, Farnworth et al., 2006). A behaviour of concern is behaviour that causes distress to the person with the disability or is disruptive to other people, causing them distress or making them uncomfortable.

Social Participation

Table 4.5 RAC Exit Group – Frequency of Visits from Family and Friends (n=34)

	Friends §		Relatives †	
Frequency of Visits	**n**	**%**	**n**	**%**
Most days	0	-	6	18%
1-3 times per week	3	9%	19	56%
1-3 times per month	5	15%	5	15%
5-11 times per year	3	9%	2	6%
1-4 times per year	7	21%	1	3%
Less than once per year	3	9%	0	–
Never	13	38%	1	3%

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

Table 4.6 RAC Exit Group – Frequency of Visits to Friends and Family (n=34)

	Visit Friends in Their Home §		Visit Relatives in Their Home †	
Frequency of Visits	**n**	**%**	**n**	**%**
5 or more times per month	0	–	2	6%
1-4 times per month	2	6%	10	29%
5-11 times per year	2	6%	6	18%
1-4 times per year	3	9%	6	18%
Seldom/never	27	79%	10	29%

§ Approximately, how often do you usually visit friends in their homes?
† Approximately, how often do you usually visit relatives in their homes?

The RAC Exit Group had limited social contact with friends. Social contact with families was more common (Tables 4.5 and 4.6).

Community Participation

Table 4.7 RAC Exit Group – Frequency of going outside (n=34)

Frequency of Going Outside	n	%
More than once per day	17	50%
Almost everyday	13	38%
Almost every week	4	12%
Almost every month	0	-
Seldom/never	0	-

Table 4.8 RAC Exit Group – Frequency of travel outside of where they live (n=28)

	Travel Outside Where They Live	
Response	**n**	**%**
More than once a day	0	-
Almost every day	16	47%
Almost every week	15	44%
Almost every month	1	3%
Seldom/never	2	6%

Community Integration Questionnaire (Willer et al., 1993)

Everyone who moved from RAC was going outside regularly – almost every week or more often (Table 4.7). Nearly half accessed the community almost daily (Table 4.8).

Table 4.9 RAC Exit Group – Frequency of participation in shopping and leisure activities outside of where they live (n=34)

	Shopping		Leisure Activities	
Response	**n**	**%**	**n**	**%**
5 or more times per month	3	9%	10	29%
1-4 times per month	18	53%	16	47%
5-11 times per year	3	9%	3	9%
1-4 times per year	3	9%	2	6%
Seldom/Never	7	21%	3	9%

Community Integration Questionnaire (Willer et al., 1993)

Many of the RAC Exit Group were shopping (62%) at least monthly and participating in community-based leisure activities (76%) at least monthly (Table 4.9).

Table 4.10 RAC Exit Group – Community Integration Questionnaire questions 1-5: "Who usually does the following tasks?" (n=34)

	Yourself Alone		Yourself and Someone Else		Someone Else	
Everyday Task	**n**	**%**	**n**	**%**	**n**	**%**
Shopping for groceries	1	3%	10	29%	23	68%
Prepares meals	0	-	9	27%	25	74%
Everyday housework	0	-	4	12%	30	88%
Plans social occasions	3	9%	11	32%	20	59%
Looks after personal finances	1	3%	3	9%	30	88%

Community Integration Questionnaire (Willer et al., 1993)

The RAC Exit Group had much higher levels of participation on home integration tasks than the Enhancement Group. While none of the Enhancement Group was involved in household shopping, meal preparation or housework, some people in the RAC Exit Group were participating in these tasks. The RAC Exit Group was also more actively involved in planning social occasions and looking after their personal finances than the Enhancement Group.

Choice

Providing the support people with complex care needs require to make everyday choices and life choices is crucial to fostering dignity and self-determination (Department of Human Services, 2002).

Table 4.11 RAC Exit Group – Areas in life that people are supported to make choices (n=33)

	No Opportunity ¤		Unlikely to Give Real Choice Ψ		Final Say Doesn't Rest with the Person ‡		Procedures in Place Δ		NA
Area of Life	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	
The content of their evening meal	4	12%	1	3%	6	18%	18	53%	4
The timing of their evening meal	2	6%	3	10%	10	30%	14	41%	
Indoor leisure e.g. TV, radio	1	3%	2	6%	2	6%	28	82%	0
Going out (e.g. pub, cinema)	2	6%	2	6%	13	39%	16	49%	0
The time they go to bed in the evening	1	3%	3	9%	7	21%	22	67%	0
The clothes they wear each day	3	9%	1	3%	2	6%	27	82%	0
Involvement of intimate partners	4	12%	2	6%	1	3%	13	38%	12
Their daytime activities	1	3%	2	6%	3	9%	27	82%	0
The time they spend in the bath or shower	4	12%	4	12%	8	24%	17	52%	0
Access to a private area	1	3%	2	6%	1	3%	29	88%	0
The furnishings in their bedroom	1	3%	0	-	2	6%	30	91%	0

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

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

‡ Some procedures mentioned through which person can express preferences but final say does not rest with the person.

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

Resident Choice Scale (Hatton et al., 2004)

Many people in the RAC Exit Group still had limited opportunities to make everyday choices (Table 4.11)

Table 4.11 provides information about the level of support and opportunity people in the Enhancement Group were given to make choices with regard to various areas of life. The planners conducted interviews with informants (the individual, their support network and paid staff) about the person's participation in making choices. Based on this information, the planner rated the person's level of participation in making choices in each area of life listed in Table 6.11.

Role Participation

It is essential that everyone has the same opportunities to participate in the life of the community and can choose the roles they want to play in society alongside other citizens (Department of Human Services, 2002). A role is defined as the expected pattern of behaviour associated with occupation of a distinctive position in society (Heard, 1977). Adult occupational, family, avocational and social roles allow people to participate in society and satisfy human needs (Oakley et al., 1986).

Table 4.12 RAC Exit Group – Current and desired future role participation (n=34)

	Current Participation in Role		Desired Future Participation in Role	
Role	n	%	n	%
Student: Attending school on a part- or full-time basis.	0	-	3	9%
Worker: Part- or full-time paid employment.	1	3%	3	9%
Volunteer: Donating services, at least once a month.	1	3%	5	15%
Caregiver: Responsibility at least once a month for the care of someone such as a child, spouse, relative or friend.	0	-	2	6%
Home maintainer: Responsibility at least once a month for the upkeep of the home such as house cleaning or yard work.	8	24%	11	32%
Friend: Spending time or doing something at least once a month with a friend.	15	44%	23	68%
Family member: Spending time or doing something at least once a month with a family member.	33	97%	33	97%
Religious participant: Involvement at least once a month in groups or activities affiliated with one's religion.	1	3%	3	9%
Hobbyist or Amateur: Involvement at least once a month in a hobby or amateur activity.	18	53%	24	71%
Participant in Organisations: Involvement at least once a month in organisations such as Rotary, Guides, etc.	7	21%	9	27%

Role Checklist (Oakley et al., 1986)

Moving from RAC provided some people (24%) with the opportunity to be involved in the home maintainer role (Table 4.10). No one living in RAC was involved in this role. Some people who moved from RAC (68%) report a desire for more involvement in friendships. Most people (97%) spent time with their family at least once per month and the same number of people wanted to participate in this role in the future. Many people in the RAC Enhancement Group were hoping to participate in a range of roles in the future. Only 9% (3 people) were parents of school-age children.

Support Needs

The CANS Section 2 provides eight levels of how long a person can be left alone.

Table 4.13 RAC Exit Group – Length of time person can be left alone (Care and Needs Scale section 2) (n=34)

CANS Level	n	%
Cannot be left alone. Needs nursing care, assistance and/or surveillance 24 hours a day.	5	15%
Can be left alone for a few hours. Needs nursing care, assistance and/or surveillance 20-23 hours per day.	19	56%
Can be left alone for part of the day but not overnight. Needs nursing care, assistance, supervision and/or direction 12-19 hours per day.	5	15%
Can be left alone for part of the day and overnight. Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills.	5	15%
Can be left alone for a few days a week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional supports a few days a week.	0	–
Can be left alone for almost all week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once per week.	0	–
Can live alone, but needs intermittent (i.e. less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support.	0	–
Can live in the community, totally independently. Does not need contact.	0	–

Care and Needs Scale (Soo et al., 2007)

The CANS Section 2 provides eight levels reflecting how long a person can be left alone. In the RAC Exit Group, 15% of people require the highest level of support, indicating they cannot be left alone and require nursing care and/or surveillance 24 hours per day.

There was no significant difference in the support needs of the group of people who moved from RAC and the group who remained in RAC and received enhancements. Both groups had high support needs, as apparent in Table 4.14.

Table 4.14 RAC Exit Group – Number of participants who require assistance for the following support needs (n=34)

Support Needs	n	%
Tracheotomy management	0	-
Nasogastric/PEG feeding	6	18%
Bed mobility/turning	16	47%
Wanders/gets lost	4	12%
Exhibits behaviours that have potential to harm self or others	4	12%
Difficulty communicating basic needs due to language impairments	24	71%
Continence	26	77%
Feeding	24	71%
Transfers/mobility	23	68%
Personal hygiene/toileting	31	91%
Bathing/dressing	33	97%
Simple food preparation	32	94%
Shopping	32	94%
Housework	34	100%

Care and Needs Scale (Soo et al., 2007)

Quality of Life Measures

The Comprehensive Quality of Life Scale (ComQol-15) (Cummins, 1997) was administered either with the participant directly or with a nominated proxy (e.g. a family member). The variability of the number of participant responses for each question was due to some nominated proxies feeling unable to answer specific questions on behalf of their family members. Other participants declined to respond to this particular tool.

Table 4.15 RAC Exit Group – Quality of life

Item	Almost Always		Usually		Sometimes		Not Usually		Almost Never	
	n	%	n	%	n	%	n	%	n	%
Q1. Time use (n=29)	5	17%	4	14%	10	35%	3	10%	7	25%
Q2. Sleep (n=30)	15	50%	8	27%	5	17%	2	7%	0	-
Q3. Safety (n=27)	22	81%	3	11%	2	7%	0		0	
Q4. Worry (n=29)	1	3%	2	7%	7	24%	4	14%	15	52%

ComQol -15 (Cummins, 1997)

Q1. In your spare time how often do you have nothing much to do?
Q2. Do you sleep well? How often?
Q3. Are you safe where you live? How often do you feel safe?
Q4. Are you ever worried or anxious during the day? How often?

Table 4.16 RAC Exit Group – Hours spent watching television per day (n=29)

Item	10 + hrs	6-9 hrs	3-5 hrs	1-2 hrs	None
Percentage of participants	10%	24%	31%	24%	10%

ComQol -15 (Cummins, 1997)

Young people who moved out of RAC were more occupied than the Enhancement Group (Table 4.15) and fewer people spent more than 10 hours watching TV (Table 4.16).

Family Support

Family members who were willing to participate were given the Family Outcome Measure to complete either on their own or with the researcher. The measure has 42 questions ranging from a number of topics including; family member coping, family cohesion, support demands (burden), relative adjustment, adequacy of service support, family member resilience and sustainability of family support. Not all family members agreed to complete this measure. The FOM was completed by a range of relatives including mothers (8 people), fathers (4 people), siblings (2 people), one partner and one daughter.

The following table summarises the responses from participating families on a selection of these questions.

Table 4.17 RAC Exit Group – Family Outcome Measure – Family member coping (n=16)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have time for myself	12%	53%	29%	6%
I worry a lot of the time	24%	35%	24%	18%
I feel in control of my life	18%	59%	18%	6%
I have plenty of opportunity to rest	18%	65%	12%	6%
I feel I need some time out	6%	29%	53%	12%
I feel overloaded	6%	35%	47%	12%
I often feel tired	18%	41%	29%	12%
I have trouble sleeping	18%	29%	53%	–

Table 4.18 RAC Exit Group – Family Outcome Measure – Family Cohesion (n=15)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
We spend more time together now	6%	38%	25%	31%
We are more intimate	13%	38%	38%	13%
We go out more	13%	50%	31%	6%
I understand my relative better now	6%	31%	56%	6%
We spend more quality time together	19%	63%	13%	6%
We are closer now (n=14)	–	20%	67%	13%

Table 4.19 RAC Exit Group – Family Outcome Measure –
Family support demands (burden) (n=16)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have to keep checking on my relative	12%	29%	41%	18%
My relative depends on me now	6%	47%	29%	18%
I make all the important decisions now	6%	29%	47%	18%
I have to be able to supervise my relative	12%	41%	35%	12%
I have to look after my relative	6%	47%	41%	6%
It is difficult to get a break from providing support to my relative	12%	41%	35%	12%
My relative needs lots of assistance	18%	41%	24%	18%
I have had to put my future plans on hold	6%	47%	35%	12%

Table 4.20 RAC Exit Group – Family Outcome Measure – Relative adjustment (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
My relative feels upset about losing some/many of his/her roles in the family	43%	36%	7%	14%
My relative gets depressed	50%	29%	7%	50%
My relative has mood swings	43%	21%	14%	21%
I have to keep my relative cheerful	36%	36%	14%	14%
My relative's personality has changed	36%	36%	14%	14%

Table 4.21 RAC Exit Group – Family Outcome Measure – Adequacy of service support (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have not been given enough information	7%	43%	36%	14%
It is difficult dealing with different staff and/or services	14%	29%	36%	21%
I feel as if our family and the staff work together like a team	14%	14%	64%	7%
I feel that my relative is not getting enough treatment	7%	21%	50%	21%
I can get the services that are needed	7%	14%	79%	_

Table 4.22 RAC Exit Group – Family Outcome Measure – Family member resilience (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I feel as though I can't cope	14%	36%	29%	21%
I am still able to laugh about things	7%	14%	57%	21%
I have someone that I can talk to if I need it	–	7%	64%	28%
I still find enjoyment in life	–	36%	50%	14%
I feel unwell a lot of the time	14%	57%	14%	14%

Table 4.23 RAC Exit Group – Family Outcome Measure – Sustainability of family support (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I enjoy supporting (caring for) my relative	–	29%	29%	43%
I cannot see myself providing support to my relative over the long term	7%	21%	36%	36%
I have more negative feelings about my relative now	14%	7%	36%	43%
My relative seems very self-centred now	14%	29%	21%	36%
I feel trapped in this situation	14%	43%	14%	29%

Qualitative Data

Shared Supported Accommodation living – the Advantages

As discussed earlier, the decision to accept the offer to move from RAC into a new SSA service was perceived as a risk for many participants. However, the analysis of the post-move interviews with participants and their families revealed a number of clear themes that highlighted the positive aspects of living in shared supported accommodation (SSA) compared to RAC.

Freedom and choices

A strong theme that emerged from the analysis of the post-move interviews was the increased feeling of freedom experienced by many of the participants in their new homes. This freedom presented in many forms including choice of activities, places to visit and meals, as well as being able to step out the front door without the institutional elements of RAC (such as entering a security code to exit the building).

> “Well I’m able to do exactly what I want whenever I want.”
> SIMONE, PARTICIPANT

> “He’s got a door outside from his room, that he can go in and out when he wants to and things like that.” JACK’S FATHER

> “It is so much a home, a house and a family home, rather than an institution.” HARRISON’S MOTHER

It was reported that some SSA staff were encouraging the participants to try new things and this was perceived as a different approach to that encountered within the RAC setting. One participant, speaking through her communication device, reflected on her newfound community participation since she had moved out of RAC:

> “The opportunity to go out, to the movies, to see Mary Poppins.”
> KRISTY, PARTICIPANT

Another participant’s family reported being pleased that the person with a disability was encouraged by staff to register to vote. He had also been linked into a specialist surfing school where he was supported to participate in modified surfing. His father reported:

> “He’s getting more opportunities to go places.” BRAD’S FATHER

A number of participants reported that, since moving from RAC to SSA, they now have more choice regarding what they do during the day. This may be in the form of a preferred recreational activity, or simple domestic tasks in which they were unable to participate in the RAC facility.

> “Right now, you know, I love it. I can play music loudly and I can play my own music.” JAYNE, PARTICIPANT

> “Clean my own clothes…just chuck them in the washing machine, put some powder in it, and psssh.” DELILAH, PARTICIPANT

Almost all participants and families reflected on the new-found opportunities the person with disability had in making choices in what they would eat for each meal.

> “You can make your own mind up what you want for tea. What you want for lunch or whatever.” KARL, PARTICIPANT

> “Just being yourself, eat when you want to eat, just be who you want to be.” POLLY, PARTICIPANT

Many spoke of the importance of house staff encouraging residents to plan together the meals they would have over the next week.

> “They discuss what they’re having for dinner…so it’s like a home environment, it’s not food being wheeled in on a trolley with 30 other meals that are cold and smell of cabbage.”
> MATTHEW’S SISTER

Some families reported a noticeable increase in the participant’s health and well-being due to their increased enjoyment of meals, and subsequent improved nutrition. One participant was previously overweight but he had lost weight since moving to the SSA as he was no longer buying take away food to eat in place of the meals served in RAC. Another family commented on a similar change:

> “They ask him a lot what would he like to eat…he looks so much better, he seems to be eating…I don’t know…better food or something.” BRAD’S MOTHER

It was apparent that, for some people moving out of RAC into a home-like environment, it took time to adjust to making choices again in their everyday activities or routines, such as making a drink or showering when they chose to do so.

One SSA manager commented on how long it took a participant to learn that he could enter the kitchen and participate in domestic tasks at times of his choice after moving out of RAC:

> “It took him six months to go into the kitchen and make his coffee.” SSA MANAGER

The same manager also reported that, for many months, the participant used to ask for permission to have a shower.

The challenge of adjusting to this new freedom, which involved having less secure entrances/exits at their new home and less rigid routines, was discussed by participants.

> “At first… it was unusual to go out the front door but now I’ve done it quite often, it’s just…it’s not so formal…you’re free. I have a life.” CAROLINE, PARTICIPANT

Better quality of life

A number of people reported noticing that their family member seemed happier since they moved out of RAC. Some reported that the participant seemed to smile more while, for those people who did not have intelligible expressive communication, others reported distinctly less vocalisations of distress, such as moaning.

> “When you go in there, he just meets you with this lovely grin and smile.” BRAD’S FATHER

> “It’s just what we wanted and he’s happy and that to me is everything.” NED’S MOTHER

A few family members referred to the change as an improvement in the participant’s quality of life:

> “The quality of his life is heaps better because he’s more relaxed.” CLINT’S PARTNER

> “I cried with joy for Vera once I received the news because I know she’s getting quality of life here whereas, in a nursing home, she would be just in a chair, and her needs – basic needs, would be met. That she was fed and showered and that would be her life. Whereas now I know she’s going to have quality of life.” VERA’S MOTHER

Family members enjoyed seeing the difference in the participant’s happiness, and this in turn positively affected their own well-being:

> “Well it’s good because I know he’s happy. He’s well looked after. The people treat him with respect, so that makes a big difference to me.” SHAUN’S MOTHER

Throughout the interviews, a particular difference that was regularly reported on when families were comparing the new SSA with RAC was that the participants were enjoying more interactions with others, particularly the staff, throughout their day:

> “The staff go out of their way to interact with the people that are here.” JACK’S FATHER

The benefits of the increase in these interactions, compared with the RAC setting, were noticed:

> “[He’s] come out of his shell a bit more.” WERNER’S MOTHER

> “We always do something…you don’t get bored there, which is what I like.” CARA, PARTICIPANT

Families noticed that staff took more time to understand the participant’s communication needs, and encourage their verbal communication.

> “They’re probably asking questions and sort of waiting for the answer perhaps. Whereas at the nursing home, they were in a hurry.” BRAD’S MOTHER

Many family members commented on the impact of the changed environment when comparing the SSA with RAC. The SSA environment was described as being calmer and more comfortable for the participants than RAC, as well as providing a sense of normality.

> “It’s made a positive [difference] and it’s going to continue to grow which would never have been possible in aged care, because it wasn’t an environment for that. It was an environment for death.” TOM’S MOTHER

> “He said it was just like winning Tattslotto to be able to move from the nursing home environment into this new house that was purpose built. It was just going to provide so much more of a normal life for him.” MATTHEW’S SISTER

One family member spoke about the change he had noticed in his brother since he’d moved out of RAC into the new SSA:

> “He looks like before he become sick. He looks beautiful. He looks clean, his hair is good now; it’s curly like it was before.”
> BEN’S BROTHER

It has relieved the pressure on the family

Many families who were highly involved in the participant’s daily life and had seen the impact living in an aged care facility had on the participant reported worrying less about the participant now that they lived in the SSA.

> “I don’t worry so much now. We’ve always had a worry.”
> MARTY’S MOTHER

This reduction in anxiety about the participant’s welfare has led to a release of long-term pressure for some families:

> “[It’s] taken a lot of pressure off the family and to everyone’s betterment and enjoyment and so on.” BRAD’S FATHER

Family members shared their sense of relief and reduced burden at seeing the quality of care provided to participants in their new homes. This reduced sense of carer burden in turn impacted positively on the family member’s own life.

> “I’ve got a bit more freedom, because I know she’s well cared for.” PATRICIA’S SISTER

> I can relax. I don't have to walk away in tears…yes…I can hug her and kiss her without cringing because she's showered regularly, and they pamper her." VERA'S MOTHER

> We can visit her twice a week so we know she's not neglected or she's not just sitting there in her room on her own. She's out mixing with the others girls or listening to them talk. It is different altogether [from RAC]." KRISTY'S MOTHER

Following on from this reduced caregiver stress, some families highlighted positive changes in their lives since their family member had moved to the SSA, such as going on holidays for the first time in a long time, being able to increase their employment hours, or spend more time with other family members such as grandchildren.

> It's making his life many, many times better than it was. It's given us a life again." BRAD'S FATHER

Another positive change for families was that many felt very welcome by staff when visiting their family member in the new SSA. Families discussed that when the participant resided in RAC the high number and regular turnover of staff meant the family were often faced with unfamiliar staff members. Families reported, in contrast, the small number of residents and a family-sensitive culture in some SSA houses meant the family felt welcome and were encouraged to feel at home.

> Even for visitors…when I go…they come, welcome, everything, you know, beautiful…'You want coffee or you want this or you want that?'" BEN'S BROTHER

Some families discussed their pleasure at being involved in the early decision making and purchase of furniture and other items for the house in order to make it more homely for the participant. Others described having a positive relationship with SSA staff:

> Well you feel important as well. Not important – that's not the word – but welcome and respected as well because we're Ned's family." NED'S MOTHER

> I'm happy when I go there because I know I'm very welcome there." BEN'S BROTHER

Many family members reported that seeing the participant happier and in a more appropriate accommodation setting led to increased happiness and relief for the person's family.

> “I’m nearly 81 and I thought ‘God, I hope he gets settled before I go’. But he’s happy about it and I’m happy about it.”
> WERNER’S MOTHER

> “I’m happier in myself too because I’m seeing Greg in a much better environment.” GREG’S MOTHER

At the time of the interviews, relationships between residents’ families had also started to develop. Many felt supported by each other, and enjoyed talking to the other residents and families, and looking out for each other.

> “When we go there, we’re…part of the family that’s there.”
> MARTY’S MOTHER

A number of families discussed that seeing the participant in their new home has led to new feelings of hopefulness of the future.

> “It’s got to improve his situation for sure. There’s no doubt about that. His situation will improve no matter what happens.”
> MARTY’S FATHER

> “I think if Ned had remained in aged care, I mean I might be exaggerating here but I don’t think Ned would live as long as he will here.” NED’S MOTHER

> “I know now I’ve got peace of mind; because I know he’s going to be cared for properly.” GREG’S MOTHER

It’s a home of ours

A strong theme that emerged from the analysis of the interviews was the sense of belonging that the participants experienced in their new home.

> “I suppose there’s a sense of security because you know it’s your home and it’s a sense of belonging…you do participate in a lot of the day-to-day things, running of the house and that, and that’s always good.” TIM, PARTICIPANT

> It is such a home environment, yeah, so that's one of the things that's just been just really good for him." HARRISON'S SISTER

For some participants, this was the first place they felt comfortable enough to call home in a long time.

> It feels like home. I never could say I wanted to be in a nursing home. I could never call it home." CAROLINE, PARTICIPANT

Many of the SSA managers that were interviewed also recognised this positive change and adjustment for the participants.

> He just said…I never have to go back to aged care do I? He said I want this to be my home for the rest of my life."
> SSA MANAGER

In some instances, some family members noted that the quieter environment had led to an improvement in behaviour for the participant in contrast to when they were living in a busy aged care facility.

> He's much calmer here than there where he was [in RAC]."
> BEN'S BROTHER

While living in RAC, many participants had shared rooms with others, and lack of private spaces meant they were required to entertain their guests in their bedroom. So for many participants, they talked about the benefits of their own room or the addition of a separate lounge room in the SSA:

> Another good thing is the front lounge room – a lot more privacy." KRISTY, PARTICIPANT

Families also noted the benefits of this new-found privacy:

> It's much better to visit him because they've got so many rooms. When I go there, they leave me alone with him…we talk, we laugh, everything is beautiful." BEN'S BROTHER

A participant reported that one of the most important things about their new home is:

> ...having my own space." DEAN, PARTICIPANT

Another factor which contributed to the accommodation feeling much more home-like was that many participants felt encouraged to welcome family and friends into the house.

> “It’s a house for young people, and it’s their house, so they can invite who they want. You can come and have a meal with them and it’s just a way of just normal life for them, instead of like a nursing home where everything is kind of rules and regulations.” SHAUN’S MOTHER

Families and participants reported that the home-like aspects of the SSA offered a more friendly and welcoming environment.

> “It’s sort of more friendly to people to want to visit I suppose. It’s more a regular home I guess, rather than a hostel sort of setting.” HARRISON’S MOTHER

I’ve got my independence

Participants and their families wanted to share examples of both small and significant ways in which they have had new opportunities to develop their independence in their personal and domestic skills. A selection of some of these skills the participants highlighted were: cooking, snack preparation, collecting mail, cleaning their room, improving their continence, dressing themselves, turning on/off TV, making themselves a drink in the kitchen, and using a microwave.

> “Within less than five months or something he was actually showering himself because the opportunity was there…it could be the timeframe but I think it’s more like the environment that has allowed him to become more independent.” CLINT’S PARTNER

For many participants, these skills had not been used for many years, as they didn’t have any opportunities in RAC where all meals, snacks and domestic services were provided for the person.

> “They get him up of a morning, he’s got to get his own bread, he’s got to make his own toast, he’s got to butter and jam it… things he hasn’t done for nearly 18 years.” MARTY’S MOTHER

One family shared the experience that her brother’s skill of being able to ask to use a urinal once living at the SSA was now able to be met, in contrast to whilst he was living in RAC:

> “The staff were thrilled to pieces that Matthew could ask for a bottle. He could always do that; it’s just no one could get there in time. So, that means that Matthew no longer has to sit in wet nappies for hours on end.” MATTHEW’S SISTER

However, for many participants and their families, the simple day-to-day opportunities of participation within their home have made a difference to the person with a disability’s quality of life. Jayne really enjoyed basic tasks associated with being a homemaker.

> “Stocking her bathroom with toilet paper; the tiniest little things are very, very important to her.” JAYNE’S FATHER

For some participants, these new opportunities led to an improvement in their initiation to help and participate in home-based activities:

> “I’m always doing something. They’re either getting me into the kitchen helping them or doing something else. I always have the option of making something and that I think it is great.”
> SIMONE, PARTICIPANT

Some family members thought the participants’ communication skills had improved from being encouraged to talk and interact with the other residents and staff much more than in aged care:

> “Here they’ve got more time, they’re understanding…they try and encourage him to talk. If he shakes his head they say ‘What did you say?’…giving him the encouragement to do more than what he can do.” SHAUN’S MOTHER

One family thought the improvements in communication skills were due to the participants feeling more settled and calm:

> “His speech, I believe, is starting to improve because he just no longer is as upset as he used to get.” MATTHEW’S SISTER

Positive behavioural changes for the participants were also noted, as demonstrated by this report of a service manager:

> “We had a [behaviours of concern] profile given to us about what he was like and what we needed to be aware of. We’ve probably seen five per cent of that.” SSA MANAGER

Additional to the behavioural, communication, and personal and domestic skills improvements highlighted for the participants, many families also noticed an improvement in physical skills since their family member’s move into the new SSA.

> “There’s heaps of change. His flexibility’s even changed, his movement.” WERNER’S MOTHER

> “I’m doing more exercise and physio.” CAROLINE, PARTICIPANT

Some participants and families thought this was due to more opportunities and encouragement to move and exercise.

> “Someone takes me to the pool. His job is, or one of his jobs is trying to keep me fit…We are doing kicking, because I live in the chair full-time and I starting kicking a couple of months ago…I was very surprised in kicking myself.” GREG, PARTICIPANT

For some, the changes in their physical abilities have been significant:

> “When Clint first moved in, he was sleeping for 90% of the day… it was explained to us that that was health related. Through taking him out and about into the community, he slowly stopped napping as frequently and now he doesn’t even nap throughout the day, which is quite a big change.” SSA MANAGER

One participant has demonstrated a significant change in his ability to eat orally as SSA staff had been providing him with opportunities to develop this skill. This has meant that his supplemental PEG feeds had reduced significantly.

> When he first came here, he was having only a little bit of solid food, maybe once a day. Now he's having a solid breakfast. He's having a solid lunch. We're looking at a solid dinner."
> TOM'S MOTHER

It's so roomy and it's got everything

A number of participants and their families commented positively on the modern features and accessible designs of some of the new SSAs, especially in comparison to many of the RAC environments.

> Bright…it's not dull…the walls are painted bright, everything blends in…It's open, there's space to walk." MARTY'S FATHER

> It couldn't be any more modern than it is…we believe it's been very, very well planned and organised and laid out very well. They've thought of pretty near everything." BRAD'S FATHER

Some family members and participants felt the planning of the design positively supported the participants' independence:

> It's got a great design for a start. I like the idea that I can build on my independent living skills and just to keep up the skills I've got even." TIM, PARTICIPANT

The open plan of the service, allowing good access both inside and out, was an important feature for many:

> It's easy for him to manoeuvre his wheelchair around. He's got good access outside." JACK'S FATHER

These design features that encouraged independence led to increased comfort for the participants and general homeliness of the service.

> It's like being at home, you know, you can watch television any time you like, you can go to the kitchen and get a drink, whereas in the nursing home you can't. It's very, very much like a real home." CLINT'S PARTNER

He’s in good hands

The majority of the participants and their families wanted to share positive experiences of interactions and care provided by the SSA staff. When describing the staff’s interactions with residents, the interviewees used the following words or phrases: friendly, more personal, extra attention, respectful, caring and taking the time to understand.

> “The staff here go out of their way to interact with the people that are here. I think he likes that. While it’s not one-on-one, in lots of instances it’s similar to that…he gets plenty of attention and interaction.” JACK’S FATHER

Some families appreciated the training the staff had received regarding working with people with disabilities, including understanding their specific and individual care and rehabilitation needs:

> “It is far more geared to slow-stream rehab for acquired brain injury than where he was.” MICK’S MOTHER

One family member commented on how the staff proactively managed her partner’s cognitive and behavioural impairments that had previously led to the participant’s absconding from the aged care facility:

> “He’s much more relaxed and the staff know how to deal with him. So if he goes towards the door they just say, ‘Come on, let’s check the mailbox’ or something.” CLINT’S PARTNER

Many participants and their families were pleased that staff members were often young and of similar age to the participants.

> “The staff are marvellous. They’re all young and they’re lovely and they all love Greg.” GREG’S MOTHER

Some families were impressed that the staff were willing to listen to any concerns and work together to resolve these:

> “I just thought, ‘We’ll give this a shot and see’, even though this was sort of in the early stages and it’s had a few teething problems along the way, but they’re quite happy to listen to any complaints or whatever and try and work things out as they go.” HARRISON’S MOTHER

Overall, a very strong theme that emerged from the analysis is that the new SSA staff were more able to provide an individualised approach to the participant’s care than RAC staff.

> I could nearly go as far as to say that in our situation…Brad couldn't be looked after better than what he is. They are just fantastic to him." BRAD'S FATHER

> I think that this is fantastic that this gentleman does not have to get up at nine o'clock, go off to a [day] program, fit into a program. He can choose to do whatever he likes for the day."
> SSA MANAGER

During the interviews, many examples of an improvement in basic care needs being met were provided, as well as how these in turn led to improved health and well-being of the participant.

> I think he's a lot healthier…I mean he has had a couple of chest infections here, but they're right onto it…he was getting more [at RAC], he nearly always had a chest infection and I think part of that was because he was lying down too much… someone who's PEG fed like Ned…to be in bed too much…it's not good for their chests." NED'S MOTHER

> Since I've moved here it [my health] has improved…the healing process of my wounds, because I've got bed sores. I'm kept out of hospital, whereas if they couldn't handle it at the nursing home, they would just send me off to the hospital or not do the dressing properly." POLLY, PARTICIPANT

> He was having like a small bit of something [oral intake] at the nursing home that either his speech pathologist or I would give him. If we weren't around, that couldn't happen. But here, he's now having breakfast and lunch." TOM'S MOTHER

Even though the majority of staff were not of a nursing background, many families did not find this an issue, as the staff provided attention to detail in the care delivered.

> I would say the vast majority of the attendant carers that we now have are, I think, as good as we've had anywhere. In fact, without a doubt, he is so far better off than he was in the nursing home it's not funny." NEIL'S FATHER

> They are very friendly because they are trained for these kind of jobs. They are very friendly and very good with him."
> BEN'S BROTHER

> “They’re all trained with disabled people so they’re all right.”
> MARTY’S FATHER

One family member provided the example of the participant becoming unwell and requiring hospital care. A staff member kept the family informed throughout the night and stayed overnight at the hospital with him. The participant’s father commented on this service compared to RAC:

> “Now if that had been at [RAC], they would have rung us up and said, ‘Brad’s crook, dah, dah, dah, we’ve put him in the ambulance and sent him off to [town name]’…end of story… ‘It’s [not] our problem, you look after it.’” BRAD’S FATHER

Another positive aspect of the staffing within SSAs that was noted by family and participants was that the staff aim to create activities and opportunities for the participants to be involved with throughout the day.

> “They make a real effort…to bring him music or play the music they know he likes.” MICK’S MOTHER

The capacity of staff to facilitate this participation was perceived to encourage the participants to get up and out of their room, interact with others and undertake activities of interest.

> “It doesn’t matter when you come, like no matter what time of day or whenever, he’s always down mixing and they’re so good…I felt that he’s a respected part of this household and he gets treated like that.” NED’S MOTHER

Another positive noted by families was that the staff created an environment of making the families welcome:

> “They really go beyond the call of duty. They’re nice when people come, you know, nothing is too much trouble. They’ll make you a cuppa, ask if you want something for lunch.”
> SHAUN’S MOTHER

One service manager discussed with the researcher the importance of leadership to encourage a positive staff culture.

> “If you move somebody out of an aged care facility and put them in a beautiful building…[if] the staff aren’t consistent… [if] the staff aren’t any more concerned than the staff were in the nursing home and the leadership is poor, you might as well just transfer from one aged care facility to another.”
> SSA MANAGER

Shared Supported Accommodation Living - Challenges

Although the majority of respondents reported moving into a SSA had a positive impact on the quality of their lives, some participants and their families wanted to discuss the challenges they faced when they moved out of aged care to a new SSA service through the Victorian YPIRAC initiative.

Giving up funding

Some participants and their families discussed the challenges they faced when their Individual Support Package (ISP) funding for activities either reduced or was ceased once they moved out of RAC.

> “Since he’s moved in, DHS has cut his ISP hours…so he was getting 10 hours ISP and so they’ve cut that down to five hours ISP…I just said, ‘Well, that’s ridiculous, he’s moved house, you know, what’s the point of him moving house and then being stuck at home all the time.’” HENRY’S MOTHER

Some families felt that the cessation in funding was too sudden and they would have preferred it to be slowly reduced throughout the participant’s transitional program.

> “The fact that it stopped so suddenly, I had a real problem with, because I felt the move was enough...[it] should have tapered off slowly.” TOM’S MOTHER

Others felt the reduction in funding negatively impacted on the participant’s involvement in community activities.

> “We’d just trained up people and they were doing his movement program…[he was going] to hydro which he hasn’t done since he’s moved here, and he was going to the football…they are making an effort now to get him out, but it’s still not as much as it was and when he goes out then they’re short staffed here.” MICK’S MOTHER

Staffing concerns

In contrast to the positive reports of the disability support workers model provided in SSAs, which was detailed above, some family members were very concerned about some of the staff working in the service and their inexperience or lack of training in specific disabilities, such as acquired brain injury.

> “I went along to the first staff meeting…went round the room and everyone introduced themselves and I was quite shocked at how inexperienced the staff were…they’ve all done some sort of certificate or whatever, but few of them with any experience.” TOM’S MOTHER

> “The staff are very nice and friendly. No doubt about it. They provide care, but I can assure you none of them know about acquired brain injury.” TONY’S MOTHER

The experience and training of staff was often linked to their confidence and ability to support a participant with high physical, cognitive and communication needs in the community.

> “Our staff are really conscious about the vulnerability of our residents and take that pretty seriously. So staff talk sometimes about being fearful or anxious about taking people out, particularly some of our residents with complex medical issues going on – epilepsy, diabetes – some of which can be quite unstable.” SSA MANAGER

Some family members felt the participants with higher physical support needs were not assisted to access the community as much as other residents.

> “I would like more community…far more community access and also the ability to come home more…the staffing is the issue here. There’s not enough staff…some of the people who can talk or are a bit more mobile get out a lot and there’s programs for them, whereas the guys like Mick [high needs]…tend not to go out very much.” MICK’S MOTHER

A particular issue that was reported by participants and families was that they felt the staff at the new service were not working as a team with the participant, families and therapists.

> “I just want the team approach. I want openness, I want transparency. I don’t want blockers put in the way. I want Mick’s health and Mick’s well-being to be put first and that hasn’t been the case in the last 12 months.” MICK’S MOTHER

One family reported that the staff were relying heavily on them as family to sort out issues relating to the participant’s care. This had caused their stress to increase since the participant had moved out of RAC.

> “We get phone calls every second night and we’ve got to run down there…it has increased a bit of stress on us because we are always worried about what’s going on.” PAULINE’S FATHER

Recruitment and retention of staff was also reported by some families to be an emerging issue for the service provider. Families were concerned that this meant that casual or unfamiliar staff were often providing support to the participants.

> “They’re struggling to find staff.” HENRY’S MOTHER

It's not a home, it's a facility

Many family members and participants were concerned about particular design issues in some of the new SSAs. These design issues were perceived to lead to an institutional feeling in some of the places, rather than a home-like environment.

> "It's not what I call a warm environment, there is no incentive for him to say, 'Look, I'd rather come out [of room] and sit in front of the bigger television with some other people.'"
> TOM'S MOTHER

Another participant pointed out a significant issue with privacy during bathing due to the limited circulation space in the bathroom.

> "If you have to use the toilet, you can't shut the door because I have to sit in a shower chair over the toilet. So it's very impractical in that sense." POLLY, PARTICIPANT

Some families spoke about how the staff still ran the service like an institution or facility, rather than a home.

> "It's not a home, it's a facility…it's designed as such and they're running it as such." NEIL'S FATHER

Missing the staff and routines of RAC

A number of families and service managers were surprised at the loss the participants felt at moving out of the aged care facility. This involved missing both the staff and familiar routines of RAC.

> "I have to say that I was just gobsmacked, I suppose, is the only way, by his grief when he moved here…he [would type] on his communication device to 'take me back to my room…take me back to [RAC name]' because that's all he's known…he should never have been in aged care to begin with. It should never have felt like that was his home." TOM'S MOTHER

In contrast to those people enjoying the calmer and quieter SSA environment, some participants found themselves missing the busy atmosphere of the RAC, where they felt there was always someone to watch or interact with:

> "Greg was missing [RAC name] very much. When he first moved here he was quite depressed because he was so used to having 50 people around him in the nursing home, whereas over here he had like four people. So it was a big, big transition." GREG'S MOTHER

> “It was more likely that there was someone to talk to [in RAC].”
> TREVOR, PARTICIPANT

One participant felt some things had been promised at the SSA, but had not been delivered, including the staff attitudes and the residents’ choice regarding staff. He spoke of the frustration that he felt the staff didn’t respect that the house is his home and the home of the other residents:

> “They treat it like they live here, not like our house…they come in and change the channel to what they want.” TREVOR, PARTICIPANT

Unlike a number of people who reported limited staff time as an issue in RAC, Trevor also felt he received less 1:1 support in SSA. He felt that this was because their role included client care, as well as domestic tasks:

> “Technically there are more staff here per resident but technically less hours per resident. The staff [in RAC] had extra cleaners and people to do the cooking, so they could spend more time with us.” TREVOR, PARTICIPANT

Resident compatibility

Some family members and participants felt that the selection of new residents was not appropriate, and not enough effort was put into selecting residents based on compatibility.

> “They’ve just [said] we’ll take you, you’ll do because you’ve been there for so long so you deserve a break…there doesn’t seem any cohesion or any searching to try and get a group together who are going to get on…it’s like getting four foreigners in the one house but none of them speak the same language.”
> GREG’S MOTHER

Some families reported that the discrepancy in the participants’ ages, interests, abilities and skills was unexpected, and they had expected that the participant would have been able to find someone to interact with, and get to know as friends, within the SSA environment.

> “My interpretation of the whole *my future my choice* thing was to create some places where…young people with disabilities could mix and interact with other young people with disabilities. So, in this particular case, it’s not happening…he’s left with, out of the four people that are here, one that he could perhaps interact with; it could’ve been better.” JACK’S FATHER

A particular issue raised was when participants with sound verbal communication skills were placed with other residents who were unable to communicate verbally or had significant cognitive impairments.

> “Prior to moving in, we were told that all the residents would be similar to Greg. So we weren't able to meet any of the residents prior to moving in…but it's very difficult because I was hoping that he would have had people that he could converse with and more like a family…a huge disappointment. I actually don't know whether I would have moved him in.”
>
> GREG'S MOTHER

In some cases, the lack of compatibility between residents led to isolation for the participants.

> “The people here are very separate…they're quite a diverse group in terms of age and disabilities.” TOM'S MOTHER

Some SSA managers noticed the isolation and distress for some new residents.

> “He went through a little stage of what was…we believe…was bordering on depression, given the fact that the other people within the house can't talk to him.” GREG'S SSA MANAGER

Chapter 5: Results — Diversion Group

Quantitative Results

Demographics

Through the YPIRAC initiative there were 11 people in the Diversion Group who were at risk of admission to RAC and received services to prevent this admission. Of these, 64% were male. The Diversion Group tended to be older (mean 43 years, SD ± 9.1, range 21-52 years) than the RAC Exit Group and younger than the Enhancement Group. Five people moved to Shared Supported Accommodation services, two people transitioned to living alone and four were supported through the Victorian YPIRAC initiative to live with family.

Disability Types

Table 5.1 Diversion Group – Disability types of participants who were diverted from RAC (n=11)

Disability Types	n	%
Acquired brain injury	5	45%
Multiple Sclerosis	2	18%
Huntington's disease	1	9%
Other neurological	1	9%
Quadriplegia	1	9%
Intellectual disability	1	9%

N.B. A person may have more than one disability type

None of the Diversion Group was minimally aware. Most (64%) were fully aware and 36% were partially aware (Table 3.5). Six people were fully able to participate in an interview while four participants were partially involved in the interview and one person did not participate. None of the participants used a communication device.

Table 5.2 Diversion Group – Health issues identified (n=11)

Health Issue	% Total Respondents	n
Hearing, Seeing and Feeling	**73%**	**8**
Hearing impairment		0
Vision impairment		4
Hypersensitivity to sensory stimuli		5
Heart and Circulation	**36%**	**4**
Heart or blood pressure problems		2
Postural hypertension		0
Limb swelling		1
Swallowing, Eating or Drinking	**27%**	**3**
Swallowing difficulties		1
Saliva management		1
Special dietary needs		2
PEG feeds		0
Weight problems (under or over)		1
Problems with appetite regulation		2
Reflux		0
Breathing	**9%**	**1**
Recurrent chest infections		0
Difficulty coughing or clearing sputum		0
Asthma		1
Sleep apnoea		0
Tracheotomy		0
Muscles and Bones	**91%**	**10**
Altered muscle tone, spasticity or muscle spasm		10
Contractures		0
Involuntary movements		3
Paralysis, loss of movement of arms or legs		4
Chronic pain		2
Fatigue		4
Osteoporosis		1
Reduced physical fitness or conditioning		5
Skin Problems	**27%**	**3**
Pressure areas, or pressure care		2
Loss of sensation		1
Skin rashes		1
Bladder	**55%**	**6**
Urinary incontinence		4
Urinary tract infections		3

Health Issue	% Total Respondents	n
Bowel (n=10)	**40%**	**4**
Faecal incontinence		2
Diarrhoea or Colitis		0
Constipation		2
Other		
Epilepsy	27%	3
Diabetes – Type 1	-	0

N.B. Participants can have more than one problem in each category

The Diversion Group had a mean of 2.7 (SD ±1.3) health conditions each, which is less than both the Enhancement (mean 4.6 (SD ± 2.6) and the RAC Exit (mean 3.7 (SD ± 1.9) groups. Specifically, the Diversion Group had less health issues related to swallowing (27%) compared with the enhancement (77%) and the RAC Exit groups (65%). The Diversion Group tended to have fewer skin problems (27%) than the Enhancement Group (64%) and a similar incidence of skin problems to the RAC Exit Group.

Mental Health

Table 5.3 **Diversion Group – Mental health problems (in previous two weeks) (n=11)**

Mental Health Symptoms	None	Minor	Mild	Moderate	Severe	Not Known
Depressive Symptoms	5	4	1			1
Self-directed injury	10					1
Problems associated with hallucinations/delusions/ confabulations	10					1
Problem drinking or drug use	9		1			1
Other	7	1	2			1

Health of the Nation Outcome Scale (HoNOS) (Fleminger et al., 2005)

Fifty per cent of the Diversion Group had symptoms of depression in the previous two weeks, which was similar to the RAC Exit Group. The ‘Other’ mental health symptoms referred to in the last line of Table 5.4 refer to anxiety and panics (3 people), sleep problems (1 person) and obsessive and compulsive problems (1 person).

Behaviours of concern

Table 5.4 Diversion Group – Behaviours of concern (n=9)

Overt Behaviour	n	% Respondents
Lack of initiation	4	44%
Verbal aggression	4	44%
Inappropriate social behaviour	2	22%
Perseveration/repetitive behaviour	1	11%
Inappropriate sexual behaviour	2	22%
Physical aggression	3	33%
Wandering/absconding	0	-

Overt Behaviour Scale (OBS) (Kelly et al., 2006)

Lack of initiation and verbal aggression were the most common behaviours of concern in the Diversion Group.

Social Participation

Table 5.5 Diversion Group – Frequency of visits from family and friends (n=11)

Frequency of Visits	Friends §		Relatives †	
	n	%	n	%
Most days	0	-	6	55%
1-3 times per week	2	18%	4	36%
1-3 times per month	5	46%	1	9%
5-11 times per year	1	9%	0	-
1-4 times per year	1	9%	0	-
Less than once per year	0	-	0	–
Never	2	18%	0	-

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

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

Table 5.6 Diversion Group – Frequency of visits to friends and family (n=11)

Frequency of Visits	Visit Friends in Their Home §		Visit Relatives in Their Home †	
	n	%	n	%
5 or more times per month	0	–	2	18%
1-4 times per month	4	36%	6	55%
5-11 times per year	1	9%	0	-
1-4 times per year	0	-	2	18%
Seldom/never	6	55%	1	9%

§ Approximately, how often do you usually visit friends in their homes?

† Approximately, how often do you usually visit relatives in their homes?

Only two people did not receive visits from friends and more than half did not visit their friends. All of the people in the Diversion Group were visited by a relative at least once per month. Most (91%) of the people in the Diversion Group were able to visit relatives in their home.

Community Participation

Table 5.7 Diversion Group – Participants were asked how often they would go outside e.g. into the garden (n=11)

Frequency of Going Outside	n	%
More than once per day	4	36%
Almost every day	6	55%
Almost every week	1	9%
Almost every month	0	-
Seldom/never	0	-

Table 5.8 Diversion Group – Frequency of travel outside of where they live (n=11)

	Travel Outside Where They Live	
Response	n	%
More than once a day	0	-
Almost every day	7	64%
Almost every week	4	36%
Almost every month	0	-
Seldom/never	0	-

Community Integration Questionnaire (Willer et al., 1993)

All of the people in the Diversion Group were getting outside (Table 5.7) and accessing the community almost every week (Table 5.8).

Table 5.9 Diversion Group – Frequency of participation in shopping outside of where they live (n=11)

	Shopping		Leisure Activities	
Response	n	%	n	%
5 or more times per month	3	27%	2	18%
1-4 times per month	6	55%	8	73%
5-11 times per year	0	-	1	9%
1-4 times per year	0	-	0	-
Seldom/Never	2	18%	0	-

Community Integration Questionnaire (Willer et al., 1993)

All people who were diverted from RAC were accessing the community for leisure. Two people in the Diversion Group never participated in shopping.

Table 5.10 Diversion Group – Community Integration Questionnaire questions 1-5: "Who usually does the following tasks?" (n=11)

	Yourself alone		Yourself and someone else		Someone else	
Everyday task	**n**	**%**	**n**	**%**	**n**	**%**
Shopping for groceries	0	-	7	64%	4	36%
Prepares meals	1	9%	4	36%	6	55%
Everyday housework	1	9%	1	9%	9	82%
Plans social occasions	1	9%	7	64%	3	27%
Looks after personal finances	2	18%	3	27%	6	55%

Community Integration Questionnaire (Willer et al., 1993)

Choice

Table 5.11 Diversion Group – Areas in life that people are supported to make choices (n=11)

	No Opportunity ¤		Unlikely to Give Real Choice Ψ		Final Say Doesn't Rest With the Person ‡		Procedures in Place Δ		N/A
Area of Life	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	
The content of their evening meal	1	9%	1	9%	2	18%	7	64%	0
The timing of their evening meal	1	9%	0	-	1	9%	9	82%	0
Indoor leisure (e.g. TV, radio)	0	-	0	-	1	9%	10	91%	0
Going out (e.g. pub, cinema) (n=10)	1	10%			4	40%	5	50%	0
The time they go to bed in the evening	1	9%	0	-	3	27%	7	64%	0
The clothes they wear each day	1	9%	0	-	1	9%	9	82%	0
Involvement of intimate partners (n=10)	2	20%	-	-	-	-	8	80%	-
Their daytime activities (n=10)	0	-	0	-	2	20%	8	80%	0
The time they spend in the bath or shower (n=10)	1	10%	1	10%	2	20%	6	60%	0
Access to a private area (n=10)	0	-	0	-	0	-	10	100%	0
The furnishings in their bedroom (n=10)	0	-	0	-	0	-	10	100%	0

¤ Nothing mentioned, no opportunity, person considered by informant to be incapable of making choices in this area.
Ψ Some procedure(s) mentioned but nothing likely to give the person much real choice.
‡ Some procedures mentioned through which person can express preferences but final say does not rest with the person.
Δ Procedures in place for person to express preferences and these are final unless clearly inappropriate or dangerous.

Resident Choice Scale (Hatton et al., 2004)

The Diversion Group tended to have more opportunities to make everyday choices than both the Enhancement Group and the RAC Exit groups.

Role Participation

Table 5.12 Diversion Group – Current and desired future role participation (n=11)

	Current Participation in Role		Desired Future Participation in Role	
Role	**n**	**%**	**n**	**%**
Student: Attending school on a part- or full-time basis	2	18%	7	64%
Worker: Part- or full-time paid employment	2	18%	6	55%
Volunteer: Donating services at least once a month	2	18%	7	64%
Caregiver: Responsibility at least once a month for the care of someone such as a child, spouse, relative or friend	3	27%	4	36%
Home maintainer: Responsibility at least once a month for the upkeep of the home such as housecleaning or yard work	5	46%	9	82%
Friend: Spending time or doing something at least once a month with a friend	5	46%	8	73%
Family member: Spending time or doing something at least once a month with a family member	11	100%	10	91%
Religious participant: Involvement at least once a month in groups or activities affiliated with one's religion	2	18%	3	27%
Hobbyist or Amateur: Involvement at least once a month in a hobby or amateur activity	7	64%	9	82%
Participant in Organisations: Involvement at least once a month in organisations such as Rotary, Guides, etc.	3	27%	5	46%

Role Checklist (Oakley et al., 1986)

The Diversion Group tended to be involved in more roles and also identified more areas of future role participation than both the Enhancement and RAC Exit groups. On average, the Diversion Group was involved in a mean 3.8 (SD ±1.7) roles while the RAC Exit Group was involved in an average of 2.5 (SD ±1.4) and the Enhancement Group was involved in a mean of 1.9 (SD ±1.3) roles. Twenty-seven per cent (3 people) in the Diversion Group were parents of school-age children.

Support Needs

Table 5.13 Diversion Group – Length of time person can be left alone (Care and Needs Scale Section 2) (n=11)

CANS Level	n	%
Cannot be left alone. Needs nursing care, assistance and/or surveillance 24 hours a day.	1	9%
Can be left alone for a few hours. Needs nursing care, assistance and/or surveillance 20-23 hours per day.	3	27%
Can be left alone for part of the day but not overnight. Needs nursing care, assistance, supervision and/or direction 12-19 hours per day.	3	27%
Can be left alone for part of the day and overnight. Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills.	4	36%
Can be left alone for a few days a week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional supports a few days a week.	0	–
Can be left alone for almost all week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once per week.	0	–
Can live alone, but needs intermittent (i.e. less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support.	0	–
Can live in the community, totally independently. Does not need contact.	0	–

Care and Needs Scale (Soo et al., 2007)

The CANS Section 2 provides eight levels of how long a person can be left alone. In the Diversion Group, only 9% of people require the highest level of support, indicating they cannot be left alone and require nursing care and/or surveillance 24 hours per day. People in the Diversion Group tend to require less intensive support than either the Enhancement or RAC Exit groups.

Table 5.14 Diversion Group – Number of participants who require assistance for the following support needs (n=11)

Support Needs	n	%
Tracheotomy management	0	-
Nasogastric/PEG feeding	0	-
Bed mobility/turning	3	27%
Wanders/gets lost	0	-
Exhibits behaviours that have potential to harm self or others	1	9%
Difficulty communicating basic needs due to language impairments	4	36%
Continence	6	55%
Feeding	4	36%
Transfers/mobility	6	55%
Personal hygiene/toileting	8	73%
Bathing/dressing	8	73%
Simple food preparation	10	91%
Shopping	11	100%
Housework	11	100%

Care and Needs Scale (Soo et al., 2007)

The Diversion Group had lower support needs than people who received enhancements and people who moved out of RAC. Thirty-six per cent of them could be left part of the day and overnight (Table 5.13). For example, only 55% of the Diversion Group required assistance with continence compared to 89% in the Enhancement Group and 77% in the RAC Exit group. They also required less assistance with tasks such as transfers and mobility and feeding.

Quality of Life Measures

The Comprehensive Quality of Life Scale (ComQol-15) (Cummins, 1997) was administered either with the participant directly or with a nominated proxy (e.g. a family member). The variability of the number of participant responses for each question was due to some nominated proxies feeling unable to answer specific questions on behalf of their family members. Other participants declined to respond to this particular tool.

Table 5.15 Diversion Group – A selection of questions from the ComQol-15 tool

ComQol Question	Almost Always		Usually		Sometimes		Not Usually		Almost Never	
	n	%	n	%	n	%	n	%	n	%
Q1. Time use (n=9)	1	11%	0	-	1	11%	4	44%	3	33%
Q2. Sleep (n=10)	4	40%	2	20%	3	30%	1	10%	0	-
Q3. Safety (n=10	7	70%	3	30%	0	-	0	-	0	-
Q4. Worry (n=10)	0	-	0	-	4	40%	1	10%	5	50%

ComQol-15 (Cummins, 1997)

Q1. In your spare time how often do you have nothing much to do?
Q2. Do you sleep well? How often?
Q3. Are you safe where you live? How often do you feel safe?
Q4. Are you ever worried or anxious during the day? How often?

Table 5.16 Diversion Group – Hours spent watching television per day (n=10)

	10 + hrs	6-9 hrs	3-5 hrs	1-2 hrs	None
Percentage of participants	11%	22%	33%	33%	-

ComQol-15 (Cummins, 1997)

People in the Diversion Group spent less time watching television than people living in the Enhancement Group.

Family Support

Informants for the FOM in the Diversion Group included three mothers, two partners and one sibling.

Table 5.17 Diversion Group – Family member coping (n=6)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have time for myself	17%	17%	50%	17%
I worry a lot of the time	-	50%	17%	33%
I feel in control of my life	-	33%	33%	33%
I have plenty of opportunity to rest	-	50%	17%	33%
I feel I need some time out	17%	66%	17%	-
I feel overloaded	-	83%	-	17%
I often feel tired	50%	17%	17%	17%
I have trouble sleeping	17%	33%	33%	17%

Table 5.18 Diversion Group – Family Cohesion (n=6)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
We spend more time together now	17%	17%	17%	50%
We are more intimate	40%		20%	40%
We go out more	17%	17%	50%	17%
I understand my relative better now	17%	33%	33%	17%
We spend more quality time together	17%		33%	50%
We are closer now		33%	33%	33%

Table 5.19 Diversion Group – Family Support demands (burden) (n=6)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have to keep checking on my relative	33%	-	50%	17%
My relative depends on me now	33%	-	33%	33%
I make all the important decisions now	17%	17%	33%	33%
I have to be able to supervise my relative	33%	-	33%	33%
I have to look after my relative	33%	-	50%	17%
It is difficult to get a break from providing support to my relative	17%	50%	17%	17%
My relative needs lots of assistance	50%	-	33%	17%
I have had to put my future plans on hold	50%	-	50%	-

Table 5.20 Diversion Group – Relative adjustment (n=5)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
My relative feels upset about losing some/many of his/her roles in the family	40%	40%	20%	-
My relative gets depressed	20%	80%	-	-
My relative has mood swings	-	80%	20%	-
I have to keep my relative cheerful	20%	60%	-	20%
My relative's personality has changed	20%	60%	20%	-

Table 5.21 Diversion Group – Adequacy of service support (n=6)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have not been given enough information	-	67%	17%	17%
It is difficult dealing with different staff and/or services	17%	17%	50%	17%
I feel as if our family and the staff work together like a team	-	33%	50%	17%
I feel that my relative is not getting enough treatment	-	33%	33%	33%
I can get the services that are needed	33%	17%	17%	33%

Table 5.22 Diversion Group – Family member resilience (n=6)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I feel as though I can't cope	17%	33%	33%	17%
I am still able to laugh about things	-	17%	50%	33%
I have someone that I can talk to if I need it	-	-	67%	33%
I still find enjoyment in life	-	-	67%	33%
I feel unwell a lot of the time	17%	33%	33%	17%

Table 5.23 Diversion Group – Sustainability of family support (n=6)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I enjoy supporting (caring for) my relative	-	-	83%	17%
I cannot see myself providing support to my relative over the long term	-	33%	17%	50%
I have more negative feelings about my relative now	17%	50%	17%	17%
My relative seems very self-centred now	17%	50%	33%	-
I feel trapped in this situation	-	50%	33%	17%

Qualitative Data

Diversion Group

Overall, the families of the Diversion Group had better outcomes than both the families of the Enhancement Group and the RAC Exit Group.

Although the living circumstances and support needs of the Diversion Group were vastly different, a number of key themes were identified through the analysis of the 11 interviews.

Being as independent as I can

All of the Diversion Group participants and their families reported that they aimed to increase their independence as much as possible through their diversion ISP. One participant who now lives alone at home with support from carers through an ISP reported that her main focus is to reduce her reliance on others.

> “I just like trying to be as independent as I can…I cook for myself and do the washing and I can hang it out okay by myself…the carers come in to take me down the street to bring the groceries home and maybe mop the floors, but I can vacuum. The only thing I can’t do it put the doona cover on.”
>
> LARA, PARTICIPANT

Some family members spoke of the difference the funding has made to encourage participants to develop their skills again in their home environment. One spouse described the difference some home modifications have made.

> “This has been set up such that he can do whatever he wants to do and needs to do and can access the house for all of that…as Ian continues to do more himself that’s the whole advantage to just have it completely accessible. So he can live his own life here.” IAN’S PARTNER

One participant described how her identity has always been tied to two main activities: paid work and participating in craft activities (specifically, beading). She is no longer able to work, but the assistance provided through the Victorian YPIRAC initiative has allowed her to remain at home and continue with her craftwork:

> “It has made an enormous difference…I do a lot of beading and I would find that that would be impossible to do in another environment other than home…I couldn’t ask a support

> person to help me…I can get my husband to help me, I can get friends to help me, anyone who comes in who can tie a knot.”
>
> PAM, PARTICIPANT

Another participant talked of the choice and control he has experienced by continuing to live at home.

> “Being in a home of my own, I have more control over what I do during the day.” TAYLOR, PARTICIPANT

Remaining in my community

Participants who received an ISP that allowed them to remain living at home commented on the importance of living in a familiar community.

> “It’s not just the physical community but that sense of community where people are around and you get a sense in your own mind that you sort of belong in a bigger place.”
>
> MARK, PARTICIPANT

> “So it’s much more comfortable to be in that position as [you’re more] established in your community than in that new community, where people are still going to be nice to you, but you’re a stranger. I’ve sort of established a bit of credibility [in familiar community]…a few brownie points, if you like, here and there without deliberately calling back those favours it sort of happens.” PHILLIP, PARTICIPANT

It has made a huge difference

All Diversion Group participants who received an ISP found it difficult to imagine their living situation without the Victorian YPIRAC initiative funded supports. Many of them reported that they would have been at high risk of being admitted to RAC.

> “[Without *my future my choice* supports] he wouldn’t have been home…I imagine in a nursing home. I don’t imagine it would have been anywhere else because we would have had no funding to get him home.” IAN’S PARTNER

Another Diversion Group participant, whose ISP allows her to remain living at home, is a parent to a teenage daughter. She reported that her daughter finds it hard to understand her mother's progressive disability, which has impacted on their relationship. The participant discussed that their relationship would have been negatively impacted on if she had unable to remain at home.

> "I just wouldn't see her…to see me in a situation with other disabled people is an anathema to her…I would totally lose contact with her…at least I can say to her when she comes home, 'Welcome home' and when she goes, 'I love you.'"
>
> PAM, PARTICIPANT

Chapter 6: Results — Enhancement Group

Quantitative Data

Demographics

There were 28 people interviewed who were in RAC and were receiving enhancement packages through YPIRAC. Eighteen of these people remained in RAC and ten subsequently moved to SSA and were also interviewed post-move. The enhancement packages received included a range of recurrent funding (e.g. a disability support worker to enable access to community-based leisure activities) and non-recurrent funding (e.g. equipment such as a communication device or customised wheelchair). Most (68%) people in the Enhancement Group were male. There was no significant difference between the age of people who received enhancements (mean 44 years, SD ± 10.7, range 20-54 years) and the age of the whole population in Victoria who received services through the YPIRAC initiative. Participants had lived in the RAC service an average of 5.5 years (range 5 months to 11 years). The mean number of people living in each RAC facility was 70 people (range 20 to 220 people).

Disability Types

Table 6.1 Enhancement Group – Disability Types (n=28)

Disability Types	n	%
Acquired brain injury	12	43%
Multiple Sclerosis	9	32%
Other neurological	1	4%
Huntington’s disease	2	7%
Cerebral palsy	2	7%
Intellectual disability	2	7%
Paraplegia	1	4%
Quadriplegia	1	4%
Other	4	14%

N.B. A person may have more than one disability type

Communication

As outlined earlier, the Enhancement Group had an overall lower level of awareness than the other groups (Table 3.5). Seven participants who received enhancement services were fully able to participate in an interview, 11 were partially involved in an interview and ten people were not able to participate in an interview. Four people used a communication device to participate.

Health

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

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

Researchers asked informants about the presence of a range of health conditions common in this population. The current evaluation process identified a wide range of health conditions in participants and found that most people in the Enhancement Group had complex combinations of health needs. People who received enhancements in RAC had up to 11 health conditions with a mean of 4.6 (SD ± 2.6) each. Everyone had at least one health condition.

Table 6.2 Enhancement Group – Health issues identified (n=22)
N.B. Participants can have more than one problem in each category

Health Issue	% Total Respondents	n
Hearing, Seeing and Feeling	**64%**	**14**
Hearing impairment		2
Vision impairment		10
Hypersensitivity to sensory stimuli		6
Heart and Circulation	**18%**	**4**
Heart or blood pressure problems		2
Postural hypertension		1
Limb swelling		2
Swallowing, Eating or Drinking	**77%**	**17**
Swallowing difficulties		12
Saliva management		5
Special dietary needs		7
PEG feeds		4
Weight problems (under or over)		5
Problems with appetite regulation		5
Reflux		3

Health Issue	% Total Respondents	n
Breathing	**32%**	**7**
Recurrent chest infections		5
Difficulty coughing or clearing sputum		4
Asthma		2
Sleep apnoea		1
Tracheotomy		1
Muscles and Bones	**96%**	**21**
Altered muscle tone, spasticity or muscle spasm		19
Contractures		8
Involuntary movements		5
Paralysis, loss of movement of arms or legs		15
Chronic pain		3
Fatigue		7
Osteoporosis		4
Reduced physical fitness or conditioning		9
Skin Problems	**64%**	**14**
Pressure areas, or pressure care		9
Loss of sensation		2
Skin rashes		5
Bladder	**82%**	**18**
Urinary incontinence		16
Urinary tract infections		5
Bowel	**82%**	**18**
Faecal incontinence		17
Diarrhoea or Colitis		1
Constipation		5
Other		
Epilepsy		8
Diabetes – Type 1		2

Mental Health

Table 6.3 Enhancement Group – Severity of mental health problems (in last two weeks) (n=26)

Mental Health Symptoms	None	Minor	Mild	Moderate	Severe	Not Known
Depressive Symptoms	11	4	4	2		5
Self-directed injury	23		1			2
Problems associated with hallucinations/delusions/ confabulations	22	2				2
Problem alcohol or drug use	24					2
Anxiety and panics	20		1			5

Health of the Nation Outcome Scale (HoNOS) (Fleminger et al., 2005)

For people in the Enhancement Group, the severity of mental health symptoms on the HoNOS (Fleminger et al., 2005) was often rated by the person with the disability themselves. Nearly 50% of people in the Enhancement Group reported symptoms of depression.

Behaviours of Concern

While there was a relatively low level of mental health symptoms in the Enhancement Group, a substantial number of behaviours of concern were identified in this sub-group.

While many people (37%) were unable or unwilling to initiate, approximately one third displayed verbal or physical aggression in the past three months. People living in RAC receiving enhancements often displayed more than one type of behaviour of concern (mean 1.5 SD ± 1.9).

Table 6.4 Enhancement Group – Behaviours of Concern identified (n=27)

Overt Behaviour	n	% Respondents
Lack of initiation	10	37%
Verbal aggression	7	26%
Inappropriate social behaviour	4	15%
Perseveration/repetitive behaviour	5	19%
Inappropriate sexual behaviour	4	15%
Physical aggression	2	7%
Wandering/absconding	3	11%

Overt Behaviour Scale (OBS) (Kelly et al., 2006)

Social Participation

Table 6.5 Enhancement Group – Frequency of visits from family and friends (n=28)

	Friends §		Relatives †	
Frequency of Visits	**n**	**%**	**n**	**%**
Most days	1	4%	8	29%
1-3 times per week	3	11%	11	39%
1-3 times per month	5	18%	4	14%
1-4 times per year	2	7%	4	14%
Less than once per year	2	7%	0	–
Never	15	54%	1	4%

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

Twenty-nine per cent of people in the Enhancement Group were visited by a relative on most days. This is likely to reflect the significant burden of care experienced by some families of people in the Enhancement Group.

Table 6.6 Enhancement Group – Frequency of visits to friends and family (n=28)

	Visit Friends in Their Home §		Visit Relatives in Their Home †	
Frequency of Visits	**n**	**%**	**n**	**%**
5 or more times per month	0	–	1	4%
1-4 times per month	1	4%	8	29%
5-11 times per year	0	-	3	11%
1-4 times per year	0	-	3	11%
Seldom/never	27	96%	13	46%

§ Approximately, how often do you usually visit friends in their homes?
† Approximately, how often do you usually visit relatives in their homes

Also indicative of the social isolation experienced by the Enhancement Group, 96% seldom or never visited friends in their home. Approximately half never visited their family.

Community Participation

Table 6.7 Enhancement Group – Participants were asked how often they would go outside e.g. into the garden (n=28)

Frequency of Going Outside	n	%
More than once per day	2	7%
Almost every day	9	32%
Almost every week	14	50%
Almost every month	0	-
Seldom/never	3	11%

Table 6.8 Enhancement Group – Frequency of travel outside of where they live (n=28)

	Travel Outside Where They Live	
Response	n	%
More than once a day	0	-
Almost every day	6	21%
Almost every week	18	64%
Almost every month	0	-
Seldom/never	4	14%

Community Integration Questionnaire (Willer et al., 1993)

Only 39% of participants living in RAC went outdoors daily (Table 6.7); while 85% of people in RAC who received enhancements travelled outside almost every week (or more often) 14% seldom or never accessed the community (Table 6.8).

Table 6.9 Enhancement Group – Frequency of participation in shopping or leisure activities outside of where they live (n=28)

	Shopping		Leisure Activities	
Response	n	%	n	%
5 or more times per month	1	4%	2	7%
1-4 times per month	12	43%	14	50%
5-11 times per year	-	-	3	11%
1-4 times per year	1	4%	2	7%
Seldom/Never	14	50%	7	25%

Community Integration Questionnaire (Willer et al., 1993)

While 47% of people in the Enhancement Group went shopping at least monthly, half never went shopping. Fifty-seven per cent participated in community-based leisure at least monthly and a quarter never accessed the community for leisure (Table 6.9).

Table 6.10 Enhancement Group – Community Integration Questionnaire questions 1-5: “Who usually does the following tasks?” (n=28)

	Yourself Alone		Yourself and Someone Else		Someone Else	
Everyday Task	n	%	n	%	n	%
Shopping for groceries	0	-	0	-	28	100%
Prepares meals	0	-	0	-	28	100%
Everyday housework	0	-	0	-	28	100%
Plans social occasions	0	-	11	39%	17	61%
Looks after personal finances	0	-	2	7%	26	93%

Community Integration Questionnaire (Willer et al., 1993)

The Enhancement Group were not involved in household shopping, meal preparation or housework. Some people in this group were involved with planning social occasions (39%) and looking after personal finances (9%).

Choice

There is enormous potential for making a significant difference to the lives of the people in the target group by increasing their sense of control making and their participation in everyday activities.

Table 6.11 Enhancement Group – Areas in life that people are supported to make choices (n=28)

	No Opportunity ¤		Unlikely to Give Real Choice Ψ		Final Say Doesn't Rest With the Person ‡		Procedures in Place Δ		NA
Area of Life	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	
The content of their evening meal	19	68%	4	14%	3	11%	0	-	2
The timing of their evening meal	22	79%	2	7%	2	7%	1	4%	1
Indoor leisure e.g. TV, radio	6	21%	4	14%	8	29%	10	36%	0
Going out (e.g. pub, cinema)	7	25%	8	29%	10	36%	3	11%	0
The time they go to bed in the evening	16	57%	8	29%	3	11%	1	4%	0
The clothes they wear each day	8	29%	9	32%	7	25%	4	14%	0
Involvement of intimate partners	10	36%	4	14%	3	11%	1	4%	10
Their daytime activities	9	32%	3	11%	11	39%	5	18%	0
The time they spend in the bath or shower	20	71%	3	11%	4	14%	1	4%	0
Access to a private area	6	21%	8	29%	3	11%	11	39%	0
The furnishings in their bedroom	2	7%	5	18%	8	29%	13	46%	0

¤ Nothing mentioned, no opportunity, person considered by informant to be incapable of making choices in this area.
Ψ Some procedure(s) mentioned but nothing likely to give the person much real choice.
‡ Some procedures mentioned through which person can express preferences but final say does not rest with the person.
Δ Procedures in place for person to express preferences and these are final unless clearly inappropriate or dangerous.

Resident Choice Scale (Hatton et al., 2004)

Table 6.11 provides information about the level of support and opportunity people in the Enhancement Group were given to make choices with regard to various areas of life. The researchers conducted interviews with informants (the individual, their support network and paid staff) about the person's participation in making choices. Based on this information, the researchers rated the person's level of participation in making choices in each area of life listed in Table 6.11. Young people living in RAC had very limited opportunity to make the everyday choices that most of us take for granted even when they were receiving additional services funded through the YPIRAC initiative. Many people had no choice in the timing (79%) or content (68%) of their evening meal or the amount of time they spent in the bath or shower (71%) (Table 6.11).

Role Participation

Table 6.12 Enhancement Group – Current and desired future role participation (n=28)

	Current Participation in Role (n = 28)		Desired Future Participation in Role (n = 27)	
Role	n	%	n	%
Student: Attending school on a part- or full-time basis	1	4%	2	7%
Worker: Part- or full-time paid employment	1	4%	2	7%
Volunteer: Donating services, at least once a month	1	4%	2	7%
Caregiver: Responsibility at least once a month for the care of someone such as a child, spouse, relative or friend	0	-	1	4%
Home maintainer: Responsibility at least once a month, for the upkeep of the home such as housecleaning or yard work	0	-	8	29%
Friend: Spending time or doing something at least once a month with a friend	8	29%	17	61%
Family member: Spending time or doing something at least once a month with a family member	24	86%	26	93%
Religious participant: Involvement at least once a month in groups or activities affiliated with one's religion	6	21%	7	25%
Hobbyist or Amateur: Involvement at least once a month in a hobby or amateur activity	11	39%	19	68%
Participant in Organisations: Involvement at least once a month in organisations such as Rotary, Guides, etc.	2	7%	5	18%

Role Checklist (Oakley et al., 1986)

The current role participation of young people in RAC receiving enhancements was largely limited to the role of family member. This group indicated a desire to be more involved in hobbies and friendships. As seen previously (Table 6.10), no one in this group had the opportunity to participate in tasks related to the role of home maintainer, which involves household shopping, meal preparation or housework. However, nearly a third had a desire for involvement in this role in the future (Table 6.12). Twenty-five per cent of people in the Enhancement Group were parents of school-age children. None of them were actively participating in this role.

Support Needs

In the Enhancement Group, 29% of people require the highest level of support, indicating they cannot be left alone and require nursing care and/or surveillance 24 hours per day.

Table 6.13 Enhancement Group – Length of time person can be left alone (n=28)

CANS Level	n	%
Cannot be left alone. Needs nursing care, assistance and/or surveillance 24 hours a day.	8	29%
Can be left alone for a few hours. Needs nursing care, assistance and/or surveillance 20-23 hours per day	15	54%
Can be left alone for part of the day but not overnight. Needs nursing care, assistance, supervision and/or direction 12-19 hours per day.	4	14%
Can be left alone for part of the day and overnight. Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills.	1	4%
Can be left alone for a few days a week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional supports a few days a week.	0	–
Can be left alone for almost all week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once per week.	0	–
Can live alone, but needs intermittent (i.e. less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support.	0	–
Can live in the community, totally independently. Does not need contact.	0	–

Care and Needs Scale (Soo et al., 2007)

Table 6.14 Enhancement Group – Number of participants who require assistance for the following areas of support need (n=28)

Support Needs	n	%
Tracheotomy management	1	4%
Nasogastric/PEG feeding	6	21%
Bed mobility/turning	17	61%
Wanders/gets lost	3	11%
Exhibits behaviours that have potential to harm self or others	5	18%
Difficulty communicating basic needs due to language impairments	19	68%
Continence	25	89%
Feeding	18	64%
Transfers/mobility	25	89%
Personal hygiene/toileting	28	100%
Bathing/dressing	28	100%
Simple food preparation	28	100%
Shopping	28	100%
Housework	27	96%

Care and Needs Scale (Soo et al., 2007)

Young people living in RAC receiving enhancements required a high level of support as indicated on the CANS (Table 6.13) and the high number of people who needed support for personal care (Table 6.14). For example, (89%) of people living in RAC receiving enhancements needed assistance to manage continence and all participants required help for bathing and dressing.

Quality of Life Measures

The Comprehensive Quality of Life Scale (ComQol-15) (Cummins, 1997) was administered either with the participant directly or with a nominated proxy (e.g. a family member). The variability of the number of participant responses for each question was due to some nominated proxies feeling unable to answer specific questions on behalf of their family members. Other participants declined to respond to this particular tool.

Table 6.15 Enhancement Group – A selection of questions from the ComQol-15 tool

Quality of Life Question	Almost Always		Usually		Sometimes		Not Usually		Almost Never	
	n	%	n	%	n	%	n	%	n	%
Q1. Time use (n=22)	9	41%	9	41%	2	9%	1	5%	1	5%
Q2. Sleep (n=22)	8	36%	7	32%	4	18%	1	5%	2	9%
Q3. Safety (n=22)	12	55%	6	27%	1	5%	2	9%	1	5%
Q4. Worry (n=20)	0	-	2	10%	7	35%	4	20%	7	35%

ComQol-15 (Cummins, 1997)

Q1. In your spare time how often do you have nothing much to do?
Q2. Do you sleep well? How often?
Q3. Are you safe where you live? How often do you feel safe?
Q4. Are you ever worried or anxious during the day? How often?

The Enhancement Group tended to have nothing to do more often than either the RAC Exit or Diversions Groups. However, they also tended to watch less television.

Table 6.16 Enhancement Group – Hours spent watching television per day (n=23)

Quality of Life Question	10 + hrs	6-9 hrs	3-5 hrs	1-2 hrs	None
Percentage of participants	35%	17%	26%	13%	9%

ComQol-15 (Cummins, 1997)

The Enhancement Group tended to have nothing to do more often than either the RAC Exit or Diversions Groups. However they also tended to watch less television.

Family Support

Table 6.17 Enhancement Group – Family member coping (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have time for myself	21%	14%	57%	7%
I worry a lot of the time	29%	43%	21%	7%
I feel in control of my life	14%	21%	50%	14%
I have plenty of opportunity to rest	29%	29%	36%	7%
I feel I need some time out	21%	29%	29%	21%
I feel overloaded	29%	29%	36%	7%
I often feel tired	21%	29%	29%	21%
I have trouble sleeping	14%	36%	36%	14%

Family Outcome Measure (Simpson & Winstanley, 2009)

Table 6.18 Enhancement Group – Family cohesion (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
We spend more time together now	7%	29%	36%	29%
We are more intimate	21%	14%	50%	14%
We go out more	29%	57%	7%	7%
I understand my relative better now	0%	50%	21%	29%
We spend more quality time together	14%	21%	43%	21%
We are closer now	0%	50%	36%	14%

Family Outcome Measure (Simpson & Winstanley, 2009)

Table 6.19 Enhancement Group – Support demands (burden) (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have to keep checking on my relative	43%	36%	7%	14%
My relative depends on me now	50%	29%	7%	14%
I make all the important decisions now	43%	21%	14%	21%
I have to be able to supervise my relative	36%	36%	14%	14%
I have to look after my relative	36%	36%	14%	14%
It is difficult to get a break from providing support to my relative	21%	29%	36%	14%
My relative needs lots of assistance	64%	7%	7%	21%
I have had to put my future plans on hold	29%	29%	29%	14%

Family Outcome Measure (Simpson & Winstanley, 2009)

Table 6.20 Enhancement Group – Relative adjustment (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
My relative feels upset about losing some/many of his/her roles in the family	43%	36%	7%	14%
My relative gets depressed	29%	29%	21%	21%
My relative has mood swings	43%	21%	14%	21%
I have to keep my relative cheerful	36%	36%	14%	14%
My relative's personality has changed	36%	36%	14%	14%

Family Outcome Measure (Simpson & Winstanley, 2009)

Table 6.21 Enhancement Group – Adequacy of service support (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have not been given enough information	7%	43%	36%	14%
It is difficult dealing with different staff and/or services	14%	29%	36%	21%
I feel as if our family and the staff work together like a team	14%	14%	64%	7%
I feel that my relative is not getting enough treatment	7%	21%	50%	21%
I can get the services that are needed	7%	14%	79%	_

Family Outcome Measure (Simpson & Winstanley, 2009)

Table 6.22 Enhancement Group – Family member resilience (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I feel as though I can't cope	14%	36%	29%	21%
I am still able to laugh about things	7%	14%	57%	21%
I have someone that I can talk to if I need it	–	7%	64%	28%
I still find enjoyment in life	–	36%	50%	14%
I feel unwell a lot of the time	14%	57%	14%	14%

Family Outcome Measure (Simpson & Winstanley, 2009)

Table 6.23 Enhancement Group – Sustainability of family support (n=14)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I enjoy supporting (caring for) my relative	–	29%	29%	43%
I cannot see myself providing support to my relative over the long term	7%	21%	36%	36%
I have more negative feelings about my relative now	14%	7%	36%	43%
My relative seems very self-centred now	14%	29%	21%	36%
I feel trapped in this situation	14%	43%	14%	29%

Family Outcome Measure (Simpson & Winstanley, 2009)

The scores on the FOM indicate a wide range of outcomes across all scales for families of young people in the Enhancement Group. Some families of young people in the Enhancement Group still experienced a significant burden of care. The families reported that they had to keep checking on their relative (21%), their relative was dependent on them (21%) and that they had to look after their relative (28%). Many (50%) families of the Enhancement Group would like time out, 43% feel trapped in the situation and 71% feel their relative is not getting enough treatment.

Qualitative Data

Enhancement Group

Many participants who decided to remain living in RAC received individual support packages that provided funding for a variety of different services or equipment items. Outlined below are some of the examples of how these newly funded items provided new opportunities for the participants to improve their quality of life. The participants and families generally refer to the Victorian YPIRAC initiative as '*my future my choice*'.

I can go to places

The addition of taxi vouchers and disability support worker hours assisted many participants to have regular access to their local community. For participants who were spending nearly all their hours in their RAC facilities, these new support services were welcome:

> "I can go to places…I can go from A to B…before I couldn't go, then I couldn't go anywhere…the hairdresser would come here." KARL, PARTICIPANT

The positive impact of the new disability support workers was a common topic raised by family members who had been distressed by seeing the participant's boredom and isolation from rarely accessing the community:

> "Her behaviour has improved because it's keeping her mind occupied going out with this worker." MARY'S PARTNER

One family member talked about how the support worker opened up new opportunities for the participant:

> "Now he swims, he goes shopping, he has donuts and Maccas… he knows the community." CRAIG'S MOTHER

Another family member discussed how the participant did not want to leave the RAC facility and go into town since his accident, as he didn't want to be seen in his wheelchair. His new support worker helped to provide additional encouragement and confidence to the participant to help him overcome this hurdle, and they now regularly access the community together.

It was reported that the support workers provided consistent, regular access to the community for the participants, which meant they no longer needed to solely rely on families to take them out. A participant spoke of the joy of being able to go shopping for family members' Christmas presents without having them present. Another family member spoke of how they felt the services had advantaged their son:

> “The problem is, he doesn’t know what he can do. He only knows what he can’t do. I think this [support worker] program’s started to go [make participant think], there is more I can do. I’m not dependent on somebody giving up their time or turning up unexpectedly. I can ring the carer.” KARL’S MOTHER

One staff member described the difference the initiative has made for a man with severe cognitive-behaviour impairments after ABI who lives in a locked facility and requires two people to support him to access the community. The service was unable to regularly spare the two staff members required to take him out. The addition of two disability support workers through the YPIRAC initiative has provided the opportunity for him to go out and have a coffee once a week. The consistency of these workers has reduced his anxiety and improved his behaviour in the community.

One RAC manager describes the importance of the additional funding to enable community access for this participant:

> “It has normalised his life more than what we could offer him as a nursing home.” RAC MANAGER

They’re looking out for him as well

In addition to providing opportunities for the participant to access the community, many family members discussed how the new support workers were spending valuable time with the participant at the aged care facility. This was reassuring for family members, as they knew someone else was able to spend one-on-one time with the participant to prevent boredom and understand their unique needs.

> “It does really affect me, it’s huge, huge. I can’t tell you what I would do if it wasn’t there. Like I said, I’ve got three wonderful people who really care about him. So they’re looking out for him as well. Fantastic!” CRAIG’S MOTHER

> “We know he’s being looked after.” RON’S FATHER

A number of families reported this has allowed them to have valuable respite, as they didn’t need to visit the participant on the day the support worker was rostered.

> “We can go away a bit, I do my fishing and that sort of thing and we can go away and know that Barry is being well looked after…this has definitely made a lot of difference to Barry and to us.” BARRY’S FATHER

More opportunities and choices

A clear theme that emerged from the interviews’ analysis was that the individualised plans afforded the participant more opportunities and choice in their lives, specific to their own unique interests and goals. This was often in the form of more appropriate, specialised equipment to allow participants to communicate, access the community and try new things.

One participant articulated the difference his new communication device has made for him. Prior to receiving the device through the initiative he was unable to communicate functionally in any form due to his progressive condition and outdated communication aides:

> “*my future my choice* has given me the opportunity to communicate again with people…it’s like going to bed a mute and waking up being able to talk and communicate again. My life has begun again as I can relate as an adult.” WAL, PARTICIPANT

A father commented on the difference the ISP has made on his son’s life:

> “Unbelievable. Gosh, like a wheelchair, he got a wheelchair out of it…he got looked after, is being looked after…it’s made an incredible difference, incredible.” RON’S FATHER

Some participants reported that funding provided for some items such as taxis to medical appointments made a substantial difference to their life. Given that most (93%) of participants were on a disability support pension, funding for travel was significant for some participants because it gave them some disposable income to spend at their discretion. One participant discussed enjoying being able to purchase small presents for his niece and nephew’s birthdays for the first time.

A father commented on how the newly funded therapy and equipment has made a difference in his son’s life:

> “Of course it does. It’s common sense, isn’t it? Before we got nothing…then suddenly I ended up with the physiotherapy, got with the speech therapy and they start getting equipment for him.” FREDDY’S FATHER

Finally, there was significant diversity in the type of enhancement package offered to participants through the YPIRAC initiative, ranging from the funding of equipment, through to weekly 1:1 attendant care support. Families identified the need for an allocated worker to monitor the implementation and ongoing delivery of the package. Some people felt that such input was lacking.

For example, the guardian of one of the participants discussed that the person has received an enhancement package for 1:1 support for the person to visit her young daughter in another area of Victoria. However, at the time of the evaluation, the guardian felt there was no one following this up to plan and implement the proposed visits.

> “When I mentioned it on my last visit it was all very vague…‘Oh well, you know, we are really not sure what is going on there’…so no-one seems to have a really good grasp of what is going on for her at a local level.” EMMA’S GUARDIAN

> “The thing than I find disappointing is we don’t know where the budget is standing, we don’t know what we can apply for him.” BARRY’S FATHER

Chapter 7: Comparisons Between Groups

A range of comparisons was made between the three sub-groups of participants (RAC Exit, Diversion and Enhancement groups) and the baseline data collected during the assessment and planning process in 2007.

The comparisons made were largely determined by the number of participants in each group. Groups generally need to have at least 20 participants to make meaningful statistical comparisons. Of the final 68 participants, 34 exited RAC, 11 had been diverted from aged care and 28 had received enhancement packages (see Figure 7.1). Both pre-move data and post-move data were obtained from 13 people.

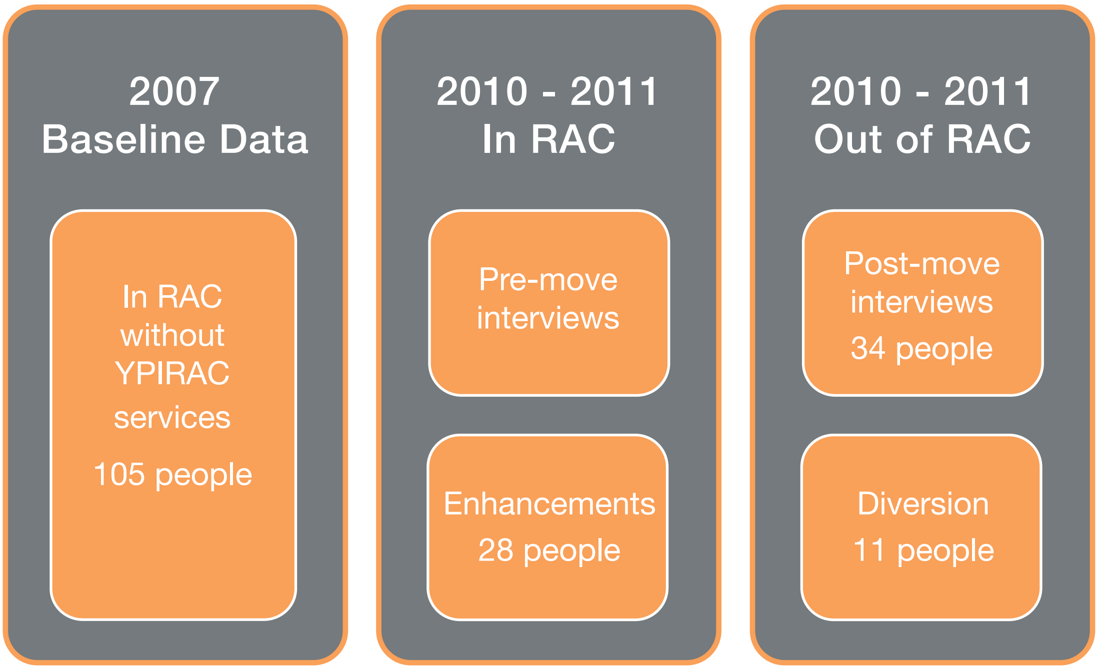


Figure 7.1 Numbers of participants in each sub-group

Twenty-nine of the 68 participants who were interviewed for this evaluation were part of the original group of participants who were interviewed as part of the *Younger People in Residential Aged Care: Support needs, preferences and future directions* report.

The following analyses were completed:

Analysis	Comparison Group 1	Comparison Group 2
Mann-Whitney Test (non-parametric) Independent samples	86 young people living in aged care (from 2007 assessment and planning data)	34 people who moved out of RAC
Mann-Whitney Test (non-parametric) Independent samples	73 young people living in aged care (from 2007 assessment and planning data)	28 people living in RAC who received enhancements
Mann-Whitney Test (non-parametric) Independent samples	28 people living in RAC who received enhancements	34 people who moved out of RAC

Analysis	Baseline Data	Outcome Data
Wilcoxon signed ranks test (non-parametric) Paired samples	13 people living in RAC (some had received enhancement packages)	Same 13 people after they moved out of RAC

Comparison of people living in RAC without enhancements with people who have moved out of RAC

The 34 people who moved out of RAC were compared with 86 people living in RAC without enhancements (collected in 2007). People who had baseline data from the 2007 assessment and planning process as well as data collected after moving out of RAC were excluded from the group of 105 from 2007 to create two discrete independent groups for this analysis, leaving 86 people in the 2007 group.

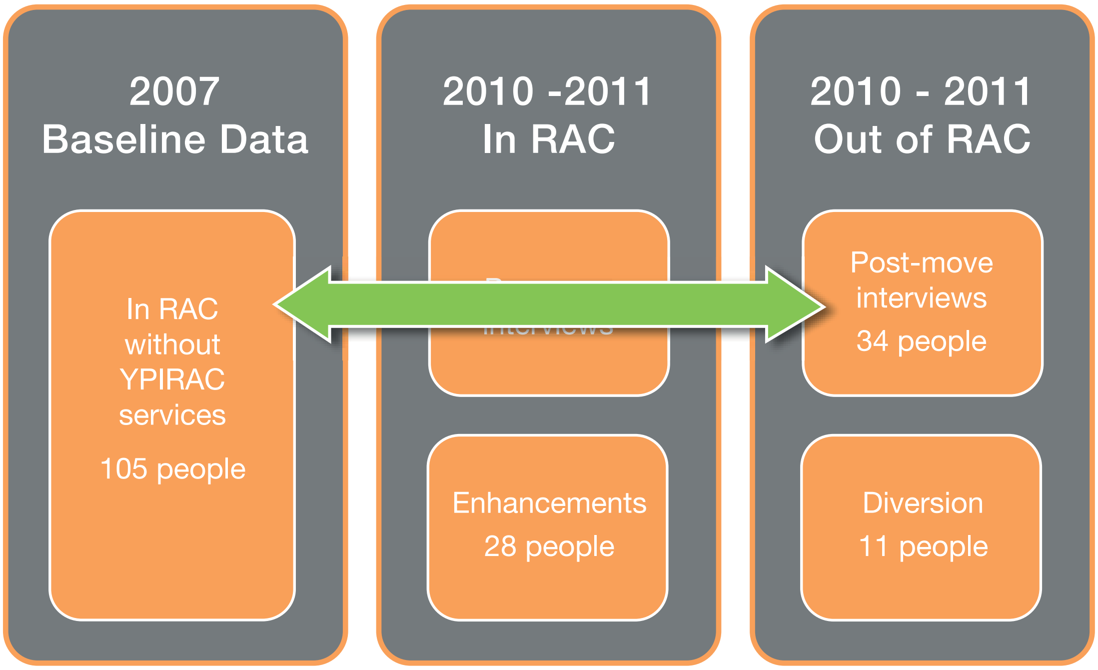


Figure 7.2 Comparison of people living in RAC without enhancements with the RAC Exit Group

Table 7.1 Differences between two groups on a range of outcome variables – 2007 baseline data (n=86) and the RAC Exit Group (n=34)

Variable	2007 Baseline Data Mean (SD)	RAC Exit Group Mean (SD)	Mann-Whitney Tests
Days out of bed in the past 7 days	6.40 (±1.38)	6.58 (±1.25)	Z = -1.31, ρ = .192
How many hours out of 24 do you typically spend in bed?	12.60 (±4.08)	11.89 (±2.89)	Z = -1.15, ρ = .252
Length of time they can be left alone (CANS Part 2)	5.58 (±1.38)	5.71 (±.906)	Z = -.036, ρ = .971
Number of life roles	2.19 (±1.32)	2.47 (±1.35)	Z = -.945, ρ = .344
Number of health conditions	3.26 (±1.94)	3.73 (±1.88)	Z = -1.20, ρ = .232
Number of behaviours of concern	2.14 (±1.83)	1.41 (±1.73)	Z = -1.83, ρ = .067

The groups were similar in the time they spent in bed, their support needs and their number of life roles and health conditions. The group who moved out of RAC tended to have fewer behaviours of concern but the difference between groups was not statistically significant.

Table 7.2 Differences between two groups in community access and social integration – 2007 baseline data (n=86) and the RAC Exit Group (n=34). Measured in days per year.

Variable	2007 Baseline Data Mean (SD)	RAC Exit Group Mean (SD)	Mann-Whitney Tests	
Frequency of going outside	280 (±282)	469 (±273)	Z = - 3.54, ρ < .001	***
Frequency of travel outside the place you live	113 (±164)	140(± 115)	Z = -2.93, ρ = .003	**
Frequency of visits from relatives	107 (±94)	108 (±90)	Z = -.754, ρ = .451	
Frequency of visits from friends	20.14 (±45.35)	14.66 (±29.34)	Z = -.182, ρ = .856	
Frequency of visits to relatives' homes	5.76 (±5.41)	9.59 (±14.04)	Z = -2.64, ρ = .008	**
Frequency of visits to friends' homes	9.31 (±4.50)	1.54 (±3.79)	Z = -.259, ρ = .796	

* ρ < .05, ** ρ < .01, *** ρ < .001.

The results summarised in Table 7.2 indicate that there was a significant difference between the two groups on five items. The group who had moved went outside more often, travelled into the community more often and participated in shopping and visited their relatives more often.

Table 7.3 Difference in CIQ Total Scores and Subscale Scores between two groups – 2007 baseline data (n=86) and the RAC Exit Group (n=34)

Variable	2007 Baseline Data Mean (SD)	RAC Exit Group Mean (SD)	Mann-Whitney Tests	
CIQ total score	4.9 (±3.00)	6.21 (±3.75)	Z = -2.05, ρ = .041	
Home integration subscale	1.00 (±0.67)	1.56 (±1.88)	Z = -.447, ρ = .655	
Social integration subscale	2.38 (±1.77)	4.12 (±2.07)	Z = -4.19, ρ < .001	***
Productivity subscale	1.59 (±1.18)	1.52 (±.89)	Z = -0.99, ρ = .921	

*** ρ < .001.

Community Integration Questionnaire (Willer et al., 1993)

Overall, the RAC Exit Group had a higher level of community integration. Specifically, people who moved out of RAC had a higher level of social integration than the group who were in RAC.

Table 7.4 Difference in CIQ Home Integration Item Scores between two groups – 2007 baseline data (n=86) and the RAC Exit Group (n=34)

Variable	2007 Baseline Data Mean (SD)	RAC Exit Group Mean (SD)	Mann-Whitney Tests
1. Who usually does shopping for groceries and other necessities in your household?	.09 (±.35)	.35 (±.54)	Z = -3.75, ρ < .001 ***
2. Who usually prepares meals in your household?	.04 (±.20)	.26 (±.45)	Z = -3.45, ρ = .001 **
3. In your home, who usually does normal everyday housework?	.03 (±.17)	.12 (±.33)	Z = -1.72, ρ = .086
5. Who usually plans social arrangements such as get togethers with family and friends?	.32 (±.51)	.50 (±.66)	Z = -1.85, ρ = .064

** ρ < .01, *** ρ < .001.

The results summarised in Table 7.4 indicate that was a significant difference between the two groups on two of the home integration items. The RAC Exit Group were more involved in household shopping and meal preparation.

Table 7.5 Differences in CIQ Social Integration Item Scores between two groups – 2007 baseline data (n=86) and the RAC Exit Group (n=34)

Variable	2007 Baseline Data Mean (SD)	RAC Exit Group Mean (SD)	Mann-Whitney Tests
6. Who usually looks after your personal finances, such as banking and paying bills?	.20 (±.45)	.15 (±.44)	Z = -.596, ρ = .551
Can you tell me approximately how many times per month you now usually participate in the following activities outside your home?			
7. Shopping	.49 (±.73)	.74 (±.57)	Z = -2.71, ρ = .007
8. Leisure activities such as movies, sports, restaurants, etc.	.49 (±.73)	1.08 (±.62)	Z = -4.65, ρ < .001 ***
9. Visiting friends or relatives	.57 (±.64)	.68 (±.64)	Z = -.936, ρ = .349
10. When you participate in leisure activities, do you usually do this alone or with others?	1.0 (±.56)	1.0 (±.55)	Z < .001, ρ = 1.00
11. Do you have a best friend in whom you confide?	.68 (±.95)	.47 (.86)	Z = -1.20, ρ = .230

***ρ < .001

Table 7.5 shows that there was only one significant difference between groups on the social integration scale. The RAC Exit group were more often involved in leisure activities (e.g. movies, sports, restaurants) than the group from 2007 who had not received enhancements.

Table 7.6 Differences in choice between two groups –
2007 baseline data (n = 86) and the RAC Exit Group (n=34)

Variable	2007 Baseline Data Mean (SD)	RAC Exit Group Mean (SD)	Mann-Whitney Test	
The content of their evening meal	1.77 (±1.03)	2.91 (±1.49)	$Z = -4.04, \rho < .001$	***
The timing of their evening meal	1.39 (±.86)	2.91 (±1.26)	$Z = -5.91, \rho < .001$	***
Indoor leisure e.g. TV, radio	2.84 (±1.26)	3.73 (±.72)	$Z = -3.88, \rho < .001$	***
Going out (e.g. pub, cinema)	2.37 (±1.28)	3.30 (±.85)	$Z = -3.81, \rho < .001$	***
The time they go to bed in the evening	2.24 (±1.20)	3.52 (±.80)	$Z = -5.02, \rho < .001$	***
The clothes they wear each day	2.68 (±1.34)	3.61 (±.93)	$Z = -3.67, \rho < .001$	***
Involvement of intimate partners	1.54 (±1.26)	1.97 (±1.84)	$Z = -.541, \rho = .589$	
Their daytime activities	2.59 (±1.18)	3.70 (±.73)	$Z = -4.93, \rho < .001$	***
The time they spend in the bath or shower	1.82 (±1.06)	3.15 (±1.06)	$Z = -5.05, \rho < .001$	***
Access to a private area	2.45 (±1.34)	3.76 (±.71)	$Z = -4.99, \rho < .001$	***
The furnishings in their bedroom	2.52 (±1.15)	3.85 (±.57)	$Z = -5.80, \rho < .001$	***

*** $\rho < .001$.

Table 7.6 shows that participants in the RAC Exit Group had more choice in ten out of 11 items of choice. The only area of life where there was no increase in choice was the involvement of intimate partners.

Table 7.7 Differences in mental health symptoms between two groups –
2007 baseline data (n=86) and the RAC Exit Group (n=34)

Variable	2007 Baseline Data Mean (SD)	RAC Exit Group Mean (SD)	Mann-Whitney Test
Self directed injury	1.54 (±1.48)	1.44 (±1.44)	$Z = -.456, \rho = .642$
Problem drinking or drug use	1.34 (±1.14)	1.44 (±1.44)	$Z = -1.44, \rho = .148$
Problems with hallucinations, delusions or confabulation	1.98 (±1.82)	1.59 (±1.64)	$Z = -1.05, \rho = .294$
Problems with depressive symptoms	3.20 (±1.65)	2.12 (±1.67)	$Z = -.466, \rho = .641$
Other mental and behavioural problems	2.48 (±1.80)	1.68 (±1.51)	$Z = -1.30, \rho = .194$

Health of the Nation Outcome Scale (HoNOS) (Fleminger et al., 2005)

The results summarised in Table 7.7 indicate that there were no significant differences between the two groups on symptoms of mental health.

Comparison of people living in RAC without enhancements with people living in RAC with enhancements

The 28 people who received enhancements were compared with 73 people living in RAC without enhancements (collected in 2007) (see Figure 7.3). People who had baseline data from the 2007 assessment and planning process as well as data collected after receiving enhancements were excluded from the group of 105 from 2007 to create two discrete independent groups for this analysis, leaving 73 people in the 2007 group.

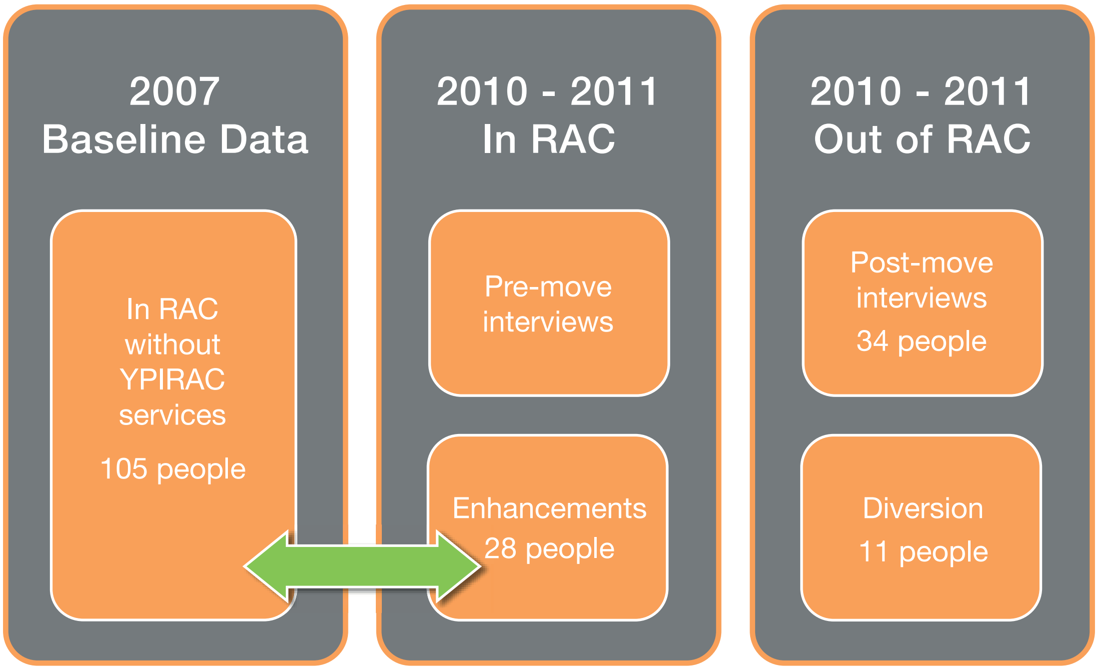


Figure 7.3 Comparison of people living in RAC without enhancements with people living in RAC with enhancements

Table 7.8 Comparison on a range of outcome measures – 2007 baseline data (n=73) and the Enhancement Group (n=28)

Variable	2007 Baseline Data Mean (SD)	Enhancement Group Mean (SD)	Mann-Whitney Tests
Days out of bed in the past 7 days	6.40 (±1.38)	6.48 (±.994)	Z = -.261, ρ = .794
How many hours out of 24 do you typically spend in bed?	12.60 (±4.08)	14.06 (±4.69)	Z = -1.86, ρ = .063
Length of time they can be left alone (CANS Part 2)	5.58 (±1.38)	6.07 (±.77)	Z = -4.33, ρ = .665
Number of life roles	2.19 (±1.32)	1.92 (±1.30)	Z = -.677, ρ = .498
Number of health conditions	3.26 (±1.94)	4.86 (±2.95)	Z = -2.01, ρ = .036 *
Number of behaviours of concern	2.14 (±1.83)	1.47 (±1.93)	Z = -2.43, ρ = .015 *

* ρ < .05.

The results summarised in Table 7.8 indicate that there was a significant difference between the two groups on two items. The Enhancement Group had more health conditions and fewer behaviours of concern than the 2007 baseline data group.

Table 7.9 Comparison of frequency of community access – 2007 baseline data (n=73) and the Enhancement Group (n=28). Measured in days per year.

Variable	2007 Baseline Data Mean (SD)	Enhancement Group Mean (SD)	Mann-Whitney Tests
Frequency of going outside	280 (±282)	198 (±240)	Z = -1.36, ρ = .174
Frequency of travel outside the place you live	113 (±164)	89 (±102)	Z = -.921, ρ = .357
Frequency of participation in shopping outside the place you live	4.71 (±4.90)	8.23 (±12.26)	Z = -.294, ρ = .769
Frequency of participation in leisure activities outside the place you live	5.27 (±5.53)	12.37 (±14.76)	Z = - 1.64, ρ = .100
Frequency of visits from relatives	107 (±94)	103 (±77)	Z = -.449, ρ = .653
Frequency of visits from friends	20.14 (±45.35)	25.25 (±56.15)	Z = -.091, ρ = .928
Frequency of visits to relatives' homes	5.76 (±5.41)	7.32 (±12.02)	Z = -1.44, ρ = .151
Frequency of visits to friends' homes	9.31 (±4.50)	0.50 (±2.65)	Z = -1.78, ρ = .076

Table 7.9 shows that there were no significant differences between the two groups in the frequency of community access and social contact.

Table 7.10 Differences in CIQ Total Scores and Subscale Scores between two groups – 2007 baseline data (n=73) and the Enhancement Group (n=28)

Variable	2007 Baseline Data Mean (SD)	Enhancement Group Mean (SD)	Mann-Whitney Tests	
CIQ total score	4.9 (±3.00)	5.68 (±2.60)	Z = -1.89, ρ = .059	
Home integration subscale	1.00 (±0.67)	1.11 (±.69)	Z = -1.05, ρ = .293	
Social integration subscale	2.38 (±1.77)	3.32 (±1.70)	Z = -2.43, ρ = .015	*
Productivity subscale	1.59 (±1.18)	1.25 (±1.00)	Z = -1.13, ρ = .257	

*ρ < .05.

While there was no significant difference between groups on the total CIQ score, the Enhancement Group scored significantly higher on the social integration subscale. They had a significantly higher level of social integration than the 2007 baseline data group.

Further examination of the social integration subscale was conducted to determine which items accounted for the difference.

Table 7.11 Differences in CIQ Social Integration Item Scores between two groups – 2007 baseline data (n=73) and the Enhancement Group (n=28)

Variable	2007 Baseline Data Mean (SD)	Enhancement Group Mean (SD)	Mann-Whitney Tests
6. Who usually looks after your personal finances, such as banking and paying bills?	.20 (±.45)	.07 (±.26)	Z = -.940, ρ = .347
Can you tell me approximately how many times per month you now usually participate in the following activities outside your home?	.49 (±.73)	.46 (±.51)	Z = -.409, ρ = .682
7. Shopping			
8. Leisure activities such as movies, sports, restaurants, etc.	.51 (±.77)	.68 (±.55)	Z = -2.06, ρ = .039 *
9. Visiting friends or relatives	.57 (±.64)	.50 (±.64)	Z = -.283, ρ = .777
10. When you participate in leisure activities, do you usually do this alone or with others?	1.01 (±.56)	1.18 (±.39)	Z = -1.84, ρ = .066
11. Do you have a best friend in whom you confide?	.69 (±.95)	.43 (.84)	Z = -1.13, ρ = .259

*ρ < .05

Table 7.11 shows that the group who received enhancements were involved in leisure activities (e.g. movies, sports, restaurants) more often than the group from 2007 who had not received enhancements.

Table 7.12 Differences in choice between two groups – 2007 baseline data (n=73) and the Enhancement Group (n=28)

Variable	2007 Baseline Data Mean (SD)	Enhancement Group Mean (SD)	Mann-Whitney Test
The content of their evening meal	1.77 (±1.03)	1.29 (±.76)	Z = -2.09, ρ = .036 *
The timing of their evening meal	1.39 (±.86)	1.29 (±.81)	Z = -.571, ρ = .568
Indoor leisure e.g. TV, radio	2.84 (±1.26)	2.79 (±1.17)	Z = -.196, ρ = .844
Going out (e.g. pub, cinema)	2.37 (±1.28)	2.32 (±.98)	Z = -.329, ρ = .742
The time they go to bed in the evening	2.24 (±1.20)	1.61 (±.83)	Z = -2.13, ρ = .033 *
The clothes they wear each day	2.68 (±1.34)	2.25 (±1.04)	Z = -1.35, ρ = .178
Involvement of intimate partners	1.54 (±1.26)	1.11 (±1.13)	Z = -1.55, ρ = .122
Their daytime activities	2.59 (±1.18)	2.43 (±1.34)	Z = -.263, ρ = .792
The time they spend in the bath or shower	1.82 (±1.06)	1.50 (±.88)	Z = -1.39, ρ = .166
Access to a private area	2.45 (±1.34)	2.68 (±1.22)	Z = -.997, ρ = .319
The furnishings in their bedroom	2.52 (±1.15)	3.14 (±.97)	Z = -2.39, ρ = .017 *

* ρ < .05.

Participants receiving enhancements had more choice than people who did not receive services in three out of 11 items of choice – the content of their evening meal, the time they go to bed in the evening and the furnishings in their room (Table 7.12).

Table 7.13 Differences in HoNOS Scores between two groups – 2007 baseline data (n=73) and the Enhancement Group (n=28)

Variable	2007 Baseline Data Mean (SD)	Enhancement Group Mean (SD)	Mann-Whitney Test
Self directed injury	1.54 (±1.48)	1.50 (±1.58)	Z = -.269, ρ = .788
Problem drinking or drug use	1.34 (±1.14)	1.50 (±1.58)	Z = -.696, ρ = .486
Problems with hallucinations, delusions or confabulation	1.98 (±1.82)	1.50 (±1.58)	Z = -1.21, ρ = .227
Problems with depressive symptoms	3.20 (±1.65)	2.30 (±2.00)	Z = -1.85, ρ = .064
Other mental and behavioural problems	2.48 (±1.80)	1.50 (±1.58)	Z = -1.71, ρ = .086

* ρ < .05.

The results summarised in Table 7.13 indicate that there were no significant differences between the two groups in mental health symptoms.

Outcomes of individuals with pre- and post-move data

Of the 34 participants interviewed post-move from RAC, 13 of them had pre-move data that was used as a baseline in the following analysis of matched pairs. The results need to be interpreted with caution because of the small sample size.

Figure 7.4 Outcomes of individuals with pre- and post-move data

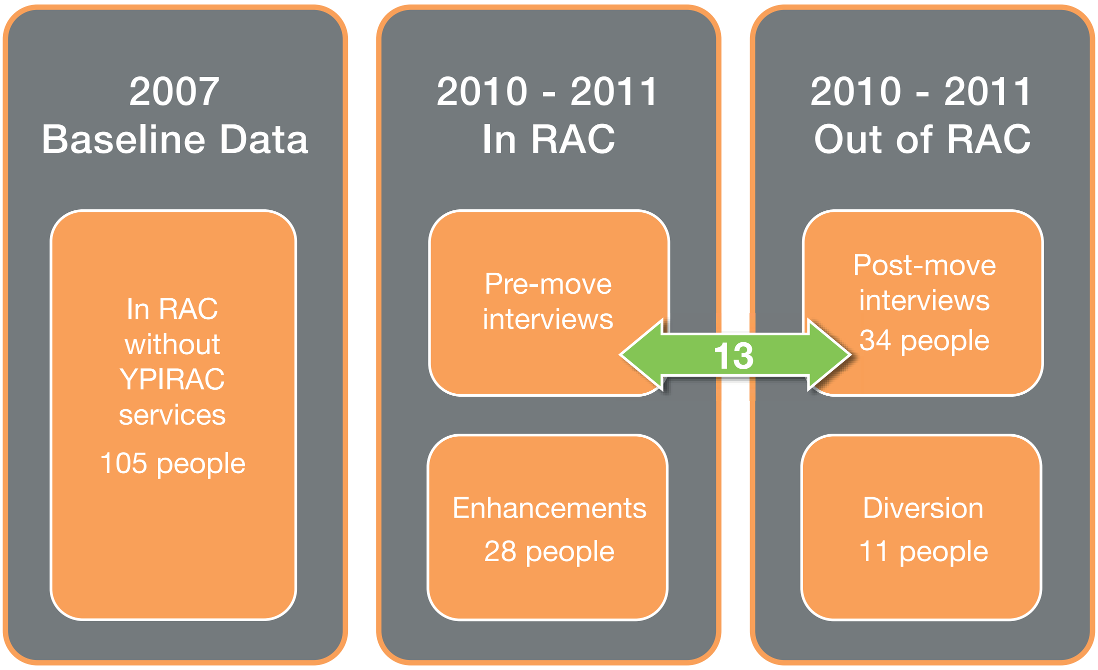


Table 7.14 Differences in a range of outcome measures pre and post-move (n=13)

Variable	Pre-move Mean (SD)	Post-move Mean (SD)	Wilcoxon signed ranks test	
Days out of bed in the past 7 days	6.4 (±1.1)	6.7 (±1.1)	Z = -1.60, ρ = .109	
How many hours out of 24 do you typically spend in bed?	14.2 (±3.8)	11.4 (±2.7)	Z = -2.10, ρ = .035	*
Length of time they can be left alone (CANS Part 2)	6.0 (±.77)	5.6 (±.95)	Z = -2.00, ρ = .046	*
Number of life roles	1.8 (±1.2)	2.8 (±1.5)	Z = -2.23, ρ = .026	*
Number of health conditions	4.6 (±2.6)	3.4 (±1.8)	Z = -.172, ρ = .863	
Number of behaviours of concern	3.4 (±1.8)	1.5 (±1.8)	Z = -1.13, ρ = .257	

* ρ < .05.

The results summarised in Table 7.14 indicate that participants spent fewer hours in bed and were able to be left alone for longer periods of time after they moved out of RAC. These participants also participated in more life roles after they moved.

Table 7.15 Tests for differences in access and social contact pre- and post-move (n=13)

Variable	Pre-move Mean (SD)	Post-move Mean (SD)	Wilcoxon signed ranks test	
Frequency of going outside (days per year)	198 (±240)	450 (±267)	Z = -2.39, ρ = .017	*
Frequency of travel outside the place you live (days per year)	81.3 (±98)	147 (±115)	Z = -1.21, ρ = .228	
Frequency of participation in shopping outside the place you live	8 (±11)	16 (±18)	Z = -.496, ρ = .620	
Frequency of participation in leisure activities outside the place you live	13 (±16)	24 (±22)	Z = -.352, ρ = .725	
Frequency of visits from relatives	100 (±74)	129 (±90)	Z = -.170, ρ = .865	
Frequency of visits from friends	4.5 (±8.8)	20.5 (±34)	Z = -2.56, ρ = .011	*
Frequency of visits to relatives' homes	7 (±11)	12 (±16)	Z = -.492, ρ = .632	
Frequency of visits to friends' homes	.46 (±2.4)	2.5 (±5.0)	Z = -.184, ρ = .854	

* ρ < .05.

Participants went outside more often and received visits from friends more often after they moved out of RAC (Table 7.15).

Table 7.16 Difference in CIQ Total Scores and Subscale Scores Pre- and Post-move (n=13)

	Pre-move Mean (SD)	Post-move Mean (SD)	Wilcoxon signed ranks test	
CIQ total score	3.6 (±3.14)	4.9 (±4.38)	Z = -1.36, ρ = .175	
Home integration subscale	0.83 (±0.67)	1.85 (±2.05)	Z = -3.34, ρ = .001	**
Social integration subscale	3.31 (±1.67)	4.63 (±2.41)	Z = -2.00, ρ = .250	
Productivity subscale	1.11 (±.95)	1.70 (±1.20)	Z = -2.24, ρ = .025	*

* ρ < .05. ** ρ < .01.

While there was no significant difference in the overall level of community integration post-move, people scored significantly higher on the home integration and productivity subscales. Further examination of the home integration subscale revealed increased involvement in shopping and meal preparation.

Table 7.17 Difference in CIQ Home Integration Items pre-move and post-move CIQ Item Scores (n=13)

CIQ Item	Pre-move Mean (SD)	Post-move Mean (SD)	Wilcoxon signed ranks test	
1. Who usually does shopping for groceries and other necessities in your household?	0 (±0)	1.23 (±.77)	Z = -2.00, ρ = .046	*
2. Who usually prepares meals in your household?	0 (±0)	1.05 (±.75)	Z = -2.24, ρ = .025	*
3. In your home, who usually does normal everyday housework?	0 (±0)	1.25 (±.71)	Z = -1.73, ρ = .083	
5. Who usually plans social arrangements such as get-togethers with family and friends?	.36 (±.49)	1.15 (±.74)	Z = -.378, ρ = .705	

* ρ < .05.

Table 7.17 shows that participants were more involved in shopping for groceries and other household necessities and meal preparation after they moved out of RAC.

Table 7.18 CIQ Social Integration Items, Wilcoxon Signed Rank Tests For Difference in pre-move and post-move CIQ Item Scores (n=13)

CIQ Item	Pre-injury Mean (SD)	Post-injury Mean (SD)	Wilcoxon signed ranks test	
6. Who usually looks after your personal finances, such as banking and paying bills?	1.11 (±.32)	1.45 (±.75)	Z = .00, ρ = 1.0	
Can you tell me approximately how many times per month you now usually participate in the following activities outside your home?				
7. Shopping	.53 (±.51)	1.48 (±.55)	Z = -.447, ρ = .655	
8. Leisure activities such as movies, sports, restaurants, etc.	.61 (±.55)	1.3 (±.72)	Z = -2.33, ρ = .020	*
9. Visiting friends or relatives	.47 (±.61)	1.38 (±.63)	Z = -.378, ρ = .705	
10. When you participate in leisure activities, do you usually do this alone or with others?	1.1 (±.42)	1.0 (±.58)	Z = -1.00, ρ = .317	
11. Do you have a best friend in whom you confide?	.44 (±.84)	.65 (.95)	Z = -1.00, ρ = .317	

*ρ < .05

Participants were more involved in community-based leisure activities after they moved out of RAC (Table 7.18).

Table 7.19 CIQ Productivity Items. Difference in pre-move and post-move CIQ Item Scores (n=13)

CIQ Item	Pre-injury Mean (SD)	Post-injury Mean (SD)	Wilcoxon signed ranks test	
12. How often do you travel outside the home?	1.11 (±.32)	1.43 (±.62)	Z = -2.24, ρ = .025	*
13. Work situation	.06 (±.33)	.09 (±.41)	Z = .00, ρ = 1.0	
14. School or training program	.00 (±.00)	.04 (±.21)	Z = .00, ρ = 1.0	
11. In the past month, how often did you engage in volunteer activities?	.06 (±.33)	.13 (±.34)	Z = .00, ρ = 1.0	

*ρ < .05

Participants travelled outside their home more often after they moved out of RAC (Table 7.19).

Table 7.20 Differences in choice pre- and post-move (n=13)

Variable	Pre-move Mean (SD)	Post-move Mean (SD)	Wilcoxon signed ranks test	
The content of their evening meal	1.39 (±.84)	3.02 (±1.4)	Z = -2.52, ρ = .012	*
The timing of their evening meal	1.28 (±.78)	3.04 (±1.2)	Z = -3.07, ρ = .002	**
Indoor leisure e.g. TV, radio	2.8 (±1.14)	3.8 (±.65)	Z = -2.72, ρ = .006	**
Going out (e.g. pub, cinema)	2.25 (±.97)	3.2 (±.97)	Z = -2.39, ρ = .017	*
The time they go to bed in the evening	1.67 (±.89)	3.4 (± .89)	Z = -3.13, ρ = .002	*
The clothes they wear each day	2.31 (±1.03)	3.6 (±.94)	Z = -2.80, ρ = .005	*
Involvement of intimate partners	1.33 (±1.3)	2.3 (±1.86)	Z = -1.39, ρ = .164	
Their daytime activities	2.53 (±1.08)	3.7 (±.67)	Z = -2.85, ρ = .004	**
The time they spend in the bath or shower	1.50 (±.91)	3.14 (±1.09)	Z = 2.97, ρ = .003	**
Access to a private area	2.72 (±1.19)	3.82 (±.62)	Z = -2.69, ρ = .007	**
The furnishings in their bedroom	3.11 (±.95)	3.84 (±.59)	Z = -2.41, ρ = .016	*

* ρ < .05. ** ρ < .01.

Similar to Table 7.6, the matched pairs analysis in Table 7.20 also showed that participants had more choice in ten out of 11 items of choice. The only area of life where there was no increase in choice was the involvement of intimate partners.

Comparison of Enhancement Group with the RAC Exit Group

In the final analysis, 28 people in the Enhancement Group were compared with the RAC Exit Group. Nine participants had received enhancements in RAC prior to moving out of RAC. People who were represented in both groups were excluded from the RAC to create two discrete independent groups for this analysis, leaving 25 people available to compare in the RAC Exit Group.

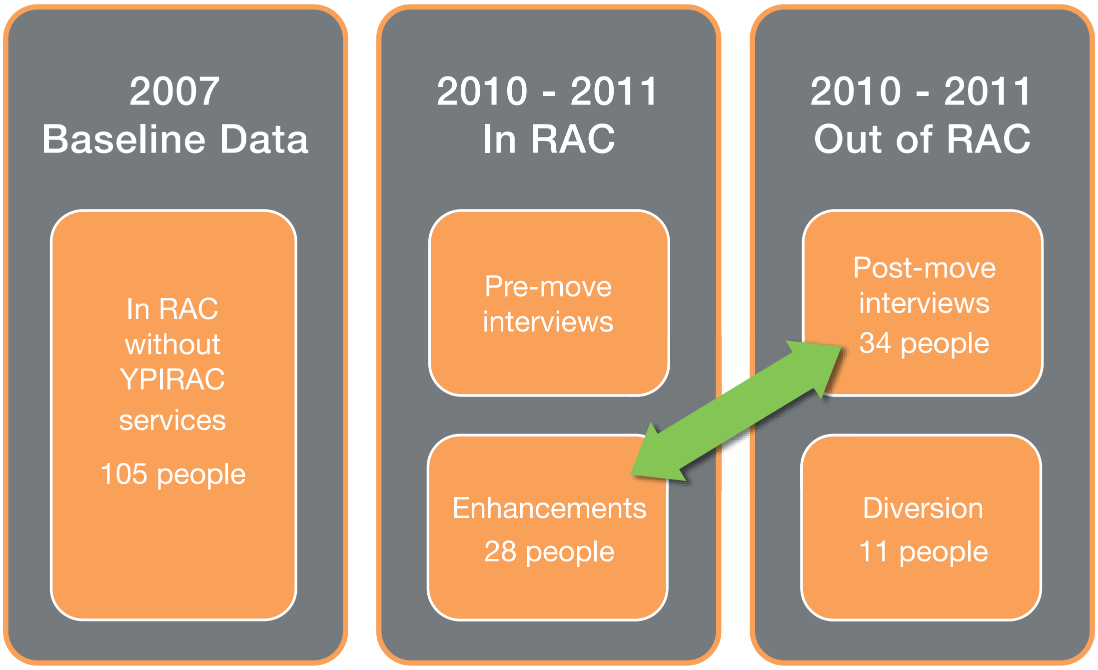


Figure 7.5 Comparison of people in Enhancement Group with RAC Exit Group

Table 7.21 Differences between two groups – Enhancement Group (n=28) and RAC Exit Group (n=25)

Variable	Enhancement Mean (SD)	Post-move Mean (SD)	Mann-Whitney Tests	
Days out of bed in the past 7 days	6.48 (±.994)	6.58 (±1.25)	Z = -.666, ρ = .505	
How many hours out of 24 do you typically spend in bed?	14.06 (±4.69)	11.89 (±2.89)	Z = -2.51, ρ = .012	*
Length of time they can be left alone (CANS Part 2)	6.07 (±.77)	5.71 (±.906)	Z = -.213, ρ = .832	
Number of life roles	1.92 (±1.30)	2.47 (±1.35)	Z = -1.74, ρ = .082	
Number of health conditions	4.86 (±2.95)	3.73 (±1.88)	Z = -1.14, ρ = .255	
Number of behaviours of concern	1.47 (±1.93)	1.41 (±1.73)	Z = -1.32, ρ = .189	

* ρ < .05.

The RAC Exit Group spent significantly less time in bed than the Enhancement Group (Table 7.21).

Table 7.22 Differences between two groups on community-based leisure and social contact – Enhancement Group (n=28) and RAC Exit Group (n=25). Measured in days per year.

Variable	Enhancement Mean (SD)	RAC Exit Mean (SD)	Mann-Whitney Tests	
Frequency of going outside	198 (±240)	469 (±273)	Z = -.318, ρ = .777	
Frequency of travel outside the place you live	89 (±102)	140(± 115)	Z = -1.31, ρ = .191	
Frequency of participation in shopping outside the place you live	8.23 (±12.26)	13.68 (±15.77)	Z = -1.85, ρ = .064	
Frequency of participation in leisure activities outside the place you live	12.37 (±14.76)	25.13 (±23.28)	Z = - 2.21, ρ = 0.27	*
Frequency of visits from relatives	103 (±77)	108 (±90)	Z = -.273, ρ = .785	
Frequency of visits from friends	25.25 (±56.15)	14.66 (±29.34)	Z = -.111, ρ = .912	
Frequency of visits to relatives' homes	7.32 (±12.02)	9.59 (±14.04)	Z = -.864, ρ = .388	
Frequency of visits to friends' homes	0.50 (±2.65)	1.54 (±3.79)	Z = -2.05, ρ = .041	*

* ρ < .05.

The RAC Exit Group visited friends more often and participated in community-based leisure more often than the Enhancement Group.

Table 7.23 Differences in CIQ Total Scores and Subscale Scores between two groups – Enhancement Group (n=28) and RAC Exit Group (n=25)

Variable	Enhancement Mean (SD)	RAC Exit Mean (SD)	Mann-Whitney Tests
CIQ total score	5.68 (±2.60)	6.21 (±3.75)	Z = -.129, ρ = .898
Home integration subscale	1.11 (±.69)	1.56 (±1.88)	Z = -.331, ρ = .740
Social integration subscale	3.32 (±1.70)	4.12 (±2.07)	Z = -1.26, ρ = .209
Productivity subscale	1.25 (±1.00)	1.52 (±.89)	Z = -1.68, ρ = .094

The results summarised in Table 7.23 indicate that there were no significant differences between the two groups on the CIQ total score or subscores.

Table 7.24 Differences in CIQ Total Home Integration Item Scores between two groups – Enhancement Group (n=28) and RAC Exit Group (n=25)

Variable	Enhancement Mean (SD)	RAC Exit Mean (SD)	Mann-Whitney Tests	
1. Who usually does shopping for groceries and other necessities in your household?	.00 (±.00)	.35 (±.54)	Z = -3.37, ρ = .001	**
2. Who usually prepares meals in your household?	.00 (±.00)	.26 (±.45)	Z = -2.67, ρ = .008	**
3. In your home, who usually does normal everyday housework?	.00 (±.00)	.12 (±.33)	Z = -1.83, ρ = .067	
5. Who usually plans social arrangements such as get-togethers with family and friends?	.39 (±.50)	.50 (±.66)	Z = -1.10, ρ = .273	

ρ < .01.

The RAC Exit Group was more involved in shopping for the household and meal preparation than the Enhancement Group (Table 7.24).

Table 7.25 Differences in CIQ Total Social Integration Item Scores between two groups – Enhancement Group (n=28) and RAC Exit Group (n=25)

Variable	Enhancement Mean (SD)	RAC Exit Mean (SD)	Mann-Whitney Tests	
6. Who usually looks after your personal finances, such as banking and paying bills?	.07 (±.26)	.15 (±.44)	Z = -.114, ρ = .909	
Can you tell me approximately how many times per month you now usually participate in the following activities outside your home?				
7. Shopping	.46 (±.51)	.74 (±.57)	Z = -1.90, ρ = .058	
8. Leisure activities such as movies, sports, restaurants, etc.	.68 (±.55)	1.08 (±.62)	Z = -2.04, ρ = .041	*
9. Visiting friends or relatives	.50 (±.64)	.68 (±.64)	Z = -1.10, ρ = .258	
10. When you participate in leisure activities, do you usually do this alone or with others?	1.18 (±.39)	1.0 (±.55)	Z = -.685, ρ = .493	
11. Do you have a best friend in whom you confide?	.43 (.84)	.47 (.86)	Z = -1.65, ρ = .099	

*ρ < .05

The results summarised in Table 7.25 indicate that there was only one significant difference between groups on the social integration subscale. The group who moved out was involved in leisure activities (e.g. movies, sports, restaurants) more often than the group who had remained in RAC and received enhancements.

Table 7.26 Differences in choice between two groups – Enhancement Group (n=28) and RAC Exit Group (n=25)

Variable	Enhancement Group Mean (SD)	RAC Exit Mean (SD)	Mann-Whitney Test	
The content of their evening meal	1.29 (±.76)	2.91 (±1.49)	Z = -4.05, ρ < .001	***
The timing of their evening meal	1.29 (±.81)	2.91 (±1.26)	Z = -3.78, ρ < .001	***
Indoor leisure e.g. TV, radio	2.79 (±1.17)	3.73 (±.72)	Z = -3.11, ρ = .002	**
Going out (e.g. pub, cinema)	2.32 (±.98)	3.30 (±.85)	Z = -2.95, ρ = .003	**
The time they go to bed in the evening	1.61 (±.83)	3.52 (±.80)	Z = -5.20, ρ < .001	***
The clothes they wear each day	2.25 (±1.04)	3.61 (±.93)	Z = -3.94, ρ < .001	***
Involvement of intimate partners	1.11 (±1.13)	1.97 (±1.84)	Z = -1.54, ρ = .123	
Their daytime activities	2.43 (±1.34)	3.70 (±.73)	Z = -4.03, ρ < .001	***
The time they spend in the bath or shower	1.50 (±.88)	3.15 (±1.06)	Z = -4.22, ρ < .001	***
Access to a private area	2.68 (±1.22)	3.76 (±.71)	Z = -3.27, ρ = .001	**
The furnishings in their bedroom	3.14 (±.97)	3.85 (±.57)	Z = -3.09, ρ = .002	*

* ρ < .05. ** ρ < .01. *** ρ < .001.

The results summarised in Table 7.26 indicate that participants had more choice in ten out of 11 items of choice – the only item that was not significantly different was the involvement of intimate partners.

Table 7.27 Differences in HoNOS Scores between two groups – Enhancement Group (n=28) and RAC Exit Group (n=25)

Variable	Enhancement Group Mean (SD)	RAC Exit Mean (SD)	Mann-Whitney Test	
Self directed injury	1.50 (±1.58)	1.44 (±1.44)	Z = -1.04, ρ = .523	
Problem drinking or drug use	1.50 (±1.58)	1.44 (±1.44)	Z = -.890, ρ = .741	
Problems with hallucinations, delusions or confabulation	1.50 (±1.58)	1.59 (±1.64)	Z = -1.90, ρ = .160	
Problems with depressive symptoms	2.30 (±2.00)	2.12 (±1.67)	Z = -0977, ρ = .349	
Other mental and behavioural problems	1.50 (±1.58)	1.68 (±1.51)	Z = -2.37, ρ = .040	*

* ρ < .05.

While there were no significant differences in symptoms related to items such as depression or substance abuse, the RAC Exit Group had more symptoms related to other mental health and behavioural problems. These other mental health and behavioural problems were related to anxiety or stress.

Chapter 8: Discussion

The evaluation of quality of life outcomes for Victorian YPIRAC participants demonstrated marked improvements in quality of life for a majority of those people who received support during this initiative, as well as their family members. For those who moved from RAC, the initiative has demonstrated that, not only can people with disabilities who have high support needs be successfully supported to live in community settings, but also that their lives are enriched when placed in more normalised, age-appropriate environments with person-centred supports. A more home-like environment and additional supports enabled some people who moved to demonstrate their potential for increasing their independence in a range of personal and domestic tasks.

The Diversion Group was typically earlier post-injury or diagnosis than the Enhancement or RAC Exit groups. Thus, many of these people had retained social and community links and held expectations of a return to age-appropriate life participation. In addition, to date they had avoided developing the range of secondary health conditions experienced by people living with profound disability for longer periods of time. The Diversion Group was more likely to return to live in the family home, having the opportunity to harness informal supports and resume existing or modified life roles that younger people who had been living in RAC for many years did not.

For those who chose to stay in RAC, enhancements made a valuable difference to participants' daily lives in allowing, for instance, receipt of an item of disability equipment to enhance comfort, communication or independence, or via the provision of a weekly outing to engage in a community-based leisure activity. These enhancements, particularly the one-to-one support of a disability support worker, also provided reassurance to the families of people living in RAC that there were other people visiting their family member on a regular basis and monitoring their health and well-being.

In the context of the range of positive findings from the quality of life evaluation, it is important to note that the improvement in quality of life came from a very low base, where many participants living in aged care led lives impoverished in the extreme. Prior to the receipt of services, many participants did not have the opportunity to make the everyday choices that most of us take for granted. They were effectively excluded from community life. They also had limited access to adaptive equipment. One man spent two years without a communication device which, once supplied through an enhancement package, now enables him to express his thoughts and needs. Others were unable to sit out of bed comfortably because they did not have a suitable wheelchair with customised seating prior to the initiative. Although the lives of people involved in the Victorian YPIRAC initiative have improved, many of them are not yet leading rich, fulfilling and meaningful lives. More needs to be done to build on the initial gains made and support the YPIRAC target group to participate in valued life roles and engage in their local community.

Differences between groups

The RAC Exit Group was significantly younger (range 21-53 years, mean 40 years, SD ±10.13) than the Enhancement Group. The average age of the RAC Exit Group was also younger than the mean age of the total population who received services through the Victorian YPIRAC initiative.

The Enhancement Group had an overall lower level of awareness than the other groups. The Diversion Group had a higher level of awareness than both the RAC Exit and Enhancement groups.

The Enhancement Group had greater prevalence of neurological conditions including Multiple Sclerosis and Huntington's disease. The RAC Exit had a greater prevalence acquired brain injury than either the Enhancement or Diversion Groups.

Participants in the Enhancement Group each had up to 11 health conditions. They had significantly more health conditions than the 2007 baseline data group who were not receiving enhancements. The RAC Exit Group tended to have fewer health conditions than the Enhancement Group. The Diversion Group had the least number of health conditions of all the groups. For example, more people in the Enhancement Group had swallowing difficulties, health conditions related to breathing such as recurrent chest infections or difficulty coughing, and skin problems such as pressure areas or rashes. The RAC Exit Group had fewer of these health issues and the Diversion Group had the smallest incidence of these health conditions.

There is a range of factors that could account for the differences in the incidence of health conditions between the three groups. People who had more health issues and degenerative conditions were more likely to stay in RAC. Many of the health problems experienced by this target group are exacerbated by lack of movement, limited opportunities to sit upright and lack of appropriate supported seating and positioning (Diab & Johnston, 2004; Mackay et al., 1999). The Enhancement Group spent more time in bed and required more assistance for bed mobility, transfers and mobility on the ground. However, the supported living environment (i.e. RAC vs. shared supported accommodation) is also likely to have had an impact on health. A supported living environment that fosters spending more time out of bed, sitting up, increased choice, social opportunities and getting out into the community more often is likely to have a significant positive impact on the incidence of secondary health conditions.

Both the Enhancement and RAC Exit groups demonstrated fewer behaviours of concern than the 2007 group who had not received enhancement services. Overt behaviours at the more severe end of the spectrum place the safety of the individual and others at risk and also contribute to the loss of opportunities to participate in social and recreational activities. The most common behaviours of concern were lack of initiation and verbal or physical aggression. Although primarily organic in origin, these behaviours can usually be traced to the presence of significant unmet needs. Often verbal or physically aggressive behaviour is the only mechanism for the person to express themselves and attempt to have their needs met (e.g. for pain relief, comfort, control). The reduction in the number of behaviours of concern was likely to be the result of providing the target group with more choice and control over their day-to-day lives and supporting engagement in meaningful occupation.

A series of group comparisons was conducted to analyse the statistically significant differences between groups on a range of outcomes related to quality of life. Overall, this series of group comparisons found that the provision of enhancement services led to some improvements in the quality of life of young people in RAC. The provision of enhancements enabled people to participate in community-based leisure activities and some increase in their opportunities to make everyday choices.

The RAC Exit Group had better outcomes than the Enhancement Group, including more frequent community access and more opportunities for making everyday choices. Young people who moved out of RAC had positive outcomes on a range of outcome measures. There was an increase in their frequency of social contact, they spent fewer hours in bed, went outside more often and were able to be left for longer periods of time after they moved out of RAC. The RAC Exit Group was also more involved in meal preparation and household shopping and participated in more life roles after they moved.

Life is better in community settings

As has been found in previous studies (Storace, 2002), this evaluation highlighted significant differences between the group living in RAC and those who returned to live in the community. The most striking change identified in people who moved to community models of accommodation and support was the opportunity to make everyday choices. This included choosing what to eat as well as the timing of going to bed: simple everyday choices normally taken for granted. There is a large body of evidence that enhancing personal control in everyday life through choice making is associated with improved quality of life, greater independence and a sense of personal dignity (Duncan-Myers & Huebner, 2000; Huebner, Johnson, Bennett, & Schneck, 2003; O'Connor & Vallerand, 1994; Wallhagen, Strawbridge, Kaplan, & Cohen, 1994; Wells & Taylor, 1991). The qualitative data identified a number of factors that enhanced opportunities for choice making, but most often cited was the change in attitudinal environment of staff providing daily support to the person with disability.

> “At first I probably missed being told what to do or when to do it because it was so structured, so run on that 24-hour clock…I think I got a little bit lost at best, but I think that would be normal for anybody. But now I don't…it's good. I don't have to have tea at 5 o'clock anymore. I can have it at 6:30pm if I want.” CAROLINE, PARTICIPANT.

> “I think it's given him some control over his life and, above all, choices. He can make the choice now of where he would like to go, what he can access, whether that's the pictures, the races…he can just go out to the pub with a couple of the blokes. It just opened a new world for Brad.” BRAD'S FATHER.

Models of health and disability emphasise the importance of the physical, social, cultural, institutional, and attitudinal environments and the influence they exert on participation, where participation is defined as involvement in a life situation (Kielhofner, 1995; 2001b). Each of these environmental influences may facilitate or impede participation. Wahl, Fange, Oswald, Gitlin and Iwarsson (2009) refer to this as "person-environment fit." The 2007 *my future my choice* study (Winkler et al., 2007b) highlighted the mismatch between the person and the environment when a young person is placed in the aged care environment, which is geared to supporting elderly people at the end stage of their life. Restricted opportunities for everyday choices was one factor in contributing to such a mismatch, which can result in boredom and behaviours of concern, as well as social isolation, anxiety and feelings of hopelessness.

> "He's got to be prompted to do everything. If you prompt him he'll do it, if you don't prompt him he won't do it. He's what we call…institutionalised. Now he's in there with [people with] dementia and Alzheimer's and he has become… a 51 year-old dementia patient through watching what they do. How they get fed. He sees his food there and he doesn't want to eat it. Folds his arms. Sooner or later somebody will come along with a spoon and feed him. I don't think he's had a knife and fork in his hand for 17 years." MARTY'S FATHER.

> "He gets fed in bed. I don't feed him in bed. I always get him in the armchair or wheelchair to feed him. But 25 year-old men don't usually get fed in bed and that really irritates me." NED'S MOTHER.

> "He's totally isolated. He doesn't mix with any of the residents at all…it's run for elderly people and …there's no consideration at all that there's a 20-something year-old here." TOM'S MOTHER

> "We found it difficult in aged care, because they're sort of just left to sit there…all she ever did was stay in bed. She just got to the stage where she just couldn't be bothered getting out of bed. So there was nothing for her to do." PATRICIA'S SISTER

In contrast, the qualitative data reported in the current study revealed that the attitudinal environment of community-based accommodation settings was quite different to that of aged care. It was apparent that, in general, staff had the time and capacity to support the individual to make choices and also understood the importance of this for the person's sense of control over their environment. Staff also came to know the person and their preferences and, due to higher staff to resident ratios, coupled with more home-like physical spaces, opportunities to participate in routine daily activities (such as menu planning) and to make choices was more regularly facilitated.

> “They’re (staff) good because they will say to him, ‘Clint, would you like to come and help with the cooking? Clint, would you like to have a drink?…’ He has to be supervised but I notice he’s getting a bit better.” CLINT’S PARTNER

> “The staff here go out of their way to interact with the people that are here.” JACK’S FATHER

> “A lot of the staff are really good; and it’s far more geared to slow-stream rehab for acquired brain injury than where he was.” MICK’S MOTHER

> “They’re probably asking questions and sort of waiting for the answer perhaps. Whereas at the nursing home, they were in a hurry.” BRAD’S MOTHER

This study also found improved levels of independence in a range of areas including communication, continence and physical function. This stemmed from a combination of factors including prescription of a necessary piece of disability equipment, a higher staff-to-resident ratio — which allowed more time to support the individual in the performance of activities — as well as a prevailing belief in the potential of the individual and their desire to aspire to increased independence. Workers provided participants with the time, support and encouragement to develop skills again. Skills development in this population takes considerable time, practice, repetition and patience, particularly when habits of dependence on others are ingrained.

Again, this contrasts significantly with the experience of those people living in RAC. As previously reported (Cameron et al., 2001), RAC managers identified that inadequate training and staffing levels, and limited resources, were significant barriers to RAC facilities being able to meet the social, cognitive and rehabilitation needs of younger people with ABI. These were also barriers to maintaining independent living skills. The current evaluation has provided many examples highlighting that RAC is not designed or resourced to meet the needs of younger people.

> “Within less than five months or something he was actually showering himself because the opportunity was there. He’s dressing himself. It could be the timeframe but I think it’s more like the environment that has allowed him to become more independent, because in the nursing home he couldn’t dress himself. You had to prompt him for everything.” CLINT’S PARTNER

> “They’re doing everything. They’re teaching him to put socks on, to put shoes on…every other place (RAC) he’s been, get him out, sit him down, let him go to sleep, wake him up at morning tea, back sitting down, wake him up at lunch time…but here he’s not restricted in any way. He can walk out the door, go out the back, come around. He knows how to get back in the back door.” MARTY’S FATHER

> “I take afternoon tea and we’ll sit around the table and it’s an opportunity for me to prompt him to go and ask the others. So he has an opportunity then to initiate discussion, go to the office and ask them if they’d like a cup of tea…he was a very hospitable person so it kind of gives him an opportunity to practice his own skills.” CLINT’S PARTNER

> “Well they try and get him to take his laundry down to where they wash the clothes here. Just every day-to-day things – when he’s in having a shower, trying to get him to wash himself a bit. Just things that the [RAC] didn’t have the time or the patience…if he needs to go to the toilet they take him straight away. He knows when he needs to go, so he doesn’t wear nappies any more.” SHAUN’S MOTHER

The other key finding of the evaluation was the significantly higher levels of community participation in the group who moved from RAC to community settings. Factors that underpinned these changes included staff ratios and attitudes of staff and the availability of disability equipment (e.g. wheelchair; an augmentative communication device). Social participation and everyday choice was also enhanced by higher staff ratios. Although family visiting was lower than when in RAC, visits from friends were more frequent. Qualitatively, some families reported the need to visit less as they believed their family member was better supported in the new accommodation setting.

> “I don’t have to be there. I can say, if my daughter says ‘Can you have one of the kids, they’re sick?’ or a friend’s sick and needs a hand, I can say ‘Yes, I can do that’. I can go up and visit Patricia tomorrow. When she was in the nursing home I’d say to them, ‘Well I’ll try to fit you in after I visit her,’ because I felt like we needed to be there to make sure she was fine.”
> PATRICIA’S SISTER

> “It has made a lot of difference to my health. Everybody noticed that I am not so tired; I’m not so exhausted.” TONY’S MOTHER

> “I miss him, because my life revolved around Greg every day for 36 years. Now I just feel…it’s taken the pressure off me as well. It gives me time now that I can do perhaps what I’d like to do without having to look at my watch and think, ‘I’ve got to get to Greg.’” GREG’S MOTHER

Family burden of care tended to decrease following the move from RAC, with many families reporting their relief that there were now other people who knew how to care for their relative. For example, families reported that staff in the new services had the time to complete the personal tasks, such as feeding, that family members had previously undertaken in RAC. While many of these changes were positive, it was also apparent that there was a significant adjustment for family members whose lives and identities had been shaped around their key life role of ‘carer’. To be needed less was a loss, and it was not always straightforward for relatives to give over the care of their family member to others. Some families reported concern regarding the capacity of support staff to deliver the care required to their family member. This was particularly the case when care needs were highly complex and based around unstable medical conditions, and concerns were heightened for some families by medication errors or preventable medical issues causing significant health consequences for the participant within the new accommodation setting.

During the time in RAC, many family members had become ‘the expert’ on their relative’s care. Families also offered knowledge of a life history of the individual that may be otherwise unknown. It is therefore vital that this expertise is acknowledged and the family is included as part of the team providing ongoing support to the individual. The transition planning, or introduction of new supports, including paid carers, must include the passing on of family members’ knowledge and involvement of the family as part of a collaborative team process. This will avoid unnecessary conflict and distress that can arise when the family feels shut out. Working in partnership with families may also eliminate some of the preventable errors and issues arising in direct care delivery.

> “It’s been very frustrating. He’s got his sort of team of therapists and they keep training staff who keep leaving. Originally when we set this place up…we were trying to get key workers to work with the people and they’d get trained and they would know all the sorts of things Mick needed…that hasn’t been adhered to and you know there’s often people who don’t know Mick very well dealing with Mick still.” MICK’S MOTHER

> “I want the team approach. I want openness, I want transparency… I want Mick’s health and Mick’s well-being to be put first and that hasn’t been the case in the last 12 months. But we are working towards it.” MICK’S MOTHER

Diverting younger people from being placed in aged care

The Diversion Group was small in number and a diverse group with a range of varied needs. Many of them were earlier post-injury or diagnosis than the Enhancement or RAC Exit groups. The people receiving diversion packages tended to be more cognitively able, or had the capacity to articulate their specific needs and wants for community living (or had a family member to provide this advocacy). This group was more likely to return to the family home with a mix of paid and informal supports than the RAC Exit Group. In general, the Diversion Group had higher expectations for improvements in function, with packages at times being used for home modifications and disability supports to return to the family home.

Being earlier post-injury or having remained living in the community even with profound disability, the Diversion Group still had links to their existing social and community networks. They saw these links as an opportunity to harness or re-establish connections following their injury or health event. This group was able to identify a range of valued life roles, independence and participation goals that they wanted to pursue, and saw opportunities to do so utilising the disability supports provided through the YPIRAC initiative. This was in contrast to people who had been living in RAC for many years, and whose expectations of recovery, independence and role participation may have diminished over time. For example, a participant in the Enhancement Group went shopping once per week for personal items, compared to a participant in the Diversion Group who was fulfilling her role as a homemaker within her family and becoming more independent in a range of domestic tasks including household shopping and meal preparation.

To move or not to move: a difficult decision

Many (64%) of the participants in the current evaluation were assessed as not having the capacity (by reason of their cognitive disability) to make decisions regarding their accommodation and support, or other lifestyle matters. Most individuals had a substitute decision maker who were, by and large, family members who provided informal support to maximise their family member’s participation, but largely made decisions on their behalf. Three participants had formal guardians to assist with decision making. In some cases, advocates were engaged to assist with decision making. Generally, the decision regarding moving from RAC to an alternative accommodation and support option was undertaken collaboratively and the individual was included in this process to the level of their ability. The qualitative data highlighted the significant difficulty families faced when making these decisions on behalf of their loved ones.

> “ I was seeing a counsellor about all this as well, and one of the things she said to me was that at least if this is happening while I’m around then I have sort of control; in that I can act on Henry’s behalf and be his voice and let them know if things

> aren't right. But even that's not quite as simple as it sounds. It's better than him not having anyone and just having to fend for himself." HENRY'S MOTHER

There were multiple and complex factors that family members considered, and invariably there were strong reasons for and against a move out of RAC. Some of the factors that people took into account in making decisions regarding moving to an alternative accommodation and support option included geographical location, services and opportunities available in the new setting, the current and future support needs of their family member (people with ongoing degenerative neurological conditions were less likely to move) as well as the other people in the living environment.

> "It was a big decision for my husband and I to make, because that's your son's life. So you don't know if you're doing the right thing or the wrong thing." GREG'S MOTHER

The original *my future my choice* study (Winkler et al., 2007) had shown that family members of individuals who had been in RAC the longest were most likely to decide against moving. The reasons for this were thought to reflect that people in the support network, which was typically depleted and often consisted of elderly parents, had adapted to their family member's placement over time. Further, knowing their family member's high care needs, relatives couldn't imagine them being met in a place other than where nursing staff were employed. Similar to the finding of Strettles et al. (2005), some of the families in the current study identified that the risks and uncertainty associated with change were sometimes too challenging to face.

> "My family…none of them wanted to make a decision. That's what I said to Mum it's fine they're all sitting on the sidelines, but if I make the wrong decision then I'm going to cop it from all of them." PATRICIA'S SISTER

Having fought so hard to get their relative into a RAC facility in the first place, they were reluctant to risk this known outcome against the possibility that the new placement would fail. There was no guarantee that they could return to the familiar setting of the previous RAC facility if the new accommodation option did not work out.

> "Now I know that three years ago he would have walked out the door tomorrow if he could have got out there but now he's quite happy…if he did move into a place and something happened — he didn't like it or all that sort of thing would he be able to get back in here? Most likely not. So I felt that he's been very cosy in here for the last two or three years."
> BARRY'S FATHER

The individuals themselves may also have become institutionalised and their expectations, as well as overt signs of psychological distress, may have diminished considerably over the course of their placement in RAC. The fact that, as O'Reilly and Pryor (2002) had found, RAC was seen as their only option points to the importance of ensuring appropriate placement of younger people with complex care needs from the outset. The superior outcomes of the Diversion Group strengthen this argument. An increased focus is required to prevent new admissions and offer timely alternatives to people who are at risk of admission to RAC.

Although the opportunity for individual choice was a guiding principle of the Victorian YPIRAC initiative, the person was typically offered limited accommodation options as an alternative to RAC. There was limited capacity to choose who the person was going to live with or who would provide their support. Often the person's choice was between staying where they were, or moving to a new shared supported accommodation being built in their geographical region.

There was a range of challenges for the individuals who were supported to participate in decision making regarding future accommodation. Many people in this target group had an acquired or late onset disability and had little or no knowledge of shared supported accommodation for people with disabilities. The cognitive skills of most of the target group were compromised, usually to a significant extent, and typically they had trouble imagining living in a place (e.g. a new shared supported accommodation setting) that was described to them, but which they had never previously seen or experienced. In consenting to move, many individuals were not clear on what they were agreeing to, especially as many of the new services were not in operation at the time a decision was made.

> “Prior to moving in, we were told that all the residents would be similar to Greg. So we weren't able to meet any of the residents prior to moving in…but it's very difficult because I was hoping that he would have had people that he could converse with and more like a family…a huge disappointment. I actually don't know whether I would have moved him in.”
>
> GREG'S MOTHER

Managing transitions

Once a decision had been made to move, a transition between the two accommodation and support options was undertaken. The qualitative data pointed to the complexity of this process, a fact that was often underestimated. Issues that arose included delays in transition from RAC once a place was identified or, alternatively, limited time to consider accepting an offer of accommodation placement and adequately plan transition.

> “So lots of delays, which was a bit heartbreaking, but I said to him, ‘Look, you will get there mate, it’s just that we’ve got to have patience and wait.’” SHAUN’S MOTHER

> “We waited a long time…we couldn’t even get in here. I think some of it could have been handled a bit differently. Some of the staff could have been trained earlier; when Jack’s coming it, it’s panic; ‘Oh, he hasn’t been trained, he hasn’t been trained’. It could have been handled a bit better.” JACK’S FATHER

Most concerning was that these issues, and a lack of clear information, led to unmet expectations and, in some cases, this caused conflict and distress once the person with a disability was placed in a new accommodation setting. For instance, some family members only became aware during transition that they would be required to meet the considerable ongoing costs of disposable items, such as continence products, which had been previously purchased for them by the RAC facility. Further, individual funding packages that enabled the person to receive direct support (e.g. enhancement package; ABI:STR program disability support worker funding) were significantly reduced or ceased when a place at the new accommodation was accepted. Some people found that they no longer had the 1:1 support they required to access the community after they moved. Conversely, other participants reported that after they moved, they obtained the 1:1 support they needed to access the community and spend time with family. Although the SSA services developed were block-funded, some services gave residents control over their individual support and enabled them to bank these hours for weekends away or holidays. This experience highlights the importance of providing clear written documentation of entitlements to assist the person and their family to make an informed decision regarding whether to move or not.

Enhancing the experience for those who remain in RAC

People who chose to stay in RAC were a sub-set of the larger group and weighted towards those who had degenerative conditions, had been in RAC the longest, displayed lower levels of initiative, fewer behaviours of concern, and had higher overall levels of social isolation (except for family who visited quite frequently).

Quality of life and participation measures revealed a group who were living extremely impoverished lives but who held goals for increased participation in friendship, hobbies and home maintainer roles. On average, they received recurrent enhancement packages of $10,000 per annum. Many of the packages were directed to addressing the systemic barriers to the community participation of people with ABI and complex care needs living in RAC as identified by Strettles et al. (2005). In particular, the enhancement packages often provided equipment and resources, such as a disability support worker, for access to the community.

While families and participants reported that the small amount of funding made a significant impact on their lives, empirical data points to the fact that the Enhancement Group's quality of life and community participation was still extremely limited. Given their low frequency of social contact and community access, the incidence and severity of mental health problems was much lower than anticipated.

Although some specific improvements in quality of life were evident from the transcripts of interviews, this change was not reflected in the overall quantitative data where there was statistically little difference between the Enhancement and the 2007 baseline data group. Exceptions were leisure and social items on the Community Integration Questionnaire.

The introduction of a disability support worker into the life of the person who remained in RAC was a highly successful intervention in many cases. However, training and ongoing monitoring of the intervention offered was typically limited and relied on the individual skills of the worker to understand and deliver supports adequate for the person with disability. For family members, the provision of such enhancement packages of direct support offered reassurance that another person was now showing an interest in, and looking out for, their relative. For the individual with a disability, it provided an opportunity for meaningful social interaction with someone often of a similar age and with whom they could share an interest (e.g. going shopping).

> “There's a lot more things I think that he's been doing – since he's had the carer. I think the carer's made a massive difference to what he's wanted to do and how he can do it. Getting out twice a week with someone who wasn't family.” KARL'S MOTHER

> “It's enabled him to take his nephew to the football in the winter which has been…of benefit for both of them…Vic would book a cab, pick his nephew up and they'd go to the MCG.”
> RAC MANAGER

The high frequency of relatives visiting on most days reflected the high burden of care experienced by some families who feel the need to be at the RAC one or more times per day to complement or check on the care provided by paid staff. Some families were actively involved in the physical care of their family member (e.g. meal time assistance) because they perceived that paid staff did not have enough time to provide the care required. Some families also felt that they needed to visit daily to compensate for the lack of stimulation experienced by many younger people in the RAC environment.

Many participants living in RAC also received funding for much needed equipment. Equipment supplied allowed some individuals to receive a specific item tailored to their disability needs (in comparison to the generic items supplied by RAC and which were then shared with elderly people). Technology such as communication aides made a significant difference to the quality of life of participants. For example:

> “He can even write notes to me now and tell me what he wants without having to go through the alphabet.” WAL’S FATHER

> “It is like going to bed a mute and waking up being able to talk and communicate again. My life has begun again; with the computer I can relate as an adult. It is unbelievable that I can now engage in serious conversation. I now think daily what occupied my time. I wasted so much time. Back on track now.” WAL, PARTICIPANT

Disability equipment prescription for this target group is often complex; items required are usually not standard, but rather require customisation, regular monitoring, as well as training for the person with disability and their support network regarding equipment use. Such training was not always provided.

Limitations of the evaluation

The key limitations of this evaluation include a potential bias in the sample, challenges in measuring quality of life in this target group, the use of multiple outcome measures in group comparisons and the timing of the post-move interviews.

The people who participated in the current evaluation may not be representative of everyone under 50 living in RAC in Victoria. Given their range of cognitive and communication issues, most people in this target group required support to respond to the invitation to participate in the Victorian YPIRAC assessment and planning process at the start of the initiative, as well as the evaluation. It is therefore likely that people who had regular contact and support from family members or a proactive support worker (e.g. case manager; allied health professional) were more likely to participate in both the assessment and planning process and the current evaluation. It is therefore possible that the people who did not participate were even more disadvantaged and socially isolated than the sample in the current evaluation.

The differences between groups in the current evaluation could in part be explained by bias in either the total sample or the sub samples in the current evaluation. This evaluation had a participation rate of 36%. Based on information provided by DHS regarding all participants in the Victorian YPIRAC initiative we know that participants in the evaluation were significantly younger than the population of YPIRAC service users. In the current evaluation, there was also a greater representation of people with ABI, lower representation of people with an intellectual disability and greater representation of people from rural and regional areas.

People in this evaluation were not randomised into the three groups – RAC Exit, Diversion and Enhancement. Therefore, the differences between groups could also be partly explained by potential bias in the sub samples. For example, we know that on average the RAC Exit group were younger, had less health conditions and were less likely to have a degenerative neurological condition than the Enhancement group. However, the findings of the comparison of the 13 people pre and post move suggest that the bias in the sub samples does not completely account for the significant differences between the three groups.

There was a range of challenges associated with the evaluation design. Firstly, many of the participants were unable to participate in an interview or respond to published measures so, where possible, tools that could by completed by a range of informants (not just the person with a disability) were utilised to measure changes in quality of life. Secondly, the participants were a heterogeneous group (e.g. disability types, support needs, health issues, priorities and preferences) who received a variety of interventions stemming from the individualised planning undertaken with each person. For example, one participant receive a customised wheelchair and a relatively small recurrent funding package for a weekly massage while others received a range of adaptive equipment and more than $110,000 in recurrent funding to enable them to live in shared supported accommodation. It was therefore challenging to predict how participants' lives were likely to change and identify suitable instruments to capture that change.

Ideally, we would have used a global measure to capture the quality of life outcomes from the YPIRAC initiative, however we were unable to identify a suitable single tool that adequately measured the changes described in previous literature (Heller, Miller, & Hsieh, 1998; Wales & Bernhardt, 2000) and that did not rely on the person with disability being the informant. In using a range of measures with this target group we did not control for the multiple comparisons between groups. There was therefore an increased risk of Type I errors (findings of false "significance") because multiple simultaneous hypotheses were tested at set p-values.

Finally, in reviewing the findings of this evaluation it is important to consider that, most often, the person with disability and their families were interviewed in the early stages post-transition to the new accommodation setting. Fifty percent of post-move interviews took place less than six months after transition to the new accommodation option. As such, the evaluation findings may have been influenced by a 'honeymoon' period, or in contrast teething problems in the new setting, when comparing that setting with RAC. Some participants may need some time to settle in to their new accommodation before they are ready to focus on skill development in the home and inclusion in their local community. Evaluating the outcomes for the RAC Exit Group at two years post-move may provide a more valid assessment of the long-term outcomes for this group.

Critical success factors to improve quality of life

Using verbatim semi-structured interview data coupled with thematic analysis, critical success factors that promote improved quality of life outcomes were identified for each of the sub-groups of people who received support through the Victorian YPIRAC initiative.

RAC Exit Group

The key critical success factors that promoted improved quality of life outcomes for the RAC Exit Group included: staff ratios, attitudes and training and the small-scale and physical design of the shared supported accommodation services developed.

Staff ratios

Staff having the time and capacity to engage with the person with disability was critical to supporting residents to make choices. In contrast to RAC, participants reported SSA staff were able to spend more 1:1 time interacting with residents and getting to know them and their preferences. In SSA, staff had time to ask residents questions and wait for people with communication impairments to respond. Although all services were block-funded, some managed to provide individual support to enable residents to access the community and spend time with family. However, other services provided limited 1:1 support for community access, which impacted the residents' opportunities for choice and community inclusion.

Staff attitudes

Some young people in RAC demonstrated the potential to increase their independence and living skills given a more appropriate accommodation environment and support model. As a result of staff taking the time to involve residents in household decisions and encouraging them to engage in domestic tasks, participants and their families reported increased involvement in household tasks. The flexible approach of SSA staff also enabled residents to make everyday choices, including the time they went to bed or the content of their meal. Less institutional environments, without the rigid routines of RAC, provided more opportunities for residents to exercise choice and control. Some staff also encouraged residents to try new community-based leisure activities, which resulted in positive outcomes for these participants.

Improved expressive communication of residents was related to SSA staff taking the time to understand the specific communication needs of residents, encouraging communication partnerships with the person with disability, and taking time to listen. Staff belief in the potential of individuals, encouragement, provision of opportunities and timely support resulted in the increased independence of some residents in domestic and personal care tasks.

The attitudes of staff were also critical to the outcomes for families. The best outcomes for both residents and families were where the SSA staff made families feel welcome, collaborated in partnership with them, listened to complaints and worked with families to resolve issues.

Staff training

Having staff with expertise in the specific needs of this target group was also seen as critical to positive outcomes for both residents and families. While some families reported that staff knew their family member well and had specialist knowledge regarding their specific disability (e.g. ABI or Huntington's disease), other families were not confident in the capacity of staff to meet the high and complex care needs of their family member. Training, supervision and retention of quality staff are critical to improved outcomes for this target group.

Small-scale physical design of the service

The improved outcomes in household participation were strongly linked to the domestic scale and physical space of most SSAs. The small scale of the service provides residents with opportunities to initially observe and then participate in routine household tasks that were not possible in the larger, institutional RAC environment. For example, residents in SSA could enter the kitchen; some were able to make themselves a drink and use the microwave. The small scale of the services also enabled staff to get to know the individual and their preferences, including involving residents in menu planning and other household decisions.

The quieter environment in SSA led to improved behavioural outcomes for some participants. For one person, improved expressive communication was attributed to a calmer environment in which he was less stressed and had more time to express himself. However, other residents found the reduced number of staff and residents in the SSA environment too quiet and more socially isolating than the busy RAC facility, where increased resident numbers led to a greater number of staff and visitors to the RAC for the person to interact with throughout the day.

Some SSA services had a separate lounge that enabled residents to spend time with friends and family in privacy. Both residents and family reported that this made a huge difference to the quality of time spent with family and friends, when compared with the limited private spaces available in RAC.

Good access to areas in and outside the SSA service fostered a sense of independence and freedom for residents. Some residents reported that being able to freely enter and exit their home made a significant difference to their sense of control in community living. This was in contrast to the RAC environment, where a security system on exits meant that some participants were not able to go outside independently.

Diversion Group

The critical success factors that promoted improved quality of life outcomes for people who received diversion packages related to an accessible home environment, fostering independence and returning to live in their previous home and familiar community.

Accessible environment

Modifications to the family home enabled people to return to community living and provided opportunities for greater independence and skill development for some participants. Ramps and wheelchairs enabled some people to independently access their local community.

Fostering independence

The provision of disability support workers to assist with elements of tasks that were initially beyond the participant's abilities allowed the person with a disability to return to valued life roles such as a homemaker, and offered targeted supports to facilitate skill development and, subsequently, independence.

Returning to their previous home

Being able to return to their previous home enabled some participants to maintain their relationships with partners and children. For others, being in their own home gave them a greater sense of choice and control and allowed access to informal social and support networks.

Returning to familiar community

Some participants who returned to their previous home had a strong sense of community belonging and were able to harness informal supports in familiar settings within their local community.

Enhancement Group

This evaluation identified three critical success factors that promoted improved quality of life outcomes for people who received enhancements: individualised and flexible funding, consistent disability support workers and monitoring enhancement package implementation.

Individualised and flexible funding

Each enhancement package was very different and tailored to the participant's skills, support needs, goals and local community. Having the flexibility to address the multiple barriers to community access was critical to positive outcomes for people in the Enhancement Group. For some people, this included the provision of a wheelchair with customised seating which enabled them to sit out of bed in comfort long enough to be able to get out into the community. Most participants (93%) were on a disability pension and had very limited disposable income after paying aged care fees. Funding for taxi vouchers to travel to the family home or access the community was highly valued by many participants.

Consistent disability support workers

Having consistent and skilled disability support workers who understood the unique needs of the participant was also critical to positive outcomes for participants. Some participants had not been out into the community for many years and required both encouragement and skilled support to re-enter society.

Monitoring enhancement implementation

Having someone who was overseeing the enhancement package to make sure all elements were implemented and reviewed to match the changing needs of the participant was also critical for positive outcomes. Some participants reported that such monitoring was not present and thus, plans for enhancements were not always delivered in a timely manner or as documented in the original planning and assessment process.

An aim of this evaluation was to make recommendations to improve outcomes for individuals receiving disability services into the future. The final chapter will outline key recommendations based on the findings from this evaluation.

Chapter 9: Recommendations

The purpose of this chapter is to outline the key issues arising from the evaluation and provide recommendations to improve outcomes for individuals receiving disability services into the future. It will also inform the Department of Human Services (DHS) regarding future decision making and service responses for the target population of the Victorian YIPRAC initiative. These recommendations are highly relevant to the implementation of a proposed National Disability Insurance Scheme to which the Victorian Government has indicated a strong commitment.

THERE ARE EIGHT KEY RECOMMENDATIONS FROM THIS EVALUATION:

Prevent new admissions of young people to aged care.

Increase the range and number of alternatives to RAC.

Proactive intervention to reduce the lifetime care costs of young people with complex care needs.

Provide timely access to assistive technology and customised equipment.

Maximise autonomy and home and community integration.

Develop disability workforce capacity.

Promote engagement and inclusion of informal support and relationships.

Support people who remain living in RAC.

Each of these recommendations will now be discussed. The evidence base for each recommendation will be outlined under key issues and then the strategies for each recommendation will be described.

Recommendation 1: Prevent new admissions of young people to aged care

Key issues

Young people in residential aged care are one of the most marginalised groups of people in Australia today and are effectively excluded from society. They tend to lose skills and their social networks diminish.

Preventing new admissions is a more efficient use of resources than waiting for people to be admitted to RAC and then moving them out. One of the main pathways of younger people into aged care is via an acute or rehabilitation hospital admission.

The health system and disability services work on very different timelines. With hospitals under increasing pressure to discharge patients as early as possible once they are medically stable, medical and allied health professionals are forced to make early predictions on the patient's suitability for rehabilitation. This can result in some young people being admitted to RAC before they have had the time they need to demonstrate their potential for recovery.

For maximum client outcomes it is important that supports are provided in a timely way. Without additional investment and continued effort, a new cohort of young people are at risk of being lost in the health, disability and aged care systems.

Strategies

Prevention of admissions to RAC from hospitals

1. Continued collaboration between disability services, acute health and the Aged Care Assessment Service (ACAS) to identify people in hospital at risk of admission to RAC, as soon as possible.
2. Proactive assessment of disability and other support needs, and planning so the person can be discharged to the least restrictive setting. The planner requires considerable expertise to be able to make an assessment of the person's potential and identify relevant services and resources within the disability and health sectors.
3. Provision of services to maximise independence and create pathways back to community living is critical to the prevention of new admissions. These may include Step Down and slow stream rehabilitation or transitional living services. See Box 1 and 2 for a description of these services.
4. Timely provision of Individual Support Packages to enable people to return home with support, or transition to shared supported accommodation settings that have the capacity to manage complex care needs.

Prevention of admissions from the community

1. Proactive assessment of individual support needs, preferences and planning.

2. Targeted intervention in a proactive and timely way rather than waiting until entry to RAC is imminent due to a crisis situation.

3. Ongoing monitoring of needs, coordination, review and modification of services at appropriate intervals. The abilities, support and health needs of this target group are not static. Young people at risk of admission to RAC require ongoing case co-ordination to identify and manage the risks that may lead to a RAC placement. Quality case co-ordination ensures the best use of finite funding available, with the harnessing of services that maximise the individual's abilities, prevent secondary conditions, and sustain informal care and supports.

4. Timely provision of additional support services to enable people to remain at home or the provision of shared supported accommodation with the capacity to manage complex care needs.

BOX 1

WHAT ARE STEP DOWN UNITS?

In Step Down Units, normally attached to acute hospitals, patients receive early allied health intervention tailored to their needs. This compares to the medically stable patient who remains in the acute bed where the input of allied health services tapers off. Currently there is only one Step Down Unit in Victoria, at the Kingston Centre in the southern region of Melbourne.

The development of Step Down Units would allow time for people with very severe ABI to 'declare their potential' and thereby increase the likelihood of an appropriate discharge destination. With early and appropriate intervention in a Step Down unit, many people improve enough to meet criteria for an admission to either fast-stream or slow-stream rehabilitation. These units also prevent and manage secondary problems that can arise such as infections, contractures, pressure areas and social and psychological difficulties.

The Step Down Program at the Kingston Centre costs approximately 60% of an acute hospital bed and provides more appropriate intervention. The provision of more Step Down programs attached to acute hospitals would provide an appropriate rehabilitation environment and discharge option for people in the target group who may otherwise be blocking beds in the acute health system and eventually be discharged to RAC. Via targeted skill development, such units may then open up more options for long-term accommodation for the person over time. However, the provision of increased Step Down Units would need to be coupled with further investment in supported accommodation options to increase the scale and range of alternatives to RAC to ensure appropriate discharge options.

BOX 2

WHAT ARE SLOW-STREAM REHABILITATION OR TRANSITIONAL LIVING SERVICES?

For some people with disabilities and their families, a move straight from an acute or sub-acute health setting to community accommodation will be too great a step and is therefore unlikely to succeed. Transitional living services provide rehabilitation in a house rather than a hospital environment. Transitional living services embed rehabilitation into everyday activities in a home-like environment. These services enable people to maximise their independent living skills and abilities, live in the least restrictive environment and, over the longer term, reduce lifetime support needs and cost of care.

People in the YPIRAC target group would most often not be eligible for existing fast-stream transitional living services in Victoria. The models of transitional rehabilitation this group requires is typically referred to as slow-stream, a term that implies a more extended timeframe required to achieve small but functionally significant gains. The length of stay in a slow-stream transitional living service program would be in the vicinity of six to 18 months and require co-ordinated multi-disciplinary allied health input.

Alfred Health has been asked by the Victorian Department of Health to commence planning for a new statewide, slow-stream rehabilitation Acquired Brain Injury service. Caulfield Hospital has conducted consultation forums to begin to develop the model of care. This new service has the potential to significantly reduce the number of admissions of people with severe ABI to RAC by giving people the time and rehabilitation required to maximise their potential so they can return to community living with support.

Recommendation 2: Increase the range and number of alternatives to RAC

Key Issues

The Victorian YPIRAC initiative developed 22 new services for 104 people in RAC or at risk of admission. All of these places are now allocated. The only way a person at risk of admission to RAC or newly admitted to RAC will be able to move into one of these services is when one of these 104 people dies or moves out of the service for another reason.

The accommodation options developed through the Victorian YPIRAC initiative were variations on a 'group home' model which suits many people in this target group, but not everyone. People placed in Shared Supported Accommodation have limited choice of who they live with and where they live, and sometimes are not compatible with each other. These predominant models of SSA do not enable people with disability to live in environments that return them to valued family and parenting roles.

SSA is most often block-funded, which makes it difficult for residents to move if their needs or preferences change over time. In this model, one organisation has a significant amount of control over the resident's lives because they are both the landlord and the service provider.

The quality of services developed through the Victorian YPIRAC initiative was varied. Some services developed more home-like environments that maximised everyday choices and skill development and provided individual support to access the community. Others services were more institutional, with more rules and rigid routines. Some people in these services spent most of their day in their room and had fewer opportunities for choice regarding home and community-based activities.

The transition of people in the target group from an acute hospital or RAC settings to a community-based accommodation option is complex, posing challenges for the individual, family and support staff. Some transitions were well-resourced and planned while others were expedited or inadequately planned. Poorly planned transitions led to limited information for the person with disability, families and the support staff at the new service to which the person was moving. They also led to unnecessary confusion, distress and, at times, behaviours of concern, for the person with a disability.

Strategies

1. Continued investment in innovative alternatives to RAC for people with disabilities and high care and complex needs.

2. Partnering with existing affordable and social housing providers is necessary to develop the scale and variety of housing required for this target group.

3. Develop new models of supported accommodation that separate housing from support and provide residents with more choice regarding their service provider, as well as co-residents. Work needs to be done to develop and pilot models for providing residents with more choice regarding their service provider and co-residents while managing bed vacancies in a way that ensures that the service is viable and sustainable.

4. Transition planning for people with the range of complex care needs that younger people in the target group experience is time-intensive and requires a team approach with the person with a disability, their family and relevant professionals. Proactive transition planning requires sound communication between all relevant parties and appropriate documentation of the plan and each step achieved. Change for many people in this vulnerable target group is very stressful. A staged process, which may include day visits, overnight stays or weekend trials at the new accommodation prior to permanent transition can be of benefit.

5. The transition process should be managed by a consistent and experienced case coordinator 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 of the individual and improve their level of independence or participation in the new accommodation environment.

6. Ongoing monitoring and evaluation of service providers to ensure that they are meeting the health and support needs of residents and developing and maintaining a staff culture that treats people with dignity and respect and provides opportunities for everyday choice, skill development and community access.

7. Further research to understand how some organisations develop and maintain a positive staff culture that fosters home and community participation, and a lifestyle of choice.

Recommendation 3: Proactive intervention to reduce the lifetime care costs of young people with complex care needs

Key Issues

Younger people living, or at risk of placement, in RAC have complex and lifetime care needs which are not static. They may increase over time, particularly in the case of degenerative conditions or as the person ages or, alternatively, may reduce as the person acquires new skills.

This group is also expensive to support, most often requiring 24-hour support. Their participation and community integration outcomes are typically poor and this population experiences a narrow margin of health. Many of the secondary health conditions experienced by this target group are exacerbated by lack of movement, limited opportunities to sit upright and lack of appropriate supported seating and positioning. Re-admissions to acute hospital settings for secondary health complications are frequent and interim or long-term hospital stays are common. The financial and emotional burden experienced by families providing informal support, whether in RAC or community settings, is significant. The support services provided to younger people in the target group therefore impacts both the health costs and outcomes for both the person with the disability and their family.

The Victorian YPIRAC evaluation has provided an evidence base of improved quality of life outcomes experienced by the target group through the provision of community-based accommodation and support models and targeted equipment, rehabilitation and other enhancement services.

The findings of this evaluation, coupled with existing literature (Gray, 2000; Riudavets et al., 2005; Sloan et al., 2009a; Sloan et al., 2009b) points to the fact that, provided with the right environment and support, people have the potential to maintain or increase their independence and reduce their lifetime care costs.

Given the lifetime care needs of this population, and the finite resources available, enhancing skill development and independence, reducing the cost and burden of care, and opening up the range of accommodation options available to them, is imperative.

Strategies

1. Early intervention to prevent secondary complications

   Prevention of secondary health complications at the earliest stages post-injury, or following exacerbation of a degenerative condition, is an important aspect in managing the lifetime care needs of this group. Timely prescription of positioning and mobility equipment, physical maintenance, behaviour management, and care planning and education of carers supporting the person with disability, is key to reducing the risk of preventable health conditions such as contractures, aspiration pneumonia or pressure areas. This early intervention requires expertise in working with people with complex care needs and will involve a targeted education program of caregivers/staff supporting the person with disability to ensure a comprehensive care plan is consistently enacted, regardless of where the person is living.

2. Step Down programs attached to acute health services

   Step Down programs provide a cost-effective model integrating health care maintenance with rehabilitation for post-acute, severely neurologically impaired patients who are otherwise deemed inappropriate or not yet ready for traditional rehabilitation programs. These programs allow younger people with complex care needs the time they require to progress following an acquired injury or stabilise in the case of exacerbation of a degenerative disease process, while receiving targeted maintenance or slow stream rehabilitation input (See Box 1).

3. Transitional community accommodation services

   Transitional community accommodation services would provide people with the time and opportunity to maximise their independent living skills and abilities, live in the least restrictive environment and, over the longer term, reduce lifetime support needs and cost of care (See Box 2).

4. Timely community-based rehabilitation services

   For those people who do transition to community living, access to timely, slow-stream, community-based rehabilitation is essential to assist to maximise the person's abilities and acquire the skills that will enable them to participate in the community and pursue a lifestyle of choice. It is vital that people have timely access to these services, as delay in intervention results in the development of a range of secondary problems (e.g. contractures, behaviours of concern) and a loss of residual skills (e.g. continence). Given the range of support needs identified, a multi-disciplinary team with expertise in working with people with multiple and complex needs or specific diagnoses is required. People in the target group require a slow-stream rehabilitation model which integrates person and family-centred principles with an understanding of how to facilitate valued life role participation. Such a model has been successfully implemented within the Acquired Brain Injury Slow to Recover Program in Victoria, which has demonstrated improvements in the quality of life of people receiving services and positive cost-benefit outcomes (Olver & Gee, 2005).

5. Hospital and medical outreach

   Given the significant and chronic health needs of some people in the target group, they require access to nursing, medical and hospital outreach services to achieve community living. 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 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 intermittent nursing care. 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. This pro-active health planning is likely to reduce the incidence of secondary complications and acute hospital presentations.

6. Case coordination

   This group has changing lifetime needs. With targeted skill development, they have the capacity to reduce their support requirements and transition to more independent accommodation options or adjust the model of care provided to them. The Victorian YPIRAC initiative demonstrated that initial assessment of the needs of each individual led to a plan being developed that targeted key areas. However, at times, this plan was not enacted, reviewed or adjusted over time as circumstances or skills changed. Given the range of support needs this population experiences, they will require long-term case co-ordination. A case co-ordinator would be required to work in partnership with them and, where appropriate, their support network, to monitor and respond to ongoing needs and deliver resources matched to the person's changing abilities over their lifetime.

Recommendation 4: Provide timely access to assistive technology and customised equipment

Key Issues

People in the target group have complex needs and require customised manual handling, mobility, communication, and environmental control equipment.

For people receiving equipment through the Victorian YPIRAC initiative whilst living in RAC, the provision of a targeted piece of equipment such as an augmentative communication device or motorised wheelchair opened up opportunities for home and community participation and improved the person's quality of life.

However, for those people moving out of RAC, equipment required was not always prescribed or supplied in a timely manner, thus delaying their transition.

Young people in RAC are not eligible for the Victorian Aids and Equipment program. Through the Victorian YPIRAC younger people in RAC have had access to aids and equipment that were essential to maintaining their health and well-being. It is important for YPIRAC to continue to have access to customised aids and equipment. While the Aged Care Subsidy fees paid to aged care providers covers physiotherapy assessment for equipment, continence equipment and basic equipment such as non-motorised wheelchairs for use within the facility, it does not cover the type of customised equipment generally required by younger people with disabilities. This could include a customised wheelchair, a pressure relieving mattress, communication device or tilt-in-space shower/commode chair.

Without adequate equipment some young people in RAC are denied the basic rights that the rest of us take for granted. Their freedom is restricted by lack of funding for appropriate wheelchairs with supported seating. Appropriate seating for many people in this target group is required to ensure that they can swallow safely, sit out of bed without experiencing pain and get outside and into the community. Their freedom of expression is limited because they do not have access to equipment that would enable them to express their basic needs.

Strategies

1. Young people in RAC need access to properly prescribed and customised equipment.

2. Young people at risk of placement in RAC can access the State-Wide Equipment Program, however the co-contribution required for the purchase of expensive items of equipment such as customised wheelchairs is prohibitive for many people in this target group.

3. There must be an allocated person responsible to coordinate maintenance, modification and replacement of adaptive equipment over time as the needs of the person change, the equipment is no longer appropriate or has been superseded.

4. Mainstream and disability technology is a growing area of opportunity to supplement direct care to meet the range of support needs of younger people with complex care needs. Patient monitoring, call systems, and smart phone technology may offer the opportunity for people with disabilities to transition from 1:1 to shared care, or be left alone for periods of time, with access to support in a timely manner as necessary. This area requires further examination, research and piloting with the target group to assess options available within a range of accommodation settings and given the variation in support needs of this population.

Recommendation 5: Maximise autonomy and home and community integration

Key issues

It is a basic human right for each person to have choice regarding privacy in their home, the time they go to bed, the content of their meals and their involvement in daily household routines. Such choices were lacking for young people living in RAC.

The YPIRAC target group is effectively excluded from the community and require specialist long-term care and supports to bring them back into the mainstream of society.

Moving out of RAC and being present in the community is only the first step to community inclusion. Assisting people with severe acquired brain injury 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).

People with high and complex care needs face greater barriers to access the community and the supports they need.

Community and mainstream services that are part of ordinary Australian life must be available and fully accessible for people with disability (Australian Government Department of Families Housing Community Services and Indigenous Affairs, 2010a).

Strategies

1. Where possible, people should be supported to remain in their own home or return to their local community so they can return to valued life roles (e.g. parent, partner, home maker) and maintain social connections.

2. In the development of new accommodation or support models for the target group, consideration must be given to staff culture and attitudes to facilitate an environment of choice and opportunities for flexible support to meet the home and community inclusion goals of each individual.

3. Disability support workers need to be trained and supported to assist the YPIRAC target group to maintain existing family and social networks and develop new social contacts. The development of a home-like environment that supports visiting by friends and families is vital.

4. Specific interventions or targeted supports must be provided, including 1:1 support, as well as customised seating, mobility equipment or accessible transport, in order for a person to be able to go outside their home, travel into the community and develop new social contacts.

5. Ongoing training, mentorship and support of Community Service Organisations providing direct support to the YPIRAC target group is required to ensure the home and community inclusion of younger people with complex care needs is maximised over the long-term.

6. Shared supported accommodation providers need the capacity to work with local government, mainstream services and shops to identify opportunities and address potential barriers to community inclusion in the local area.

7. Further research is required to pilot and evaluate interventions that are successful in facilitating the life role participation and community inclusion of younger people remaining in RAC, as well as those moving to community living.

Recommendation 6: Develop disability workforce capacity

Key Issues

Younger people in the target group have high and complex care needs that require management by a consistent and experienced workforce. This workforce primarily consists of disability support workers, house managers, nurses, personal care attendants, case managers and allied health professionals.

Low staff ratios, high turnover, and a staff culture where choice, dignity and privacy of the individual were not always considered had a significant, negative impact on the quality of life of young people living in RAC.

This evaluation pointed to the fact that, given their care needs, this group requires skilled support from others to maintain health and well-being, access their community, participate in meaningful activities and pursue a lifestyle of choice.

Some Victorian YPIRAC participants reported significant issues with disability support worker training and leadership in the delivery of enhancement packages of support in RAC, or in the new accommodation setting.

As a result of the five-year Victorian YPIRAC initiative, over 115 people with high care and complex needs who have lived in aged care or were at risk of admission are now supported to live in the community. This has put additional strain on a disability sector that was already struggling to find qualified, skilled disability support workers.

Strategies

1. A comprehensive strategy is required to deliver a committed and capable disability workforce. This strategy will need to include: support worker recruitment and development, the instilling of a culture of innovation, and the development of a system of leadership to promote the desired culture of service delivery (PricewaterhouseCoopers, 2011). This culture would include staff attitudes that facilitate individual choice, privacy, dignity and respect, and offer the time and social environment for the person with disability to communicate their needs and test out new skills within home and community settings.
2. As part of the Victorian YPIRAC initiative, Disability Services at DHS invested in targeted training of Community Service Organisations providing accommodation and support to the target group. Further investment by both Disability Services and the individual Community Service Organisations in training, mentorship and ongoing support of the disability workforce is required (e.g. facilitating community inclusion, skill development, working with families and managing behaviours of concern).

3. For those people remaining in RAC, the provision of enhancement packages that enable employment of trained disability support workers can improve the person's choice, control, community access and participation, thus increasing their quality of life. However, such packages require implementation planning and monitoring over time to ensure the supports are delivered in an accountable and skilled manner.

4. The existing Community Service Organisations who have developed the initial shared supported accommodation options as part of the Victorian YPIRAC initiative have considerable knowledge of the challenges and benefits of service development and delivery. This knowledge should be shared to strengthen workforce capacity for younger people with complex care needs. The opportunity to explore and document key learnings in the existing workforce should be harnessed to inform future service and workforce development.

Recommendation 7: Promote engagement and inclusion of informal support and relationships

Key Issues

Families of some younger people living in RAC experience distress regarding their family member's situation. In addition, they experience caregiver burden in providing high levels of informal support to supplement the staffing delivered within RAC.

Some family members described the significant burden experienced in making a decision on behalf of the person with disability to move out of RAC, and the lack of information available in the decision making process.

Many families reported experiencing relief when offered a more appropriate accommodation option for their family member and this reduced their burden of care. For a few families, the high levels of informal support provided and a high burden of care continued once the participant transitioned to more age-appropriate supported accommodation.

For the few people with disability who moved back to a family home, there was a reliance on daily gratuitous care provided by family members to supplement packages of paid support in order for the person to achieve community living.

Some people in this target group were highly dependent on family members for social contact, which can increase the burden experienced by families. Research has shown that family functioning and distress can be mediated by the degree of community participation achieved by the person with disability (Winstanley et al, 2006).

Strategies

1. Wherever appropriate, families should be included in each step of the planning and assessment, and transition process.
2. Provision of timely, accurate and detailed information to assist with decision making regarding accommodation options, as well as planning transitions, is vital and would ideally be coupled with the knowledgeable support of a case co-ordinator or advocate to work in partnership with the person with disability and their family to help identify the pros and cons of the available choices.
3. Targeted intervention to maximise social and community integration for the person with disability will assist to ensure sustainability of informal support provided by families over the long term.

Recommendation 8: Support people who remain living in RAC

Key Issues

In June 2011, 133 people under 50 years of age remained living in RAC in Victoria.

The Victorian YPIRAC initiative has only gone some way to creating the level of systemic change required to prevent new admissions of young people to RAC. However, more work is needed.

Based on admission rates over the past decade, 70-80 Victorians under 50 are likely to be at risk of admission to RAC each year.

The 72 people in Victoria who were receiving recurrent enhancement packages through the YPIRAC initiative will continue to receive these services. However, approximately 61 young people remain in RAC without additional services. These 61 people and any new admissions will need to compete for general disability funding or wait for turnover of existing packages.

Young people in RAC live impoverished lives and are effectively excluded from society. Fifty-four per cent never receive a visit from a friend and many have limited opportunity to make the everyday choices that most of us take for granted, such as the content of their evening meal or when they go to bed. The equipment and enhancements provided through the Victorian YPIRAC initiative had a significant, positive impact on this target group. Enhancement packages have enabled people to communicate their needs, go outside more often, and access community-based leisure.

Strategies

1. Develop a centralised register to identify, assess and regularly review younger people living in RAC and monitor changes in their support needs and preferences regarding future accommodation and supports.

2. Provision of allied health professional support to younger people living in RAC to maintain existing cognitive, behavioural, physical, communication and living skills and, where possible, to develop a greater level of independence in daily tasks. These skills will serve to open up the range of possible future accommodation options available to the person, and prevent the development of secondary complications or hospital re-admissions.

3. Continued access to enhancement supports will enable young people in RAC to be supported to make choices in their day, develop skills, access the community, and maintain contact with family and friends.

Chapter 10: Conclusion

The Victorian YPIRAC initiative achieved the target agreed between the State and Federal governments at the start of the five-year initiative with a net reduction of 88 people (40%) people under 50 living in RAC. The initiative has also made a measureable difference to the quality of life of service users. This program has demonstrated that not only can this target group be supported to live in community settings, but also their lives are enriched when they are placed in more normalised, age-appropriate environments with person-centred supports. The people who moved out of RAC had more frequent community access and were provided with more opportunities to make everyday choices. There was also an increase in their frequency of social contact, they spent fewer hours in bed, went outside more often and were able to be left for longer periods of time after they moved out of RAC. A more home-like environment and additional supports enabled some people who moved to demonstrate their potential for increasing their independence in a range of personal and domestic tasks.

However, this evaluation also found that improving the quality of life of people with profound disability does not end with the provision of new accommodation. More needs to be done for the target group of the Victorian YPIRAC initiative in order to build on the initial gains made, particularly in assisting people to re-integrate more fully into community life, increase their independence in daily tasks and rebuild valued life role participation that offers social connectedness. Community inclusion for people with severe disabilities does not happen spontaneously – supporting this target group to become part of their local community requires individualised support and skilled workers with time and tenacity.

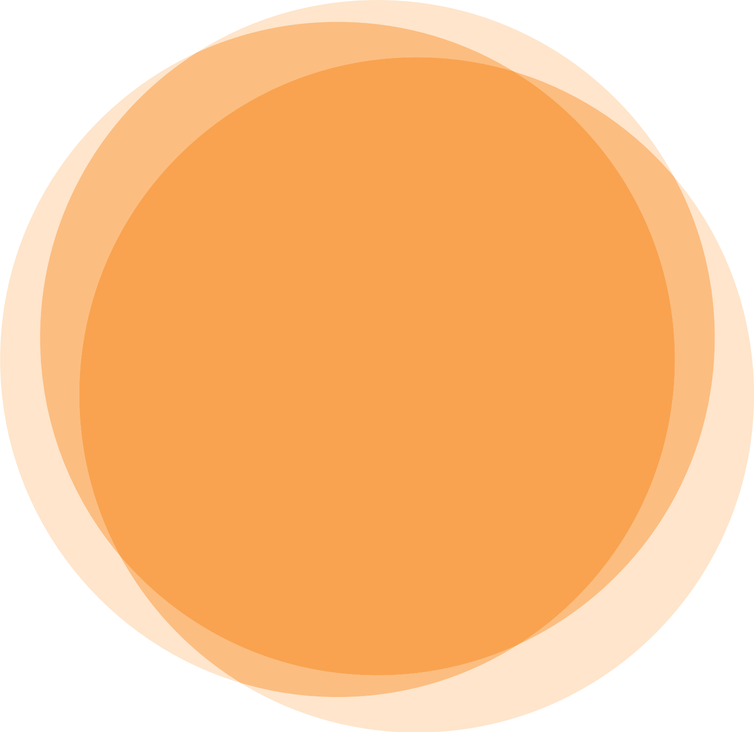
People who were diverted from placement in RAC typically had the best quality of life outcomes. The Diversion Group was more likely to return to live in the family home, having the opportunity to harness informal supports and resume existing or modified life roles that younger people who had been living in RAC for many years did not.

The changes in quality of life outcomes were less dramatic for people who remained in RAC and received enhancement services such as disability equipment to enhance comfort, communication or independence or individual support for weekly outings to engage in a community-based leisure activity. The provision of enhancements enabled people to participate in community-based leisure activities and increased their opportunities to make everyday choices.

Twenty-two new supported accommodation services were developed through the initiative, and all places within these services have now been allocated to individuals. As a result, age-appropriate supported accommodation options, as an alternative to RAC, are once again limited. So, without continued investment, a new group of young people with high support needs will again be entering RAC.

We now understand the complex support needs and preferences of this target group and are aware of the inappropriateness of RAC placement and its impact on quality of life outcomes. RAC facilities are set up to care for people at the end-stage of their life – not young people who need support to reach their full potential and live their lives with the everyday choices the rest of us take for granted.

The Victorian YPIRAC initiative has raised awareness in the health and aged care sectors and created expectations that Disability Services will provide more appropriate accommodation and support for this target group. However, further systemic change and sustained investment in the development of alternative accommodation options are required in order to meet these expectations and prevent new admissions.



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About the Authors

Dr Di Winkler, Libby Callaway, Nadine Holgate and Sue Sloan all have extensive experience in the areas of occupational therapy, case management, neuropsychology, teaching, research and publication.

Di Winkler is an Occupational Therapist who has worked with people with severe brain injury for more than 20 years. Di was the Chief Occupational Therapist at Ivanhoe Manor Private Rehabilitation Hospital prior to developing a private practice working with people with acquired brain injury in the community. Di has recently completed her PhD at Monash University, which features five published studies focusing on the social inclusion of young people in nursing homes.

Libby Callaway is an accredited occupational therapist with 18 years of experience working with people with severe disabilities. Libby is currently working as a Researcher in the Occupational Therapy Department at Monash University and is also the director of a community occupational therapy practice providing services to people with severe neurological conditions.

Sue Sloan is an accredited Occupational Therapist and Clinical Neuropsychologist with more than 30 years of experience working with people with neurological conditions. Both Libby Callaway and Sue Sloan hold lecturing positions at Monash University in the departments of Occupational Therapy and Psychology, respectively. Libby and Sue are regularly involved in the training of health professionals and attendant carers.

Nadine Holgate is an Occupational Therapist & Family Therapist with over ten years experience in working with children and adults living in the community with severe neurological conditions and their families.

Dr Di Winkler

Libby Callaway

Nadine Holgate

Sue Sloan

About the Summer Foundation

Established in 2006, the Summer Foundation aims to resolve the issue of young people living in nursing homes. The Foundation has adopted a social inclusion framework to address the multiple disadvantages experienced by young people in this target group. Social inclusion refers to a society in which all people are valued and have the opportunity to participate in the community such that they may lead a rich, full and meaningful life.

The Summer Foundation, in collaboration with others, utilises a range of strategies to influence health, housing and disability services policy and practice. These strategies are depicted in figure one and described below. The Summer Foundation is not able to implement all of these strategies in isolation; it collaborates with other organisations and government to create positive change.

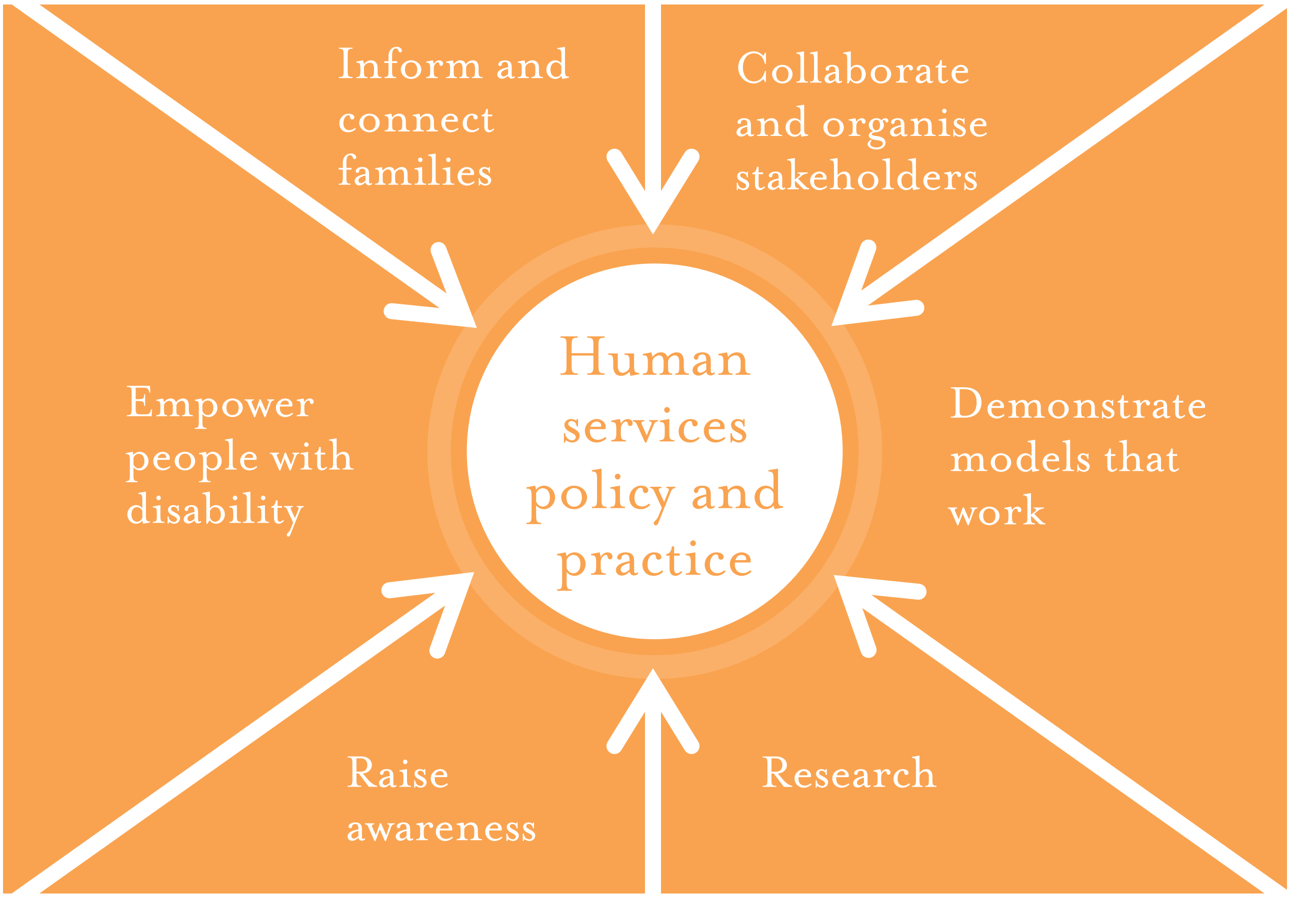


Figure 1. Strategies used by the Foundation to effect positive policy and practice change

What is the Summer Foundation doing?

Creating a movement

Supporting people with disability to provide leadership to existing stakeholders and engage the corporate sector and general public

Empowering

Enabling young people in nursing homes and their families to be informed, make choices and tell their stories

Providing an evidence base

Conducting and fostering research that provides an evidence base for policy change

Building expertise

Fostering innovation and collaboration to improve the quality of services

Developing integrated supported housing

Increasing the range and number of supported accommodation options.

Work to Date

Over the past five years the Summer Foundation has had ten research articles published in peer reviewed journals and produced five reports that provide an evidence base for policy change related to this target group.

Key publications include:

- The "From a home to their homes" DVD and booklet to enable people with disability and families make an informed choice about housing and support options
- "Young people in nursing homes" White Paper which summarises recent research regarding the social inclusion of young people in nursing homes, and further outlines the policy and practical challenges related to this issue.
- "Younger People in Residential Aged Care: Support needs, preferences and future directions", which aggregates the data of 105 people under 50 living in aged care in Victoria.

BUILDING BETTER LIVES®

For young people in nursing homes

Launched in 2009, Building Better Lives is a statewide collaborative campaign led by the Summer Foundation that brings a range of disability organisations together under the one banner to resolve the issue of young people in nursing homes in Victoria.

Through the Building Better Lives ambassador program, ten young people with a disability have been able to tell their story and engage in systemic advocacy. Since the inception of the program, Ambassadors have participated in a wide range of media opportunities and spoken at community events and conferences.

Appendix 1: Semi-structured interview topics

People participating in interview

Person 1 (Name): ____

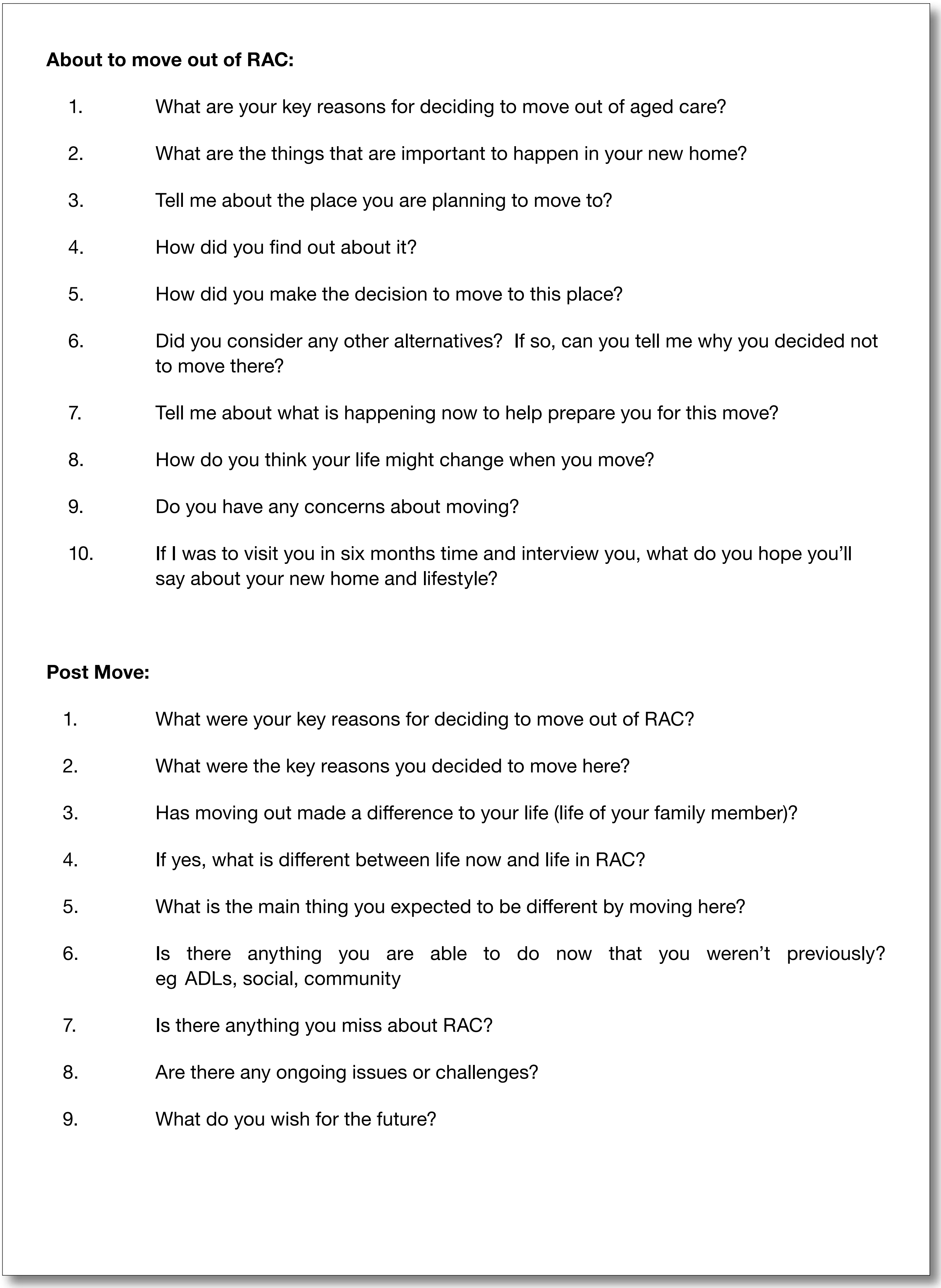
Person 2 (Name / Relationship to Person): _________________________________

Current Living Situation (all participants):

1. Tell me about where you live now?
2. How long have you lived here?
3. What do you like about living here?
4. What do you dislike about living here?
5. How does this place (and the supports you receive here) meet your everyday needs?
6. Do you have any needs or expectations that aren't met?

Enhancement Group:

1. Have you been offered an alternative accommodation option to where you are now?
    a. If yes, can you tell me what you were offered and why you have not moved there?
    b. If not, does an alternative interest you at this point in time?
2. What enhancements have been received? (use section 3 as a guide.)
3. What are the key differences between life in RAC with and without enhancements?
4. How have the enhancements you received made a difference in your life?
5. Who helped to organise the enhancements you received?
6. Were there any barriers to implementing these enhancements and how were these managed? E.g. problems or delays?
7. Are there any ongoing issues or challenges?
8. What are your hopes and aspirations for the future?



About to move out of RAC:

1. What are your key reasons for deciding to move out of aged care?
2. What are the things that are important to happen in your new home?
3. Tell me about the place you are planning to move to?
4. How did you find out about it?
5. How did you make the decision to move to this place?
6. Did you consider any other alternatives? If so, can you tell me why you decided not to move there?
7. Tell me about what is happening now to help prepare you for this move?
8. How do you think your life might change when you move?
9. Do you have any concerns about moving?
10. If I was to visit you in six months time and interview you, what do you hope you'll say about your new home and lifestyle?

Post Move:

1. What were your key reasons for deciding to move out of RAC?
2. What were the key reasons you decided to move here?
3. Has moving out made a difference to your life (life of your family member)?
4. If yes, what is different between life now and life in RAC?
5. What is the main thing you expected to be different by moving here?
6. Is there anything you are able to do now that you weren't previously? eg ADLs, social, community
7. Is there anything you miss about RAC?
8. Are there any ongoing issues or challenges?
9. What do you wish for the future?

Diversion Group only:

1. What has it meant for you to remain living at home and your community (if relevant)?
2. If you didn’t receive MFMC, where do you think you’d be living now?
3. Has the initiative delivered what you were expecting?
4. Have there been any difficulties?
5. Are there any ongoing issues or challenges?
6. How have the MFMC supports made a difference to your life?
7. What are your hopes for the future?

Appendix 2: Additional Tables

Table A1 Post Move ABI group - Demographics

Demographics	n	%
Gender (n=22)		
Male	16	73%
Female	6	27%
Language (n=22)		
English speaking background	20	91%
Non-English speaking background	2	9%
Marital status (n=22)		
Never married	16	73%
De facto	-	-
Married	3	14%
Separated but not divorced	1	5%
Divorced	2	9%
Disability Support Pension (n=21)		
Yes	21	100%
No	-	-

The age of the participants in the current evaluation ranged between 22 and 53 years with the mean being 39 years of age.

The mean number of co-residents was 6.1.

Table A2 Post-Move ABI group – Communication ability (n=22)

Ability to communicate with interviewer	n	%
Verbal independent	4	18%
Verbal with difficulty (required additional time or modified questions)	10	45%
Combination of verbal communication and communication device	1	5%
Communication device only	4	18%
Unable to communicate with interviewer	3	14%

Table A3 Post-Move ABI group - Levels of awareness: (n=22)

Level of awareness	Post Move ABI Group %
Fully aware: Alert and orientated to time, place and person	32%
Partially aware: Awake but had profound memory difficulties and had significant levels of confusion	64%
Minimally aware: Minimally conscious state, vegetative state or coma	5%

Table A4 Post-Move ABI Group – Health issues identified (n=22)

Health issue	% total respondents	n
Hearing, seeing and feeling	56%	
Hearing impairment		1
Vision impairment		9
Hypersensitivity to sensory stimuli		7
Heart and circulation	23%	
Heart or blood pressure problems		4
Postural hypertension		1
Limb swelling		2
Swallowing, eating or drinking	56%	
Swallowing difficulties		12
Saliva management		4
Special dietary needs		5
PEG feeds		4
Weight problems (under or over)		4
Problems with appetite regulation		4
Reflux		2
Breathing	18%	
Recurrent chest infections		-
Difficulty coughing or clearing sputum		-
Asthma		3
Sleep apnoea		-
Tracheotomy		-
Muscles and Bones	91%	
Altered muscle tone, spasticity or muscle spasm		17
Contractures		9

Involuntary movements		2
Paralysis, loss of movement of arms or legs		6
Chronic pain		4
Fatigue		9
Osteoporosis		2
Reduced physical fitness or conditioning		9
Skin Problems	18%	
Pressure areas, or pressure care		1
Loss of sensation		-
Skin rashes		4
Bladder	73%	
Urinary incontinence		15
Urinary tract infections		1
Bowel	86%	
Faecal incontinence		14
Diarrhoea or Colitis		3
Constipation		7
Other		
Epilepsy		9
Diabetes – Type 1		2

N.B. Participants may have more than one problem in each category

Table A5 Post Move ABI Group – Severity of mental health problems (in last 2 weeks) (n=22)

Mental health symptoms	None	Minor	Mild	Moderate	Severe	Not known
Depressive Symptoms	12	4	3	1	0	2
Self-directed injury	21	-	-	-	-	1
Problems assoc with hallucinations/ delusions/ confabulations	20	-	-	-	-	2
Problem alcohol or drug use	21	-	-	-	-	1
Anxiety and panics	20	1	-	1	-	-

Health of the Nation Outcome Scale (HoNOS) [Fleminger, 2005 #756]

Table A6 Post-Move ABI Group- Behaviours of concern identified (n=22)

Overt Behaviour	n	% of respondents
Lack of initiation	7	32%
Verbal aggression	8	36%
Inappropriate social behaviour	1	5%
Perseveration/repetitive behaviour	6	27%
Inappropriate sexual behaviour	5	23%
Physical aggression against other people	3	14%
Physical aggression against objects	4	18%
Wandering/absconding	3	14%
Physical acts against self	2	9%

Overt Behaviour Scale (OBS) [Kelly, 2006 #705]

Table A7 Levels of severity for each behaviour of concern (n=22)

Verbal aggression			
Level 1 (e.g. shouts angrily)	Level 2 (e.g. mild personal insults)	Level 3 (e.g. moderate threats)	Level 4 (e.g. threats of violence)
5	5	4	1
Inappropriate social behaviour			
Level 1 (e.g. socially awkward)	Level 2 (e.g. nuisance / annoyance)	Level 3 (e.g. oppositional)	Level 4 (e.g. unlawful behaviour, risk to self or others)
1	0	0	0
Perseveration			
Level 1 (repetition of non-harmful behaviour)	Level 2 (behaviour causes minor physical harm)	Level 3 (behaviour causes serious harm)	N/A
6	1	0	
Inappropriate sexual behaviour			
Level 1 (sexual talk/ touching others, non-genital)	Level 2 (exhibitionism/ masturbation)	Level 3 (touching others, genital)	Level 4 (coercive sexual behaviour)
4	2	0	0
Physical aggression against others			
Level 1 (threatening gestures)	Level 2 (strikes, kicks)	Level 3 (attack causing mild/ moderate injury)	Level 4 (attack causing severe physical injury)
1	1	1	0
Physical aggression against objects			
Level 1 (e.g. slams doors)	Level 2 (e.g. throws objects)	Level 3 (e.g. breaks objects/ smashes windows)	Level 4 (e.g. sets fire/throws objects dangerously)
2	2	0	0
Physical acts against self			
Level 1 (e.g. hits self)	Level 2 (e.g. bangs head, throws self)	Level 3 (e.g. inflicts small cuts or bruises)	Level 4 (e.g. mutilates self)
1	1	0	0

Wandering / absconding			
Level 1 (e.g. goes to prohibited areas, low risk of harm)	Level 2 (e.g. leaves safe environment, high risk of harm)	Level 3 (e.g. leaves secure premise, may physically resist attempts to stop)	N/A
3	2	0	
Total Level 1 Behaviours = 23	**Total Level 2 Behaviours = 14**	**Total Level 3 Behaviours = 5**	**Total Level 4 Behaviours = 1**

N.B. each person may display more than one level of each behaviour

Table A8 Post-Move ABI Group – Home and Community access (n=22)

	Yes without help		No, needs help	
Home and Community access	n	%	n	%
Move about inside home	15	68%	7	32%
Get in and out of home	11	50%	11	50%
Access the local community	3	14%	19	86%

Table A9 Post-Move ABI Group- Frequency of visits from family and friends (n=22)

	Friends §		Relatives †	
Frequency of visits	n	%	n	%
Most days	-	-	6	27%
1-3 times per week	1	5%	9	41%
1-3 times per month	4	18%	3	14%
4-11 times per year	2	9%	2	9%
1-4 times per year	5	23%	1	5%
Less than once per year	3	14%	-	-
Never	7	32%	1	5%

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

Table A10 Post-Move ABI Group – Frequency of visits to family and friends (n=22)

	Visit friends in their home §		Visit relatives in their home †	
Frequency of visits	n	%	n	%
5 or more times per month	-	–	1	5%
1-4 times per month	1	5%	8	36%
5-11 times per year	1	5%	2	9%
1-4 times per year	3	14%	4	18%
Seldom/never	17	77%	7	32%

§ ‘Approximately, how often do you usually visit friends in their homes?’
† ‘Approximately, how often do you usually visit relatives in their homes?’

Table A11 Post-Move ABI Group - CIQ Total Scores and Subscale Score

Variable	2007 Baseline date Mean (SD)	Post Move ABI group Mean (SD)
Home integration subscale	0.94 (± 1.03)	1.12 (± 1.59)
Social integration subscale	2.38 (± 1.77)	2.75 (± 1.89)
Productivity subscale	1.59 (± 1.18)	1.49 (± .929)
CIQ total score	4.92 (± 3.00)	5.06 (± 3.16)

Community Integration Questionnaire [Willer, 1993 #76]

Table A12 Post-Move ABI Group – Participants were asked how often they would go outside e.g. into the garden (n=22)

Frequency of going outside	n	%
More than once per day	12	56%
Almost every day	8	36%
Almost every week	2	9%
Almost every month	-	-
Seldom/never	-	-

Table A13 Post-Move ABI Group – Frequency of travel outside of where they live (n=22)

	Travel outside where they live	
Response	n	%
More than once a day	-	-
Almost every day	11	50%
Almost every week	10	45%
Almost every month	1	5%
Seldom/never	-	-

Community Integration Questionnaire [Willer, 1993 #76]

Table A14 Post-Move ABI Group – Frequency of participation in shopping or leisure activities outside of where they live (n=22)

	Shopping		Leisure Activities	
Response	n	%	n	%
5 or more times per month	2	9%	6	27%
1-4 times per month	13	59%	13	59%
5-11 times per year	1	5%	1	5%
1-4 times per year	2	9%	1	5%
Seldom/Never	4	18%	1	5%

Community Integration Questionnaire [Willer, 1993 #76]

Table A15 Post-Move ABI Group – Community Integration Questionnaire questions 1-5 "Who usually does the following tasks?" (n=22)

	Yourself alone		Yourself and someone else		Someone else	
Everyday task	**n**	**%**	**n**	**%**	**n**	**%**
Shopping for groceries	-	-	7	32%	15	68%
Prepares meals	-	-	6	27%	16	73%
Everyday housework	-	-	4	18%	18	82%
Plans social occasions	3	14%	3	14%	16	73%
Looks after personal finances	-	-	2	9%	20	91%

Community Integration Questionnaire [Willer, 1993 #76]

Table A16 Post-Move ABI Group – Areas in life that people are supported to make choices (n=21)

	No opportunity ¤		Unlikely to give real choice Ψ		Final say doesn't rest with the person ‡		Procedures in place Δ		NA
Area of life	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	
The content of their evening meal	3	14%	1	5%	6	29%	9	43%	2
The timing of their evening meal	3	14%	3	14%	6	29%	8	38%	1
Indoor leisure e.g. tv, radio	-	-	2	10%	2	10%	17	81%	-
Going out (e.g. pub, cinema)	1	5%	2	10%	9	43%	9	43%	-
The time they go to bed in the evening	-	-	3	14%	5	24%	13	62%	-
The clothes they wear each day	2	10%	1	5%	2	10%	16	76%	-
Involvement of intimate partners	3	14%	2	10%	1	5%	8	38%	7
Their daytime activities	-	-	2	10%	3	14%	16	76%	-
The time they spend in the bath or shower	3	14%	4	19%	4	19%	10	48%	-
Access to a private area	-	-	2	10%	1	5%	18	86%	-
The furnishings in their bedroom	-	-	-	-	2	10%	19	90%	-

¤ Nothing mentioned, no opportunity, person considered by informant to be incapable of making choices in this area.
Ψ Some procedure(s) mentioned but nothing likely to give the person much real choice.
‡ Some procedures mentioned through which person can express preferences but final say does not rest with the person.
Δ Procedures in place for person to express preferences and these are final unless clearly inappropriate or dangerous.

Resident Choice Scale [Hatton, 2004 #702]

Table A17 Role Participation
Post-Move ABI Group – Current and desired future role participation (n=22)

	Current participation in role		Desired future participation in role	
Role	n	%	n	%
Student: Attending school on a part or full-time basis.	0	-	2	9%
Worker: Part- or full-time paid employment.	0	-	1	5%
Volunteer: Donating services, at least once a month.	0	-	2	9%
Caregiver: Responsibility at least once a month for the care of someone such as a child, spouse, relative or friend.	0	-	2	9%
Home maintainer: Responsibility at least once a month for the upkeep of the home such as housecleaning or yard work.	6	27%	9	41%
Friend: Spending time or doing something at least once a month with a friend.	11	50%	15	68%
Family member: Spending time or doing something at least once a month with a family member.	21	95%	21	95%
Religious participant: Involvement at least once a month in groups or activities affiliated with one's religion.	0	-	0	-
Hobbyist or Amateur: Involvement at least once a month in a hobby or amateur activity.	11	50%	16	73%
Participant in Organisations: Involvement at least once a month in organisations such as Rotary, Guides etc.	4	18%	6	27%

Role Checklist [Oakley, 1986 #456]

Table A18 Post-Move ABI Group – Length of time person can be left alone (n=22)

CANS level	n	%
Cannot be left alone. Needs nursing care, assistance and/or surveillance 24 hours a day.	4	18%
Can be left alone for a few hours. Needs nursing care, assistance and/or surveillance 20-23 hours per day	14	64%
Can be left alone for part of the day but not overnight. Needs nursing care, assistance, supervision and/or direction 12-19 hours per day.	3	14%
Can be left alone for part of the day and overnight. Needs a person each day (up to 11 hours) for assistance, supervision, direction and/or cueing for occupational activities, interpersonal relationships and/or living skills.	1	5%
Can be left alone for a few days a week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional supports a few days a week.	0	–
Can be left alone for almost all week. Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once per week.	0	–
Can live alone, but needs intermittent (i.e. less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support.	0	–
Can live in the community, totally independently. Does not need contact.	0	–

Care and Needs Scale [Soo, 2007 #985]

Table A19 Post-Move ABI Group – Number of participants who require assistance for the following support need (n=22)

Support needs	n	%
Tracheotomy management	0	-
Nasogastric/PEG feeding	4	18%
Bed mobility/turning	9	41%
Wanders/gets lost	4	18%
Exhibits behaviours that have potential to harm self or others	3	14%
Difficulty communicating basic needs due to language impairments	17	77%
Continence	18	82%
Feeding	16	73%
Transfers/mobility	14	64%
Personal hygiene/toileting	21	96%
Bathing/dressing	21	96%
Simple food preparation	21	96%
Shopping	20	91%
Housework	22	100%

Care and Needs Scale [Soo, 2007 #985]

Table A20 Post-Move ABI Group - Personal Wellbeing Index (n=8)

How satisfied are you with...	Post-Move ABI Group Mean (SD) n = 8	Australian Normative Mean (SD)
Your life as a whole?	7.4 (± 3.1)	7.1 (± 2.4)
Your standard of living?	6.9 (± 3.4)	7.7 (± 1.1)
Your health?	8.0 (± 1.8)	7.5 (± 0.6)
What you are achieving in life?	6.6 (± 2.8)	7.4 (± 0.8)
Your personal relationships?	7.0 (± 2.0)	8.0 (± 1.0)
How safe you feel?	7.9 (± 2.6)	7.8 (± 1.6)
Feeling part of your community?	4.4 (± 2.1)	7.1 (± .97)
Your future security?	7.1 (± 3.3)	7.1 (± 1.3)

Personal Well Being Index [International Well Being Group, 2006 #1186]

Table A21 Post-Move ABI Group – A selection of questions from the ComQol-15 tool

Quality of Life Question	Almost always		Usually		Sometimes		Not Usually		Almost Never	
	n	%	n	%	n	%	n	%	n	%
Q1. Time use (n=18)	3	17%	3	17%	6	33%	3	17%	3	17%
Q2. Sleep (n=19)	10	53%	5	26%	4	21%	0	-	0	-
Q3. Safety (n=17)	15	79%	1	5%	1	5%	0	-	0	-
Q4. Worry (n=17)	1	5%	1	5%	5	26%	2	11%	9	47%

ComQol -15 [Cummins, 1997 #958]

Q1. In your spare time how often do you have nothing much to do?
Q2. Do you sleep well? How often?
Q3. Are you safe where you live? How often do you feel safe?
Q4. Are you ever worried or anxious during the day? How often?

Table A22 Post-Move ABI Group- Comparison with normative data on the ComQol

Quality of Life Question	Post-Move ABI group Mean (SD) n=19	Normative data Mean (SD)
Time use	3.00 (± 1.33)	4.13 (± 1.00)
Sleep	4.32 (± 0.82)	3.96 (± 1.07)
Safety	4.94 (± 0.62)	4.76 (± 0.56)
Worry	2.26 (± 1.52)	3.62 (± 1.05)
Television	3.00 (± 1.19)	2.88 (± 1.50)

ComQol -15 [Cummins, 1997 #958]

Table A23 Post- dMove ABI Group – Hours spent watching Television per day (n=18)

Quality of Life Question	10 + hrs	6-9 hrs	3-5 hrs	1-2 hrs	None
Percentage of participants	11%	22%	33%	22%%	11%

ComQol-15 [Cummins, 1997 #958]

Family Support

Table A24 Post-Move ABI Group – Family Outcome Measure Subscales (n=12)

Family Outcome Measure Subscale	RAC Exit Mean (SD) n=12	Score Range	Higher scores represent
Family member coping	13.1 (±3.8)	0-24	Increased coping
Family cohesion	10.1 (±3.4)	0-18	Increased closeness
Support demands (burden)	11.1 (± 4.9)	0-24	Reduced support demands
Relative adjustment	7.7 (± 2.8)	0-15	Improved adjustment
Adequacy of service support	9.3 (± 3.3)	0-15	Improved service support
Family member resilience	10.0 (±1.7)	0-15	Increased resilience
Sustainability of family support	9.9 (± 2.4)	0-15	Increased likelihood long term support sustainable

Family Outcome Measure [Simpson, 2009 #960]

Table A25 Post-Move ABI Group – Family member coping (n=12)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have time for myself	-	17%	58%	25%
I worry a lot of the time	17%	42%	25%	17%
I feel in control of my life	-	25%	67%	8%
I have plenty of opportunity to rest	-	25%	67%	8%
I feel I need some timeout	-	33%	50%	17%
I feel overloaded	-	33%	50%	17%
I often feel tired	8%	42%	33%	17%
I have trouble sleeping	8%	33%	58%	-

Family Outcome Measure [Simpson, 2009 #960]

Table A26 Post-Move ABI Group – Family cohesion (n=11)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
We spend more time together now	9%	36%	27%	27%
We are more intimate	9%	27%	45%	18%
We go out more	18%	54%	18%	9%
I understand my relative better now	-	27%	72%	-
We spend more quality time together	-	27%	63%	9%
We are closer now	-	27%	54%	18%

Family Outcome Measure [Simpson, 2009 #960]

Table A27 Post-Move ABI Group – Support demands (burden) (n=12)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have to keep checking on my relative	-	33%	42%	25%
My relative depends on me now	-	42%	33%	25%
I make all the important decisions now	-	42%	42%	17%
I have to be able to supervise my relative	8%	33%	42%	17%
I have to look after my relative	8%	33%	50%	8%
It is difficult to get a break from providing support to my relative	8%	42%	33%	17%
My relative needs lots of assistance	8%	42%	25%	25%
I have had to put my future plans on hold	-	42%	42%	17%

Family Outcome Measure [Simpson, 2009 #960]

Table A28 PostMove ABI Group – Relative adjustment (n=12)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
My relative feels upset about losing some/many of his/her roles in the family	8%	24%	50%	17%
My relative gets depressed	8%	33%	50%	8%
My relatives has mood swings	17%	25%	58%	-
I have to keep my relative cheerful	8%	42%	42%	8%
My relative's personality has changed	-	58%	25%	17%

Family Outcome Measure [Simpson, 2009 #960]

Table A29 Post-Move ABI Group – Adequacy of service support (n=12)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I have not been given enough information	8%	50%	33%	8%
It is difficult dealing with different staff and/or services	8%	42%	42%	8%
I feel as if our family and the staff work together like a team	8%	8%	67%	17%
I feel that my relative is not getting enough treatment	17%	25%	42%	17%
I can get the services that are needed	-	42%	50%	8%

Family Outcome Measure [Simpson, 2009 #960]

Table A30 Post-Move ABI Group – Family member resilience (n=12)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I feel as though I can't cope	8%	42%	42%	8%
I am still able to laugh about things	-	8%	67%	25%
I have someone that I can talk to if I need it	-	8%	67%	25%
I still find enjoyment in life	-	-	75%	25%
I feel unwell a lot of the time	8%	50%	33%	8%

Family Outcome Measure [Simpson, 2009 #960]

Table A31 Post-Move ABI Group – Sustainability of family support (n=11)

Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
I enjoy supporting (caring for) my relative	9%	18%	54%	18%
I cannot see myself providing support to my relative over the long term	18%	45%	36%	-
I have more negative feelings about my relative now	18%	45%	36%	-
My relative seems very self-centred now (n=10)	20%	60%	20%	-
I feel trapped in this situation	36%	-	36%	27%

Family Outcome Measure [Simpson, 2009 #960]

Comparisons

Table A32 Differences between two groups on a range of outcome variables – 2007 data (n=86) and people with ABI who moved out of RAC

Variable	2007 Data Mean (SD)	ABI Post-move Mean (SD)	Mann-Whitney Tests
Days out of bed in the past 7 days (n=21)	6.40 (±1.38)	6.71 (±1.10)	Z = -1.45, ρ = .148
How many hours out of 24 do you typically spend in bed? (n=21)	12.60 (±4.08)	11.69 (±2.50)	Z = -.275, ρ = .784
Length of time they can be left alone (CANS Part 2) (n=22)	5.58 (±1.38)	5.95 (±.72)	Z = -.512, ρ = .609
Number of life roles (n=22)	2.19 (±1.32)	2.41 (±1.14)	Z = -1.66, ρ = .097
Number of health conditions (n=22)	3.26 (±1.94)	3.62 (±1.60)	Z = -.268, ρ = .788
Number of behaviours of concern (n=22)	2.14 (±1.83)	1.64 (± 1.89)	Z = -.515, ρ = .607

Table A33 Differences between two groups – 2007 data (n=86) and people with ABI who moved out of RAC (n=22). Measured in days per year.

Variable	2007 Data Mean (SD)	ABI Post-move Mean (SD)	Mann-Whitney Tests	
Frequency of going outside	280 (±282)	496 (± 269)	Z = -2.72, ρ = .007	**
Frequency of travel outside the place you live	113 (±164)	148(± 115)	Z = -1.36, ρ = .173	
Frequency of visits from relatives	107 (±94)	118 (±98)	Z = -1.38, ρ = .168	
Frequency of visits from friends	20.14 (±45.35)	11.29 (±22.45)	Z = -.633, ρ = .527	
Frequency of visits to relatives' homes	5.76 (±5.41)	9.05 (±12.98)	Z = -2.18, ρ = .029	*
Frequency of visits to friends' homes	9.31 (±4.50)	1.36 (±3.42)	Z = -.321 , ρ = .748	

* ρ < .05, ** ρ < .01.

Table A34 Difference in CIQ Total Scores and Subscale Scores between two groups – 2007 data (n=86) and people with ABI who moved out (n=22)

Variable	2007 Data Mean (SD)	ABI Post-move Mean (SD)	Mann-Whitney Tests	
CIQ total score	4.9 (±3.00)	5.73 (±2.95)	Z = -1.52 , ρ = .129	
Home integration subscale	1.00 (±0.67)	1.50 (±2.00)	Z = -.257, ρ = .797	
Social integration subscale	2.38 (±1.77)	3.77(±1.51)	Z = -3.27, ρ = .001	**
Productivity subscale	1.59 (±1.18)	1.40 (±.60)	Z = -.367, ρ = .714	

** ρ < .01.
Community Integration Questionnaire (Willer et al., 1993)

Table A35 Difference in CIQ Home Integration Item Scores between two groups – 2007 data (n=86) and people with ABI who had moved out of RAC (n=22)

Variable	2007 data Mean (SD)	ABI Post-move Mean (SD)	Mann-Whitney Tests	
1. Who usually does shopping for groceries and other necessities in your household?	.09 (±.35)	.32 (±.48)	Z = -2.01, ρ = .045	*
2. Who usually prepares meals in your household?	.04 (±.20)	.27 (±.46)	Z = -2.05, ρ = .041	*
3. In your home, who usually does normal everyday housework?	.03 (±.17)	.18 (±.39)	Z = -1.50, ρ = .133	
5. Who usually plans social arrangements such as get togethers with family and friends?	.32 (±.51)	.41 (±.73)	Z = -.752, ρ = .452	

* ρ < .05

Table A36 Differences in CIQ Social Integration Item Scores between two groups – 2007 data (n=86) and people with ABI who had moved out of RAC (n=22)

Variable	2007 Data Mean (SD)	ABI Post-move Mean (SD)	Mann-Whitney Tests	
6. Who usually looks after your personal finances, such as banking and paying bills?	.20 (±.45)	.09 (±.29)	Z = -.454, ρ = .650	
Can you tell me approximately how many times per month you now usually participate in the following activities outside your home?				
7. Shopping	.49 (±.73)	.82 (± .59)	Z = -2.23, ρ = .026	*
8. Leisure activities such as movies, sports, restaurants, etc.	.49 (±.73)	1.09 (±.53)	Z = -3.74, ρ < .000	***
9. Visiting friends or relatives	.57 (±.64)	.59(±.59)	Z = -.454, ρ = .650	
10. When you participate in leisure activities, do you usually do this alone or with others?	1.0 (±.56)	1.0 (±.44)	Z = -.159, ρ = .874	
11. Do you have a best friend in whom you confide?	.68 (±.95)	.18(±.59)	Z = -2.33, ρ = .020	*

* ρ < .05, ** ρ < .001.

Table A37 Differences in choice between two groups – 2007 data (n=86) and people with ABI who had moved out of RAC (n=21)

Variable	2007 Group Mean (SD)	ABI Post-move Mean (SD)	Mann-Whitney Test	
The content of their evening meal	1.77 (±1.03)	2.81(±1.40)	Z = -3.23, ρ = .001	**
The timing of their evening meal	1.39 (±.86)	2.81(±1.25)	Z = -4.74, ρ = .000	***
Indoor leisure e.g. TV, radio	2.84 (±1.26)	3.71(±.64)	Z = -3.58, ρ = .000	***
Going out (e.g. pub, cinema)	2.37 (±1.28)	3.24(±.83)	Z = -2.75, ρ = .006	**
The time they go to bed in the evening	2.24 (±1.20)	3.48(±.75)	Z = -4.24, ρ = .000	***
The clothes they wear each day	2.68 (±1.34)	3.52(±.98)	Z = -3.16, ρ = .002	**
Involvement of intimate partners	1.54 (±1.26)	2.0(±1.79)	Z = -.985, ρ = .325	
Their daytime activities	2.59 (±1.18)	3.67(±.66)	Z = -4.24, ρ = .000	***
The time they spend in the bath or shower	1.82 (±1.06)	3.0(±1.14)	Z = -3.48, ρ = .000	***
Access to a private area	2.45 (±1.34)	3.76(±.62)	Z = -4.09, ρ = .000	***
The furnishings in their bedroom	2.52 (±1.15)	3.90(±.30)	Z = -5.08 , ρ = .000	***

** ρ < .01, *** ρ < .001.

Table A38 Differences in mental health symptoms between two groups – 2007 data (n=86) and people with ABI who had moved out of RAC

Variable	2007 Group Mean (SD)	ABI Post-move Mean (SD)	Mann-Whitney Test
Self directed injury (n=11)	1.54 (±1.48)	1.23(±1.07)	Z = -.189, ρ = .850
Problem drinking or drug use (n=10)	1.34 (±1.14)	1.23(±1.07)	Z = -1.56, ρ = .118
Problems with hallucinations, delusions or confabulation (n=11)	1.98 (±1.82)	1.45(±1.47)	Z = -1.85, ρ = .065
Problems with depressive symptoms (n=11)	3.20 (±1.65)	2.05(±1.56)	Z = -.288, ρ = .773
Other mental and behavioural problems (n=11)	2.48 (±1.80)	1.41(±1.22)	Z = -1.22, ρ = .223

Health of the Nation Outcome Scale (HoNOS) (Fleminger et al., 2005)

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