
CONSIDERATIONS FOR NATIONAL DISABILITY INSURANCE SCHEME DESIGN:

The health and disability
interface for people with
complex needs living in shared
supported accommodation.

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AUTHORS

Libby Callaway^{1,3}

Mark Brown²

Peta Fensham-Cobb²

Tom Worsnop³

Deborah Farrell⁴

1 Monash University Occupational Therapy Department

2 Yooralla

3 Summer Foundation

4 Multiple Sclerosis Limited

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LIST OF ABBREVIATIONS

| | |
|---------------|--|
| ABI | Acquired Brain Injury |
| AT | Assistive Technology |
| COAG | Council of Australian Governments |
| DSO | Disability Service Organisation |
| DSS | Department of Social Services |
| ILC | Information, Linkages and Capacity Building |
| ISP | Individual Support Package |
| MS | Multiple Sclerosis |
| NDIA | National Disability Insurance Agency |
| NDIS | National Disability Insurance Scheme |
| NDS | National Disability Strategy |
| PEG | Percutaneous Endoscopic Gastrostomy |
| RAC | Residential Aged Care |
| SSA | Shared Supported Accommodation |
| YPIRAC | Younger People in Residential Aged Care |

01

**EXECUTIVE
SUMMARY**

BACKGROUND

Young people with a complex combination of disability and health support needs experience a restricted range of housing and support options to meet their lifetime requirements¹. This group often experience prolonged and repeat hospital admissions, and are at high risk of entry to residential aged care (RAC) given the limited alternatives available to them². The five-year National Younger People in Residential Aged Care (YPIRAC) Initiative (2006-2011) invested \$242M to create new shared supported accommodation placements and fund packages to divert participants from RAC or enhance RAC placements. Whilst this initiative resulted in some short term improvements, it did not create the systemic change necessary to stem the flow of young people into RAC in Australia³.

In 2011, the Council for Australian Governments formally endorsed a ten-year National Disability Strategy (NDS)⁴. The NDS sets out six priority areas within a 10-year plan for improving life for Australians living with disability. One of the key areas is promotion of health and wellbeing⁵. This priority area focuses on the delivery of health services and health promotion, and the interaction between health and disability systems to improve wellbeing for the person with disability⁴. This was followed by a once-in-a-lifetime disability reform, with Australia's National Disability Insurance Scheme (NDIS) launched in trial sites in July 2013⁶. The NDIS provides funding for the support, services and equipment that people with disability require to meet their functional needs related to disability. Given the complex and specialised needs of young people who's health needs are inextricably linked to disability outcomes, there is a requirement to plan specifically to meet the needs of this group within the full scheme design of the NDIS.

RESEARCH AIMS

Through a collaborative project partnership, this research had the following aims:

1. Examine the characteristics, support and equipment needs and participation outcomes of people with significant and permanent disability living in shared supported accommodation (SSA) funded by the YPIRAC or other recent disability or government initiatives.
2. Compare this aggregated data with existing data on young people living in residential aged care to examine outcomes across these two settings.

The evidence gathered through this project has been documented to inform full scheme design of the NDIS for this target group, and guide capacity building for NDIS planners, participants and their families.

METHODOLOGY

Data were collected from nominated Disability Service Organisation (DSO) site managers of existing SSAs funded by the YPIRAC or other targeted disability or government initiatives. A customised anonymous online survey was developed and used for data collection. The survey asked the respondent to report the number of residents at the site, then provide aggregate estimates of primary disability type, health conditions, supports received, and home, social and community participation rates. Items on this survey were formulated to allow some comparison, where possible, with previous research with YPIRAC⁸. Data were collected on the characteristics and outcomes of 173 residents from 25 SSA sites delivered by 12 DSOs across Victoria, the ACT and New South Wales.

RESULTS

Survey respondents were asked to nominate the primary disability type experienced by each resident in a particular setting, using NDIA disability categories. The most common disability type reported was acquired brain injury or intellectual disability (46%) followed by Multiple Sclerosis or other neurodegenerative disorder (42%).

Compared to existing data on young people living in RAC in Victoria^{7, 8}, in a typical week the SSA group displayed greater involvement in home and community life, including greater time spent out of bed, visits received from friends and relatives, traveling outside the home and participation in community based shopping or leisure tasks. Community travel was most often via taxis or private vehicle, with few reporting public transport use in a typical week. Visiting to friends and relatives and economic participation (i.e. work, study or volunteerism) rates were low for the group.

The results of this study begin to demonstrate the extent and complexity of the support requirements experienced by people with disability with complex disability and health support needs who live in SSA:

- As a cohort that typically requires daily support with multiple 'core activities', their disability supports will undoubtedly represent a significant proportion of NDIS funds within the full Scheme roll out.
- The daily lives of this group – and therefore the disability related support they require – are inextricably linked to numerous health-related issues secondary to the primary functional disability experienced.
- The accommodation models developed through the five-year YPIRAC initiative, or those comparative SSA models for people with complex needs, are associated with greater opportunities for autonomy, control and social and community participation when compared with aggregate data available on young people living in RAC.

| VARIABLE | RESPONSE | PERCENTAGE OF GROUP (N=173) |
|---|--|--|
| Support needed | Self care | 80% |
| | Mobility | 79% |
| | Cognitive supports | 77% |
| | Communication | 50% |
| | PEG feeding | 12% |
| | Tracheostomy care | 2% |
| Secondary health condition | Bladder or bowel dysfunction | 76% |
| | Musculoskeletal issues | 54% |
| | Specialised needs relating to eating, drinking or swallowing | 45% |
| | Sensory issues | 42% |
| | Skin issues | 40% |
| | Epilepsy | 23% |
| | Service utilisation | Allied health services from SSA provider |
| Allied health services from external agency | | 60% |
| Palliative care | | 18% |

IMPLICATIONS

In the absence of other alternatives, these research findings point to the benefit in maintaining small-scale shared residential settings beyond NDIS transition as one of a range of possible options for this cohort.

Stemming from these research findings, there are five key implications for full Scheme design:

1. The health and disability interface for NDIS participants with complex healthcare needs to be recognised and coordinated
2. Scheme participants, family members and NDIS planners and support coordinators require education and capacity building to understand and effectively plan for the complexity of supports required by this group in order to influence outcomes
3. Lifetime care costs and outcomes will be improved with early intervention within an insurance model approach, through engagement during the planning process, at the point of entry to RAC, or in alternative accommodation models such as SSA
4. There is a need for skilled coordination of supports, delivered by appropriately trained or experienced practitioners working across health and disability, to ensure a holistic response to the needs of people at risk of entry to RAC or long term inpatient hospital admissions
5. Participation and individual outcomes can be enhanced through moves from RAC to small-scale, well located and designed supported accommodation, however there is more work to be done to build the social and economic participation of people with disability and complex health needs.

These implications provide directions for the full NDIS roll out for this particular target group, which has relevance for other Scheme participants living with a range of disability types.

In addition to these implications, the research findings point to three key enablers required within a well designed NDIS to adequately address the support needs of this target group:

1. Assistive technology must be harnessed within an NDIS to influence participant outcomes
2. NDIS participants require a range of accommodation options and building of 'housing careers' and pathways
3. The National Disability Insurance Agency will require a continued, strong focus on Information, Linkages and Capacity Building (ILC) within an NDIS to maximise engagement with mainstream services such as health, employment, education and public transport.

CONCLUSION

The recent Federal government Senate Inquiry into Adequacy of Existing Residential Care Arrangements Available for Young People with Severe Physical, Mental or Intellectual Disabilities in Australia⁹ recommended that in all jurisdictions, the NDIS needs to take a specialist approach to young people with complex disability who might be at risk of RAC placement. The Inquiry report highlighted the need for the Scheme to be informed about, and prepared to engage with, current disability-specialist supported accommodation models where this is the preference of the participant, and utilise existing evidence to inform further development of changing traditional or innovative housing and support models for this group. Full Scheme design is planned to begin in mid 2016. The following report provides research evidence to inform, and further details regarding, the key implications and enablers for full National Disability Insurance Scheme design for young people with complex healthcare needs.

02

**BACKGROUND
TO THIS
RESEARCH**

Young people with disability and complex health support needs are one of the most marginalised groups in Australia, having little choice or control over their living arrangements. Commonly, these individuals experience prolonged inpatient hospital stays or are placed in residential aged care (RAC) facilities, as these are often the only high support settings made available to them⁹. Specific to placement in RAC, previous research has demonstrated that such settings lead to particularly poor quality of life and community participation outcomes^{2,7,10}.

There is growing recognition that young people with disability should not be forced to live in RAC because there are no other options for them⁹. Shared supported accommodation (SSA) services have provided some people with an alternative to RAC that is capable of meeting disability-related complex health support needs in a setting more conducive to choice, control, and self-determination. However, limited vacancies and resources constrain the improvements available through these smaller-scale SSA residential models. The introduction of the National Disability Insurance Scheme (NDIS), with its needs-based funding and focus on enhancement of social and economic participation, represents a significant opportunity for both those people who experience complex support needs and are currently living in SSA, those who continue to reside in RAC or hospitals, and those at risk of RAC placement or long term inpatient admission.

YOUNG PEOPLE IN RESIDENTIAL AGED CARE (YPIRAC)

Young people placed in residential care are known to experience particularly poor health and participation outcomes. Eighty-eight percent live with three or more secondary health conditions, most commonly issues with continence; changes in muscle tone, spasticity or muscle spasm; impaired swallowing; skin or pressure issues; or medical conditions such as epilepsy or diabetes⁸. Forty-nine per cent are never visited by friends and 33% don't have the opportunity to participate in recreational activities or visit family and friends outside the aged care setting⁸. These support needs are difficult to meet within the end-of-life care model delivered within residential aged care. The staffing ratios and service structures provided by aged care nursing homes are not designed for the needs of this group.

To address the social justice issue of young people in residential aged care, a joint Council of Australian Government \$244M National Young People with Disability

in Residential Aged Care Initiative was implemented from 2006-2011. The Victorian YPIRAC initiative, called *my future my choice*, was allocated \$60 million, with the target group being those Victorians aged under 50 years living in RAC. The national YPIRAC initiative had three key objectives:

1. Move younger people with disability currently in residential aged care into more appropriate supported disability accommodation, where supported disability accommodation can be made available and only if the individual chooses to move;
2. Divert future admissions of younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation; and
3. Enhance the delivery of specialist disability services to those younger people with disability who choose to remain in residential aged care, and if residential aged care remains the only available suitable supported accommodation option¹¹.

As part of the national initiative, a range of supported accommodation settings were developed across Australia. In Victoria alone, 22 new shared supported accommodation settings, most often consisting of group home or cluster unit models, were delivered and 115 Victorians with disability and resulting complex healthcare needs moved or were diverted from RAC¹².

Although the five-year national YPIRAC initiative impacted the issue of young people in residential aged care, it did not create the systemic change required to stem the flow of young people with disability and resulting high and complex needs into RAC³. However, the initiative has provided a significant opportunity to understand the range of outcomes of people who moved from RAC to the smaller-scale residential settings developed. This includes comparing the characteristics and health and participation outcomes of people living in SSAs developed through the five-year initiative, as well as those people with high and complex needs living in other specialised small-scale residential settings as alternatives to hospital or aged care. This knowledge is particularly important given the current major national disability reform underway with the launch of Australia's National Disability Insurance Scheme (NDIS).

THE NDIS AND PEOPLE WITH COMPLEX HEALTH SUPPORT NEEDS

Recommended by a Productivity Commission Inquiry into Disability Care and Support, the NDIS has been designed to reform a disability service system which is “inequitable, underfunded, fragmented, and inefficient and gives people with disability little choice”¹³. Initially launched from July 2013 in key trial sites across Australia, the Scheme has been designed to support people with significant and permanent disability to identify, proactively plan for, and purchase the necessary and reasonable equipment, support and services that they require to achieve their personal goals for community living¹⁴. For people with complex disability-related needs, once full scheme roll out is achieved, the NDIS will fund reasonable and necessary supports and equipment¹⁵, for those people currently living in RAC, SSAs, transitioning from hospital, and those living in the community. There remains, however, lack of clarity regarding the complex interface between disability, health, aged care and allied health services for NDIS participants. Delegation of responsibility of rehabilitation support to the health sector is a currently identified issue in the NDIS trial sites¹⁶, and is in contrast to the state-based disability service systems which funded some community based rehabilitation support.

The recent Federal government Senate Inquiry into Adequacy of Existing Residential Care Arrangements Available for Young People with Severe Physical, Mental or Intellectual Disabilities in Australia recommends that in all jurisdictions, the NDIS needs to take a specialist approach to young people with complex disability who might be at risk of RAC placement⁹. The Senate Inquiry panel also recommended the Australian government develop a joint taskforce with a role in identifying young people in RAC, and taking action to improve their living situation. This includes oversight of transition to alternate accommodation for all young people in RAC who include this as a goal within their NDIS planning. This aspiration highlights the need for the Scheme to be informed about, and prepared to engage with, current disability-specialist supported accommodation models where this is the preference of the participant, and utilise existing evidence to inform further development of changing traditional or innovative housing and support models for this group. Of note, the NDIA has recently revised their quoting guidelines for shared supported accommodation¹⁷. The NDIA has indicated that it will carry out a review of shared supported accommodation arrangements over the coming months. This month, the Department of Social Services (DSS) announced a \$10M Specialist Disability Accommodation Initiative outside the NDIS trial sites, and the National Disability Insurance Agency (NDIA) released a call for Request for Information regarding proposals for innovative housing pilots in the Victorian trial site.

With these recommendations in mind, and the knowledge that full Scheme design is now being undertaken in preparation for the 2016 roll out, the aims of this research project were to:

1. Examine the characteristics, support and equipment needs and participation outcomes of people with significant and permanent disability living in shared supported accommodation (SSA) funded by recent disability or government initiatives.
2. Compare this aggregated data with existing data on young people living in residential aged care to examine outcomes across these two settings.

The evidence gathered through this project is documented to inform design of the NDIS and the operational guidelines for full Scheme roll out for this target group. The information will also guide education, capacity building and planning processes for NDIS participants and their families, planners, and policy developers.

A relative confidence interval of roughly 50% relative to the statistic, at the 95% level (or a relative standard error of 25%. For example, if it's estimated that 2000 people in a population require a given support, then the confidence interval would range from 1000 to 3000.

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METHOD

DESIGN

An anonymous survey design was used in this project. This methodology was chosen as an efficient way to gather aggregate data on resident characteristics, services utilised and participation outcomes in a project delivered within a short timeframe (April-August 2015) and with only limited organisational resources available. Given its design, this project was approved as a low risk study by the Monash University Human Research Ethics Committee (project approval CF15/908-2015000405).

QUESTIONNAIRE

Data were collected via a customised online questionnaire (see Appendix 1) filled out by a nominated representative from the organisation delivering the SSA. Organisations were asked to arrange for the direct site manager to complete the questionnaire where possible. In the case of three SSA sites, a more senior regional manager provided the responses. The questionnaire asked the respondent to report the number of residents at the site, then provide estimates regarding disability type, health conditions experienced, supports received, and home and community participation rates. Items on this survey were formulated to allow some comparison, where possible, with previous research with YPIRAC^{8,12}.

PARTICIPATING SSA ORGANISATIONS AND SITES

Thirty-three accommodation sites, run by 15 organisations, were selected for invitation to participate in this survey. This comprised all sites known have received funding under the Victorian Young People in Residential Aged Care initiatives, as well as key sites funded through the ACT and NSW Young People in Residential Aged Care initiatives for which the service provider was known by the research group. Eleven Victorian sites were selected because they were known by the researchers to provide supported accommodation to people with complex health needs that were comparable to the YPIRAC target group, albeit not being funded through the YPIRAC initiative. Of the organisations invited, 12 agreed to participate, and from these, 25 sites submitted data by the project deadline.

From the sites that submitted data, the total number of residents reported on was 173. The average number of residents per site was 6.92 (range 4 – 12 residents per site). Only 16 residents (9%) were aged over 65 at the time of the survey, and these residents were from only three sites, thus the majority of residents for which aggregate data was reported fell into the eligible age range for the NDIS. The most common dwelling type was a “residential house / group home model” (72% of sites), followed by cluster units (12%), duplex houses (8%), and 8% of sites were not defined.

STUDY LIMITATIONS

Survey questions were not posed directly to residents of the SSA sites; rather, the manager of each site was asked to estimate the number of residents that met each specified criteria. This approach provides a useful means to gauge the extent that trends identified in previous research hold true in 2015 for a larger population of people with disability and complex needs living in SSA. This is important given that detailed statistics on this cohort are not readily available. For example, because SSA residents represent a small fraction of people with disability, the ABS Survey of Disability, Aging and Carers produces statistics for this group with large confidence intervals. The Disability Services National Minimum Data Set is high level and limited by its reliance on service providers to collect and report client data¹⁸.

However, the inherent limitation of the current survey was that it relied somewhat on the recall and subjective judgement of SSA or regional managers. Given this, results of this study should be interpreted only where there is a very large and consistent trend, and should be confirmed with further research.

In addition, the study methods used, and low-risk research design, did not allow the gathering of potentially identifying individual data on residents, including gender. This may further limit the interpretation of results.

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RESULTS

Except where otherwise specified, all results were arrived at by summing the number of residents reported to meet the criterion across all sites and dividing by the total number of residents across all sites. Therefore, results represent percentages of all residents, with each individual having equal weight regardless of the numbers at a specific site.

DISABILITY & NEED FOR ASSISTANCE

Survey respondents were asked to nominate the primary disability type experienced by each resident in a particular setting, using NDIA disability categories. Some respondents nominated more than one primary disability type for an individual; however, the most common disability type reported was acquired brain injury or intellectual disability (46%) followed by Multiple Sclerosis or other neurodegenerative disorder (42%).

Regarding residents' need for assistance, the results indicate a majority require assistance with mobility, self-care, or communication; moreover, over three-quarters require assistance with cognitive supports. Refer to Table 1.

TABLE 1. RESIDENTS' NEED FOR ASSISTANCE WITH BROAD ACTIVITY AREAS

| | % of residents |
|--|----------------|
| Self-care (e.g., dressing, washing, eating a meal, going to the toilet) | 80% |
| Mobility (e.g., getting in or out of a bed or chair, moving around at home, getting around away from home) | 79% |
| Cognition (e.g., making decisions or thinking through problems) | 77% |
| Communication (e.g., understanding or being understood by others) | 50% |

SECONDARY HEALTH CONDITIONS

Table 2 presents the proportion of residents reported to experience various categories of health condition. It is seen that bladder and bowel issues were the most common, being an issue for over three-quarters of residents. Other health issues were present for substantial minorities. Although these results can't establish precise patterns of comorbidity, the results suggest many residents experience multiple health issues.

TABLE 2. PROPORTION OF RESIDENTS EXPERIENCING SELECTED HEALTH CONDITIONS

| | % of residents |
|--|----------------|
| Bladder or bowel issues (e.g., incontinence, constipation) | 76% |
| Issues involving muscles or bones | 54% |
| Problems or special requirements with eating drinking or swallowing | 45% |
| Mental health problems (e.g., symptoms of depression, anxiety, hallucination, problem drinking or drug use) | 43% |
| Impaired hearing, vision, or hypersensitivity to sensory stimuli | 42% |
| Skin issues (e.g., soars, rashes, loss of sensitivity) | 40% |
| Behaviours of concern (e.g., aggression, inappropriate sexual behaviour, "absconding", lack of initiation) | 32% |
| Epilepsy | 23% |
| Heart, blood, or other circulatory conditions | 14% |
| Difficulty or special requirements with breathing | 10% |
| Diabetes | 8% |

SUPPORTS PROVIDED

To gauge the range of supports currently provided to residents, respondents were asked to report the numbers receiving each support category in the previous 12 months. These numbers were reported first in terms of supports provided directly by the organisation. Separately, numbers were reported in terms of supports provided by an external provider. Table 3 summarises these results. It is noteworthy that, with the exception of tracheotomy management, all supports were more likely to be provided by the SSA provider than by parties external to the SSA.

TABLE 3. PROPORTION OF RESIDENTS RECEIVING SELECTED SUPPORTS

| | % of residents receiving support from: | |
|--|--|-------------------|
| | SSA provider | External provider |
| 24-hour staff presence | 92% | 26% |
| Support staff for resident/s to attend external services | 89% | 49% |
| Transport services (e.g. private vehicle transport) | 86% | 53% |
| Specialist assessments (e.g. OT, continence nurse, speech pathology assessment) | 82% | 64% |
| Active overnight support | 74% | 16% |
| Periods of 1 to 1 support | 73% | 49% |
| Specialist products (e.g., gloves, bandages, PEG nutrition) | 69% | 33% |
| Services from allied health staff (e.g., physio, OT, psychology/counselling) | 68% | 60% |
| Mobility equipment (e.g. ceiling track or portable hoist; mobile shower commode) | 65% | 43% |
| Special staff training | 64% | 40% |
| Periods of 2 to 1 support (2 staff supporting 1 resident) | 64% | 19% |
| Enrolled or registered nursing staff | 58% | 18% |
| Home automation or environmental control assistive technology | 50% | 13% |
| Other specialist equipment or devices (e.g., communication aids, blood pressure monitor) | 41% | 27% |
| Palliative care | 16% | 3% |
| Nasogastric or PEG nutrition support | 12% | 10% |
| Periods of 3 to 1 support (3 staff supporting 1 resident) | 9% | 4% |
| Tracheotomy management | 2% | 3% |

COMMUNITY PARTICIPATION AND QUALITY OF LIFE

Previous research has examined various community participation and quality of life outcomes of young people with disabilities living in residential aged care⁸. Some of these indicators were amenable to exploration in the current study. Table 4 compares the proportion who reportedly experience each activity in a typical week, and compares this with previous research on young people living in RAC². Some of the indicators in the present study were not included in the research with young people in RAC.

Quality of life indicators – including time spent out of bed, traveling outside the SSA, receiving visitors, and involvement in home and community activities – were higher for the SSA than the RAC group. Of note, however, visiting family and friends in the community and economic participation rates (i.e., formal education, work, or volunteering) continued to be low for this cohort. Participants were reported to use taxis and private vehicles for transport at a much higher rate than public transport. Refer to Table 4.

TABLE 4. PROPORTION OF RESIDENTS EXPERIENCING SELECTED HOME AND COMMUNITY PARTICIPATION OUTCOMES IN A TYPICAL WEEK

| | SSA cohort in this study (%) | RAC cohort ⁸ (%) |
|---|------------------------------|-----------------------------|
| Spend time out of bed | 99% | 71% |
| Receive a visit from a friend | 34% | 10% |
| Receive a visit from a relative | 53% | 42% |
| Visit a friend in their home | 14% | 0% |
| Visit a relative in their home | 22% | 5% |
| Travel outside of where they live | 75% | 31% |
| Participate in shopping or leisure outside of where they live | 83% | 23% |
| Engage in formal education, work, or volunteering | 14% | - |
| Participate in meal preparation | 43% | - |
| Participate in doing household chores | 37% | - |
| Travel by taxi | 56% | - |
| Travel by private vehicle | 46% | - |
| Travel by public transport | 13% | - |

The present study captured aggregate data on 173 residents of SSAs across 25 sites, focusing on sites most likely to cater for young people with disability who experience high and complex needs. As a cohort that typically requires daily support with multiple 'core activities', their disability supports will undoubtedly represent a significant proportion of NDIS funds within the full Scheme roll out. They also represent a group where the NDIS can make a large difference in quality of life and participation outcomes. As full scheme roll out approaches, these data can help guide the transition of current SSA residents into the Scheme. These data also provide some insights as to characteristics of people living or at risk of placement in RAC. In what follows, the direct implications of this study are first discussed, before turning to a discussion regarding key enablers required to adequately address the support needs of this group within a National Disability Insurance Scheme.

05

DISCUSSION

The results of this study begin to demonstrate the extent and complexity of support needs experienced by people with disability with a complex combination of disability and health needs who live in shared supported accommodation. As a cohort that typically requires daily support with multiple 'core activities', their disability supports will undoubtedly represent a significant proportion of NDIS funds within the full Scheme roll out. This research demonstrates that the daily lives of this group – and therefore the supports they require – are influenced by numerous health-related issues secondary to the primary functional disability experienced. The research also provides evidence that the accommodation models developed through the five-year YPIRAC initiative (or those comparative SSA models for people with complex needs) are associated with greater opportunities for autonomy, control and social and community participation when compared with aggregate data available on young people living in RAC. In the absence of alternatives, this points to the benefit in maintaining small-scale shared residential settings beyond NDIS transition, as one of a range of possible options for this cohort.

Stemming from these research findings, there are five key implications for full NDIS Scheme design:

1. The health and disability interface for NDIS participants with complex healthcare needs to be recognised and coordinated;
2. Scheme participants and family members, NDIS planners, and policy makers informing the design of the NDIS, need education and capacity building to effectively plan for the range and complexity of supports required by this group and - given these complexities – participants will require the provision of targeted supports for this education and capacity building prior to NDIS plan approval;
3. Lifetime care costs and outcomes will be improved with early intervention within an insurance model approach, through engagement of the young person at the point of entry to RAC, or preferably via diversion from RAC placement, using alternative supported accommodation models or NDIS funding for targeted equipment, home modifications and person-centred supports for the person to return to community living;
4. There is a need for skilled coordination of supports, delivered by people experienced in working across the health and disability sectors, to ensure a holistic response to the needs of people at risk of entry to RAC;

5. Participation can be enhanced through moves from RAC to small-scale, well located and designed supported accommodation; however, there is more work to be done to build the social and economic participation of people with disability and resulting complex needs.

These implications provide directions for the full NDIS roll out for this particular target group, which has relevance for other Scheme participants living with a range of disability types. The implications also point to capacity building necessary for NDIS planners, health professionals, direct support workers, participants and their families to influence positive Scheme impacts and outcomes.

Additionally, three key enablers are required to adequately address the support needs of this group:

1. Assistive technology must be harnessed within an NDIS to improve outcomes;
2. NDIS participants require a range of accommodation options and building of 'housing careers';
3. An ongoing focus on Information, Linkages and Capacity Building (ILC) within an NDIS is necessary.

Each of these implications and enablers will now be discussed.

THE HEALTH AND DISABILITY INTERFACE FOR NDIS PARTICIPANTS WITH COMPLEX HEALTHCARE NEEDS TO BE DEFINED AND COORDINATED

Compared to the outcomes for young people with disability placed in residential aged care, or those who experience prolonged stays in acute and subacute hospital beds, this research provides further evidence that functional outcomes are significantly improved when support is provided in smaller-scale settings, with a focus on both disability and health needs, using a collaborative systems approach¹⁶. A well-defined interface between disability-funded (NDIS) and health-funded (Health Department) services will ensure timely coordination of care planning, which has been demonstrated as important and effective in previous initiatives, such as the Continuous Care Pilot undertaken in Victoria during the five-year Younger People with Disability in Residential Aged Care Initiative¹⁹.

The high rates of health issues such as bladder, bowel, eating and swallowing issues reported for the SSA residents in this study suggest that health supports may be difficult to disentangle from disability supports. Clearly, for participants to maximise community participation, disability supports need to be planned with recognition of these issues. Conversely, effective treatment and management will need to be planned around and in recognition of disability supports. Further, there is a need for an interface between health and disability systems with regard to direct staff training, supervision and ongoing competency assessment. A majority of residents in the present study required specialist training of support staff; currently, much of this training is provided 'in-house' by disability providers.

The NDIS Act separates health and disability, so a new interface needs to be planned. This research project has identified that shared supported accommodation settings are currently required to coordinate the health and disability interface with residents. The block funding and purpose-built nature of SSAs examined has, in some instances, allowed for this integration of health and disability needs. In general, participants in this survey were more likely to access nursing or allied health input via the SSA provider, rather than from an external provider with funding for these services harnessed through state-based Disability Services.

If this planning of the health and disability interface does not occur in preparation for full NDIS roll out, there is a risk that a greater number of people living with complex secondary health conditions relating to their disability – regardless whether they live in private residential settings or in an SSA – will end up entering aged care nursing homes or rely further on acute hospital system (including Emergency Departments) in order to attempt to meet their health care needs. This target group continue to be highly susceptible to secondary conditions that can make them critically ill or result in premature death. Proactive management of these health conditions within SSA will offer both quality of life and cost benefit within a lifetime care framework. For example, failure to provide appropriate equipment to address a person's positioning needs, increases the risk of secondary health complications developing, and associated pain or discomfort.

Current reports from the NDIS trial sites indicate that health supports that were previously funded through the State disability sector are not being funded by the NDIS as they are seen as the responsibility of Health rather

than the Scheme. The assumption that participants and their families will have capacity sufficient to negotiate support between the NDIS and health system is flawed. It is unlikely participants and families will know what is available and best meets individual needs; particularly unlikely for participants with newly acquired disability. Unless there is immediate effort put into the Health system interface for this target group, the risk of decline in health and functionality and therefore outcomes is significant.

Timely supply and maintenance of health-related assistive technologies will assist in maximising independence and the social and economic participation of people with disability; a key aspiration of the NDIS. An approach that separates health and disability without recognition of the need for a disability model approach to health related outcomes, has led to reports of NDIS refusing to fund these because they are the responsibility of Health. Unless developmental work is done now to build support into the planning process and ensure Health will provide these aspects, then this group is at risk of reduced outcomes and increased risk of health complications.

The early intervention support model espoused within the NDIS is a welcome contrast to the previous priority-need driven, rationed approach of disability funding or the view of disability as a permanent and static condition that requires the same level of support across a lifetime. Full NDIS scheme design offers an opportunity to plan for early intervention to positively influence long term outcomes. It is well documented that recovery from acquired neurological disability occurs over a prolonged period of time – often a lifetime¹. Well-informed planning and timely implementation and review of supports focussed on maximising participation rates will improve outcomes for this participant population. The combination of disability and health-funded support includes the need for therapy and allied health support similar to slow stream rehabilitation models recommended within the national rehabilitation strategy proposed by the recent Senate Inquiry held for this target group⁹.

The interface between health and disability support for individuals with a 'narrow margin of health' resulting from secondary health conditions relating to their disability²⁰ is imperative to maintaining good health and wellbeing within community living and reducing Scheme costs. A framework that clearly identifies planning support available to participants and families and outlines roles and responsibility of Health and the NDIA will minimise the impost on participants and families to advocate within the silos of two complex systems¹⁶. This framework should

also consider current relevant health reforms (e.g. the Federal government's recent options discussion paper 'Better outcomes for people living Chronic and Complex Health Conditions through Primary Health Care' as part of primary healthcare reforms²¹).

Without appropriate community based support, people with complex support may be forced to reside in residential aged care. Alternatively this group may experience repeated hospital admissions and ultimately long term stays or 'bed blocking' in acute hospital wards²² if their needs heighten, are not well managed, or become too complex to be met in community settings. This creates a significant financial impost on the health care system with acute hospital beds costed at \$782.00 per day for a shared ward and \$3,167.00 per day in intensive care²³. The need for skilled community nursing and experienced community based allied health support to maintain optimal health and wellbeing in light of ongoing disability needs to be clarified in the approach the NDIA takes to supporting this population. This will ensure health risks are minimised and a decline in condition is not the result of poor planning or under resourcing. The findings from this research can be used to further inform the discussions between the NDIA and Health and inform capacity building activities for people with disability, families and planners.

NDIS PLANNERS, SCHEME PARTICIPANTS AND FAMILY MEMBERS NEED CAPACITY BUILDING TO EFFECTIVELY PLAN FOR LIFETIME SUPPORTS

Consistent with the finding of the recent Senate Inquiry⁹, most people living in the shared supported accommodation services surveyed have severe or profound limitations as a result of a developmental or acquired cognitive disability or neurodegenerative conditions. Post injury or diagnosis, many will be struggling to understand the health and disability sector they find themselves within. This highlights the need for informed pre-planning, inherently underpinned by information and knowledge building. During the NDIS planning phase, people with disability and their families will likely rely on the Scheme planning process to understand what is possible and the targeted support that will be required to achieve specific goals.

For those with a newly acquired disability, such as an acquired brain injury or recent diagnosis of Multiple Sclerosis, the disability sector is largely unknown. In an NDIS planning process reliant on a person identifying goals and discussing necessary support, it is likely that

plans that lack holistic planning or quality impacts will result, unless at least one party in the planning partnership is well educated and informed. In this case, it is likely that people with disability and their families will rely on NDIS planners to help them understand what is 'reasonable and necessary'¹⁵ to plan for and thus these planners will require capacity building regarding the planning needs of this group. In addition, the participants and their support networks will require assistance to understand what is available to them by way of funded disability and supplementary health support within an NDIS, as well as through mainstream services. A comprehensive understanding of the rehabilitation needs of people with catastrophic injury, and the health impacts likely to result from the changing needs arising from degenerative conditions, will enable participants and their families to be informed about their likely needs, and can frame associated goals in planning.

LIFETIME CARE COSTS AND OUTCOMES WILL BE IMPROVED WITH EARLY INTERVENTION WITHIN AN INSURANCE MODEL APPROACH

The Productivity Commission's Inquiry Report on Disability Care and Support sought to provide direction for a social insurance model taking a long-term view, with strong incentive to 'fund cost effective early interventions' (p.2) and 'maximise outcomes, and a direct stake [of the NDIS participant and families] in cutting waste and unnecessary services' (p.11)¹³. This insurance model is underpinned by principles including the understanding that investment in well-planned supports, and early intervention and maintenance or prevention of loss of skills for those with degenerative conditions, results in increased social and economic participation and the potential for reduction of funded formal support and Scheme costs, over time. These insurance principles are particularly pertinent to people with disability living with complex needs, like the group of participants in this research - a complex disability should not result in expectations of exclusion from social and economic opportunity. There is an existing body of evidence in Australia that contextualised, slow stream rehabilitation coupled with well planned equipment, accommodation and support can positively influence both participation and cost of care^{1,24,25}.

According to a recent report to the Disability Reform Council²⁶, 86% of plans under the NDIS have at least one support described as early intervention. This aligns with the slow stream rehabilitation approach required to maximise outcomes for people with the long periods

of progress towards goals often the result of significant injury or acquired disability. It may be that these supports are not funded by the NDIS, however agreements with Health about the roles and responsibilities, and effective coordination across both sectors is required to maximise results. This should not be negotiated as needs arise but planned and proactive where possible, consistent with the insurance model.

THERE IS A NEED FOR SKILLED COORDINATION OF SUPPORTS

Given the identified importance of an effective health and disability interface for this target group, and the complexity of their needs, specific attention and approaches to pre-planning, planning, coordination and implementation of NDIS supports in a timely manner will be pivotal. This coordination will allow participants to receive timely access to the equipment and supports they require to achieve a level of social and economic participation aligned with their goals and aspirations. Such coordination will also ensure that secondary conditions relating to the functional disability are accommodated or addressed via the application of customised equipment and supports.

The need for coordination of support to implement packages under the NDIS has been recognised in the new support clusters definition and pricing framework published recently²⁷, which state, 'Higher intensity complex support coordination may be paid where a participant requires assistance from a support worker with additional qualifications and experience relevant to the participant's complex needs. If such support is provided or guided by a health professional because of the needs of the participant, the health professional rates apply for that support' (p.6). The NDIA defines support coordination as 'assistance to strengthen participants' abilities to coordinate and implement supports and participate more fully in the community' (p.6).

Given the complexity of support needs of the participants in the SSAs surveyed in this study, and the responsiveness required to review the needs of this population over time, ongoing coordination of support or timely and responsive review of NDIS plans is expected to be higher or more frequent for this target group than other Scheme participants. 'Specialist support coordination' is likely to be a necessary support required within an NDIS plan for a majority of this target group, not an exception.

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DISABILITY**

There is limited opportunity to contribute to the management of a household whilst residing in a residential aged care facility. Greater opportunities to engage in everyday homemaking tasks, and the physical and social environment in which a person lives, were demonstrated in the data on the group residing in SSA, as well as in previous research¹⁰. Whilst shared supported accommodation may not always maximise opportunities for independence, the data suggests that increased participation in the home environment is an outcome of this model compared to residential aged care. Given the high level of support required for study participants in areas such as mobility and self-care, the indication that 46% had the opportunity for some participation in household chores and meal preparation highlights the increase in meaningful life role participation relating to homemaking available in shared supported accommodation and further potential opportunities that exist.

When compared with previous research undertaken with YPIRAC⁸, survey data from this study indicated that SSA residents spent more time out of bed, travelling outside of their accommodation, and visiting with friends and relatives compared with young people in residential aged care. This supports the intentions of the NDIS to enhance the social and economic participation of Scheme participants via individualised supports. However, both economic participation and social contact remained low for this group demonstrating the ongoing marginalisation which may be experienced by people with high and complex disability. Although visits to a person in SSA, or visiting by the person in the community, were of higher frequency than for those living in RAC, frequency of visiting still remained low across the SSA group. Survey data indicated that only 8% of SSA residents were engaged in activities relating to education and paid or voluntary work. These two areas require a targeted approach, and sustained attention, within an NDIS to build social and economic participation outcomes.

ASSISTIVE TECHNOLOGY MUST BE HARNESSED WITHIN AN NDIS TO IMPROVE OUTCOMES

Survey results indicate that residents of SSA experience a range of disabilities, and resulting complex care needs, that necessitate the timely supply of customised assistive technology (AT) solutions. Sixty five percent of the group had access to mobility equipment and 50% to home automation or environmental control AT provided through the SSA provider, whilst 43% had mobility equipment and 13% had environmental control AT sourced externally. Beyond the traditional AT items necessary for this group, such as motorised and manual wheelchairs, hoists and showering aids, the development of smartphone and tablet technology has diminished the gap between disability-specific and mainstream technology²⁸. This has created the opportunity for people with disability and their families to access mainstream technology options. The desirability and perceived social acceptance of these mainstream options increase potential for more integrated lives. Current and emerging technology offers the real potential for people with significant and permanent disability to live with the level of independence or autonomy that many of us take for granted²⁹, and could change the way supported accommodation is delivered to residents.

However, it should also be noted that this group may experience potential barriers to assistive technology uptake and ongoing use, which may include low income, limited support available to build technology usage and skill development, and impaired cognitive communication ability²⁸. The level of knowledge of both NDIS participants and planners regarding assistive technology needs and opportunities may influence participants' potential to apply assistive technology solutions within goal setting. A number of the people in this study's target group do not have the cognitive and or communication capacity to indicate their preferences regarding assistive technology options. They may not have natural supports available to them to assist.

Information and resources to gain knowledge on possible assistive technology solutions will need to be developed and made accessible to NDIS participants and their families. Planners will also require knowledge in this area to be drawn upon during a planning process. This will ensure that technology is harnessed in useful way within an NDIS to build the social and economic participation of people with disability and also has the real potential to influence Scheme costs.

Some NDIS participants and their support networks will require peer support, training and/or intermittent input to harness the full capability of technology supplied, and avoid technology abandonment²⁹. This should also be

considered within planning processes. If the person with disability and their family are not aware of possibilities in this area, they may benefit from the input of an expert assistive technology assessment within NDIS plans. Such an assessment would allow opportunity to consider possibilities for assistive technology prescription relating to the person's needs, goals and aspirations.

The current research provides further evidence to support the need for development of the Assistive Technology Innovation Framework drafted within the NDIS discussion paper released earlier this year²⁹ and the final paper released last month. There is a need to assess the most cost effective long-term approaches for the provision of smart home technology on a larger scale for people with disabilities, and the potential to create a market that provides incentives for reduced costs. With a concerted focus and strong leadership from the NDIA, it will be possible to find ways for NDIS participants to gain longer-term opportunities that technology can offer. However, within the context of SSAs and other supported housing setting, careful consideration needs to be given by the NDIA to establishing where responsibility for the various elements of the smart home technology systems install and maintenance lies within SSA settings. The range of SSAs examined in this research points to the opportunity for the NDIA to collaborate with providers to pilot retrofit of home automation and communication technologies in order to influence the model of support, and environmental enablement. The opportunity for retrofits or pilots of assistive technology has been pointed to in DSS guidelines for the \$10M Specialist Disability Accommodation Initiative planned for outside the NDIS trial sites which was announced this month.

NDIS PARTICIPANTS REQUIRE A RANGE OF ACCOMMODATION OPTIONS AND BUILDING OF 'HOUSING CAREERS'

This research provides insights for the NDIA regarding a specific target group – those people with high and complex needs who are living in shared supported accommodation. Through the current trial of the Scheme, some participants living in such settings in the Hunter and Barwon regions have already transitioned to the NDIS. The NDIA has recently indicated that it will carry out a review of shared supported accommodation arrangements over the coming months. This month, the Department of Social Services (DSS) announced a \$10M Specialist Disability Accommodation Initiative outside the NDIS trial sites, and the National Disability Insurance Agency (NDIA) released a call for Request for Information regarding proposals for innovative housing pilots in the Victorian trial site. The draft NDIS Housing paper, Optimising the 'User Cost of Capital' for Housing as Part of Delivering the NDIS Sustainably and Efficiently³⁰, talks about the principles that underpin the National Disability Insurance Agency's (NDIA) view on housing for participants within the Scheme, including a person's right to live as independently and autonomously as possible. The paper also acknowledges the particular needs of participants with complex support needs and how these needs might influence choices made by this group. Specifically, it states, "there are likely to be some participants with high support needs who may choose to enter specialist disability accommodation rather than live in more community based settings with support" (p.9). This draft paper discusses the need to consult with relevant stakeholders to inform housing strategy – utilising past research and the current study can inform this discussion for the population of people living in or at risks of living in inappropriate placements such as residential aged care or health services and hospital wards.

This study provides further evidence that residential aged care is not the only option when a young person with disability has high and complex needs. Although it may be assumed that placement in RAC comes from medical necessity, the sites examined through this research, each with only 4-12 residents experiencing multiple core limitations and numerous health-related issue, with the appropriate resources SSA providers can and do provide and facilitate a range of complex supports. Further, it is apparent from this and other research that participation rates and quality of life is favourable when living in small-scale supported residential settings compared to RAC. Although there remain areas of practice to improve for SSA residents, it seems difficult to argue that any person's needs are best met in RAC. RAC placements occur not due to medical necessity, but rather for systemic reasons. In an NDIS environment, a variety of options must be considered and harnessed as viable alternatives to RAC.

AN ONGOING FOCUS ON INFORMATION, LINKAGES AND CAPACITY BUILDING (ILC) WITHIN AN NDIS IS NECESSARY

Australia's National Disability Strategy (NDS), running from 2010-2020, sets out priority areas within a 10-year plan for improving life for Australians living with disability. One of the key priority areas focuses on the delivery of health services and health promotion, and the interaction between health and disability systems to improve wellbeing for the person with disability⁴. However, there continue to be a range of barriers within other mainstream service systems, including housing, education, employment and transport systems, which may further reduce social and economic participation for people living with significant and permanent disability beyond the influence of the disability itself.

Given this, there is an ongoing and urgent need for a parallel and large scale piece of work relating to Information, Linkages and Capacity Building within a National Disability Strategy. Unless this work is delivered in a timely manner, these system barriers will reduce the effectiveness and increase the cost of the NDIS. For example, without the provision of accessible public transport in close proximity to home, a person with disability may experience a heightened need for support to travel into their community (e.g. via supply of accessible vehicle or provision of 1:1 support for vehicle transfers). Following, if the attitudinal barriers to employment of people with disability remain, efforts to influence the economic participation of NDIS participants will prove difficult. If the NDIS is to truly influence choice and control for people with disability within a market-driven system, attitudinal, economic, social and physical environmental barriers must be addressed at a national level.

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CONCLUSION

People with complex needs resulting from functional impairment related to disability living in SSA require a skilled pre-planning and planning approach, and are likely to require ongoing specialised supports, within an NDIS. These elements should be coupled with a robust and coordinated health interface, given the range of secondary health conditions stemming from the functional disability.

The translation of existing SSA to an NDIS framework provides opportunities for these models to be enhanced through individualised approaches, and to allow for the opportunity for individual tenants to move to alternative housing options as their needs change.

This research begins to build an evidence base to inform full Scheme design, and consider cross-sector collaboration, necessary for this target group.

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**APPENDIX 1:
SURVEY**

1. Your Organisation/Company

2. Are you a direct manager of the supported accommodation site for which you are filling this survey out?

3. What type of SSA site is this?

- Residential house/group home model?
- Unit located on the same property as a residential house/group home
- Cluster unit collocated with other units on a block of land
- Duplex house/unit (i.e. one of two dwellings on one block of land, connected by some share space)
- High support unit/hostel
- Other (please specify)

4. In total, how many residents currently live at this site?

5. How many of the [Q4] residents are over 65 years of age?

NDIA report statistics in terms of certain “primary disability” categories. “Primary disability” means the disability that causes the most difficulty for the person. How many of the [Q4] residents have a primary disability that is best included under each category?

- Autism or related disorders
- Intellectual disability or acquired brain injury
- Cerebral palsy
- Other physical disability
- Multiple Sclerosis or other neurodegenerative disorder
- Schizophrenia or other psychiatric disability
- Sensory or speech disability

6. How many [Q4] residents usually need assistance to do each of the following: Mobility (e.g., getting in or out of a bed or chair, moving around at home, getting around away from home)

- Self-care (e.g., dressing, washing, eating a meal, going to the toilet)
- Communication (e.g., understanding or being understood by others)
- Cognition (e.g., making decisions or thinking through problems)

**7. How many of the [Q4] residents have the following types of health issues?
(In each case provide your best estimate.)**

- Impaired hearing, vision, or hypersensitivity to sensory stimuli
- Heart, blood, or other circulatory conditions
- Problems or special requirements with eating drinking or swallowing
- Difficulty or special requirements with breathing
- Issues involving muscles or bones
- Skin issues (e.g., soars, rashes, loss of sensitivity)
- Bladder or bowel issues (e.g., incontinence, constipation)
- Mental health problems (e.g., symptoms of depression, anxiety, hallucination, problem drinking or drug use)
- Behaviours of concern (e.g., aggression, inappropriate sexual behaviour, “absconding”, lack of initiation)
- Epilepsy
- Diabetes

8. What special supports does your service directly provide (i.e., services provided by your organisation’s staff or goods purchased by your organisation)? For each, estimate how many of your [Q4] residents were directly provided the support in the past 12 months.

- Specialist assessments (e.g. OT, continence nurse, speech pathology assessment)
- Tracheotomy management
- Nasogastric or PEG nutrition support
- Special staff training
- Periods of 1 to 1 support
- Periods of 2 to 1 support (2 staff supporting 1 resident)
- Periods of 3 to 1 support (3 staff supporting 1 resident)
- 24-hour staff presence
- Home automation or environmental control assistive technology
- Mobility equipment (e.g. ceiling track or portable hoist; mobile shower commode)

- Other specialist equipment or devices (e.g., communication aids, blood pressure monitor)
- Specialist products (e.g., gloves, bandages, PEG nutrition)
- Enrolled or registered nursing staff
- Services from allied health staff (e.g., physio, OT, psychology/counseling)
- Active overnight support
- Transport services (e.g. private vehicle transport)
- Support staff for resident/s to attend external services
- Palliative care

9. What special supports are provided to residents by external providers? (i.e., goods or services purchased by a resident themselves or provided by an external provider without a subcontracting relationship) For each, estimate how many of the [Q4] residents received the support in the past 12 months.

- Specialist assessments (e.g. OT, continence nurse, speech pathology assessment)
- Tracheotomy management
- Nasogastric or PEG nutrition support
- Special staff training
- Periods of 1 to 1 support
- Periods of 2 to 1 support (2 staff supporting 1 resident)
- Periods of 3 to 1 support (3 staff supporting 1 resident)
- 24-hour staff presence
- Home automation or environmental control assistive technology
- Mobility equipment (e.g. ceiling track or portable hoist; mobile shower commode)
- Other specialist equipment or devices (e.g., communication aids, blood pressure monitor)
- Specialist products (e.g., gloves, bandages, PEG nutrition)
- Enrolled or registered nursing staff
- Services from allied health staff (e.g., physio, OT, psychology/counseling)
- Active overnight support

- Transport services (e.g. private vehicle transport)
- Support staff for resident/s to attend external services
- Palliative care

10. How many of the [Q4] residents experience the following in a typical week? (In each case provide your best estimate.)

- Spend time out of bed
- Receive a visit from a friend
- Receive a visit from a relative
- Visit a friend in their home
- Visit a relative in their home
- Travel outside of where they live
- Participate in shopping or leisure outside of where they live
- Engage in formal education, work, or volunteering
- Participate in meal preparation
- Participate in doing household chores
- Travel by taxi
- Travel by private vehicle
- Travel by public transport

11. How many of the [Q4] residents experience the following in a typical month? (In each case provide your best estimate.)

- Spend time out of bed
- Participate in meal preparation
- Participate in doing household chores
- Receive a visit from a friend
- Receive a visit from a relative
- Visit a friend in their home
- Visit a relative in their home

- Travel outside of where they live
- Participate in shopping or leisure outside of where they live
- Engage in formal education, work, or volunteering
- Attend community events (e.g. music festival, rally, cultural festival)
- Travel by taxi
- Travel by private vehicle
- Travel by public transport

12. How many of the [Q4] residents: (In each case provide your best estimate.)

- Have an advanced care plan (i.e., a plan for a person's future health and personal care in the event that the person is unable to make decisions or communicate)?
- If the SSA is based in Victoria, receive ABI: Slow To Recover funding?

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