Ageing, Disability & Home Care

Department of Family and Community Services

Ageing in Place: Impacts of Ageing on Accommodation Services – Research Project Report

December 2011
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**Glossary**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ACP</td>
<td>Attendant Care Program</td>
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<tr>
<td>ACPDU</td>
<td>Attendant Care and Physical Disability Unit</td>
</tr>
<tr>
<td>ADHC</td>
<td>Ageing, Disability &amp; Home Care, Department of Family and Community Services NSW</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>AIP</td>
<td>Ageing in Place</td>
</tr>
<tr>
<td>ACP</td>
<td>Attendant Care Program</td>
</tr>
<tr>
<td>APD</td>
<td>Accommodation Policy and Development Directorate</td>
</tr>
<tr>
<td>CACP</td>
<td>Community Aged Care Package</td>
</tr>
<tr>
<td>CRS</td>
<td>Commonwealth Rehabilitation Service</td>
</tr>
<tr>
<td>EACH</td>
<td>Extended Aged Care at Home</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living scale</td>
</tr>
<tr>
<td>IASP</td>
<td>Individual Accommodation Support Package</td>
</tr>
<tr>
<td>LPA</td>
<td>Local Planning Areas</td>
</tr>
<tr>
<td>LRC</td>
<td>Large Residential Centres</td>
</tr>
<tr>
<td>MDS</td>
<td>Disability NSW Minimum Data Set</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Government Organisation</td>
</tr>
<tr>
<td>PwC</td>
<td>PricewaterhouseCoopers</td>
</tr>
<tr>
<td>SDAC</td>
<td>Survey of Disability, Ageing and Carers</td>
</tr>
<tr>
<td>ST</td>
<td>Stronger Together</td>
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<tr>
<td>ST2</td>
<td>Stronger Together 2</td>
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Executive Summary

Introduction and Background
Ageing, Disability and Home Care (ADHC,) has commissioned the Ageing in Place (AIP) project as part of its Priority Initiative Further develop the Spectrum of semi-independent living models. Ultimately, the aim of this project is to develop an ageing in place strategy for ADHC funded and operated accommodations services.

The Ageing in Place initiative responds to this challenge through the development and implementation of an evidence based strategy that better meets the needs of people with a disability who are ageing.

For Ageing in Place to be successful, it must build on existing service strengths within and external to the existing disability support framework and link to relevant community care, specialist equipment, support, housing and health and aged care infrastructure and services.

This report is the product of the ageing in place research. This report comprises two main parts:

1. Future Service Model, Service Modifications and Options
2. Service Delivery Map - including:
   
   • The mapping of the different service types across age cohorts (supply and demand)
   • Mapping the existing accommodation client base (supply)
   • Mapping the impact of ageing on service delivery
   • Comparing the two sources of data to identify any capacity challenges at a regional level.

Key Findings
A key finding of the NSW Ombudsman’s Report on Reviewable Deaths in 2008 & 2009 re the deaths of people with disabilities in care was that none of the 49 people who died during 2008-2009 who had chronic disease were linked to a chronic disease management or out of hospital program of any type\(^1\). The Centre for Education and Research on Ageing at the University of Sydney identified that approximately 40% of people in a study of 215 people with intellectual disability living in supported accommodation in NSW had a chronic disease\(^2\). It follows that there is likely a large number of people with a disability living in group homes or receiving drop-in services who are not enrolled in any chronic care program. All NSW Local Health Districts have a requirement to monitor the number of people enrolled in the Connecting Care program for people with chronic disease. It would be advantageous to further monitor which of these enrolled people have a disability and live in ADHC funded supported accommodation. Or conversely who in the over 40 age group in supported accommodation with chronic disease are not enrolled.

The likely health status for the current group home population is represented in the following figure. The estimates are indicative only and are derived from a number of sources\(^3,4,5\).

---


\(^3\) ibid 1

\(^4\) ibid 2
Given this profile a more proactive approach to health management is needed for people with disabilities in supported accommodation. ADHC should be in a position to know the percentage of people with chronic disease enrolled in chronic disease management programs.

The following table provides an estimate of the support needs of clients of all ages who live in 24/7 supported accommodation, based on the 2009/10 MDS data. The support need estimates are based on a number of sources, including those identified for the figure above. The estimates for ageing in specialist accommodation and disability aged care are based on the Commonwealth Department of Ageing provision ratios for aged care places for the general population aged over 70 years. The forecasted increases are based on the PwC estimates of 2.4% per annum.

Table 1  Estimated demand for supports for people in 24/7 accommodation – all aged clients

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<tbody>
<tr>
<td>No added supports</td>
<td></td>
<td>1488</td>
<td>1,523</td>
<td>1,560</td>
<td>1,597</td>
<td>1,636</td>
<td>1,675</td>
</tr>
<tr>
<td>Enhanced (DSW) supports</td>
<td></td>
<td>496</td>
<td>508</td>
<td>520</td>
<td>532</td>
<td>545</td>
<td>558</td>
</tr>
<tr>
<td>Augmented supports (CACP, EACH etc)</td>
<td></td>
<td>1984</td>
<td>2,031</td>
<td>2,080</td>
<td>2,130</td>
<td>2,181</td>
<td>2,233</td>
</tr>
<tr>
<td>Palliative care</td>
<td></td>
<td>496</td>
<td>508</td>
<td>520</td>
<td>532</td>
<td>545</td>
<td>558</td>
</tr>
<tr>
<td>Ageing in specialist accommodation</td>
<td></td>
<td>218</td>
<td>223</td>
<td>229</td>
<td>234</td>
<td>240</td>
<td>246</td>
</tr>
<tr>
<td>Disability aged care (Casuarina Grove type)</td>
<td></td>
<td>218</td>
<td>223</td>
<td>229</td>
<td>234</td>
<td>240</td>
<td>246</td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td></td>
<td>50</td>
<td>51</td>
<td>52</td>
<td>53</td>
<td>55</td>
<td>56</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>4,959</strong></td>
<td><strong>5,068</strong></td>
<td><strong>5,189</strong></td>
<td><strong>5,314</strong></td>
<td><strong>5,442</strong></td>
<td><strong>5,572</strong></td>
</tr>
</tbody>
</table>

The following table shows the estimated demand for people in 24/7 accommodation for people aged over 41 years.

**Table 2  Estimated demand for supports for people in 24/7 – clients aged 41 years and over**

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<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
</tr>
<tr>
<td>No added supports</td>
<td>817</td>
<td>30%</td>
<td>836</td>
<td>856</td>
<td>877</td>
<td>898</td>
<td>919</td>
</tr>
<tr>
<td>Enhanced (DSW) supports</td>
<td>272</td>
<td>10%</td>
<td>279</td>
<td>285</td>
<td>292</td>
<td>299</td>
<td>306</td>
</tr>
<tr>
<td>Augmented supports (CACP, EACH etc)</td>
<td>1,089</td>
<td>40%</td>
<td>1,115</td>
<td>1,142</td>
<td>1,169</td>
<td>1,197</td>
<td>1,226</td>
</tr>
<tr>
<td>Palliative care</td>
<td>272</td>
<td>10%</td>
<td>279</td>
<td>285</td>
<td>292</td>
<td>299</td>
<td>306</td>
</tr>
<tr>
<td>Ageing in specialist accommodation</td>
<td>120</td>
<td>4.4%</td>
<td>123</td>
<td>126</td>
<td>129</td>
<td>132</td>
<td>135</td>
</tr>
<tr>
<td>Disability aged care (Casuarina Grove type)</td>
<td>120</td>
<td>4.4%</td>
<td>123</td>
<td>126</td>
<td>129</td>
<td>132</td>
<td>135</td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td>27</td>
<td>1%</td>
<td>28</td>
<td>29</td>
<td>29</td>
<td>30</td>
<td>31</td>
</tr>
<tr>
<td>Total</td>
<td>2,722</td>
<td>100%</td>
<td>2,782</td>
<td>2,849</td>
<td>2,917</td>
<td>2,987</td>
<td>3,059</td>
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</table>

**Principal Recommendations**

1. **The current service and program structure is too complex and costly to administer**

The current service system is not in line with the move to individualised funding and the planned implementation of the National Disability Insurance Scheme. The service system needs to be simplified, facilitating a shift of the market to a more person-centred approach so that:

- Planning is more focussed
- Information about services will be better communicated
- Clients and families can better understand the services available.

2. **Funding and administration needs to be simplified**

This will be marked by a move away from program based funding arrangements.

- Implement individualised funding with pooling across current programs for flexibility and portability (e.g. Drop-in and HACC funding).

- Phase in individualised funding using a three option approach as implemented by the Attendant Care Program (Direct, Cooperative and Employer) with the aim to shift to direct funding in accordance with demand from clients, carers, families and their supporters.
3. **Encourage new accommodation models, home modifications and equipment funding models**

This will occur through a pathways and partnership approach between Housing NSW, The Ministry of Health and the Commonwealth Department of Health and Ageing to assist ageing clients to age in place or move to suitable accommodation of their choice.

4. **Work with the NSW Ministry of Health to ensure all people with a disability with chronic disease are enrolled in the Connecting Care program and to work with Medicare Locals. ADHC should require service providers to provide information on the number of clients with chronic diseases who are enrolled in the Connecting Care Program.**

This will occur through a partnership with the NSW Ministry of Health and the Intellectual Disability Network of the NSW Agency for Clinical Innovation. At a local level ADHC Regions should partner with Local Health Districts and Medicare Locals. The National Health Reform represents an opportunity for ADHC to improve healthcare for people with disability through working with Medicare Locals whose charge is “to support the day-to-day delivery of better integrated GP and primary health care services in the community, ensuring more patients can get the care that they need in the right settings.”

The Medicare Locals\(^8\) have the responsibility of providing better integrated care, enabling people to navigate the local health care system. Key roles of these organisations are to:

- Facilitate allied health care and other support for people with chronic conditions
- Work with local health care professionals ensuring integrated and accessible services people need
- Identification of groups of people missing out on GP and primary care, and targeting gaps in services
- Assist with the transition of patients out of hospital to aged care through working with Local Hospital Networks
- Deliver preventive health and health promotion programs to communities with identified risk factors
- Target gaps in primary health care services for aged care recipients through a flexible aged care funding pool.

This role of the Medicare Locals represents an opportunity for ADHC who should be proactively seeking opportunities to work with Local Health Districts and Medicare Locals perhaps starting with a region where there are large numbers of ageing clients and the organisations involved are well established (eg, Hunter).

5. **Develop an action plan and business case to identify the priorities for the service modification options**

An action plan is needed to identify the priorities for the service modification options and this is a subject of the next and final report in this series.


Summary

1. Introduction and Background

Ageing, Disability and Home Care (ADHC) has commissioned the Ageing in Place (AIP) project as part of its Priority Initiative Further develop the Spectrum of semi-independent living models. Ultimately, the aim of this project is to develop an ageing in place strategy for ADHC funded and operated accommodations services.

There is a need for support services and care for people with a disability to be person centred. Effective Ageing in Place services and support is a key component, particularly to meet increasing demand as the ageing population of people with disabilities and their carers seek alternative accommodation and support solutions.

The Ageing in Place initiative responds to this challenge through the development and implementation of an evidence based strategy that better meets the needs of people with a disability who are ageing.

For Ageing in Place to be successful, it must build on existing service strengths within and external to the existing disability support framework and link to relevant community care, specialist equipment, support, housing and health and aged care infrastructure and services.

This service delivery map is the third document in a suite of ageing in place research:

The scoping pathways research noted the increasing demand for services for people with a disability who are both ageing and living longer. This significant growth in demand (2.4% p.a) is driven by population. It was estimated that only 13.4% of people with Grade A\(^9\) support needs are currently accessing accommodation or accommodation support services (In-home/Drop-in accommodation support services, Attendant Care Program, Home and Community Care (HACC) Services).

More than 73% of clients utilising accommodation or accommodation support services are aged greater than 35 years. Variation occurs between Local Planning Areas (LPAs) for both demand and supply of services, with South West Sydney and the Far North Coast identified as areas where supply is low in contrast to forecast demand.

The literature review and scoping pathways research highlighted the lack of screening and assessment as a significant issue for ageing clients with a disability, and that home modifications and special equipment is needed as people age. The need for flexible funding options and individual packages based on person-centred plans were also highlighted. It was concluded that reform of the service system and innovation are needed to meet the demands of ageing clients and their carers.

The demand and service response options research, together with the findings from the consultations with consumers, carers and families, service providers and ADHC, highlighted the building blocks, service modifications and high level service options to address the identified needs of people with a disability who are ageing.

\(^9\) Grade A is a subset of the population with severe/profound core activity limitation, with constant, frequent or regular support needs. These categories were derived from the 2003 ABS Survey of Disability, SDAC Confidential Unit Record File and developed by PwC in conjunction with ADHC in 2005.
Key findings from this research included:

- There is a lack of planning and information available to plan for people with a disability.
- Service providers with large numbers of ageing clients are experiencing financial strain.
- Carers are worried about the future for the person with a disability they care for.
- The service system is fragmented and program centred rather than person-centred, and people with a disability and their carers are confused about what services are available and have difficulty finding information.
- There is no consistent approach to assessing the needs of ageing clients.
- Access to the health and aged care systems is problematic for people with a disability.
- Easy access to equipment and assistance with home modifications is needed to support people to age in place.
- In addition to disability funding, there should be access to aged care packages to support people with a disability as they age.
- Service providers are concerned about the COAG reforms and the age cut-off at 64 years as are consumers. Many of those with physical disabilities who are only able to access HACC services rather than the Attendant Care Package will struggle to have sufficient support to age in place in the community.
- Some innovative models and approaches are emerging; ADHC has been successfully funding pilots of a number of models.
- Stronger Together: The second phase funding will assist in addressing unmet need, particularly Local Support Co-ordination and the Supported Living Fund.
- High level service options were developed covering accommodation, services, health services and lifestyle.

This report has two main parts:

1. Future Service Model, Service Modifications and Options
2. Service Delivery Map - including:
   - The mapping of the different service types across age cohorts (supply and demand)
   - Mapping the existing accommodation client base (supply)
   - Mapping the impact of ageing on service delivery
   - Comparing the two sources of data to identify any capacity challenges at a regional level.

2. **Principal Recommendations**

1. **The current service and program structure is too complex and costly to administer**

The current service system is not in line with the move to individualised funding and the planned implementation of the National Disability Insurance Scheme. The service system needs to be simplified, facilitating a shift of the market to a more person-centred approach so that:

- Planning is more focussed
- Information about services will be better communicated
- Clients and families can better understand the services available.

2. **Funding and administration need to be simplified**

This will be marked by a move away from program based funding arrangements.
• Implement individualised funding with pooling across current programs for flexibility and portability (e.g. Drop-in and HACC funding).

• Phase in individualised funding using a three option approach as implemented by the Attendant Care Program (Direct, Cooperative and Employer) with the aim to shift to direct funding in accordance with demand from clients, carers, families and their supporters.

• Utilise Community Aged Care Packages to assist ageing clients.

3. **Encourage new accommodation models, home modification and equipment funding models**

This will occur through a pathways and partnership approach between Housing NSW and The Ministry of Health to assist ageing clients to age in place or move to suitable accommodation of their choice.

4. **Work with the NSW Ministry of Health to ensure all people with a disability with chronic disease are enrolled in the Connecting Care program and to work with Medicare Locals.**

This will occur through a partnership with the NSW Ministry of Health and the Intellectual Disability Network of the NSW Agency for Clinical Innovation. At a local level ADHC Regions should partner with Local Health Districts and Medicare Locals. The National Health Reform represents an opportunity for ADHC to improve healthcare for people with disability through working with Medicare Locals whose charge is “to support the day-to-day delivery of better integrated GP and primary health care services in the community, ensuring more patients can get the care that they need in the right settings.”

The Medicare Locals\(^\text{11}\) have the responsibility of providing better integrated care, enabling people to navigate the local health care system. Key roles of these organisation are to: facilitate allied health care and other support for people with chronic conditions; work with local health care professionals ensuring integrated and accessible services people need; identification of groups of people missing out on GP and primary care, and targeting gaps in services; assist with the transition of patients out of hospital to aged care through working with Local Hospital Networks; deliver preventive health and health promotion programs to communities with identified risk factors; and target gaps in primary health care services for aged care recipients through a flexible aged care funding pool. This role of the Medicare Locals represents an opportunity for ADHC.

5. **Develop an action plan and business case to identify the priorities for the service modification options**

An action plan and business case is needed to identify the priorities for the service modification options and this is a subject of the next and final report in this series.

The following simplified model shows the elements of future service delivery within a person-centred approach. This builds on models described in the literature review for this project.

### 3. **Simplified Service Model**

A simplified service model is needed that focuses on the person.

---


4. Overview - Future Service Delivery Model

This section discusses the future service delivery model for people in non-24/7 accommodation settings and 24/7 accommodation settings.

The table below provides an overview of the future service delivery model.

<table>
<thead>
<tr>
<th>Individual Aim:</th>
<th>Living at home</th>
<th>Transitioning to community living</th>
<th>Living in the community</th>
<th>Living in residential services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live a good life with family.</td>
<td>Live a good life with whom I choose</td>
<td>Live a good life in a place of my own.</td>
<td>Live a good life in a supportive residential environment.</td>
<td></td>
</tr>
<tr>
<td>Location:</td>
<td>With family</td>
<td>With family</td>
<td>With whom I choose with Drop-in support or Attendant Care</td>
<td>With others with high level support</td>
</tr>
<tr>
<td>Supports Aims:</td>
<td>Support individual and family to enable the individual to remain at home with family however long they choose, and then commence the transition process to community living, unless assessed as requiring ongoing residential care.</td>
<td>Identify appropriate accommodation. Work with individual, family and friends to develop support network, and identify informal supports available. Teach necessary skills and set up supports to prepare for living in community (eg. ILSI, Lifestyle Planning).</td>
<td>Maximise the number of individuals living in the community with service supports. Support individual to remain in the community through ability to flex supports in times of need. Continue to work with support network, to identify how individual can realise aspirations and develop informal supports.</td>
<td>Minimise numbers of individuals in residential services. Support individual to pursue dreams, wishes and aspirations.</td>
</tr>
</tbody>
</table>

Funding: Individualised Individualised Individualised Individualised

This matrix is significantly simpler than the existing framework shown on page 28.
5. Future service modification options – People in non-24/7 accommodation settings

This section discusses the future service modification options for people in non-24/7 accommodation settings. The non-24/7 service modification options are quite different compared to people resident in 24/7 accommodation settings.

A number of options have been developed, broken into five different elements namely:

- Funding
- Accommodation
- Supports
- Lifestyle
- Health.

**Funding**

For funding the key modifications include:

- Shifting from block to individualised funding to improve person-centred planning and ensure the individual, with their network of support, actively participates in the planning and delivery of support services tailored to meet that individual’s aims, goals and objectives. The funding should be flexible and portable.
- Implement different funding model options (as per the Attendant Care Program) – direct, cooperative and employer.
- Implement funds pooling for drop-in and HACC funding for people aged under 65 years.

**Accommodation**

For accommodation the key modifications include:

- Increasing housing stock through discussions with Housing NSW to identify strategies to increase access by people with a disability – a number of models from other jurisdictions have been suggested (e.g. mixed equity, co-residency, group self-build and moveable units.
- Provide the incentives for those individuals in the community to remain living in the community, either in their existing residence or alternate accommodation with service supports to age in place.
- Work with Housing NSW to develop schemes to improve access to home modifications – models from other jurisdictions are outlined in the body of this report.
- Work with Housing NSW to develop incentives to modify existing housing stock to meet universal housing design standards to enable people with a disability to age in place.
- Implement the Jay Nolan approach to move clients from group homes to community living where feasible.
- Increase assess to home modification funding (low interest loan approach).
- Expand the pilot project Independent Living Support Initiative aimed at people with a disability and their ageing parents /carers
- Increase housing stock including mixed equity housing stock e.g. co-residency, group self-build, moveable units, model descriptions are provided in the body of the report.
- Utilise existing family assets where available – a number of models are proposed.
- Encourage universal design accommodation for older people.
Supports
For supports the key modifications include:

- Implement Futures Planning. ADHC has piloted this model successively in the Northern Region, the ACT has a similar framework\textsuperscript{12,13}.
- Ensure early baseline information for people with Down Syndrome (age 25 years) is collected.
- Detailed assessments should be undertaken for people with an intellectual disability at age 40 to identify any signs of ageing or dementia.
- Joint services for clients and carers are needed, for example HACC services.
- Local Support Coordination is needed (implementation planned for 2012).
- Case management roles will need to change with implementation of individualised funding.
- Encourage building up of circles of support. Models such as Keyring and Microboards are good examples which are discussed in the body of this report.
- Increase the use of supportive technology, particularly for ageing clients. Such technology is used in the retirement village sector and aged care.
- Drop-in services may need to increase as clients age. The need to increase drop-in services may be mitigated in part through utilisation of more mainstream community services as discussed below.
- Access to equipment is needed as people age, some models are discussed in the body of the report.
- Access to mainstream community services for older people should be encouraged. This approach may reduce the need for an increase in drop-in services for some people.
- Upskilling of service provider staff is needed regarding ageing issues. Some service providers with older clients are already addressing this issue with their staff.
- Services should be available seven days per week as needed. This may mean telephone support rather than face-to-face services.

Lifestyle
For lifestyle the major modifications include:

- Encourage utilisation of natural supports and build up circles of support. With individualised funding this will overall improve clients’ quality of life, and in many cases, has the potential to reduce formal service hours.

Health
For health the major modifications include:

- Improve access to community aged care services as people age, access to Community Aged Care Packages is needed to supplement disability services (this was the subject of the Aged Care Innovative Pool Disability Aged Care Interface Pilot and worked well according to the evaluation\textsuperscript{14} and service providers consulted).
- All clients aged over 50 years should have a comprehensive health care plan.
- Improve access to mainstream services and specialist clinics.

\textsuperscript{12} http://aslarc.scu.edu.au/Futures%20Planning%20for%20Older%20Carers%20of%20Adults%20with%20Disabilities%20Phase%202%20January%202010.pdf
\textsuperscript{14} http://www.aihw.gov.au/publication-detail/?id=6442467901
• Health care co-ordination is needed for clients with complex health needs. The primary and secondary health care model utilised for residents of licensed boarding houses appears to work well for most residents. The average cost per person in 2009/10 was $1,205 p.a.\textsuperscript{15}
• Improve understanding of the disability sector by health care professionals. This would involve working with The Ministry of Health and appropriate professional colleges.
• Reduce barriers between disability and aged care sectors through promotion the benefits to service providers of establishing relationships with local ACAT teams would assist. Funds pooling across the two sectors would also assist.

6. Future Service Modifications for ageing people living in 24/7 accommodation

This section discusses the future service modification options for ageing people living in 24/7 accommodation, in particular in group homes, which is where the majority live.

Funding

How this option is implemented is dependent on which of the overarching options described above is chosen.
• Consider pooling of funds to support clients – Accommodation, Flexible Respite, HACC funding once client is assessed as having additional need for support (this could be as young as 40, although more commonly for clients aged in their 50s). Pooling of Commonwealth funded Community Aged Care Packages (CACP) would be more problematic [n.b access to these latter 3 packages requires an ACAT assessment as discussed above]. The recent Productivity Commission report on Disability Care and Support\textsuperscript{16} recommends that “upon reaching pension age” people with a disability choose whether they wish to continue to be supported by the NDIS or move to the aged care system. They do not appear to recommend funds pooling across disability and aged care programs (see Chapter 3).
• The Ministry of Health note in their Protocols and Procedures Manual for ACATs (2007)\textsuperscript{17} that “A number of ACATs that have directed their local Disability services to the purchasing of this tool from MINDA have noticed an 80-90% drop in numbers of referrals from this source”.

Accommodation

• Where needed fund home modifications to support ageing clients (noting new houses are purpose built to meet universal design standards

Supports

• Supports provided are components of the packages described above – either HACC or CACP. The key components of these packages are:
  o Personal Care
  o Nursing
  o Transport (eg. to appointments)
  o Allied health
  o Client care co-ordination
  o Case management

\textsuperscript{15} Operational Performance Committee – Review of the Boarding House Reform Program, April 2010 p.7
Health

- **Develop a Memorandum of Understanding with The Ministry of Health** for provision of services to people with a disability who are ageing, one is already in place for the provision of services to people with an intellectual disability and mental illness. The recent Productivity Commission report explicitly recommends such MOUs be developed between the NDIS and health sectors in each state.

- For those clients with chronic and complex health care needs, ensure there is a comprehensive care plan coordinated by an experienced community nurse with input from the client’s GP. This plan would have input from specialists and other health care professionals (similar to the approach used by the Primary and Secondary Health Care Program funded by ADHC for the licensed boarding house sector).

- **ADHC should be working with The Ministry of Health** to ensure those clients with severe chronic disease are enrolled in The Ministry of Health’s Connecting Care (Severe Chronic Disease Management) Program.

- Victoria’s Department of Human Services has a **Disability Services - Aged Care Assessment Services Protocol**. This protocol is designed to ensure that Disability Services and ACAS collaborate in planning the care of people with a disability under the age of 65 years who are at risk of entering a residential aged care facility. A similar protocol does not seem to exist in NSW and development of similar protocol should be considered.

- **Work with the new Medicare Locals** through the ADHC regions – in particular accessing coordinated mainstream services – community nursing, GP, allied health and other community health services. The Primary Care Partnerships in Victoria provide an indication of how the Medicare Locals might facilitate the delivery of coordinated services for those individuals in their community who have complex or chronic care needs. A common service coordination assessment tool (SCCT) is also a feature of the Victorian service model. The Commonwealth Government has also stipulated that from 2012/13 Medicare Locals will be provided with flexible funding to target gaps in primary health care services for people in aged care. It could be argued that people with disability should be similarly provided for.

- **Work with the Ministry of Health Agency for Clinical Innovation** (ACI) who have established an Intellectual Disability Network. Their first Steering Committee meeting was held on 29/3/2011 and a three year pilot project has been funded, described below. The aims of the Intellectual Disability Network are to:

  - “Lead the way as a model to ensure that people with intellectual disabilities in our community receive fair and equitable access to health services throughout NSW
  - Provide expert advice and clinical leadership to the NSW Department of Health on matters relating to patient care, models of care, education, research, and other related areas
  - Build workforce capacity to facilitate the inclusion of people with intellectual disabilities in mainstream health services
  - Enhance capacity for continuous improvement within specialised and general services.”

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• “The Illawarra Shoalhaven Local Health District has been awarded the tender to establish a pilot Specialised Clinical Service for People with intellectual disability. The Pilot Service will be developing a partnership model for integrated health services for people with intellectual disability in regional and rural New South Wales and is expected to be operational by April 2011.
• People with intellectual disability will be provided with a comprehensive health assessment, consultation with experienced multidisciplinary teams and specialists and referral to support services. The Service will also provide direct treatment for specific health conditions, coordinate access to services and provide advice, education and training to health professionals in mainstream services who see people with intellectual disability.
• At the completion of the three years the Pilot Service and the Clinical Network will be independently evaluated and findings reported to The Ministry of Health.”

Lifestyle

• **Facilitate access to age appropriate lifestyle activities**, particularly once working clients retire from employment. Individual lifespan planning should focus on this as clients age.

Ageing in Place Report

1. Introduction and Background

1.1 Ageing in Place initiative

Under Stronger Together and Stronger Together: the Second Phase (ST2), ADHC has committed to increasing assistance and options for people with a disability to live at home and to increase the range of specialist accommodation services, including options and technologies that promote ageing in place.

As part of the ST2 Priority Initiative B3.6 *Further develop the Spectrum of Accommodation Models: semi-independent living models*, the ADHC Accommodation Policy and Development (APD) Directorate is developing an Ageing in Place (AIP) Strategy. APD has contracted Mercury Advisory to undertake the Ageing in Place Project.

The Ageing in Place Project responds to the Priority Initiative through development and implementation of evidence based actions to better meet the needs of people with a disability who are ageing. For Ageing in Place to be successful it must build on existing service strengths within and external to the existing disability support framework and link to relevant community care, transport, welfare, equipment support, housing and health and aged care infrastructure and services.

1.2 Ageing in Place Project Reporting

The Ageing in Place Project has a suite of research which informed this report:

1. The scoping pathways research noted the increasing demand for services for people with a disability who are both ageing and living longer.

This significant growth in demand (2.4% p.a) is driven by population. It was estimated that only 13.4% of people with Grade A\(^{22}\) support needs are currently accessing accommodation or accommodation support services (In-home/Drop-in accommodation support services, Attendant Care Program, Home and Community Care (HACC) Services).

More than 73% of clients utilising accommodation or accommodation support services are aged greater than 34 years. Variation occurs between Local Planning Areas (LPAs) for both demand and supply of services, with South West Sydney and the Far North Coast identified as areas where supply is low in contrast to forecast demand.

The literature review and scoping pathways research highlighted the lack of screening and assessment as a significant issue for ageing clients with a disability, and that home modifications and special equipment is needed as people age. The need for flexible funding options and individual packages based on person-centred plans were also highlighted. It was concluded that

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\(^{22}\) Grade A is a subset of the population with severe/profound core activity limitation, with constant, frequent or regular support needs. These categories were derived from the 2003 ABS Survey of Disability, SDAC Confidential Unit Record File and developed by PwC in conjunction with ADHC in 2005.
2. Key findings from the demand and service response options research included:

- There is a lack of planning and information available to plan for people with a disability.
- Service providers with large numbers of ageing clients are experiencing financial strain
- Carers are worried about the future for the person with a disability they care for
- The service system is fragmented and program centred rather than person-centred, and people with a disability and their carers are confused about what services are available and have difficulty finding information
- There is no consistent approach to assessing the needs of ageing clients
- Access to the health and aged care systems is problematic for people with a disability
- Easy access to equipment and assistance with home modifications is needed to support people to age in place
- In addition to disability funding, there should be access to aged care packages to support people with a disability as they age
- Service providers are concerned about the COAG reforms and the age cut-off at 64 years as are consumers. Many of those with physical disabilities who are only able to access HACC services rather than the Attendant Care Package will struggle to have sufficient support to age in place in the community
- Some innovative models and approaches are emerging; ADHC has been successfully funding pilots of a number of models
- Stronger Together: The second phase funding will assist in addressing unmet need, particularly Local Support Co-ordination and the Supported Living Fund
- High level service options were developed covering accommodation, services, health services and lifestyle.

3. This report brings together findings from the research and includes:

1. Current NSW Accommodation Framework
2. Future Service Model, Service Modifications and Options
3. Pathways
4. Service Delivery Map - including:
   - The mapping of the different service types across age cohorts (supply and demand)
   - Mapping the existing accommodation client base (supply)
   - Mapping the impact of ageing on service delivery
   - Comparing the two sources of data to identify any capacity challenges at a regional level.

1.3 Layout of this report

This report is the third major deliverable of this project. The report is laid out in the following way:

- Section One  Introduction and Background
- Section Two  Project Aim and Key Principles
- Section Three  Project Methodology
- Section Four  Current NSW Accommodation Framework
- Section Five  Current client population
- Section Six  Futures Service Modifications
- Section Seven  Futures Service Options

Ageing in Place – Research Project Report
• Section Eight  Pathways
• Section Nine  Service Delivery Challenges
• Section Ten  Appendices
2. Project Aim and Principles

2.1 Project aim and purpose of this report

The aim of the project is to enable ADHC to meet its commitments under Stronger Together related to Ageing in Place by providing:

- A comprehensive understanding of ageing target groups
- The impacts of ageing on current accommodation client support needs
- The evidence base to develop a position on providing supports to people with a disability who are ageing
- The necessary information and planning to develop and reform the ADHC service system to accommodate ageing
- An opportunity to continue to build capacity within the ADHC service.

The purpose of this report is to:

- Provide a service response options and service map paper for future service modifications and development
- Provide a clear justification and outline of a new direction for the provision of services for ageing ADHC clients.

2.2 Key principles of ageing in place

**People centred** – The person is at the centre of planning and service delivery is designed in concert with the person according to their wishes, wants and needs. It is based on the values of human rights, independence, choice and social inclusion, and is designed to enable people to direct their own services and supports, in a personalised way rather than attempting to fit within pre-existing service systems. Planning should include families and carers as required.

**Choice** – Clients can choose with whom, how and where they live and to live as independently as possible. More choice in accommodation types (e.g. transitional accommodation to facilitate moving from home or group home to community living), and flexible accommodation funding options (e.g. part funding by person or family) should be encouraged. The range of options to select from should include remain at home, group home, community living (living in the general community, which could include living within an intentional community, as long as the community is inclusive and not limited to people with a disability only) or other aged related solution common to the wider community.

**Equity and fairer and more transparent access** – Having clear published equitable and fair eligibility criteria including ability to identify eligibility early, clear assessment processes, appropriate and transparent prioritisation mechanisms and funding models.

**Flexibility** – Having choices and flexible models of services, accommodation and funding to reflect changes needed as people age.

**Maximising Ageing in Place** - Assist people to remain in their home alone, or with a carer and to assist ageing carers. This includes assisting people with disabilities and their families with planning for the future, including financial decision making through programs such as piloted by ADHC in the Northern Region e.g. Futures Planning.
Options the same as the general population – People with a disability who are ageing should have the same options as the general population who are ageing. This should be true of accommodation options. Health assessments and retirement options for the person with the disability and their carers are also important.

A sustainable support system – Staff skills need to be adapted to support older clients (e.g. aged care training and awareness of dementia). Effective information for planning is needed. Funding to match is essential or the system will not be sustainable, there is a need to service a broader range of people with a range of needs, particularly the older cohort of people with a disability.

Linking services to need – Better planning and assessment will facilitate the linking of services to need. Client wishes as well as needs must be considered.

Creating more options for people living in specialist support services – This includes development of more innovative accommodation options rather than just traditional group home settings. One innovation ADHC has recently implemented is the Individual Accommodation Support Package (IASP), which provides a package of funding which will enable a person with a disability to live independently, or remain in their current home. This package enables the person with the disability and/or their carer to actively participate in the decision making process about the planning, implementation and delivery of service supports including service provider.
3. **Project Methodology**

**Overview of the Methodology**

The methodology for the Ageing in Place Project comprises three stages as outlined below:

*Figure 2 Ageing in Place project methodology*

### Stage One
- **Existing Need & Service Sector Scoping**
- **Project Set-up & Planning**
  - Workshop to agree methodology & plan
  - Literature Review & Best Practice Research
  - Analysis of demand & supply data
  - Develop consultation strategy
  - Consult with key stakeholders
  - Develop data collection tools & instruments
  - Map impact of ageing on service delivery

### Stage Two
- **Demand & Service Response Options Research**
  - Surveys, Focus groups, Key informant interviews, workshops
  - Participants to include disability service providers, clients & families, Regional office staff, HACC & Aged Care Providers
  - Options Analysis and Gap Analysis
  - Workshop Options with SPDU/AMDRG

### Stage Three
- **Reporting**
  - Consultation with key sector stakeholders
  - Produce Final Report
  - Produce Final Action Plan

**Methodology**

This report has three main parts:

1. **Current NSW Accommodation Framework**
2. **Future Service Model, Service Modifications and Options**
3. **Pathways Service Delivery Map** - including:
   - The mapping of the different service types across age cohorts (supply and demand)
   - Mapping the existing accommodation client base (supply)
   - Mapping the impact of ageing on service delivery (Comparing the two sources of data to identify any capacity challenges at a regional level)

ADHC provided data regarding the number of places under service types 1.01-1.08, including the additional places allocated under Stronger Together and Stronger Together 2 from 2008-09 to 2012-13, and the associated expenditure. This data was broken down into ADHC operated and ADHC
funded services at a regional level. Further information on the Methodology can be found in Appendix A.
4. Current NSW accommodation framework

4.1 Overview

In this section of the report the current accommodation framework is outlined providing a basis for consideration on the future service modifications and options.

As highlighted in the following table the current program based service delivery model is complex and complicated for clients, carers (particularly ageing carers) and service providers to understand. There are a small number of programs with individualised funding – the Attendant Care Program and the newer programs – the Independent Living Skills Initiative and the Individual Accommodation Support Package. Some additional information has been added to the framework provide some examples and type of funding model utilised.

Table 4 ADHC Current accommodation framework - additional information added

<table>
<thead>
<tr>
<th>Accommodation Category</th>
<th>Large Residential Centre</th>
<th>Village model</th>
<th>Cluster model</th>
<th>Villas and apartments</th>
<th>Co-located models</th>
<th>Group Home</th>
<th>Flexible Packages</th>
<th>Alternative Family Placement</th>
<th>Drop-in support</th>
<th>In-home support/Attendant Care</th>
<th>Boarding House</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Support</td>
<td>High Support</td>
<td>Low to high support</td>
<td>Low support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service description</td>
<td>Legacy model operating for clients with an intellectual disability, high support needs, requiring 24 hour support</td>
<td>Designed for clients with an intellectual disability, high support needs, requiring up to 24 hour support</td>
<td>Designed for clients with an intellectual disability, high support needs, requiring up to 24 hour support</td>
<td>Designed for clients with an intellectual disability, high support needs, requiring up to 24 hour support</td>
<td>Designed for clients with an intellectual disability, high support needs, requiring up to 24 hour support</td>
<td>Designed for clients with an intellectual disability, high support needs, requiring up to 24 hour support</td>
<td>Packages of support provided by a service for clients with an intellectual disability or other disability with high support needs requiring up to 24/7 support</td>
<td>Support provided in a continuing or new alternative family with associated support managed by a service provider for people with an intellectual disability with low to high support needs regardless of decision-making capability</td>
<td>Designed for clients with an intellectual or other disability with low to moderate support needs, higher levels of decision-making capability, requiring up to 35 hours of direct support</td>
<td>Designed for clients with a disability with low to moderate support needs, higher levels of decision-making capability, requiring up to 35 hours of direct support</td>
<td>Private for profit shared accommodation services licensed under the Youth and Community Services Act 1973 where two or more people with a disability reside</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Accommodation Category</th>
<th>Large Residential Centre</th>
<th>Village model</th>
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<th>Drop-in support</th>
<th>In-home support/Attendant Care</th>
<th>Boarding House</th>
</tr>
</thead>
<tbody>
<tr>
<td>Classification of services</td>
<td>All ages</td>
<td>Not children</td>
<td>Aged care</td>
<td>Others to be determined</td>
<td>Not children</td>
<td>Complex health</td>
<td>Behavioural</td>
<td>All ages</td>
<td>Others to be determined</td>
<td>Behavioural</td>
<td>Criminal justice</td>
</tr>
<tr>
<td>Model of service</td>
<td>Nature</td>
<td>Single or multiple providers for each element</td>
<td>Split model with different providers for each element</td>
<td>Split model with different providers for each element</td>
<td>Split model with different providers for each element</td>
<td>Split model with different providers for each element</td>
<td>Split model with different providers for each element</td>
<td>Split model with different providers for each element</td>
<td>Single or multiple providers</td>
<td>Mostly single private provider. Some split models where required</td>
<td></td>
</tr>
<tr>
<td>Accommodation Support</td>
<td>Up to 24/7 support with Activities of Daily Living (ADL). Instrumental activities of daily living (IADL) and skills maintenance provided by staff employed by LRC</td>
<td>Up to 24/7 support with ADL, IADL and skills maintenance single provider</td>
<td>Up to 24/7 support with ADL, IADL and skills maintenance single provider</td>
<td>Up to 24/7 support with ADL, IADL and skills maintenance single provider</td>
<td>Up to 24/7 support with ADL, IADL and skills maintenance single provider</td>
<td>Up to 24/7 support with ADL, IADL and skills maintenance single provider</td>
<td>Support with ADL, IADL and skills development single provider. Yet to be fully developed.</td>
<td>Care and support delivered by a carer other than family who receives a Carer Allowance from a funded non-government agency</td>
<td>Up to 35 hours direct support with ADL and IADL. Recently added further two levels of support – up to 50 hours; and up to 70 hours – which is time limited.</td>
<td>Minimum direct support. Board and lodgings provided by licensee. ADL, IADL, and skills development may be provided by other funded agencies (e.g. HACC)</td>
<td></td>
</tr>
<tr>
<td>Participation in Community</td>
<td>Some clients in community participation/day activities/employment for up to 5 days</td>
<td>Clients in external community participation/day activities/employment for adults</td>
<td>Clients in external community participation/day activities/employment for adults</td>
<td>Clients in external community participation/day activities/employment for up to five days per week</td>
<td>Clients in external community participation/day activities/employment for adults and school</td>
<td>Clients in external community participation/day activities/employment for adults and school for children for up to five days per</td>
<td>Clients in external community participation/day activities/employment for up to five days per</td>
<td>Clients may be in employment or other day activities</td>
<td>Clients may be in employment or other day activities</td>
<td>Not prescribed by ADHC. Clients may be in employment or other activities. ADHC funds Acting Living Initiative (ALI)</td>
<td></td>
</tr>
<tr>
<td>Accommodation Category</td>
<td>Large Residential Centre</td>
<td>Village model</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>per week</td>
<td>five days per week</td>
<td>school for children for up to five days per week</td>
<td>and school for children for up to five days per week</td>
<td>for children for up to five days per week</td>
<td>week</td>
<td>week</td>
<td>week</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case Management</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td>Provided where appropriate</td>
<td></td>
</tr>
<tr>
<td>Professional Support</td>
<td>Behaviour support and other therapy services from government, non government or private sector as required.</td>
<td>Behaviour support and other therapy services from government, non government or private sector as required.</td>
<td>Behaviour support and other therapy services from government, non government or private sector as required.</td>
<td>Behaviour support and other therapy services from government, non government or private sector as required.</td>
<td>Behaviour support and other therapy services from government, non government or private sector as required.</td>
<td>Behaviour support and other therapy services from government, non government or private sector as required.</td>
<td>Behaviour support and other therapy services from government, non government or private sector as required.</td>
<td>Access to services through public health system</td>
<td>Not prescribed: privately owned. ADHC funds primary &amp; secondary health program</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accommodation support provider</td>
<td>Funded provider/government</td>
<td>Funded provider/government</td>
<td>Funded provider/government</td>
<td>Funded provider/government</td>
<td>Funded provider/government</td>
<td>Funded provider/government</td>
<td>Payments to carer through funded provider</td>
<td>Funded provider/government</td>
<td>Funded provider</td>
<td>Private sector</td>
<td></td>
</tr>
<tr>
<td>Number of places per accommodation service</td>
<td>10-480 beds on same site</td>
<td>80-100 places on same site</td>
<td>20-50 places contiguous (multiple title) on same site (single title)</td>
<td>Six-10 places across five sites contiguous (single or multiple title) or in close geographic proximity</td>
<td>Five-10 places (single title)</td>
<td>Five places (single title)</td>
<td>To be determined</td>
<td>Individual</td>
<td>Up to 10 places across multiple sites in close geographic proximity (plus facilities for support worker)</td>
<td>Unlimited</td>
<td>Not determined by ADHC. Can vary significantly between licensed boarding houses</td>
</tr>
<tr>
<td>Type and nature of asset</td>
<td>Modified hospital model</td>
<td>Groups of Five-10 bedrooms, single storey, contemporary home-like accommodation</td>
<td>Groups of Five-10 bedrooms, single storey, contemporary home-like accommodation</td>
<td>Contemporar y single storey villa and apartment accommodation</td>
<td>Co-located contemporary accommodation units with five – 10 bedrooms under two rooftines in</td>
<td>Contemporar y single storey housing comprising five bedrooms</td>
<td>Not prescribed: dependent on package required by clients</td>
<td>Not prescribed: family home</td>
<td>Contemporar y housing, including villas, apartments and client's home</td>
<td>Not prescribed: family home</td>
<td>Boarding house – privately owned</td>
</tr>
</tbody>
</table>

*ADHC: Aboriginal and Islander Health Council*
<table>
<thead>
<tr>
<th>Accommodation Category</th>
<th>Large Residential Centre</th>
<th>Village model</th>
<th>Cluster model</th>
<th>Villas and apartments</th>
<th>Co-located models</th>
<th>Group Home</th>
<th>Flexible Packages</th>
<th>Alternative Family Placement</th>
<th>Drop-in support</th>
<th>In-home support/Attendant Care</th>
<th>Boarding House</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Large Residential Centre</td>
<td>Cluster model</td>
<td>Villas and apartments</td>
<td>Co-located models</td>
<td>Group Home</td>
<td>Flexible Packages</td>
<td>Alternative Family Placement</td>
<td>Drop-in support</td>
<td>In-home support/Attendant Care</td>
<td>Boarding House</td>
</tr>
<tr>
<td></td>
<td></td>
<td>like accommodation units (single title) on units. More than six bed units limited to specialist models where appropriate</td>
<td>comprising one to three bedrooms</td>
<td>duplex, apartment, house plus granny flat arrangements</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Examples</td>
<td>Hunter Residences, Stockton; Riverside Centre, Orange; Metro Residences, Rydalmere</td>
<td>Casuarina Grove</td>
<td>Summer Hill Group Homes, Norton Road Group Homes</td>
<td>Mainly funded provider model?</td>
<td>Wadalba, other funded provider models</td>
<td>A large number of funded provider and government examples spread throughout NSW</td>
<td>Individual Accommodation Support Package (IASP)</td>
<td>Many examples of drop-in support – the majority are funded provider operated</td>
<td>20 clients with Direct Funding; 105 clients with Cooperative model – 1 service provider; rest are employer model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding Model</td>
<td>Block</td>
<td>Block</td>
<td>Block</td>
<td>Block</td>
<td>Block</td>
<td>Individual</td>
<td>Individual</td>
<td>Block and Individual</td>
<td>Individual</td>
<td>Nil apart from AI and primary &amp; secondary healthcare services</td>
<td></td>
</tr>
</tbody>
</table>

29 | Ageing in Place – Research Project Report
The table below shows the current service delivery model for accommodation only represented by the current Minimum Data Set (MDS) code.
1.01 is Large Residences
1.02 is Small Residences
1.03 is Hostels
1.04 is Group Homes (also some clients receiving Leaving Care, Boarding House Relocation, Criminal Justice services)
1.05 is Attendant Care
1.06 is Drop-in accommodation support (also some clients receiving Leaving Care, Boarding House Relocation, Criminal Justice, Individual Accommodation Support Package and the Independent Living Skills Initiative package)
1.07 is Leaving Care
1.08 is Emergency Response (also some clients receiving Boarding House Relocation services).

People living at home with a carer could participate in the Independent Living Skills Initiative (ILSI) – if implemented post-pilot, receive an Attendant Care Package if eligible, receive HACC services if eligible. They may access funding, if eligible for respite and community access activities such as Community Participation, Life Choices or Active Ageing (all individualised) or standard day programs.

The table highlights the type of funding available.

Table 5  Outline of current Accommodation Support Services from the Minimum Data Set

<table>
<thead>
<tr>
<th>Funding</th>
<th>1.01-1.03</th>
<th>1.04</th>
<th>1.05</th>
<th>1.06</th>
<th>1.07</th>
<th>Nil (at home with carer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Block</td>
<td>Block</td>
<td>Individual</td>
<td>Block and Individual</td>
<td>Block</td>
<td>Block and Individual</td>
<td></td>
</tr>
<tr>
<td>Accommodation</td>
<td>Inclusive</td>
<td>Inclusive</td>
<td>Exclusive</td>
<td>Exclusive</td>
<td>Inclusive</td>
<td>Exclusive</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>b. Leaving Care</td>
<td></td>
<td>b. IASP</td>
<td>b. Leaving Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>c. Criminal Justice</td>
<td></td>
<td>c. DHASI</td>
<td>c. Criminal Justice</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>d. Boarding House Relocation</td>
<td>d. Leaving Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>e. YPIRAC</td>
<td>e. YPIRAC</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>f. Criminal Justice</td>
<td>f. Leaving Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>g. Leving Care</td>
<td>g. Leaving Care</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>Inclusive</td>
<td>Inclusive plus Life Choices &amp; Active Ageing as available</td>
<td>Exclusive</td>
<td>Inclusive</td>
<td>Community Access /Day program</td>
<td></td>
</tr>
<tr>
<td>Health Coordination</td>
<td>Inclusive</td>
<td>Inclusive</td>
<td>Exclusive</td>
<td>Inclusive</td>
<td>Nil</td>
<td></td>
</tr>
</tbody>
</table>

24 ILSI and IASP
5. Current client population in 24/7 accommodation

5.1 Overview

The current client population receiving 24/7 accommodation services resides in group homes or large residences (LRCs).

The mean age at death of people living in all LRCs is 60.8 years. The average age at death of people living in all group homes is 49 years. As reported in the Ombudsman’s Report the number of years at their last location is illustrative – 23-25 years for LRCs and 4-5 years for group homes.

The recent Productivity Commission Report into Disability Care and Support discusses (p.148), that for example in the 1950s someone born with Down Syndrome could expect to live to approximately 15 years referring to Thase, 1982. The report states that in the current decade life expectancy is getting close to 60 years and continues to increase referring to Torr et al, 2010, and Tracy 2010, p.83.

In 2008/09 there were 4,383 clients living in group homes in NSW. In 2009/10 this had increased to 4,458. Almost one fifth (19.1%) are aged over 50 years.

This section is primarily focussed on the group home client population as the large residences predominantly have a medical/nursing model and ageing clients can be supported and cared for. In contrast, the group home service model is staffed by residential support workers, reliant on services outside the group home to support ageing clients.

5.2 Age profile

The following table show the age profile of people living all group homes in 2008/09.

<table>
<thead>
<tr>
<th>Accommodation Types</th>
<th>0-14</th>
<th>15-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65+</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group homes</td>
<td>51</td>
<td>450</td>
<td>862</td>
<td>1,186</td>
<td>980</td>
<td>625</td>
<td>229</td>
<td>4,383</td>
</tr>
<tr>
<td>Residential homes</td>
<td>1</td>
<td>9</td>
<td>102</td>
<td>393</td>
<td>597</td>
<td>456</td>
<td>258</td>
<td>1,816</td>
</tr>
<tr>
<td>Other accommodation support services</td>
<td>39</td>
<td>347</td>
<td>540</td>
<td>585</td>
<td>651</td>
<td>396</td>
<td>123</td>
<td>2,681</td>
</tr>
<tr>
<td>All</td>
<td>91</td>
<td>806</td>
<td>1,504</td>
<td>2,164</td>
<td>2,228</td>
<td>1,477</td>
<td>610</td>
<td>8,880</td>
</tr>
</tbody>
</table>

Source: PwC data analysis

26 Ibid
The following table shows the age profile for people living in both ADHC operated and ADHC funded group homes for 2009/10. ADHC operated group homes have a higher proportion of younger people aged 40 years and under while ADHC funded group homes have a higher proportion of older people aged 51-60 and 61-70.

Table 7  Age profile percentages - people in ADHC operated & ADHC funded group homes 2009/10

<table>
<thead>
<tr>
<th></th>
<th>40 and under</th>
<th>41-50</th>
<th>51-60</th>
<th>61-70</th>
<th>70 and Above</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHC Operated</td>
<td>53%</td>
<td>25%</td>
<td>14%</td>
<td>6%</td>
<td>2%</td>
<td>100%</td>
</tr>
<tr>
<td>ADHC Funded</td>
<td>41%</td>
<td>25%</td>
<td>22%</td>
<td>9%</td>
<td>2%</td>
<td>100%</td>
</tr>
<tr>
<td>Total</td>
<td>45%</td>
<td>25%</td>
<td>19%</td>
<td>8%</td>
<td>2%</td>
<td>100%</td>
</tr>
<tr>
<td>% ADHC funded as proportion of total</td>
<td>61%</td>
<td>67%</td>
<td>76%</td>
<td>75%</td>
<td>76%</td>
<td>67%</td>
</tr>
</tbody>
</table>

Source: ADHC MDS 2009/10

### 5.3 Support Needs

**Key points**

- The table below shows the self care profile of the ADHC operated group home clients. 56% of clients are “unable to do or always need help or supervision”.
- The level of dependency for self care is higher in the ADHC operated group homes (56%) as compared to ADHC funded group homes (35%) as is shown in the following tables.
- For both ADHC funded group homes and ADHC operated group homes, however, this dependency declines once client are aged 51 and over, reflecting possibly the early deaths of these clients with a mean age at death of 45 years, or a move to residential aged care, shown in the decline in the overall numbers of clients aged 51-60 compared to 61-70. In NSW in 2010 there were 304 people aged less than 50 years and 2,059 aged 50-64 years living in residential aged care.
- ADHC operated group home clients had a lower mean age at death of 44 years, compared to ADHC funded or NGO group homes with a mean age at death of 53 years.
- With less younger clients moving to residential aged care and improvements in health outcomes, all group homes may face increasing dependency as clients age.
- There are a larger number of clients aged over 50 years in the ADHC funded group homes (33% - 998 people) compared to the ADHC operated group homes (22% - 322 people).

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30 Ibid 10
31 Ibid 10

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32 Ageing in Place – Research Project Report
Table 8  ADHC Operated Group Home Clients – Self Care Profile 2009/10

<table>
<thead>
<tr>
<th>Life Area</th>
<th>40 and under</th>
<th>41-50</th>
<th>51-60</th>
<th>61-70</th>
<th>70 and Above</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Care</td>
<td>Unable to do or always needs help or supervision</td>
<td>480</td>
<td>206</td>
<td>95</td>
<td>38</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Sometimes needs help or supervision</td>
<td>245</td>
<td>143</td>
<td>89</td>
<td>45</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Does not need help or supervision and may or may not use aids and/or equipment</td>
<td>37</td>
<td>17</td>
<td>17</td>
<td>7</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Missing information/Not Stated</td>
<td>23</td>
<td>11</td>
<td>4</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>785</td>
<td>377</td>
<td>205</td>
<td>94</td>
<td>23</td>
<td>1,484</td>
</tr>
</tbody>
</table>

Source: ADHC MDS Data 2009/10

Table 9  ADHC Funded Group Home Clients – Self Care Profile 2009/10

<table>
<thead>
<tr>
<th>Life Area</th>
<th>40 and under</th>
<th>41-50</th>
<th>51-60</th>
<th>61-70</th>
<th>70 and Above</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Care</td>
<td>Unable to do or always needs help or supervision</td>
<td>521</td>
<td>251</td>
<td>178</td>
<td>71</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Sometimes needs help or supervision</td>
<td>482</td>
<td>362</td>
<td>348</td>
<td>140</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>Does not need help or supervision and may or may not use aids and/or equipment</td>
<td>138</td>
<td>88</td>
<td>99</td>
<td>51</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Missing information/Not Stated</td>
<td>85</td>
<td>49</td>
<td>21</td>
<td>17</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>1,226</td>
<td>750</td>
<td>646</td>
<td>279</td>
<td>73</td>
<td>2,974</td>
</tr>
</tbody>
</table>

Source: ADHC MDS Data 2009/10

The following figure shows the Vermont Score Analysis for ADHC operated group homes that are budgeted for in 2011. There were 33 clients without scores. The subsequent figure shows the Vermont Scores across NSW for the ADHC operated group homes.

Key Points
- Category Four has the highest number of clients, reflecting the high support needs of clients in ADHC operated group homes in all regions
- The highest number of clients are in the Categories Three, Four and Five
- The Western Region has no clients in Categories One and Two
- The Northern Region has almost all their clients in Categories Four and Five
- The non-metro Regions have similar numbers of Category Four and Five clients, apart from the Southern Region which has a larger number of Category Four clients
- For NSW as a whole there are more than double the Category Four clients vs Category Five.
5.4 Likely Ageing Profile

There are several factors that will impact on the likely ageing profile of people living in group homes. These factors include:

- Ageing as experienced by everybody – this can be arthritis, hypertension, health disease etc
- Ageing due to a genetic condition such as Down Syndrome which has a known link to early onset Alzheimer’s Disease
- Ageing due to an early onset of a chronic disease associated with a disability, particularly a profound or severe disability
- Increase in demand for 24/7 accommodation due to (a) ageing carers resulting in loss of informal care and (b) population growth.

PwC analysis showed the estimated growth in the number of people with Grade A support needs by LPA for 2008/09 to 2035/36. This is shown in the figure below. The annualised growth rate is shown for each LPA which ranges from -0.88% per annum to 1.68% per annum.

Figure 5 Projection of people with Grade A support needs – 2008/9 to 2035/36

The table below shows the growth of the number of people with Grade A support needs by LPA to 2020/2021 only, rather than to 2035/36 as shown in the figure above.

The table shows on average across all LPAs an **11%** increase in the number of people with Grade A support needs over the next ten years to 2020/21. Those LPAs with the highest projected population growth have the largest increases eg. Cumberland Prospect and South West Sydney.
Table 10 Growth in the population with Grade A support needs by NSW LPA to 2021 - < 65 year olds

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Central West</td>
<td>2,033</td>
<td>2,030</td>
<td>2,028</td>
<td>2,024</td>
<td>2,023</td>
<td>2,015</td>
<td>2,020</td>
<td>-1%</td>
<td>2,003</td>
<td>1,997</td>
<td>1,998</td>
<td>1,986</td>
<td>1,980</td>
<td>1,972</td>
<td>1,969</td>
<td>1,961</td>
<td>-3%</td>
</tr>
<tr>
<td>Cumberland/Prospect</td>
<td>7,179</td>
<td>7,300</td>
<td>7,421</td>
<td>7,541</td>
<td>7,662</td>
<td>7,832</td>
<td>7,920</td>
<td>8,058</td>
<td>7%</td>
<td>8,196</td>
<td>8,333</td>
<td>8,455</td>
<td>8,593</td>
<td>8,714</td>
<td>8,836</td>
<td>8,958</td>
<td>9,150</td>
</tr>
<tr>
<td>Hunter</td>
<td>7,209</td>
<td>7,272</td>
<td>7,334</td>
<td>7,396</td>
<td>7,458</td>
<td>7,550</td>
<td>7,566</td>
<td>7,611</td>
<td>3%</td>
<td>7,656</td>
<td>7,701</td>
<td>7,749</td>
<td>7,784</td>
<td>7,819</td>
<td>7,850</td>
<td>7,872</td>
<td>7,914</td>
</tr>
<tr>
<td>Illawarra</td>
<td>4,267</td>
<td>4,299</td>
<td>4,332</td>
<td>4,365</td>
<td>4,397</td>
<td>4,438</td>
<td>4,454</td>
<td>4,479</td>
<td>3%</td>
<td>4,504</td>
<td>4,528</td>
<td>4,569</td>
<td>4,574</td>
<td>4,596</td>
<td>4,618</td>
<td>4,640</td>
<td>4,658</td>
</tr>
<tr>
<td>Mid North Coast</td>
<td>3,794</td>
<td>3,820</td>
<td>3,857</td>
<td>3,894</td>
<td>3,931</td>
<td>3,958</td>
<td>3,992</td>
<td>4,015</td>
<td>3%</td>
<td>4,039</td>
<td>4,063</td>
<td>4,073</td>
<td>4,104</td>
<td>4,121</td>
<td>4,138</td>
<td>4,156</td>
<td>4,135</td>
</tr>
<tr>
<td>New England</td>
<td>2,942</td>
<td>2,934</td>
<td>2,926</td>
<td>2,918</td>
<td>2,910</td>
<td>2,898</td>
<td>1,969</td>
<td>1,976</td>
<td>-2%</td>
<td>1,964</td>
<td>1,951</td>
<td>1,946</td>
<td>1,935</td>
<td>1,913</td>
<td>1,900</td>
<td>1,888</td>
<td>1,871</td>
</tr>
<tr>
<td>Northern Sydney</td>
<td>4,063</td>
<td>4,017</td>
<td>4,117</td>
<td>4,145</td>
<td>4,179</td>
<td>4,228</td>
<td>4,228</td>
<td>4,245</td>
<td>2%</td>
<td>4,262</td>
<td>4,276</td>
<td>4,314</td>
<td>4,335</td>
<td>4,355</td>
<td>4,375</td>
<td>4,416</td>
<td>7%</td>
</tr>
<tr>
<td>South-West Sydney</td>
<td>8,893</td>
<td>9,024</td>
<td>9,155</td>
<td>9,286</td>
<td>9,416</td>
<td>9,613</td>
<td>9,689</td>
<td>9,824</td>
<td>6%</td>
<td>9,963</td>
<td>10,102</td>
<td>10,338</td>
<td>10,426</td>
<td>10,611</td>
<td>10,797</td>
<td>11,242</td>
<td>23%</td>
</tr>
<tr>
<td>Southern Highlands</td>
<td>2,054</td>
<td>2,077</td>
<td>2,100</td>
<td>2,123</td>
<td>2,146</td>
<td>2,173</td>
<td>2,187</td>
<td>2,206</td>
<td>4%</td>
<td>2,225</td>
<td>2,244</td>
<td>2,273</td>
<td>2,290</td>
<td>2,267</td>
<td>2,314</td>
<td>2,331</td>
<td>2,346</td>
</tr>
<tr>
<td>Total</td>
<td>64,459</td>
<td>65,081</td>
<td>65,702</td>
<td>66,324</td>
<td>66,946</td>
<td>67,630</td>
<td>68,060</td>
<td>68,553</td>
<td>3%</td>
<td>68,052</td>
<td>69,546</td>
<td>70,443</td>
<td>70,597</td>
<td>71,049</td>
<td>71,582</td>
<td>72,096</td>
<td>72,787</td>
</tr>
</tbody>
</table>

Sources: 2003 ABS SDAC, 2006 Census of Population and Housing and NSW Department of Planning Population Projections (2006-2036) from PwC Analysis

The table below summarises the estimated growth in demand for places overall, due to population growth and also reduced informal care.

Table 11 Estimated growth in demand 2009 - 2036

<table>
<thead>
<tr>
<th>Growth factor</th>
<th>Growth 2009 to 2036</th>
<th>additional places annually</th>
<th>Annual Growth to 2014</th>
<th>Annual Growth to 2019</th>
<th>Annual Growth to 2024</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase due to population growth</td>
<td>2080</td>
<td>74</td>
<td>84</td>
<td>72</td>
<td>71</td>
</tr>
<tr>
<td>Increase due to reduced informal care</td>
<td>23247</td>
<td>830</td>
<td>908</td>
<td>874</td>
<td>841</td>
</tr>
<tr>
<td>Total</td>
<td>25326</td>
<td>905</td>
<td>991</td>
<td>946</td>
<td>912</td>
</tr>
</tbody>
</table>

The AIHW Bulletin - Health of Australians with disability: health status and risk factors published in November 2010 reported that in 2007/08 almost half of people (46%) with a severe or profound disability aged 15-64 years reported poor of fair health, in comparison to 5% for people without a disability.

The AIHW also reported that almost half (48%) of people with a severe or profound disability had mental health problems, in comparison to 6% for those without a disability. The AIHW also noted the presence of physical long term conditions for people with a severe or profound disability with mental health problems compared to people without a disability and mental health problems. For

33 ibid
34 ibid

36 Ageing in Place – Research Project Report
people with severe or profound disability the most commonly reported conditions were mental health problems, back problems, cardiovascular diseases, arthritis and asthma.\textsuperscript{35}

The same AIHW report\textsuperscript{36} also showed for people with a severe of profound disability aged under 65 years:

- They were more likely to acquire a specific long term health condition earlier than people of the same age with the same long term health condition but no disability.
- The proportion who had diabetes or a high sugar level prior to age 25 years was 23% versus 7% for the non-disabled population.
- The proportion who had acquired arthritis before the age of 25 years was 14% compared to 6%; and acquired the condition between the age of 25 and 44 years was 41% versus 26%.
- The proportion who had first experienced osteoporosis before the age of 45 years was 43% versus 31%.
- The proportion who had an injury acquired before the age of 25 years was 69% versus 63%.

In line with the AIHW report above, an audit of health status and health care practices\textsuperscript{37} was carried out by the Centre for Education and Research on Ageing at the University of Sydney in collaboration with ADHC on 215 people with intellectual disability living in supported accommodation in NSW. People had been referred to specialist Rehabilitation Medicine Teams in Southern Sydney over the period 2004 - 2006. The aim of the study was to create health profiles for people with intellectual disabilities seen in the specialist clinics and to understand how well service providers were meeting the standards of the Health Policy. 170 of the people in the study lived in group homes operated either by ADHC or four NGOs.

The results of the study showed:

- Chronic disease prevalence increased with age. Chronic diseases included diabetes, hypertension, respiratory disease and arthritis. Approximately 40% of those aged over 40 had a chronic disease. This rose from less than 10% for those aged between 20 and 39 years.
- An elevated Body Mass Index (BMI) was closely related to development of a chronic disease.
- There was a higher prevalence of psychiatric disorders and depression in the older age group (aged 40 years plus).
- Health status overall was much better for people with a mild intellectual disability compared to those with profound intellectual disability. People in the severe and moderate categories also had a health status that was much lower than those with a mild intellectual disability.
- 95% of people had a health care plan of some type, and all previously had a comprehensive health assessment undertaken by their GP.
- 85% of people had accessed specialist health care practitioners.
- Some had waited significant periods for home modifications and new equipment.
- Overall there was “effective monitoring and optimisation of health status” and “a high degree of compliance with the Ministry of Health Care Policy” for this group of 215 people with complex health care needs.

PwC undertook analysis as part of this project and as the primary disability distribution between group homes and large residences the data was grouped together. The figure below shows that

\textsuperscript{35} ibid
\textsuperscript{36} ibid
\textsuperscript{37} http://www.cera.usyd.edu.au/resources_general_disability.html
people with intellectual disabilities accounted for the majority of clients in group homes and residences (approximately 75%).

**Figure 6 Primary disability profile people in group homes and large residential NSW 2008/09**

![Primary disability profile](image)

**Conclusion**

Using the CERA study as a guide - for the people residing in group homes it can be hypothesised for those aged over 40:

- At least 40% are likely to have a chronic disease such as diabetes, hypertension, respiratory disease or arthritis
- People with a mild intellectual disability are more likely to be well
- People with a profound intellectual disability are more likely to have a chronic disease and have a much lower health status, as will those with a severe or moderate intellectual disability
- Are more likely to have a psychiatric disorder or depression

From other studies:

- People residing in group homes who have Down Syndrome between 30% and 50% are likely to develop Alzheimer’s Disease by the age of 60 years\(^38\)
- According to recent studies the average age of diagnosis of Alzheimer’s Disease for people with Down Syndrome has been increasing over time from 50 years to mid 50s\(^39\)
- Down Syndrome NSW\(^40\) estimates there are 6,000 people living with Down Syndrome in NSW.

From PwC’s analysis:


\(^{39}\) ibid

75% of people residing in group homes and large residences have an intellectual disability – however there is no information available to understand what percentage of these have Down Syndrome.

From the recent NSW Ombudsman’s Report of Reviewable Deaths:\textsuperscript{41}: 

Of the 651 people with disabilities who died in care between 2003 and 2009:

- 80 people or 12% had Down Syndrome or 11 people per annum. 13 out of the 26 whose principal cause of death was Down Syndrome, had dementia.
- 15.5% or 81 people died with a neoplasm or cancer as the principal cause of death.

From the above studies it can be estimated that:

- Approximately 9% of people in group homes (or 401 people) are likely to live with Down Syndrome. Out of these between 30% and 50% (or 2.7% to 4.5%) may develop dementia by their mid to late 50’s. Therefore between 120 and 200 may develop dementia.
- Approximately 40% may develop a chronic disease such as diabetes, hypertension, respiratory disease or arthritis
- Up to 15% may require palliative care dependent on the cancer type and disease progression
- The remainder (approximately 40%) may be relatively well.

Figure 7 Estimated likely health status of group home population

![Likely health status of group home population](image)

A further extrapolation of these assumptions is shown in the following tables.

The following table provides an estimate of the support needs of clients of all ages who live in 24/7 supported accommodation, based on the 2009/10 MDS data. The support need estimates are based on a number of sources, including those identified for the figure above. The estimates for ageing in specialist accommodation and disability aged care are based on the Commonwealth Department of Ageing provision ratios for aged care places for the general population aged over 70 years\textsuperscript{42}. The forecasted increases are based on the PwC estimates of 2.4% per annum.

---


The following table shows the estimated demand for people living in 24/7 accommodation for people aged over 41 years.

### Table 12  Estimated demand for supports for people in 24/7 accommodation – all clients, all ages

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
</tr>
<tr>
<td>No added supports</td>
<td>1488</td>
<td>30%</td>
<td>1,523</td>
<td>1,560</td>
<td>1,597</td>
<td>1,636</td>
<td>1,675</td>
</tr>
<tr>
<td>Enhanced (DSW) supports</td>
<td>496</td>
<td>10%</td>
<td>508</td>
<td>520</td>
<td>532</td>
<td>545</td>
<td>558</td>
</tr>
<tr>
<td>Augmented supports (CACP, EACH etc)</td>
<td>1984</td>
<td>40%</td>
<td>2,031</td>
<td>2,080</td>
<td>2,130</td>
<td>2,181</td>
<td>2,233</td>
</tr>
<tr>
<td>Palliative care</td>
<td>496</td>
<td>10%</td>
<td>508</td>
<td>520</td>
<td>532</td>
<td>545</td>
<td>558</td>
</tr>
<tr>
<td>Ageing in specialist accommodation</td>
<td>218</td>
<td>4.4%</td>
<td>223</td>
<td>229</td>
<td>234</td>
<td>240</td>
<td>246</td>
</tr>
<tr>
<td>Disability aged care (Casuarina Grove type)</td>
<td>218</td>
<td>4.4%</td>
<td>223</td>
<td>229</td>
<td>234</td>
<td>240</td>
<td>246</td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td>50</td>
<td>1%</td>
<td>51</td>
<td>52</td>
<td>53</td>
<td>55</td>
<td>56</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>4,959</td>
<td>100%</td>
<td>5,068</td>
<td>5,189</td>
<td>5,314</td>
<td>5,442</td>
<td>5,572</td>
</tr>
</tbody>
</table>

### Table 13  Estimated demand for supports for people in 24/7 – clients aged 41 years & over

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
</tr>
<tr>
<td>No added supports</td>
<td>817</td>
<td>30%</td>
<td>836</td>
<td>856</td>
<td>877</td>
<td>898</td>
<td>919</td>
</tr>
<tr>
<td>Enhanced (DSW) supports</td>
<td>272</td>
<td>10%</td>
<td>279</td>
<td>285</td>
<td>292</td>
<td>299</td>
<td>306</td>
</tr>
<tr>
<td>Augmented supports (CACP, EACH etc)</td>
<td>1089</td>
<td>40%</td>
<td>1,115</td>
<td>1,142</td>
<td>1,169</td>
<td>1,197</td>
<td>1,226</td>
</tr>
<tr>
<td>Palliative care</td>
<td>272</td>
<td>10%</td>
<td>279</td>
<td>285</td>
<td>292</td>
<td>299</td>
<td>306</td>
</tr>
<tr>
<td>Ageing in specialist accommodation</td>
<td>120</td>
<td>4.4%</td>
<td>123</td>
<td>126</td>
<td>129</td>
<td>132</td>
<td>135</td>
</tr>
<tr>
<td>Disability aged care (Casuarina Grove type)</td>
<td>120</td>
<td>4.4%</td>
<td>123</td>
<td>126</td>
<td>129</td>
<td>132</td>
<td>135</td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td>27</td>
<td>1%</td>
<td>28</td>
<td>29</td>
<td>29</td>
<td>30</td>
<td>31</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2,722</td>
<td>100%</td>
<td>2,782</td>
<td>2,849</td>
<td>2,917</td>
<td>2,987</td>
<td>3,059</td>
</tr>
</tbody>
</table>

The following table shows the estimated demand for people receiving Drop-in services for all clients of all ages.
Table 14  Estimated demand for supports for people receiving Drop-in services – all clients, all ages

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ageing in Place</td>
<td>No. %</td>
<td>No. %</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
<td>No.</td>
</tr>
<tr>
<td>No added supports</td>
<td>1,416 50%</td>
<td>1,449 50%</td>
<td>1,484 50%</td>
<td>1,520 50%</td>
<td>1,556 50%</td>
<td>1,594 50%</td>
<td></td>
</tr>
<tr>
<td>Enhanced (DSW) supports</td>
<td>283 10%</td>
<td>290 10%</td>
<td>297 10%</td>
<td>304 10%</td>
<td>311 10%</td>
<td>319 10%</td>
<td></td>
</tr>
<tr>
<td>Augmented supports (CACP, EACH etc)</td>
<td>566 20%</td>
<td>580 20%</td>
<td>594 20%</td>
<td>608 20%</td>
<td>623 20%</td>
<td>637 20%</td>
<td></td>
</tr>
<tr>
<td>Palliative care</td>
<td>283 10%</td>
<td>290 10%</td>
<td>297 10%</td>
<td>304 10%</td>
<td>311 10%</td>
<td>319 10%</td>
<td></td>
</tr>
<tr>
<td>Ageing in specialist accommodation</td>
<td>125 4.4%</td>
<td>128 4.4%</td>
<td>131 4.4%</td>
<td>134 4.4%</td>
<td>137 4.4%</td>
<td>140 4.4%</td>
<td></td>
</tr>
<tr>
<td>Disability aged care (Casuarina Grove type)</td>
<td>125 4.4%</td>
<td>128 4.4%</td>
<td>131 4.4%</td>
<td>134 4.4%</td>
<td>137 4.4%</td>
<td>140 4.4%</td>
<td></td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td>28 1%</td>
<td>29 1%</td>
<td>30 1%</td>
<td>30 1%</td>
<td>31 1%</td>
<td>32 1%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2,831 100%</td>
<td>2,893 100%</td>
<td>2,963 100%</td>
<td>3,034 100%</td>
<td>3,106 100%</td>
<td>3,181 100%</td>
<td></td>
</tr>
</tbody>
</table>

The following table shows the estimated demand for people receiving Drop-in services for clients aged over 41 years.

Table 15  Estimated demand for supports - people receiving Drop-in - clients aged 41 years & over

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No added supports</td>
<td>740 50%</td>
<td>758 50%</td>
<td>776 50%</td>
<td>795 50%</td>
<td>814 50%</td>
<td>833 50%</td>
<td></td>
</tr>
<tr>
<td>Enhanced (DSW) supports</td>
<td>283 10%</td>
<td>290 10%</td>
<td>297 10%</td>
<td>304 10%</td>
<td>311 10%</td>
<td>319 10%</td>
<td></td>
</tr>
<tr>
<td>Augmented supports (CACP, EACH etc)</td>
<td>566 20%</td>
<td>580 20%</td>
<td>594 20%</td>
<td>608 20%</td>
<td>623 20%</td>
<td>637 20%</td>
<td></td>
</tr>
<tr>
<td>Palliative care</td>
<td>283 10%</td>
<td>290 10%</td>
<td>297 10%</td>
<td>304 10%</td>
<td>311 10%</td>
<td>319 10%</td>
<td></td>
</tr>
<tr>
<td>Ageing in specialist accommodation</td>
<td>125 4.4%</td>
<td>128 4.4%</td>
<td>131 4.4%</td>
<td>134 4.4%</td>
<td>137 4.4%</td>
<td>140 4.4%</td>
<td></td>
</tr>
<tr>
<td>Disability aged care (Casuarina Grove type)</td>
<td>125 4.4%</td>
<td>128 4.4%</td>
<td>131 4.4%</td>
<td>134 4.4%</td>
<td>137 4.4%</td>
<td>140 4.4%</td>
<td></td>
</tr>
<tr>
<td>Specialist palliative care</td>
<td>28 1%</td>
<td>29 1%</td>
<td>30 1%</td>
<td>30 1%</td>
<td>31 1%</td>
<td>32 1%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1,480 100%</td>
<td>2,202 100%</td>
<td>2,254 100%</td>
<td>2,309 100%</td>
<td>2,364 100%</td>
<td>2,421 100%</td>
<td></td>
</tr>
</tbody>
</table>
6. Future Service Modifications

6.1 Overview
In this section we describe the future service modifications. The service model is person-centred and covers:

- Accommodation
- Funding
- Health
- Supports
- Lifestyle

6.2 Simplified Service Model
It is proposed that the future service model be simplified to:

**Table 16  Proposed future service model**

<table>
<thead>
<tr>
<th>Person’s Goal or Aim:</th>
<th>Living at home</th>
<th>Transitioning to community living</th>
<th>Living in the community</th>
<th>Living in residential services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living at home</strong></td>
<td>Live a good life with family.</td>
<td>Learn necessary skills to live a good life in the community.</td>
<td>Live a good life in a place of my own.</td>
<td>Live a good life in a supportive residential environment.</td>
</tr>
<tr>
<td><strong>Supports Aims:</strong></td>
<td>Support individual and family to enable individual to remain at home however long they choose, and then commence the transition process to community living, unless assessed as requiring ongoing residential care.</td>
<td>Identify appropriate accommodation. Work with individual, family and friends to develop support network, and identify informal supports available. Teach necessary skills and set up supports to prepare for living in community.</td>
<td>Maximise the number of individuals living in the community with service supports. Support individual to remain in the community through ability to flex supports in times of need. Continue to work with support network, to identify how individual can realise aspirations and develop informal supports.</td>
<td>Minimise numbers of individuals in residential services. Support individual to pursue dreams, wishes and aspirations. Utilise community aged care packages to support ageing clients.</td>
</tr>
</tbody>
</table>

### 6.3 What service modifications are needed to implement the new service model for people living in non 24/7 accommodation?

The table below shows the service modification options needed to implement the new service model highlighted in the previous table. Each of these service modification options is described in more detail in the following section.

**Table 17  Future service modifications needed to implement the new service model**

<table>
<thead>
<tr>
<th>Somewhere to live - Accommodation</th>
<th>Living at home</th>
<th>Transition to community living</th>
<th>Living in the community</th>
<th>Living in residential services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living at home</strong></td>
<td>• Increase access to home modification funding (low interest loan approach)</td>
<td>• Continue Independent Living Skills Initiative</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Implement Jay Nolan approach to move to community living where appropriate.</td>
</tr>
<tr>
<td><strong>Transition to community living</strong></td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Implement Jay Nolan approach to move to community living where appropriate.</td>
</tr>
<tr>
<td><strong>Living in the community</strong></td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Implement Jay Nolan approach to move to community living where appropriate.</td>
</tr>
<tr>
<td><strong>Living in residential services</strong></td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Implement Jay Nolan approach to move to community living where appropriate.</td>
</tr>
</tbody>
</table>

### 6.3 What service modifications are needed to implement the new service model for people living in non 24/7 accommodation?

The table below shows the service modification options needed to implement the new service model highlighted in the previous table. Each of these service modification options is described in more detail in the following section.

**Table 17  Future service modifications needed to implement the new service model**

<table>
<thead>
<tr>
<th>Somewhere to live - Accommodation</th>
<th>Living at home</th>
<th>Transition to community living</th>
<th>Living in the community</th>
<th>Living in residential services</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living at home</strong></td>
<td>• Increase access to home modification funding (low interest loan approach)</td>
<td>• Continue Independent Living Skills Initiative</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Implement Jay Nolan approach to move to community living where appropriate.</td>
</tr>
<tr>
<td><strong>Transition to community living</strong></td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Implement Jay Nolan approach to move to community living where appropriate.</td>
</tr>
<tr>
<td><strong>Living in the community</strong></td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Implement Jay Nolan approach to move to community living where appropriate.</td>
</tr>
<tr>
<td><strong>Living in residential services</strong></td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Increase housing stock including Mixed equity housing stock e.g. co-residency, group self-build, moveable units</td>
<td>• Implement Jay Nolan approach to move to community living where appropriate.</td>
</tr>
<tr>
<td>Living at home</td>
<td>Transition to community living</td>
<td>Living in the community</td>
<td>Living in residential services</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------</td>
<td>-------------------------</td>
<td>-------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>family assets where available</td>
<td>Encourage universal design for older people</td>
<td></td>
</tr>
</tbody>
</table>

### A good life – Supports
- Implement Futures Planning
- Early baseline information collected for people with Down Syndrome (age 25 years)
- Detailed assessment for people with intellectual disability at age 40 years – identify signs of ageing, dementia
- Local Support Coordination (implementation planned 2012)
- Case management roles will need to change
- Build up Circles of Support
- Joint services for client and carer
- Access to equipment
- Continue Independent Living Skills Initiative
- Local Support Coordination (implementation planned 2012)
- Build up Circles of Support
- Early assessment for people with Down Syndrome
- Detailed assessment for people with intellectual disability at age 40 years – identify signs of ageing, dementia
- Local Support Coordination
- Build up Circles of Support
- Increase use of supportive technology
- Drop-in services may need to increase as clients age
- Access to equipment
- Case management roles will need to change
- Upskilling service provider staff re ageing
- Early assessment for people with Down Syndrome
- Detailed assessment for people with intellectual disability at age 40 years – identify signs of ageing, dementia
- Build up Circles of Support
- Increase use of supportive technology

### Lifestyle
- Community Participation for young people
- Lifestyle Choices
- Active Ageing
- Utilise natural supports
- Access mainstream community services
- Utilise natural supports
- Access mainstream community services
- Community Participation for young people
- Lifestyle Choices
- Active Ageing
- Utilise natural supports
- Access mainstream community services
- Lifestyle Choices
- Active Ageing
- Utilise natural supports
- Access mainstream community services

### Health
- Access to mainstream and specialist clinics
- Health care coordination
- Educate health professionals about disability
- Reduce barriers between disability and aged care
- Access to mainstream and specialist clinics
- Health care coordination
- Educate health professionals about disability
- Reduce barriers between disability and aged care
- Access to mainstream and specialist clinics
- Health care coordination
- Educate health professionals about disability
- Reduce barriers between disability and aged care
6.4 Future Service Modifications for ageing people living in 24/7 accommodation

A first step is to identify the ageing clients living in group homes. This should be done through assessment with the Broad Screen Checklist of Observed Changes (BSCOC) tool developed by Minda in South Australia. ADHC has already used this tool with residents of LRCs e.g. former residents of Peat Island. The tool is currently being used to assess clients for Specialist Supported Living Allocation and Eligibility.

The BSCOC provides an assessment score across the following domains:

- Health
- Physical Competencies
- Sensory Integration
- Perceptual/Cognitive
- Social/Emotional
- Activities of Daily Living.

The assessment could be used to stratify the clients into 5 broad groups:

1. Those that are well and show no signs of ageing
2. Those that are showing minor ageing symptoms (eg. decreased mobility, slower), need help with ADLs and IADLs
3. Those with a chronic illness (eg. arthritis, osteoporosis, hypertension, thyroid condition, heart disease etc)
4. Those that have significant ageing symptoms as evidenced by their BSCOC scores
5. Those that are receiving palliative care (numbers are likely to be small at any one time) as not all people with cancer require palliative care.

For those in categories 2, 3 and 4 the following options should be considered. It is assumed that those in category 5 are already receiving palliative care support. People in category 3 will also require additional healthcare supports in addition to those provided to HACC or CACP.

People in category 3 with a chronic illness should be eligible for The Ministry of Health’s Chronic Disease Management Program. A new initiative is The Connecting Care (Severe Chronic Disease Management) Program. Its mission is to deliver more effective health management for people aged 16 years and over with chronic diseases covered by the Program at very high risk or high risk of unplanned hospital or Emergency Department presentation. The aim is to enrol 43,000 people over the next four years.43 Refer to the Health in the Service Modification Options section below.

There are two groups of clients in group homes.

1. Group One has no signs of ageing or dementia
2. Group Two is shown to have signs of ageing on assessment. For this second group there are three major overarching service options for providing additional support to ageing clients in group homes.

The options for Group Two are shown below.

### 6.4.1 Options Analysis for Group Two

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
<th>Estimated No. Users in 10 years (people aged between 40 and 70 who need additional assistance due to ageing)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Option One Disability Supports</td>
<td>Provide additional disability support funding when clients are assessed as needing additional supports due to ageing. This is likely to be a more costly option as additional RSW hours would be needed.</td>
<td>2,492</td>
</tr>
<tr>
<td>Option Two HACC Supports</td>
<td>Provide additional support through HACC services for clients. For clients aged under 65 years this is attractive as ADHC will be solely responsible for the funding under the National Disability Agreement. This is a less costly option than Option One as HACC service costs are lower. Other jurisdictions eg. Western Australia state that residents of group homes are able to access HACC supports as long there is no duplication.</td>
<td>2,492</td>
</tr>
<tr>
<td>Option Three CACP Supports</td>
<td>Provide additional support through Community Aged Care Packages (CACP) (as outlined in the National Disability Agreement). This would require an ACAT assessment.</td>
<td>2,492</td>
</tr>
</tbody>
</table>

Community Aged Care Packages (CACPs) are individually planned and coordinated packages of care. They are tailored to help frail older Australians remain living in their own homes. The Australian Government funds them to provide for the complex care needs of older people. The packages include:
- meal preparation
- laundry
- assistance with continence management
- transport
- personal care
- social support
- home help
- gardening; and
- temporary in-home respite care.

**NSW clients with a disability aged less than 70 are accessing CACP packages less than other States**

It is likely that NSW residents aged less than 70 years access CACP packages at a far lower rate than Victoria and Queensland. This difference does not appear to be explained by Indigenous status, particularly for Victoria. For CACP the percentage of Indigenous clients were NSW 2.8%, Victoria

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44 Refer to Section 7.5 Health for detailed analysis
1.8% and Queensland 3.8%. The differences between NSW and Queensland are illustrated in the following table. This suggests that in NSW more people with a disability aged less than 70 years should be accessing Community Aged Care Packages.

<table>
<thead>
<tr>
<th>Age group</th>
<th>NSW Clients</th>
<th>VIC Clients</th>
<th>QLD Clients</th>
<th>QLD Clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-59</td>
<td>1.5%</td>
<td>201</td>
<td>2.3%</td>
<td>240</td>
</tr>
<tr>
<td>60-64</td>
<td>1.8%</td>
<td>241</td>
<td>2.4%</td>
<td>250</td>
</tr>
<tr>
<td>65-69</td>
<td>4.2%</td>
<td>562</td>
<td>6.8%</td>
<td>709</td>
</tr>
<tr>
<td>Total all ages</td>
<td>1,004</td>
<td>1,200</td>
<td>695</td>
<td></td>
</tr>
</tbody>
</table>

Source: Aged care packages in the community 2009-10: A statistical overview (AIHW, 2011)

Options Two and Three are the most likely options to be considered and are recommended. These are discussed in detail below.

**Options Two and Three**

Both Options Two and Three would require assessments.

**Assessment with BSCOC**

- Noting the ADHC group home population has the highest proportion of Profound and Severe clients [source AIHW, etc] the population aged over 50 years needs to be assessed with the Minda tool BSCOC to identify clients who have ageing issues.


Assessment by ACAT (Option Three only)

- People who are found to have significant ageing issues should be referred and assessed by an ACAT team.

Both Options Two and Three have a package component.

CACP packages (Option Three only)

- Clients assessed by the ACAT as eligible, should have a care plan developed and receive CACP, EACH or EACHD packages to top up their disability funding. The National evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot\(^{48}\) found on average that a mean 2.8 hours of additional personal assistance per week was required by clients (who had a disability who were ageing) participating in the pilot. The NSW Ombudsman’s recent report on reviewable deaths\(^{49}\) refers in a positive way to a case study on page 83 where a service was responsive to the needs of a client living in a group home who also received additional support through the aged care disability pilot.

- The current version of the National Disability Agreement refers to the “Community Aged Care Package election commitment – this is a commitment to provide top up disability supports for people living in group homes who are clearly demonstrating increased needs due to ageing”.\(^{50}\) It is not clear how this commitment has been translated into policy.

- Current ACAT Operational Guidelines – “CACP providers are not funded or resourced to provide care to younger people with a disability. As outlined above, State and Territory Governments are responsible for providing disability services under the Commonwealth/State Disability Agreement. In the case of community care, support is by provision in the Home and Community Care (HACC) Program to include younger people with a disability as part of its target group. If HACC and disability services in an area have waiting lists, it is more appropriate for younger people with a disability to be on those waiting lists than on a CACP waiting list.

ACATs should assess only a younger person with a disability for CACP services if they have already been assessed through disability services and there are clearly no other care alternatives in the area. In such circumstances younger people with a disability may be considered for a Package if they need the intensity, type and model of care a CACP can provide. As with older people, younger people with a disability must meet the criteria specified in the Approval of Care recipients Principles and assessed as eligible by an ACAT. Given the spread of disability and HACC services, this will not be a common occurrence.”

HACC packages (Option Two only)

- **Access to HACC supports once assessed** as having additional support needs (ADLs and IADLs). The COAG reforms mean that the NSW Government will be responsible for users of HACC services aged less than 65 years or 50 years for Indigenous people. In other states (eg. Western Australia\(^{51}\), Victoria and Queensland) it appears from their guidelines that provision of HACC services can occur in group homes where the resident’s contract does not include these services and there is no overlap with existing service provision. It is also stated that residents of group homes and retirement village may also purchase these services.

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\(^{48}\) ibid


\(^{51}\) ibid
The COAG reforms provide an opportunity for ADHC. Provision of HACC type services to group home residents who are ageing and require HACC type support, provides a person-centered and potentially cost effective solution for ADHC to continue to support these clients in their homes.

It should be noted that in 2008/09 13% of clients in supported accommodation (1.01, 1.02, 1.03, 1.04 and 1.08) were receiving HACC services, the majority were receiving less than 1 hour of care per day. 39% were receiving Community Support services (therapy support for individuals, case management, behaviour/specialist intervention, early childhood intervention or counselling).

6.4.2 Service modification options

Funding
How this option is implemented is dependent on which of the overarching options described above is chosen.

Consider pooling of funds to support clients – Accommodation, Flexible Respite, HACC funding once client is assessed as having additional need for support (this could be as young as 40, although more commonly for clients aged in their 50s). Pooling of Commonwealth funded Community Aged Care Packages (CACP) would be more problematic [n.b access to these latter 3 packages requires an ACAT assessment as discussed above]. The recent Productivity Commission report on Disability Care and Support recommends that “upon reaching pension age” people with a disability choose whether they wish to continue to be supported by the NDIS or move to the aged care system. They do not appear to recommend funds pooling across disability and aged care programs (see Chapter 3).

The Ministry of Health notes in their Protocols and Procedures Manual for ACATs (2007) that “A number of ACATs that have directed their local Disability services to the purchasing of this tool from MINDA have noticed an 80-90% drop in numbers of referrals from this source”. The tool referred to is the BSCOC tool.

Accommodation

Where needed fund home modifications to support ageing clients (noting new houses are purpose built to meet universal design standards.

Supports

Supports provided are components of the packages described above – either HACC or CACP. The key components of these packages are:

- Personal Care
- Nursing
- Transport (e.g. to appointments)
- Allied health
- Client care co-ordination
- Case management
- Social support
- Domestic Assistance
- Meals and meal preparation

52 http://www.adhc.nsw.gov.au/__data/assets/file/0009/237177/ASUSTAIN.PDF
Home maintenance.

**Health**

- **Develop a Memorandum of Understanding with The Ministry of Health** for provision of services to people with a disability who are ageing, one is already in place for the provision of services to people with an intellectual disability and mental illness.\(^{55}\) The recent Productivity Commission report explicitly recommends such MOUs be developed between the NDIS and health sectors in each state\(^ {56} \).
- For those clients with chronic and complex health care needs ensure there is a comprehensive care plan coordinated by an experienced community nurse with input from the client’s GP. This plan would have input from specialists and other health care professionals [similar to the approach used by the Primary and Secondary Health Care Program funded by ADHC for the licensed boarding house sector].
- ADHC should be **working with The Ministry of Health** to ensure those clients with severe chronic disease are enrolled in The Ministry of Health’s Connecting Care (Severe Chronic Disease Management) Program. Up to 40% of ADHC clients may develop a chronic disease (eg. diabetes, hypertension, respiratory disease or arthritis). In 2008/9 there were 4,383 people living in group homes, if 40% have a chronic disease then 1,753 people may require enrolment in a chronic disease management program. This number will increase by 11% by 2021/2022 to 1,946 people.
- Victoria’s Department of Human Services has a **Disability Services - Aged Care Assessment Services Protocol**. This protocol is designed to ensure that Disability Services and ACAS collaborate in planning the care of people with a disability under the age of 65 years who are at risk of entering a residential aged care facility.\(^ {57} \) A similar protocol does not seem to exist in NSW and development of similar protocol should be considered.
- **Work with the new Medicare Locals** through the ADHC regions – in particular accessing coordinated mainstream services – community nursing, GP, allied health and other community health services. The Primary Care Partnerships in Victoria provide an indication of how the Medicare Locals might facilitate the delivery of coordinated services for those individuals in their community who have complex or chronic care needs. A common service coordination assessment tool (SCTT) is also a feature of the Victorian service model. The Commonwealth Government has also stipulated that from 2012/13 Medicare Locals will be provided with flexible funding to target gaps in primary health care services for people in aged care. It could be argued that people with disability should be similarly provided for.
- **Work with the Ministry of Health Agency for Clinical Innovation** (ACI) who have established an Intellectual Disability Network. Their first Steering Committee meeting was held on 29/3/2011 and a three year pilot project has been funded, described below. The aims of the Intellectual Disability Network are to:
  - “Lead the way as a model to ensure that people with intellectual disabilities in our community receive fair and equitable access to health services throughout NSW
  - Provide expert advice and clinical leadership to the NSW Department of Health on matters relating to patient care, models of care, education, research, and other related areas
  - Build workforce capacity to facilitate the inclusion of people with intellectual disabilities in mainstream health services

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o Enhance capacity for continuous improvement within specialised and general services."

- "The Illawarra Shoalhaven Local Health District has been awarded the tender to establish a pilot Specialised Clinical Service for People with intellectual disability. The pilot service will be developing a partnership model for integrated health services for people with intellectual disability in regional and rural New South Wales and is expected to be operational by April 2011.
- People with intellectual disability will be provided with a comprehensive health assessment, consultation with experienced multidisciplinary teams and specialists and referral to support services. The Service will also provide direct treatment for specific health conditions, coordinate access to services and provide advice, education and training to health professionals in mainstream services who see people with intellectual disability.
- At the completion of the three years the Pilot Service and the Clinical Network will be independently evaluated and findings reported to The Ministry of Health." 58

Lifestyle

- Facilitate access to age appropriate lifestyle activities, particularly once working clients retire from employment. Individual lifespan planning should focus on this as clients age.

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7 Future service options

The following service modification options provide the vehicle for a shift in the service model to facilitate ageing in place. This section outlines what the options would look like in practice, and some underlying evidence to support these options. Note that these options will be supported by steps for implementation in the Draft Action Plan.

The options being addressed are:

Funding
- Implement individualised funding
- Implement a funding approach that is flexible and portable
- Unlink accommodation from service delivery
- Consider pooling of different funding streams
- Consider different individualised funding models
- Consider phased implementation.

Accommodation
- Increase Housing Stock
- Encourage mixed equity housing stock
- Utilise existing family assets where available
- Implement incentives to modify housing to meet universal housing design standards
- Implement incentives to live in the community with service support
- Increase access to home modification funding

A good life:

Supports
I. Implement futures planning
II. Joint services for client and carer
III. Local support coordination
IV. Case manager role will need to change
V. Supports provided seven days a week as needed
VI. Increase use of supportive technology to support community living
VII. Drop-in supports increase as person ages
VIII. Up-skilling existing service providers
IX. Access to equipment (e.g. hoists, wheelchairs)

Lifestyle
I. Utilise natural supports and build up circles of support
II. Access mainstream community services for older people

Health
I. Access to community aged care services as people age
II. Access to mainstream services and specialist clinics
III. Health care co-ordination
IV. Improve understanding of disability sector by health care professionals
V. Reduce barriers between disability and aged care sectors.
7.1 Options – Funding

Summary:

The key options identified for Funding are:
- Implement individualised funding
- Implement a funding approach that is flexible and portable
- Unlink accommodation from service delivery
- Consider pooling of different funding streams
- Consider different individualised funding models
- Consider phased implementation.

These options will be complemented with a table outlining Key Considerations for Implementation under the following areas:
- Policy
- People
- Process
- Infrastructure.

I. Implement Individualised Funding

Person centred planning is significant to people with a disability who are ageing in place, as the feedback provided through the consultation phase indicated that:
- Clients wanted different supports and services as they grew older
- Whilst the need for personal care increased, clients wanted to retire from employment, have more time for rest and leisure
- For those in group homes the option to remain in their own home rather than having to participate in the planned day program activities if they chose.

It has also been identified in the literature review for this project that:
- There is a lack of options for rural families regarding accommodation so there is a risk that they place the person with the disability in accommodation that is a long distance away, which can result in the loss of social and cultural contacts for the person with the disability.\(^{59}\)
- There is evidence that individuals with a disability value the extent to which they have autonomy about lifestyle choices.\(^{60}\)

Individualised funding provides that choice through:
- Providing individuals with a package of funding assessed to be sufficient to support the individual within the community.
- Enabling the individual to increase control over their lives
- Enhancing their participation in the community through active participation in care planning including the type, quantity and delivery of service supports.

\(^{59}\) Ageing in Place: Impacts of Ageing on Accommodation Services Literature Review
\(^{61}\) Williams, R “Individualised Funding – A summary review of it’s nature and impact, and key elements for success, Julia Farr Association, Adelaide Australia 2007
II. **Implement a funding approach that is flexible and portable**

Individualised funding which is flexible and portable would enable individuals to:

- Change location if they chose with the assurance that they will continue to have the means to access service supports.
- Select different service supports if the individual’s needs changed, or change service provider if they were dissatisfied with the supports provided.
- Have an individualised funding package, with service providers accountable to the package recipient for how the package was utilised resulting in more person-centred service delivery.
- Have a package based on initial assessed needs, reassessed at regular intervals and adjusted to meet changed needs.
- Have alternatively, a higher level of funding for people aged greater than 50 who needed additional supports, similar to the Level 1 – Level 3 funding categories currently used by the Attendant Care and Physical Disability Unit.

III. **Unlink accommodation from service delivery**

- Individualised funding also requires the unlinking of support services from accommodation, to enable portability.
- It was identified by David and Faye Wetherow who first pioneered the concept of Micro-boards that it was necessary to separate the auspicing of services from the auspicing of accommodation to enable individuals to change housing if necessary without losing service supports.
- More importantly was the ability to change service providers without potentially losing their home, and any underlying social community supports attached.

IV. **Consider pooling different funding streams**

Key features include:

- Simplification of client support programs along the lines that the Victorian Department of Human Services has implemented would assist clients and families in understanding the services available. Funds could also be targeted at the services which address the clients identified needs.
- Breaking down the barriers between the current different service types i.e. Accommodation, Community Access, and Respite to enable pooling of funds would enable a more individualised comprehensive person-centred approach.
- Enableing HACC funding to be pooled as part of the individual package would also deliver a more person-centred approach.
- Feedback from consultations indicated a lack of coordination where a number of service providers delivered different components of care without a lead agency coordinating and facilitating service delivery. Risky situations could develop and remain unresolved, e.g. a hole in the carpet next to person’s bed (which could potentially trip the person) remaining unrepaired after some months. No-one saw it as their role to address the problem.

V. **Consider different individualised funding models**

- ADHC’s Attendant Care Program (ACP) operates under three different funding models – the employer model, the cooperative model; and more recently ACPDU piloted and then

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61 [http://www.communityworks.info/articles/microboard.htm](http://www.communityworks.info/articles/microboard.htm)

62 [http://www.communityworks.info/articles/microboard.htm](http://www.communityworks.info/articles/microboard.htm)
implemented the direct funding model. This was the first ADHC program to facilitate direct funding, and the results of the evaluation showed positive outcomes for those participating.

- The employer model has ACP funds paid to a pre-approved ACP service provider who employs the carers and is accountable to ADHC for expenditure and service quality, and the majority of ACP clients have services provided under the employer model.

- The cooperative model has funds paid to a pre-approved service provider who manages the funds, provides administrative support and is accountable to ADHC for expenditure and service quality. Clients are the employers of attendant carers and are responsible for managing them. As of June 2010 only 1 service provider was pre-approved to provide services under the cooperative model and 105 clients currently use this model.

- The direct funding model has funds paid directly to the client who is responsible for purchasing approved services and managing their care. The client is accountable to ADHC for expenditure and service quality. Only 21 clients use the direct model.

VI. Consider phased Implementation

In order to phase in implementation:
- Individualised funding for other programs outside of the ACP could be made available only under the employer model initially
- Moving to individual funding under the co-operative and direct models to be considered after individualised funding is implemented.

Key considerations for implementing funding options are outlined in the table below.

<table>
<thead>
<tr>
<th>Table 20</th>
<th>Key Considerations for Implementation - Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key considerations for implementation</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Policy</strong></td>
<td>Many service types currently are block funded, and there will be a need to develop new policies and guidelines for those services.</td>
</tr>
<tr>
<td></td>
<td>Review existing policy to determine barriers to pooling of funding between different service types.</td>
</tr>
<tr>
<td></td>
<td>Review policy to determine if HACC funding could be pooled for those under 65 in new environment.</td>
</tr>
<tr>
<td></td>
<td>Review eligibility criteria as part of policy and guidelines above.</td>
</tr>
<tr>
<td></td>
<td>Determine relationship with other ADHC services provided (eg. Respite, Community access).</td>
</tr>
<tr>
<td></td>
<td>Develop guidelines on expenditure regarding purchasing supports – what can and cannot be purchased.</td>
</tr>
<tr>
<td></td>
<td>Identify key outcomes.</td>
</tr>
<tr>
<td></td>
<td>Determine quality monitoring framework.</td>
</tr>
<tr>
<td><strong>People</strong></td>
<td>Promote the concept of Circles of Support to people with a disability and their families.</td>
</tr>
<tr>
<td></td>
<td>Promote the Lifestyle Planning Policy to key stakeholders</td>
</tr>
<tr>
<td></td>
<td>Existing ADHC and NGO service providers may be opposed to changes in policy and process. Significant marketing and education will be required.</td>
</tr>
</tbody>
</table>

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### Key considerations for implementation

<table>
<thead>
<tr>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Promote Circles of Support to support individualised planning process</td>
</tr>
<tr>
<td>- Many current contracts are block funded and will require review or amendment in new environment.</td>
</tr>
<tr>
<td>- Process to determine how individual budgets should be allocated and administered, including eligibility, and assessment.</td>
</tr>
<tr>
<td>- Who will reassess and when, what tools would be used.</td>
</tr>
<tr>
<td>- How will individualised funding fit within the personal planning process.</td>
</tr>
<tr>
<td>- Fiscal administration – what models would be used. Could fiscal administration be out-sourced?</td>
</tr>
<tr>
<td>- Determine outcome measurements.</td>
</tr>
<tr>
<td>- Develop process to enable individuals to change service providers, if service provider provides fiscal administration.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Infrastructure</th>
</tr>
</thead>
<tbody>
<tr>
<td>- ADHC will need to investigate how current IT and Information Systems could accommodate individualised funding.</td>
</tr>
<tr>
<td>- NGO’s may need some form of financial assistance to modify existing IT systems to accommodate accounting for individualised funding, for those providers who have not been funded under individualised funding previously.</td>
</tr>
</tbody>
</table>

These considerations will be developed in more detail in the Action Plan.

### 7.2 Options – Accommodation

For accommodation options the key modifications identified are:

I. Increase Housing Stock

II. Encourage mixed equity housing stock

III. Utilise existing family assets where available

IV. Implement incentives to modify housing to meet universal housing design standards

V. Implement incentives to live in the community with service support

VI. Increase access to home modification funding

#### I. Increase housing stock

- The ACP and the Drop In programs are exclusive of accommodation.
- One of the barriers identified for people ageing was the lack of available accommodation designed to enable ageing in place.

- Additional housing stock will be required to underpin increasing the number of places delivered under the 1.06 Drop-in-in-home service type from 2008-09 to 2012-13, including the ILSI program. In the last year Housing NSW has transferred a significant number of assets to
the Community Housing Sector. The Community Housing Sector has capacity to leverage these assets to grow the supply of affordable housing. Strategies ADHC should explore include:

- Work with NSW Housing to ensure that when future asset transfers occur, there should be some commitment to providing places specifically for people with a disability.

- Working with community housing providers to increase housing stock for people with a disability.

- Encouragement development of sites that provide clustered accommodation, enabling implementation of the Keyring model (outlined as part of the appendices), or development of other intentional communities as outlined in the HOME – Home Occupiers Mutual Enterprise model (also included in appendices).

- Supporting the development of retirement village style for older people who wish to live in this accommodation option\(^6^4\).

II. **Encourage Mixed Equity Housing Stock**

Other incentives to increase housing stock for people with a disability to enable community living should also be researched and developed. A number of different models are discussed below.

**Model One – Mixed Equity Program**

- The Victorian Disability Housing Trust which is now part of Housing Choices Australia is a good example of one strategy to encourage mixed equity housing stock. Housing Choices Australia (HCA) uses a mixed equity program\(^6^5\), which is available to those people with a disability who require support to living in the community and are willing to make a financial commitment towards their long term home.

- The person with the disability must demonstrate they have the ability to contribute towards the initial project costs, have stable financial management and a commitment to this model in providing their long term home.

- HCA retains title over the property, with the applicant having a signed property partnership agreement which secures their financial interest in the property. The nominated tenant has secure tenure through a residential lease with HCA.

**Model Two – Family Equity Investment (1)**

- Another model developed initially by Supported Housing Ltd which now is a subsidiary of HCA used family equity investment.

- The security was a loan agreement plus a mortgage, with the typical loan being $150k, and the initial equity proportion being 50%.

- There was a market return on investment, and SHL had a 3 month exit clause if required.

**Model Three – Family Equity Investment (2)**

- A further model developed by an NGO partner of SHL involved the NGO partnering with families of people with disability.

- The families funded construction on NGO land. This built upon the development of shared infrastructure for development and ongoing support.

- The family equity funded construction costs only with the project managed for free by SHL.

- The investment was based on aged care bonds, and depreciated each year by 2%.

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\(^6^4\) A number of people with disability consulted expressed an interest in this model of accommodation.

• It is unclear if this development was to assist in the development of an intentional community, or was specifically targeted at people with disability.

**Model Four – Moveable Units**
The Department of Human Services, Housing in Victoria has a scheme called “Moveable Units”. Key features include:
• Self-contained units that can be set up in the back yard of a house.
• Designed to assist people with support needs keep living independently whilst maintaining close contact with family or friends.
• Suitable for 1-2 people, and can have 2 bedrooms for those who need an additional bedroom.
• People are eligible to rent these units if they are a permanent resident, are aged 55 years or over, in receipt of an Australian Disability Support pension and meet further financial eligibility criteria.

ADHC could work with Housing NSW to explore if a similar model could be implemented in NSW.

**III. Utilise existing family assets where available**

Some families of people with a disability:
• Do have access to funding.
• Would be prepared to assign family assets, including residential property to people with a disability
• Need the assurance that the person with the disability would be provided with the ongoing service supports to maintain them in the residence long term.

Access to an individual package would enable the person with a disability to remain in the assigned property with appropriate supports. This may act as an incentive for those families who may have the assets available, but have concerns regarding access to supports on a long term basis.

**Model One – Co-residency schemes**
Examples include:
• Co-residency schemes, as administered by Achieve Australia and Perth Home Care Services are an option for those ageing in place.
• The Perth Home Care Service – Homeshare scheme identifies people who need companionship and practical supports and matches them with people, screened and found to be reputable. Co-residents need to be willing to provide such assistance and contribute towards household expenses, in return for free accommodation.
• Uniting Care in Victoria also has a similar model.

**Model Two – Group Self Build**
The Department of Human Services, Housing in Victoria has developed an innovative model for the general community called Group Self Build.

Features of the model include:
• Provide participants with a bridging loan to purchase land and build a home.

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67 http://www.studentservices.uwa.edu.au/__data/page/15868/Homeshare_WA_brochure_text_only__2_.pdf
Instead of providing a cash deposit, participants contribute 20 hours per week over a 12 month period to build each other’s houses.

A building adviser is available to coordinate the building process and provide guidance.

Participants must be a permanent resident of Australia

Meet income and asset eligibility limits

Be able to commit 20 hours per week for 12 months to the project

Do not currently own a home

Can provide evidence of their financial capacity to repay the bridging loan on the completion of the project – where the equity generated through the construction of the home is used to help participants access long term housing finance in order to repay the bridging loan.

This model could be adapted to support individuals with a disability obtain their own home. The following would be needed by family members:

- The financial capacity to repay the bridging loan over time.
- Ability to substitute for the individual to provide the 20 hours per week over the 12 month period to build, unless the individual was assessed as competent to do the building under supervision, and appropriate supervision provided.

The house designs provided would need to include options suitable for people with physical disability and ideally be to universal housing design standards. Discussions would need to be held with Housing NSW to explore if this model could be adopted in NSW.

**IV. Incentives for service providers and community housing to modify existing housing stock to meet Universal Housing Design standards**

- Universal design is defined as the being the design of products and environments to be used by all people to the greatest possible extent without the need for adaptation or specialised design.  

- Universal housing design refers to housing that is designed to meet the needs of people of all ages and abilities through application of the principles of universal design, which are internationally recognised.

- Housing which conforms to universal housing design will enable people to age in place, therefore incentivising housing providers to modify existing stock would have a positive impact upon people ageing with a disability, enabling them to remain at home longer, as it is recognised that older people with a disability prefer to age in place.

Strategies include:

- Work with other government agencies to develop incentives for service providers who provide residential services, community housing providers and other housing providers to modify existing stock to meet universal design standards.

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V. Incentives to live in the community with service support

- To meet the capacity challenge clients should be given the incentive to live in the community with supports.
- There are some people with disabilities who may be unable to remain in their family home (inappropriate design) who could live in the community with appropriate supports.
- Evidence from the Literature Review supports this where providing ‘extra care’ housing in the U.K. was seen as an alternative to residential aged care where ageing in place was not seen as practical (Wright et al. 2009).

Incentives to live in the community with supports should:

- Be targeted at people living in group homes or large residential centres who could live in the community with supports. During the consultation phase of this project examples were provided of this occurring successfully.

Positive evidence of living in the community includes:

- In a paper evaluating the benefits of individualised funding, Stainton and Boyce identified key benefits in terms of perceptions of independence and client control.
- Findings of a study conducted with people living with a disability in Tampa Bay Florida found that people valued highly the extent to which they retained control over their lifestyle. This includes what was happening to them and their environment, and their overall feelings of satisfaction about their lifestyle. The life they lead was strongly influenced by their perceptions of personal autonomy.
- Providing individuals with the ability to have greater control over their lifestyle; to live in the environment of their choice; with the people they chose to live with; should provide sufficient incentive for a number of people to consider community living.
- Identification of those in residential care i.e. residential centres, group homes who have expressed the desire to live in the general community with appropriate service supports i.e. early adopters can also influence others to consider such steps (e.g. McCall Gardens experience).

Jay Nolan Community Services Case Study

Key features of the Jay Nolan Case Study include:

- In 1992 Jay Nolan Community Services (JNCS) responded to those residents in their group homes who had requested to live in the community, by planning and supporting those residents to do so.
- The program was voluntary.

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73 http://members.shaw.ca/bsalisbury/NAReport%20-%20Tim%20Stainton.PDF
75 Williams, R “Individualised Funding – A summary review of it’s nature and impact, and key elements for success, Julia Farr Association, Adelaide Australia 2007
• JNCS worked with one resident at a time, asking the residents to outline what they wanted to achieve with their life, and developed supports and identified resources to enable this to happen.
• Places were held open to ensure that the person with the disability had the reassurance that they could return if community living did not meet their needs.
• Once early adopters had successfully adjusted to community living, other residents requested that they also be transitioned into the community, to the extent that it had a snowball effect.
• The vacant group homes places were not backfilled, and as it became clear that the former residents were successfully living in the community, the group homes were eventually were closed and sold.
• JNCS successfully relocated the 90% of the residents of their group homes into the community, and were able to close their 3 day behaviour management programs as a result. (More information is provided at Appendix A).

What does this mean for ADHC?
• Data provided by ADHC on the supports needs of users sorted by the different accommodation service types suggested there could potentially be clients in 1.01-1.04 service types who could be capable of community living, with the appropriate supports. However, without access to assessment data at the client level this is unable to be quantified.
• Incentives could include:
  o Keeping places available for those in residential services who wish to move to community living.
  o Time-limiting the places to ensure individuals were having their needs met in the community and didn’t wish or need to return to residential living. This would provide reassurance to current residents (and their families), who were assessed as capable of living in the community with support.

VI. Increase access to home modification funding

• People with a disability are often financially disadvantaged as a result of their disability. However some people with a disability have acquired their own home.
• Making home modifications to enable the person with a disability to remain in their own home safely can be expensive, particularly widening doorways, building ramps and modifying bathrooms to accommodate the additional needs of a person with a disability who is showing signs of ageing i.e. requiring a walking frame as an aid to mobilise safely.
• Providing access to home modification funding for those unable to afford such modifications will enable people with a disability living in their own homes to remain in their own home for longer with the appropriate supports. This is supported by the literature review which identifies that significant home modifications are required to enable older people with a disability to remain at home\(^{77}\).
• Whilst there is an existing Home Modifications Scheme available, feedback from consultations indicate that there is a long waiting list. Additional funding to enable people with a disability to age in place should be considered.

Local and Overseas Models
• Public bodies in Victoria Australia, Canada, and Massachusetts USA provide interest-free or low interest loans. Key features include:

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\(^{77}\) Ageing in Place: Impacts of Ageing on Accommodation Services Literature Review
Availability to people requiring health and safety related renovations or modifications to the principal place of residence, to enable them to remain in their own home.
- Certain eligibility criteria apply, and there are upper limits to the amounts that can be borrowed.
- An evaluation of the Massachusetts program, which is interest-free, found that most of the participants would not have been able to access alternate finances to undertake the home modifications.
- Providing people with a disability the option to access low interest or interest-free loans to undertake home modifications would increase access for people with a disability.

Considerations for implementing accommodation options are outlined in the table below.

### Table 21: Key Considerations for Implementation – Accommodation

<table>
<thead>
<tr>
<th>Key Considerations for implementation</th>
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<tbody>
<tr>
<td><strong>Policy</strong></td>
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<tr>
<td>• Develop policy regarding co-residency schemes</td>
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<tr>
<td>• Work with Housing NSW to</td>
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<tr>
<td>o Increase housing stock</td>
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<tr>
<td>o Investigate mixed equity housing stock options</td>
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<tr>
<td>o Develop incentives for modifying existing housing stock to meet Universal Housing Design standards</td>
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<tr>
<td>o Examine options for providing low-interest or interest-free loans for home modifications</td>
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<tr>
<td>o Examine options for providing Group Self-Build scheme for people with disabilities in NSW</td>
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<tr>
<td>o Examine options for providing Moveable Units for people with disabilities in NSW.</td>
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<tr>
<td><strong>People</strong></td>
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<tr>
<td>• Develop a strategy and communication plan to promote</td>
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<tr>
<td>o Co-residency schemes</td>
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<tr>
<td>o Mixed equity housing stock</td>
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<tr>
<td>o Group Self-Build scheme</td>
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<tr>
<td>o Housing modification loans</td>
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<tr>
<td>o Moveable units</td>
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<tr>
<td>• Provide training to key stakeholders on policy changes</td>
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<tr>
<td><strong>Process</strong></td>
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<tr>
<td>• In conjunction with Housing NSW develop application process, eligibility criteria and guidelines for</td>
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<tr>
<td>o Co-residency schemes</td>
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<tr>
<td>o Mixed equity housing stock</td>
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<td>o Group Self-Build scheme</td>
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<td>o Moveable units</td>
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<td>o Housing modification loans</td>
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<tr>
<td><strong>Infrastructure</strong></td>
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<tr>
<td>• Web-site modification required to communicate</td>
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<tr>
<td>o Co-residency schemes</td>
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<tr>
<td>o Mixed equity housing stock</td>
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<td>o Moveable units</td>
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<td>o Housing modification loans</td>
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</tbody>
</table>
### 7.3 Supports

The key service modifications needed for Supports are discussed in this section and are shown in the highlighted section below.

| I. | Implement futures planning |
| II. | Joint services for client and carer |
| III. | Local support coordination |
| IV. | Case manager role will need to change |
| V. | Services provided seven days a week as needed |
| VI. | Increase use of supportive technology to support community living |
| VII. | Drop-in services increase as person ages |
| VIII. | Up-skilling existing service providers |
| IX. | Access to equipment (e.g. hoists, wheelchairs) |

#### I. Planning and Futures Planning

To achieve a truly person-centred approach the following is needed:

- Effective planning is critical for assisting people to age in place. This ensures that the person with the disability is receiving the appropriate supports to enable them to achieve their personal goals and aspirations.
- Planning built on the person’s goals and aspirations will enable appropriate service responses, such as how a person ageing with a disability can be supported in the environment of their choice. The majority of people with a disability consulted were very clear that they wanted to remain in their own home as they got older or move to a retirement village. This needed to be inclusive of people with a disability, or only for people with a disability. Those consulted were also realistic acknowledging that there were circumstances when a transfer to residential aged care was in their best interest because of high medical needs.
- Planning should involve family and friends, identify existing natural supports and networks, and seek to build upon and enhance these networks.

**Futures Planning**

Key features of this model include:

- Aiming to plan for an orderly transition when the ageing carer is no longer able to provide supports for the person with a disability living at home with them
- Prevention of a crisis occurring. Evidence from the literature review suggests that a crisis often precedes the need for accommodation; crisis often results in limited choices re accommodation. Having little knowledge of what support services are available, and delays through concern for the future of the person with the disability, the suitability of accommodation and the cost can contribute to the crisis.  

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skills training and were too dependent to live without 24/7 support. There is no time for independent skills training and transition to drop-in support type models, or the identification and implementation of alternate supports (i.e. circles of support).

- ADHC has piloted this model successively in the Northern Region, the ACT has a similar framework.79,80
- ADHC is also funding a Support Coordination for Older Parent Carers program for older mainstream parents aged over 60 years and Indigenous parents aged over 45 years. This program is available in different areas of NSW, mainly regional areas.

II. Joint services for carer and client

- Data available from PwC supports findings from consultations that some parent carers who are still caring for the person with the disability are also facing the problems of ageing. There are approximately 2,500 ageing parent carers in NSW who are aged over 65 years whose children are recipients of CSTDA/NDA services.
- The literature review found that carer stress and strain are likely to increase as carers and care recipients age, impacting health.81
- Providing supports through the provision of joint services for carer and client, where deemed appropriate, would enable the client to remain in the family home. This could include personal care, housework, transport and other services which would relieve the burden on the carer to continue supporting the person with the disability.

Retirement village model

- An example of how joint services could benefit both carer and client is through development of a retirement village complex, which would provide support for both the ageing carer and the person with the disability.
- One disability service provider is considering development of such a complex in their local community. The advantage in this model is that the person with the disability can remain in their home after the carer passes away or has moved to residential aged care.

III. Local support co-ordination

As highlighted previously one of the ADHC initiatives under Stronger Together 2 is to implement Local Support Coordination.

Key features include:

- The Local Support Co-ordinators will assist the person with the disability and their carer to navigate the complex service system.
- A key part of their role is to look outside the sphere of professional supports and work with the identified circles of support to identify and develop informal supports.
- It is envisaged that the Local Support Coordinator will maintain on-going contact with the person with a disability living in the community. They can refer the person with a disability, or assist them to identify the appropriate service as the person requests or needs assistance.

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• As identified earlier, supporting individualised funding and planning through building and developing relationships, both with professional services, and mainstream service providers and community supports is the role of Local Support Coordinators.
• The Local Support Coordinator would work with the individual and circle of supports (or alternately work with the individual to develop and build a circle of supports if required), and once the plan is developed, ensure all necessary approvals to facilitate implementation.

IV. Case management will need to change
There are a number of issues with the current case management model identified through consultations with carers. These issues include:

• Case management is not ongoing. Once a client’s service management plan has been implemented and evaluated as meeting the individual’s needs, the case manager will close that particular file.
• There is no mechanism for ongoing review once the file is closed. A review would only occur at the carer’s request and six months ago some carers interviewed indicated there was a waiting list for case management.

The suggested changes to the case management model include:

• Support the planning process through effective facilitation to enable articulation of the individuals’ goals and ambitions.
• Assist in the identification of natural and service supports to enable the individual to work towards filling those goals and aspirations.
• Effective case management should have an empowering role rather than a helping one.82
• To achieve an individual’s goals and objectives a case manager needs good awareness of the service system. The case manager should not be constrained by attempts to have an individual’s needs channelled into the existing and familiar service supports.
• Seeking ideal or optimal answers to what is precisely needed by the individual, as defined by the individual rather than make minor personalised adjustments to existing service models.83
• If existing case managers are used to an environment that has historically constrained supports into existing support channels, then there is a risk that this group may undermine the concept of individualised funding through their inability to change.
• In a review of individual funding84 Robbi Williams identifies that there is a culture of professional risk aversion in the provision of disability services which remains. This is despite the move from a medical to a community care model, as professional staff have remained in charge of assessment, care planning, service coordination and administration. Williams also identifies a perception that people with a disability are more vulnerable in a community setting. “It is the bias towards ‘duty of care’ and how that is then expressed in service design and delivery that commits a significant disservice to people with a disability”.85

• If the case manager acts as a gatekeeper for the service system and determines eligibility for the extent of service or the amount of resources that will be allocated; has a limited amount of time due to caseload; and mainly places people into professional services; then Williams argues that a

82 http://www.nswhacdos.org.au/_resource/resource-30c-written-resource-developed-by-participants/7e149b15-e7c5-48ee-9b9f-b5d8d33ed910
84 Williams, R “Individualised Funding – A summary review of it’s nature and impact, and key elements for success, Julia Farr Association, Adelaide Australia 2007
85 Ibid p 10
different role is required to facilitate planning and brokerage for the person with a disability, as a significant amount of their time will be needed to build and develop relationships.

Funding has been identified under Stronger Together 2 for Local Support Coordinator roles, and these are the roles that could best be suited to planning and facilitating development of individual plans. In other jurisdictions implementing self-directed funding the traditional case manager role has disappeared altogether being “replaced by planners, brokers and facilitators who assist people with a disability and their families to develop person centred plans, and research purchasing options”.

V. Services provided seven days a week as needed

- A number of service providers in the Ageing in Place consultations and surveys indicated they did not provide support services seven days a week.
- Provision of a seven day a week service for supports, or some form of back up support service for people with a disability after hours and on weekends would provide those ageing with a disability with the security to ensure they are able to remain living within the community.
- There is evidence that older people with a disability prefer to age in place, and that people with disabilities have particular needs as they age\(^{87}\), including increased support for daily activities of living.
- Individualised funding, combined with person-centred planning would enable individuals to determine what services and supports they wanted, including the timing and delivery of those services and supports. This could include identification of services required either seven days a week, after hours or on weekends – the identification and demand driving a change of approach, or a change of service provider.

VI. Increase use of supportive technology to support community living

- Use technological advances to assist residents to remain at home longer such as personal alarms, and non intrusive monitoring of residents. For example sensors to advise if a resident has fallen, or if there is an indication that something may be wrong i.e. fridge or pantry not opened in 24 hours, couch or bed occupied too long, an occupant has entered a stairwell but not exited\(^{88}\).
- Systems like these are used extensively in retirement and aged care living.
- The system can be customised to send alerts by text, email and/or phone call.
- Utilising these monitoring systems would enable the person with the disability who is ageing to remain at home, with the reassurance that there are systems in place that will trigger follow up in case the person with the disability has a fall or other potentially life-threatening medical event.
- Use of a computer with Skype software or an equivalent would facilitate communication with support staff and reduce the need for face to face visits in some instances, which was mentioned by a number of people interviewed.


\(^{87}\) Ageing in Place: Impacts of Ageing on Accommodation Services Literature Review

VII. **Drop-in services increase as person ages**

- From work Mercury Advisory has undertaken for ADHC on the Drop In Review project, one option could be to have a smaller number of different levels of funding for individuals utilising drop-in services, with a price list, similar to the Attendant Care Package.
- Currently the Drop-in service model is block funded so the service providers manage the funding for clients. Although there are funding bands for the Drop-in service model many service providers do not use the banding at all to manage clients’ service hours. The Drop-in service model also has a fifth funding band where services greater than 50 hours per week are needed, which is meant to be time-limited. Currently, ADHC does not have the information to know when this time limit is exceeded and or the client’s needs have changed.
- The literature review identifies that people with disabilities have particular needs as they age, including increased support for activities of daily living.\(^{89}\) Persons over a certain age bracket i.e. 50 years need to be regularly assessed to determine if they need a higher level of support.
- The number of ADHC Drop-in clients aged over 50 in 2009/10\(^{90}\) was 505 living in ADHC funded accommodation and 43 clients living in ADHC operated accommodation.
- Service providers reported that older clients needed to attend a large number of medical and dental appointments, in some cases requiring an additional staff member to transport them. There are a number of options that should be explored for transport such as community transport, and the Patient Transport Service provided by NSW Ambulance\(^{91}\). However access to both these options may differ greatly according to location.

One approach to mitigating the increase in drop-in services as people age is to increase their circles of support and increase natural or informal supports in the community.

VIII. **Up-skilling staff of service providers**

- During the consultations, service providers identified that existing staff required additional skills to better understand and therefore support people ageing with a disability across the range of accommodation services.
- A number of service providers had commenced up-skilling their staff to gain a certificate in aged care, in addition to a certificate in disability services. This was easily facilitated through organisations registered as training organisations, or who had partnerships with registered training organisations offering these qualifications.
- Up-skilling staff supporting people with a disability who are ageing with a Certificate III in ageing in addition to disability qualifications will provide significant benefits. Both the staff and the person with a disability will benefit from the skills which will enable identification and appropriate support for the issues of ageing in addition to the issues of disability.
- It is not known how many staff would need to be upskilled, a survey of service providers is needed to ascertain the number of staff who have gained a certificate in aged care in addition to having a certificate in disability care.

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\(^{89}\) Ageing in Place: Impacts of Ageing on Accommodation Services Literature Review
\(^{90}\) MDS 2009/10
IX. Access to equipment (e.g. hoists, wheelchairs)

- EnableNSW provides funding for assistive technology devices to eligible applicants. The assistive technology devices funded fall into four categories:
  - Communication
  - Mobility
  - Respiratory function
  - Self Care.
- EnableNSW provides the most cost-effective clinically appropriate devices that meet the person’s assessed functional need. Devices provided will primarily promote long term functioning in the community.\(^\text{92}\)
- Those in the Young People in Residential Aged Care Program (YPIRAC) are advised to apply to ADHC for funding under that program.
- Other government funded equipment programs in NSW include but are not limited to:
  - Australian Hearing Service – auditory aids
  - CRS Australia – supportive aids and appliances for Australians aged 16 to 65
  - Community Options Projects – goods and equipment to maintain independence
  - Continence Aids Assistance Scheme – for Australians aged 16 to 65
  - Rehabilitation Appliances Program – provides aids and appliances to eligible veterans and war widow(er)s.

Issues include:

- Feedback from the consultations with carers, service providers and consumers indicate there are long waiting lists to receive equipment with some applicants waiting years as opposed to months. A review of the PADP program undertaken by PwC in 2006 supported that view.\(^\text{93}\)

Changes needed include:

- Increase available funding for the provision of aids and equipment where provision of those aids and equipment will assist people to remain living in the community safely.
- Another option is to make interest-free or low interest loans available to individuals to purchase aids and equipment, similar to the option identified for home modifications in an earlier section.

### Table 22 Key considerations for implementation - Supports

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<tr>
<th>Key considerations for implementation</th>
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<tbody>
<tr>
<td><strong>Policy</strong></td>
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<tr>
<td>- Develop policy regarding Local Support Coordination</td>
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<tr>
<td>- Develop policy to support and encourage circles of support i.e. Micro-boards, Keyring and Co-housing models</td>
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<tr>
<td>- Review policy regarding Drop In services to enable change in level and for time limited additional hours for people whose needs are increasing due to ageing</td>
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<tr>
<td>- Develop policy to support use of supportive technology for people with a disability who are ageing where appropriate</td>
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<tr>
<td>- Develop policy to enable an individual to pool funds from different sources e.g. Drop-In and HACC</td>
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### Key considerations for implementation

<table>
<thead>
<tr>
<th>People</th>
<th>Process</th>
<th>Infrastructure</th>
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<tbody>
<tr>
<td>• Develop policy regarding provision of low interest or interest-free loans to purchase aids and equipment including eligibility criteria</td>
<td>• Develop guidelines for role of Local Support Coordinator in Individual Planning process</td>
<td>• Develop web-site with significant access to local community information at regional and state level.</td>
</tr>
<tr>
<td>• Local Support Coordinators need specific training to facilitate individualised planning for people ageing i.e. PATH training[^94]</td>
<td>• Develop guidelines to support the implementation of circles of support i.e. Micro-boards, Keyring and Co-Housing</td>
<td>• Develop web-site to provide information and contacts to support circles of support models.</td>
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<tr>
<td>• Consider future role of Case Managers, particularly in light of implementation of Local Support Coordinator role</td>
<td>• Develop guidelines on use of supportive technology</td>
<td>• Develop guidelines to administer low interest or interest-free loans to purchase aids and equipment</td>
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<tr>
<td>• Ensure Local Support Coordinators are not gatekeepers for resource</td>
<td>• Develop guidelines to administer low interest or interest-free loans to purchase aids and equipment</td>
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<tr>
<td>• Ensure Local Support Coordinators are fully aware of needs of older people through training</td>
<td>• Communicate role of Local Support Coordinator to key stakeholders</td>
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<tr>
<td>• Communicate role of Local Support Coordinator to key stakeholders</td>
<td>• Promote models for delivery of joint services for carer and client to key stakeholders</td>
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<tr>
<td>• Promote concept of natural supports to key stakeholders</td>
<td>• Promote the individual planning process to identify and implement services seven days a week as needed</td>
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<tr>
<td>• Encourage service providers to consider use of supportive technology where appropriate</td>
<td>• Promote low interest or interest free loans to purchase aids and equipment to people with disability and their family and/or carers</td>
<td></td>
</tr>
<tr>
<td>• Promote low interest or interest free loans to purchase aids and equipment to people with disability and their family and/or carers</td>
<td>• Encourage disability service providers to access certificate III in aged care for all disability support staff caring for those ageing with a disability.</td>
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</table>

### 7.4 Lifestyle

The key service modifications for lifestyle are discussed in this section.

I. Utilise natural supports and build up circles of support
II. Access mainstream community services for older people

I. Utilise natural supports and build up circles of support

Micro-boards, Keyring, JNCS and Co-housing models all utilise natural supports and build up circles of support using different approaches to support individuals who want to live in the community.

Model One – Microboard

Features of the Microboard model are:

- Includes the individual, family, friends and any other people the person with the disability thinks relevant
- Undertakes a planning process which is facilitated by an experienced individual using the PATH process (Planning Alternative Futures with Hope) – a team facilitated graphic planning process.\(^{95}\)

Model Two - Keyring

Features of the Keyring model are:

- Intentional focus on relationships, connections, contribution and mutual support.
- A community live in member (a paid staff member) whose role it is to identify and support the individuals to develop relationships and connections.
- Individuals may be able to build sufficient informal supports so they reduce and then no longer require formal supports.\(^{96}\)
- Jay Nolan Community Services (JNCS), described above, uses a facilitator to work with an identified circle of support for the individual when developing supported living packages. In a case study JNCS describes how a person reduced their formal supports as a result of this approach.
- Having and developing circles of support not only identifies natural informal supports but assists the individual to build and develop further informal support networks.

II. Access mainstream community services for older people

- A recent project undertaken for the Respite Directorate\(^ {97}\) required consultations with 60 carers of people utilising ADHC centre-based respite.
- Part of the research included understanding the services utilised by the individuals concerned.
- One of the findings was that there were very little mainstream community services utilised by this group.
- Feedback from carers was mainstream community services had been accessed, however these were group services. A number of those services had been assessed by the carer as not meeting the needs of the person with the disability, and were therefore discontinued.
- Individual planning should be supported and facilitated through the Case Manager and or the Local Support Coordinator. A key component should be identification and linking of the person to mainstream community services for older people, where those services link into the person’s goals and aspirations.

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\(^{95}\) http://www.communityworks.info/articles/path.htm
\(^{96}\) http://www.keyring.org/site/KEYR/Template/Generic3col.aspx?pageid=244&cc=GB
\(^{97}\) Understanding the respite needs and service profile of users of ADHC centre-based respite
Table 23  
Key considerations for implementation – Lifestyle

<table>
<thead>
<tr>
<th>Key considerations for implementation</th>
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<tbody>
<tr>
<td><strong>Policy</strong></td>
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<tr>
<td>• Ensure current draft Lifestyle Planning Policy meets needs of people ageing with a disability (i.e. consider retirement options)</td>
</tr>
<tr>
<td>• Ensure resources are available about Retirement Planning for people with ageing with a disability</td>
</tr>
</tbody>
</table>

7.5 Health

I. Access to community aged care services as people age

- Aged care packages are available to the general community, and can provide assistance with housework, personal care, transport and medications (Community Aged Care Packages or CACP). Those with medical conditions also receive nursing care (Extended Aged Care at Home or EACH). A specific EACH package is available to support those with dementia (EACHD). The Commonwealth has also introduced self-directed packages (Consumer Directed Care) covering CACP, EACH, EACHD and respite.

- The Department of Health and Ageing notes:

  “Whilst there is no minimum age for ACAT approval, the target population for aged care is older people and residential aged care services are designed specifically to meet the needs of frail older people, and are not oriented to provide for the needs of younger people with disability. Age alone should not, however, be used by an ACAT as the sole reason to reject a person’s referral for assessment.”

- Developing good relationships with the local ACAT team will assist service providers to facilitate receipt of community aged care packages for those individuals with a disability living in the community who are showing signs of ageing, to enable older people with a disability to age in place.

- The pooling of funds to enable for individuals to achieve more individualised outcomes is discussed as part of the Funding section.

- As noted on page 42 NSW appears to have lower utilisation of CACP for people aged less than 70 years.

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Table 24 10 Year Projection of group home residents with high self care needs (age >40 & <70) using PwC annual growth estimates due to population growth & reduction in informal care (2.4% p.a)

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Self Care</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to do or always needs help or supervision</td>
<td>839</td>
<td>859</td>
<td>880</td>
<td>901</td>
<td>922</td>
<td>945</td>
<td>967</td>
<td>991</td>
<td>1,014</td>
<td>1,039</td>
<td>1,064</td>
</tr>
<tr>
<td>Sometimes needs help or supervision</td>
<td>1,127</td>
<td>1,154</td>
<td>1,182</td>
<td>1,210</td>
<td>1,239</td>
<td>1,269</td>
<td>1,299</td>
<td>1,331</td>
<td>1,362</td>
<td>1,395</td>
<td>1,429</td>
</tr>
<tr>
<td>Total needing self care assistance</td>
<td>1,966</td>
<td>2,013</td>
<td>2,062</td>
<td>2,111</td>
<td>2,162</td>
<td>2,214</td>
<td>2,267</td>
<td>2,321</td>
<td>2,377</td>
<td>2,434</td>
<td>2,492</td>
</tr>
</tbody>
</table>

Sources: ADHC MDS data 2009/10 and PwC analysis

II. Access to mainstream services and specialist clinics

Feedback from carers and service providers is that there is limited access to mainstream services and specialist clinics. Key factors include:

- A lack of services and specialist clinics in rural areas. Whilst the latest Commonwealth budget has attempted to address this through making Medicare rebates available for online consultations with various specialists on referral from a medical practitioner\(^99\), this may pose problems for some people with a disability.
- Lack of telemedicine options. Australian Association of Developmental Disability Medicine Inc. and the National and NSW Councils for Intellectual Disability in a submission to the National Health and Hospitals Reform Commission in March 2009\(^100\) recommended telemedicine as a strategy to provide access to specialist clinics for people living in rural and regional areas. The Queensland Centre for Intellectual and Developmental Disability provides such as service. It is not clear if a similar telemedicine service is available in NSW.
- Lack of understanding of disability in mainstream services and specialist clinics. Carers and service providers reported that they were finding it difficult to access mainstream health service providers who were willing to take the extra time required to address the specific needs of the person with the disability.

One of the reasons for relocating a person with a disability into residential aged care was when their health had deteriorated to the point that they needed to be transferred for their own safety and physical well-being. Potential strategies to mitigate against this include:

- Improving access to mainstream health services including specialist clinics would assist in the early identification and treatment of medical conditions which if left untreated would have a detrimental impact upon the person with the disability and their ability to age in place. The literature review identified that co-morbid conditions are associated with disabilities as people age\(^101\).
- Service providers working with the Medicare Locals to ensure people with a disability have access to chronic disease management programs. Current Commonwealth reforms include the formation of Primary Health Care Organisations (PHCOs) or Medicare Locals commencing in 2011 through to June 2012. Each PHCO will be a not-for-profit organisation who will have the

\(^{101}\) Ageing in Place – Impacts of Ageing on Accommodation Services – Literature Review
responsibility for coordinating and integrating primary health care services to meet the needs of their local communities. In NSW the PHCO will most likely align with the Local Health Districts. One of the roles of the PHCO is to play a particular role by targeting services to meet identified gaps in service delivery\textsuperscript{102}. The formation of PHCO could have an impact upon improving access to mainstream health services, community health centres specialist clinics and chronic disease management.

III. Health care co-ordination

A number of service providers have health care co-ordination for their clients, employing staff to undertake that role, including on occasions, some health care service delivery. However, this not routine for all service providers.

Advantages of health co-ordination include:

- Care co-ordination provided by a registered nurse experienced in primary health care, or community aged care ensures that people with a disability can more easily access health services when deemed clinically appropriate.
- Care coordination would support people with a disability receive better care through ensuring regular health screening and assessment. The literature review identified that lack of health screening and assessment is a significant issue and early screening provides benefits\textsuperscript{103}.
- It would be beneficial if the person undertaking the care coordination would work in partnership with a Local Support Coordinator, once implemented, to maximise outcomes. A number of people with a disability have chronic diseases which have been targeted under Commonwealth and state government chronic disease initiatives i.e. the NSW chronic care collaborative initiatives. These programs ensure eligible people are linked into those initiatives to maximise health outcomes. Also ensuring those people with a long term disability caused by mental health illness, or those with dual diagnosis are linked into their community mental health team will ensure those conditions are appropriately managed.

Strategies include:

- Utilising the Community Options Services program (COPS) designed to deliver case management services to individuals with complex care needs living within the community. It is unclear if this service would be available to coordinate and facilitate the delivery of health care services to people with a disability living in the community in all regions of NSW. Certainly the COPS program delivers such services in the Tweed Valley in NSW however; it was unclear if this was consistent across NSW.
- Working with the Primary Health Care Organisations or Medicare Locals. It is unclear what role the PHCOs or Medicare Locals will have in care coordination services, and this should be explored further as PHCOs are implemented throughout NSW. From experience with the Primary Care Partnerships in Victoria, upon which the model is based, it is likely to be a major role for them.
- Supporting the establishment of a role in each PHCO, similar to that of the Primary and Secondary Health Care Workers for Boarding House residents, accessible to people who did not

\textsuperscript{102} http://www.gpconnections.com.au/icms_docs/77660_Health_Reform___AGPN_Fact_Sheet_3_-_PHCOs_explained.pdf
\textsuperscript{103} Ageing in Place – Impacts of Ageing on Accommodation Services – Literature Review
have such supports available. This would ensure that all individuals with a disability living in the community could access appropriate health supports.

- Health care co-ordination is needed for clients with complex health needs. The primary and secondary health care model utilised for residents of licensed boarding houses appears to work well for most residents. The average cost per person in 2009/10 was $1,205 p.a.\(^\text{104}\)

- Accessing aged care funding such as the Community Aged Care Package (CACP). Large residential services currently have resources allocated to ensure residents access the necessary health care services; however it is unclear to what extent group homes are resourced to undertake health care coordination. An evaluation of the Aged Care Innovation Pool – Disability Aged Care Interface Pilot\(^\text{105}\) where aged care packaging funding was provided in a large residential centre identified that there was improved care for all ageing residents resulting from a small investment in allocated hours. Implementation of a similar model of care for all disability residential support services would result in improved health outcomes for individuals in disability residential support services.

- Accessing YPIRAC funding or similar. Consultations were undertaken with people with a disability who were in residential aged care, supported through the Younger People in Residential Aged Care (YPIRAC) program. Those individuals regarded the program very highly. Some service providers also use the Drop-In program for the same purpose e.g. to provide disability service supports to older people with a disability in residential aged care who are not eligible for YPIRAC, for example if they are aged greater than 65 years. There needs to be formal recognition that people with disabilities who move into residential aged care who are aged more than 65 years need a similar, particularly if they have intellectual disabilities, have no family locally and have lived many years in supported accommodation.

IV. Improve understanding of disability sector by health care professionals

Key issues identified include:

- A lack of understanding of the disability sector by the health sector. Feedback from clients, carers and service providers outline the health sector’s lack of understanding of the disability services sector.

- Poor discharge planning. A number of assumptions are made about the disability service sector, based on the health service sector, which are incorrect e.g. all residential disability service providers have clinical staff available to clinical care after discharge. Those assumptions lead to inadequate discharge planning and care delivery, which can lead to re-admission. In some cases people with a disability have been discharged back into the community without adequate supports available. It was assumed that the disability service provider was capable and had capacity to undertake follow up care.

- Cases were cited by service providers and clients, where health care professionals, not understanding (or wanting to understand) the initial limitations of the person with a disability e.g. speech difficulties, attributing certain signs and symptoms to the disability, when in fact are part of the underlying medical condition.

\(^{104}\) Operational Performance Committee – Review of the Boarding House Reform Program, April 2010 p.7

\(^{105}\) http://www.aihw.gov.au/publication-detail/?id=6442467901
• Improving understanding of the issues faced by people with a disability who are ageing, and their particular circumstances, including current supports will assist in a better standard of health care delivery to people ageing with a disability.

• ADHC needs to work with The Ministry of Health and the appropriate professional colleges to improve understanding about the health access issues for people with disabilities.

V. Reduce barriers between disability and aged care sectors

Feedback from service providers, supported by the literature review undertaken into Ageing in Place earlier during this project identified that barriers exist between aged care and disability services. Partnerships need to be established between the two sectors, so additional support for those ageing with a disability does not rest solely with disability service providers. Some good examples of disability and aged providers working together include:

• Disability organisations who provide both disability and aged care services are well placed to reduce barriers through internal structures (i.e. Uniting Care, Wesley Mission).
• One smaller disability organisation has indicated they are currently holding discussions with an aged care provider to establish a joint venture.
• Another disability service provider strategically recruited a specialist with aged care expertise onto their board of management, which has resulted in improved local partnerships.

Actions needed to address these barriers include:

• Promoting the benefits to disability service providers of established relationships with aged care service providers including local ACAT teams would encourage disability service providers.
• Funds pooling across the two sectors would also assist in reducing barriers.

Key considerations for implementing health options are outlined in the table below.

<table>
<thead>
<tr>
<th>Table 25</th>
<th>Key considerations for implementation - Health</th>
</tr>
</thead>
</table>
| **People** | • Market to community aged care providers benefits of providing services to people with disability  
              • Encourage service providers to develop relationships with local community aged care providers and ACAT teams  
              • Promote demand and access requirements to mainstream aged community services for people with a disability to providers.  
              • Ensure Local Support Coordinators work with their local PHCO/Medicare local to maximise access to primary health services for people with a disability, particularly those that are ageing |

These considerations will be developed in more detail as part of the Action Plan.
8. Pathways

Pathways to the new service models are:

- From family home to independent community living which would include a transitional phase to enable the necessary skill development (e.g. ILSI) and supports to be put in place to enable the individual to reside in the community;
- From family home to residential support services;
- From community living where the residence is no longer adequate to support the individual, into community living which adequately supports the individual due to age related changes;
- From community living to residential support services if needed.

In this section we discuss what is needed to implement these pathways:

1. Futures planning
2. Early ageing
3. Assessment for people with Intellectual Disability over 40
4. Referral triggers
5. Points of Access, Screening and Assessment Criteria
6. Service delivery

8.1 Futures Planning

- Future planning for the individual with a disability should begin early.
- There are identified critical points of family stress i.e. age 2-4 (realisation), age 6-9, age 11-13, and approaching 18.\(^\text{106}\)
- Assessments and reviews should be undertaken with the Local Support Coordinator working with the family to ensure all necessary supports and services are available to maintain the individual in their home environment for as long as possible.
- For those in supported or open employment, retirement planning should also be undertaken, so that the individual can transition into alternatives to employment that maintain some level of community and social engagement.
- As part of the individual planning process, those individuals in supported or open employment should be considering how long they want to continue on in their current workplace.
- Any indication that the individual would like to reduce hours and/or retire from employment should be initiating discussions about the retirement planning process with the individual and their circle of supports.
- For some individuals the level of disability may be sufficiently high, or behaviours so complex that community living may not be an option. However for a number of individuals with a

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disability, community living is a realistic option if the individual is able to be supported to do so.

- Currently young people with a moderate to high level disability who have completed Year 12 and meet other eligibility criteria, may access one of two post school programs if they are assessed as requiring an alternative to employment or further education in the medium or longer term.

- ADHC is working with schools and transitional teachers to ensure information about these options is made available to the individual with the disability prior to year 12.

- Ensuring the Local Support Coordinator with the family is also engaged in this process will assist in developing a holistic futures plan that not only considers the individual’s employment or alternative to employment, but also identifies the individual’s future aims and objectives regarding living arrangements.

ADHC has piloted the Futures Planning model successively in the Northern Region, the ACT has a similar framework. 

8.2 Baseline assessment to assist with detecting early ageing

- For those individuals who have a disability associated with early ageing i.e. Down Syndrome and early onset dementia undertaking a base-line assessment of ADLs, IADLs and general abilities is very important. Baseline data collection may include the ability to hold a conversation at around the age of 25, and making a video record will enable ongoing monitoring and early detection of any changes which are critical in ensuring timely intervention, planning and action.

8.3 Assessment for people with Intellectual Disability over 40

- For people with an intellectual disability over 40 (2,447 clients were aged over 40 in 2009/10 and 75% of these clients or 1,835 clients had an intellectual disability), ensuring a routine assessment with a standardised assessment tool e.g. BSCOC, developed to assess individual for signs of early ageing will ensure early detection, so that early planning can be undertaken on how the individual can be supported through the ageing process, shaped by the individual’s aims and objectives.

- Identifying the individual’s goals, aims and objectives and supporting them to live a good life, through an understanding of the individual’s capability. This can be developed through some form of assessment tool to assist in developing the individual plan. This will also assist in identifying appropriate informal and formal supports, which will assist the individual to realise those goals.

• Ensuring that all individuals who will require some level of service support in the future are
registered with the register of future need (or equivalent) to ensure ADHC has some indication
that the nominated form of service (or its equivalent) will be needed in the future. If
appropriately maintained and updated, this register will provide data for planning purposes.

For people living in the family home, early planning of a transition when the carer can no longer
provide the necessary informal supports will prevent a crisis before the need for accommodation.
Crisis preceding accommodation often leaves the remaining family/friends with limited options and
little knowledge, and may prevent the individual being transferred to residential aged care.

### 8.4 Referral Triggers

• Effective futures planning by the Local Support Coordinator, the individual and the circle of
supports will identify the necessary trigger points for referral, and the indicative timing of those
triggers. Planning would identify a person’s wish for alternate accommodation, which may be
supported by family, friends, service providers or other supports, which would in turn trigger
referral for assessment for a support package.

• Other individuals may have an identified need or expressed wish to move from other
accommodation (e.g. recent exit from Criminal Justice system, Leaving Care, residential disability
service). This would act as a trigger for referral for initial assessment or for those already
accessing disability services, subsequent re-assessment. Some individuals may have had long
term hospitalisation from an injury or trauma which has resulted in physical and/or intellectual
disability (e.g. Acquired Brain Injury). The disability may also have resulted from deterioration of
an existing medical condition (i.e. Multiple Sclerosis, Cancer) which would trigger referral for
assessment for support.

• Individual planning should include a referral trigger for those individuals remaining in the family
home whose carers are ageing. Alternatively, where there is an indication of a potential
breakdown in the current home which could lead to an inability to continue support (i.e. carer
terminal illness, break-down of live-in carer relationship).

• Referral can be made in a planned considered manner rather than at point of crisis. Assessment
of the person with a disability, at point of crisis when there are additional stresses placed upon
that individual (e.g. separation anxiety from long term carer) may result in the individual being
assessed as having lower capabilities than otherwise may be the case.

• Another referral trigger for assessment for support is where there are identified changes in the
person with the disability.

• Having the initial standardised assessment tools e.g. BSCOC undertaken for those with Down
Syndrome, or those with intellectual disability over 40 would enable rapid identification of
deterioration of skills which would justify referral for (re)assessment for services.

• A standardised assessment would detect any noticeable deterioration of functional level,
increased support needs due to issues associated with ageing or deterioration of the medical
condition which resulted in the disability. This should also trigger referral for (re)assessment for
support.
8.5 Points of Access, Screening and Assessment Criteria

- Access for assessment for support at this point of time is managed at a regional level. Whilst the demand for service exceeds the capacity to deliver, a centralised intake system will be required to ensure equitable access for support, for those who meet eligibility criteria for service support.

- In this context assessment is defined as the critical appraisal of the person’s capabilities based on a standardised tool. A number of assessment tools developed specifically for the disability sector are available and used by disability service providers, including I-CAN and the Supports Intensity Scale, as well as ADHC’s use of BSCOC as previously mentioned.

- The intake system would administer the register of future need, in addition to intake for residential support services. The intake system would also make the final determination regarding the individual support package to be provided.

- For sensible individual planning to take place, resources, including financial resources available need to be determined. The individualised support packages would be determined by the assessed number of support hours required by the individual to live a good life. A standardised assessment tool which provided a consistent approach to determining the number of support hours needed would assist the process. This assessment would be determined on a range of factors, including but not limited to mobility, behaviours, ability to socialise and interact with others, undertake personal care; and capacity for skill development. The assessment should be as objective as possible to eliminate any potential for bias, and should include input from the individual, carers, and those who have had recent professional associations with the individual which could include, but not be limited to teachers, disability service providers and/or clinical service providers.

- The intake system would consider each application, and to those individuals whose applications for support were approved, a funding package assigned which should cover all necessary supports. This package would continue, for a set period of time at which the individual would be re-assessed unless re-assessment was triggered early by circumstances as outlined above.

8.6 Supports planning pathways

A decision process flow is outlined on the following page that would provide the foundation for service planning. This process assumes that the individual is eligible, has undertaken all necessary assessments, and has an individual support package approved. The process outlines all the options that have been discussed to be considered as part of the individual planning process with the first process considering if the individual could continue to reside in their current accommodation (assuming that is the individual’s preference):

- Would home modifications and/or supportive technology enable the person to remain at home?
  - Are home modifications feasible and able to be implemented?

- Would additional carer supports i.e. respite, day activities, home care, enable individual to remain at home?

- Any additional informal supports enable individual to remain at home?
• Additional drop in support hours able to be funded through existing support package?
• Would CACP/EACH/EACH-D enable individual to remain at home?
  o Does ACAT assessment support allocation of package?

The role of the Local Support Coordinator would be to facilitate discussions to consider each point in this process as part of the Individual Plan. Where it was the decision of the individual, supported by the circle of supports that a particular option was not appropriate then the next option should be considered until either a plan is developed which is achievable within the given budget or alternate accommodation is determined to be the most appropriate option.
Figure 8 Supports planning pathway part one

Local Support Coordinator consultation with person and information circle of supports

Would home modifications and/or supportive technology enable person to remain at home?

No

Yes

Are home modifications and/or supportive technology feasible and implementable?

No

Yes

Are other funding sources available?

No

Yes

Utilise if feasible

Does person need additional supports to remain at home?

No

Yes

Approve plan and budget, move to implementation

Would additional carer supports in respite, accessing day programs enable person to remain at home?

No

Yes

Does person need additional supports to remain at home?

No

Yes
Figure 9 Supports planning pathway part two

1. Any additional informal supports to enable the person to remain at home?
   - Yes
   - No

2. Does person need additional supports to remain at home?
   - Yes
   - No

3. Are additional Drop-in support hours able to be funded through existing service support package?
   - Yes
   - No

4. Does person need additional supports to remain at home?
   - Yes
   - No

5. Approve plan and budget, move to implementation
Figure 4 Supports planning pathway part three

Would CACP/EACH or EACHD enable person to remain at home?

Yes

No

Does ACAT assessment support allocation of Community Aged Care Packages?

Yes

No

Consider alternate accommodation options

Approve plan and budget, move to implementation
Whilst this process is designed for those individuals with a disability who are ageing, this process could be used for younger individuals whose personal preference, supported by family and friends, would be to remain in the family home.

**Pathway options community living**

If the decision is to consider alternate accommodation options, a second decision support process has been generated which considers the various options available for community living;

- Is accommodation utilising universal housing design indicated by assessment?
  - Can service supports be modified within existing support package to maintain individual in new accommodation setting?

- Would alternate accommodation designed to universal design standards enable the individual to remain in the community?
- Is alternate accommodation designed to universal housing design standards accessible?
- Can service supports be modified within existing service support package to maintain individual in new accommodation setting in community?

If community living is determined appropriate, and the plan and budget approved, then part of the implementation process includes transition to community living.

Both two processes outlined would be consistent with the Independent Living Skills Initiative currently under implementation by ADHC in partnership with Down Syndrome NSW.
Transition to community living needs will include:

- Independent Living Skills assessment to determine the individuals’ current living skills with a gap analysis to identify and put plans in place to remedy such gaps, initially through supports. The ultimate aim is to enable the individual to obtain living skills, to the extent the individual is capable, through training and skill development.
- Risk management plan to identify and manage all known risks to individual and/or care service providers.
- Identification and relocation of individual to appropriate accommodation once all initial supports are put in place.
• Monitoring and ongoing review by individual and circle of supports to ensure model of service delivery satisfies individual’s stated aims and objectives.

Pathway options for residential care

The last decision support process, if the individual in conjunction with the family, friends and circle of supports decide against community living, considers the options for residential care.

Figure 12  Pathway options for residential care
Lifestyle related services would be included as part of the individual planning process. The Community Participation, Lifestyle Choices and Active Ageing programs have the option for self management. If the budget for these programs were incorporated into the individual support package, the individual plan would have all the service supports that met the individual’s specific identified needs.

8.7 Health support services

- Commonwealth health reforms include changes to the structures that deliver primary care services.
- New Primary Health Care Organisations (Medicare Locals) will be established in various communities that will have as one of their objectives, targeting areas of unmet service need and facilitating access to service to fill those gaps.
- Ensuring Local Support Coordinators establish and maintain sound relationships with Medicare Locals will ensure the Medicare Local continues to focus upon and promote strategies, and deliver services to improve access to primary health care by individuals with disability.
- Involving the party identified as responsible for health care coordination in the development of the individual planning process for those residing or relocating into community living will ensure optimal health outcomes.

8.8 Fit of Service Options with Principles for Ageing in Place

How do these models match against ageing in place principles?

The principles for effective ageing in place are:

- **People centred** – The person is at the centre of planning and service delivery is designed in concert with the person according to their wishes, wants and needs. It is based on the values of human rights, independence, choice and social inclusion, and is designed to enable people to direct their own services and supports, in a personalised way\(^{109}\) rather than attempting to fit within pre-existing service systems\(^{110,111}\). Planning should include families and carers as required.

- **Choice** – Clients can choose with whom, how and where they live and to live as independently as possible. More choice in accommodation types (e.g. transitional accommodation to facilitate moving from home or group home to community living), and flexible accommodation funding options (e.g. part funding by person or family) should be encouraged. The range of options to select from should include remain at home, group home, community living (living in the general community, which could include living within an intentional community, as long as the


\(^{110}\) Kormann & Petronko: (2003) Crisis and Revolution in Developmental Disabilities: The Dilemma of Community Based Services. The

Behavior Analyst Today, 3 (4), 434 -443

community is inclusive and not limited to people with a disability only) or other aged related solution common to the wider community.

- **Equity and fairer and more transparent access** – Having clear published equitable and fair eligibility criteria including ability to identify eligibility early, clear assessment processes, appropriate and transparent prioritisation mechanisms and funding models.

- **Flexibility** – Having choices and flexible models of services, accommodation and funding to reflect changes needed as people age.

- **Maximising Ageing in Place** - Assist people to remain in their home alone, or with a carer and to assist ageing carers. This includes assisting people with disabilities and their families with planning for the future, including financial decision making through programs such as piloted by ADHC in the Northern Region e.g. Futures Planning. The estimated number of ageing carers that would benefit from this pilot can be estimated at approximately 500 people (based on 8,100 carers Australia wide aged greater than 65 years, estimating one third are from NSW and allowing for an estimated 20% participation rate).

- **Options the same as the general population** – People with a disability who are ageing should have the same options as the general population who are ageing. This should be true of accommodation options. Health assessments and retirement options for the person with the disability and their carers are also important.

- **A sustainable support system** – Staff skills need to be adapted to support older clients (e.g. aged care training and awareness of dementia). Effective information for planning is needed. Funding to match is essential or the system will not be sustainable, there is a need to service a broader range of people with a range of needs, particularly the older cohort of people with a disability.

- **Linking services to need** – More detailed planning regarding demand for supports and assessment will facilitate the linking of services to need. Client wishes as well as needs must be considered.

- **Creating more options for people living in specialist support services** – This includes development of more innovative accommodation options rather than just traditional group home settings. One innovation ADHC has recently implemented is the Individual Accommodation Support Package (IASP), which provides a package of funding which will enable a person with a disability to live independently, or remain in their current home. This package enables the person with the disability and/or their carer to actively participate in the decision making process about the planning, implementation and delivery of service supports including service provider.

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114 Draft Independent Accommodation Support Package Program Guidelines v1.1 APD, ADHC, February 2011
9. Service delivery challenges

This section outlines the capacity challenge expected to come to the service system due to the decline in informal care provided by ageing informal carers and families. This is one area of future demand that is expected to stimulate service adaptations to make effective responses.

Ageing in place has implications for future service delivery. Services will require modifications to address the impact of ageing for existing persons with disability currently within the disability service system, as outlined above. It has also been recognised within this project that there will be an additional burden placed upon the disability service sector due to ageing carers.

There are a number of people with disability who are being supported to live in the community by carers. Evidence from the literature review supports the findings of the consultations – that parents are more likely to care for someone with a mental or intellectual disability, whilst spouses were more likely to care for someone with a physical disability. The literature review identified that carer stress and strain was likely to increase as the carer and the care recipient aged, impacting upon the carer’s health.

PwC was engaged to assist with quantitative analysis to assist understanding the client profile of people within ADHC funded and operated accommodation services, the population who may require accommodation support not in the service system, and the impact of ageing carers. From the analysis undertaken by PwC, it was determined that a significant number of clients aged over 45 not in accommodation support services are cared for by people aged over 65 years – which is the ageing parent carer population. At some stage those ageing parent carers will not be in the position to continue providing ongoing care, which will place additional demand for accommodation support services.

One of the main drivers of future support needs will be the declining availability of informal care. A large proportion of care and support to those with Grade A support needs is provided by informal carers (i.e. family, friends and other unpaid providers of support). In the PwC Report Ageing, Disability and Home Care: Stronger Together: A new direction for disability services in NSW – the second phase it was identified from the 2006 census data that the changing sex and age profile of the population alone results in a decline in informal care of 1% p.a. Socio-economic factors such as higher female workforce participation rates, decreases in couples with children and decreases in family sizes all pose threats to the provision of care to the informal care sector. This excludes any allowance for decreased capacity to care due to the age and/or declining health of the carer. Allowing a 0.5% decrease p.a. (as a result of decreased capacity to care), results in an estimated decrease in informal care of 1.6% p.a.

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115 Grade A support is a subset of the population with severe/profound core activity limitation. These categories were derived from the 2003 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) Confidential Unit Record File (CURF) and developed by PwC in conjunction with ADHC in 2005.

9.1 Capacity Issues

As highlighted in the research:-

- The growth in demand for people with grade A support needs over the next 28 years is driven by the following key factors:
  - Population growth approx 0.8% pa
  - Decline in informal care of 1.6% pa.
- The impact from reducing informal care is very significant given that accommodation services currently meets only 13.4% of demand. Therefore any single percentage drop in informal care results in a 4.5% increase in demand for formal care. Accordingly the 1.6% drop above theoretically increases demand for formal care services by 7.2% each year.
- The annual growth of between 912 and 991 people is very significant compared to the 8,880 places for formal care in NSW in 2008-09.
- The rate of growth will pose significant pressure on the disability support system as a whole should it not adapt to the changing needs environment.
- In such an environment with greater ageing profiles of carers and clients, ADHC will need to re-deploy its services to effectively plan and encourage innovative solutions essential to close gaps in a cost effective manner.
- Based on the modelling undertaken by PwC\(^\text{117}\), the capacity challenge will increase in NSW. The significant growth in demand (2.4% p.a) is driven by demographics with the largest driver being the projected reduction in informal care.

These trends indicate the need to re-deploy service capacity to make a more responsive and cost-efficient set of services available, tailored to the levels and points of need, rather than continue to provide the services that have addressed demographic issues to date.

\(^{117}\) PWC Accommodation Demand Projection – Results by LPA and Age
Appendices

Appendix A – Outline of different service models

Abbeyfield Australia

Abbeyfield Australia is a national not for profit community housing provider which offers a community based housing option for older people and people with a disability who are in need of housing and support. Three types of accommodation are provided:

- Assisted independent living for adults with mild intellectual disabilities
- Low care (hostel) aged care accommodation
- Assisted independent living for those aged 55+

Accommodation is targeted at low income earners with the fortnightly fee schedule indexed to the aged care and disability pensions. However review of the Abbeyfield Australia strategic plan suggests that the Board may reconsider this approach in order to generate additional income from those with the financial capacity to pay more, to assist Abbeyfield Australia to achieve its long term goal of increased capacity.

If there is identified community need, and the initial capital funding is available, Abbeyfield Australia will assist with

- Assessing housing needs
- Developing financially sustainable housing models
- Design of attractive and functional housing
- Providing quality community based housing options

Abbeyfield has identified obtaining initial capital funding as the major hurdle in the developing any new Abbeyfield House.

Features of an Abbeyfield house include:

- Ten residents sharing a spacious purpose built house
- The houses are non-institutional in design and operation, and blend into the existing streetscape
- Every resident has their own bedsitter with en-suite facilities - which residents are expected to furnish.
- A guest room is available for visiting family and friends.
- A fully furnished lounge room, dining room and laundry are provided.
- Catering is provided with two meals provided midday and evening weekdays. Breakfast provisions are made available. A single meal is provided on weekends with provisions for the other meal made available.
- Each house has their own professional housekeeper, whose role is to keep the common areas clean, do shopping and provide meals. Residents are to maintain and clean their own bedsitter including en-suite and do their own laundry.

Houses are initiated, developed and managed by volunteers from local communities in partnership with Abbeyfield Australia, to be responsive to local identified need.

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It is unclear if the design of Abbeyfield Houses incorporates the elements of Universal Design to enable ageing in place. There are no specified mechanisms to encourage community involvement and active participation for those without established networks.

Potential residents would need to have some initial capital available to furnish their rooms and fit out their en-suite.

**Apartments for Life**

Apartments for Life is based on the Humanitas model which has been successful in The Netherlands.

The Humanitas care philosophy and starting point is the enhancement of human happiness for clients with a physical or somatic handicap. Cure and care and therefore not the core business; the focus is upon delivery of services which address two aspects – the individual aspect - maximising the ability the individual has to control their own life and the community aspect – maximising the sense of belonging. Humanitas developed apartments which enabled individuals choice in where and how they lived, whilst offering community involvement. Humanitas ensured individuals could age in place by ensuring all apartments were usable by those in wheelchairs, and the necessary clinical supports were readily available.

The Benevolent Society has adapted the Humanitas model and implemented what is known as Apartments of Life in Australia, with a complex in the process of being developed in Waverley NSW.

The key aims of the Apartments for Life project is

- 95% of residents will never have to face the disruption and cost of moving to a nursing home.
- Older people will be able to remain in their community, close to families, friends and established local networks.
- The potential for social isolation is reduced through the creation of a new social hub within the complex, promotion of contacts with family and friends, and strengthening links with the local community.
- Apartments will be affordable to people on a range of incomes, reflecting local diversity.

These aims will be achieved through a combination of the following:

1. **The design of the apartments, buildings and external open spaces**
   - Self-contained apartments with courtyards or balconies
   - Meeting areas and balconies on each floor to promote socialising with others or to use as a place to meet families/friends
   - No steps or stairs, and corridors wide enough for wheelchairs and other walking aids
   - Bathrooms suitable for those ageing who are unstable on their feet or those with a disability
   - Built in safety features including lifts that can be used in the event of fire
   - Use of modern technology to monitor residents' health and well-being unobtrusively, and to make life easier for residents to obtain assistance when they need it i.e. sensors, personal alarms

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120 [http://www.humanitas.nu/static/index.html](http://www.humanitas.nu/static/index.html)
2. Inclusion of affordable housing

- The goal of this project initially was to provide 40% of the apartments as affordable housing. 30% would be offered at discounted entry prices, for local older people who could not afford to pay full price because of the value of their current home. The remaining 10% would be rental housing for disadvantaged older people.

- This goal was set based on the premise that the complex would have 140 units. However under a Land and Environmental Court ruling the plans had to be amended and only 128 units have been approved. The Benevolent Society is now assessing their ability to deliver the 40% affordable housing whilst maintaining financial viability.

3. Assisted access to support services and care

- Apartments for Life will have a Care Advisor to help residents obtain necessary care assistance from local care agencies in the area – connecting them to the type of care and supports needed including but not limited to
  - Personal care
  - Housekeeping, laundry, meal preparation
  - Nursing
  - Loans of equipment i.e. walking frames
  - Help with paperwork i.e. paying bills
  - Day care for people with dementia
  - Respite for carers

4. On-site services, facilities and social activities

- Community facilities will include rooms of various sizes for flexible use i.e. local club meetings, craft groups, social activities, fitness groups, etc.
- A café will be on site which will offer meals, a child-friendly area and provide basic supplies for people with limited mobility.
- A day centre for people with dementia.
- Consulting rooms for doctors and health professionals.
- A program of social and recreational activities.

5. A philosophy of respect for residents’ individuality and autonomy

- Whilst this project will result in housing suitable for those with a disability, the material suggests that the main target are those ageing who are living in Waverley, as the “substantial affordable housing will enable older people to stay in the area”.

HOME – Home Occupiers Mutual Enterprise

- HOME is a group of parents of people with disabilities, professionals and individuals concerned about the lack of housing options available for people with a disability in the Inner West of Sydney NSW. HOME aims to establish long term accommodation and assistance for people with significant support needs, through the development of an intentional community.

- The proposal is a purpose built environmentally sustainable apartment block with up to 40 dwellings. The dwellings will be built to conform to Universal Design standards. 15% of the residences will be allocated to people with intellectual and/or physical disability.
The apartment block will be located within walking distance of public transport, shops, libraries, health services and recreational facilities. A Community Coordinator will be located on-site, along with a commercial café, and a community centre.

It is proposed that formal supports will be made available for residents with a disability who are unable to qualify for inclusion on any accommodation vacancy register, with one apartment to house support staff. Home has established a partnership with Uniting Care Supported Living who would provide the formal supports, and a Community Housing provider to manage the building.

A feasibility study has been undertaken and presented to ADHC.

**Microboards**

A Microboard is a small group of committed family, friends and other interested community individuals who join together with an individual with a disability to form a small not-for-profit organisation. The Microboard supports the person to plan to live a good life which achieves their goals, wishes and dreams. The Microboard may be facilitated by an over-arching organisation which has expertise in the establishment and maintenance of Microboards. Microboards develop personal support services for individuals with disabilities, through obtaining and managing individualised funding for that individual.

The first example of Microboards came about in Canada. At that time, the vast majority of services were provided in a congregate or group setting. All government funding for disability services required services be delivered to a certain number of places.

If the person requiring support did not require the supports outlined by a vacant place, they went onto a waiting list until another type of place became available.

If a person occupied a place, and the type of service available under that place did not really meet the person’s needs, there was very little opportunity to change the service configuration since alternative places were almost always full and there were long waiting lists for vacancies arising.

Because there were disincentives for the service providers to make changes those who were capable of making advances remained under inappropriate service arrangements that did not facilitate individual advancement. Conversely those who needed more supports through increasing challenges or difficulties were forced to remain in services that could no longer meet their needs.

Due to the congregate nature of service delivery, most service recipients’ were disconnected from relationships and opportunities in the general community.

All the power and control were perceived to be in the hands of the service provider – not the individual supported, their family or their local community.

Work was done with the government funding agency and two new operating strategies were adopted.

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[121](http://www.tnmicroboards.org/modules.php?name=Content&pa=showpage&pid=7)
[2](http://www.microboard.org.au/page/Home)
[3](http://www.communityworks.info/articles/microboard.htm)
1. Acceptance of the concept of individualised funding based upon a negotiated agreement related to a specific persons support needs, and segregating those funds so they could not be used for another individual
2. Separate the provider auspices that controlled the provision of housing from the auspices that controlled the provision of service where the services were residential in nature.

Separating the provision of housing from services meant that people could change location without losing supports, or more importantly change service provider without losing their home, jobs or local networks.

These changes set the ground-work for the implementation of Microboards.

Research was undertaken and it was determined that the smallest unit of organisation that would be eligible for government funding would be a three person not for profit organisation which could be organised to meet the needs of one individual The board of this organisation or “Microboard” as it came to be known included the person receiving supports, their family and friends.

The first Microboard was created with two initial principles – the first that the Microboard would refrain from controlling or owning the house that the person occupied – and the Microboard would only serve one person. A pilot project was undertaken establishing Microboards for 3 individuals, and since that initial pilot there are now over 450 Microboards operating in British Columbia, Canada.

Microboards are operating in a number of countries including at least 3 states in the USA, Northern Ireland, and more recently in WA, Australia under the auspices of a voluntary organisation known as Vela Microboards Australia.

All Microboards facilitated through Vela Microboards Australia are established using the following principles:

- Microboard members must have a personal, unpaid relationship with the person for whom the Microboard is created.
- All people are assumed to have the capacity for self-determination. This capacity will be acknowledged, respected, and demonstrated in all dealings of the Microboard.
- All decisions made by a Microboard will demonstrate regard for the person’s safety, comfort, and dignity.
- The more variables there are in a person’s life, the more important it is that the support/services are customised and individualised.
- All Microboard members will conduct their board business in the spirit of mutual respect, cooperation, and collaboration.
- All paid services developed and/or contracted by the Microboard are customised and individualised not just based on availability.
- Microboards will only negotiate contracts with people and/or agencies able to demonstrate a proven ability to provide services as identified by the Microboard. Their primary relationship is with the person. These services will be person centred and customised.
- People who work through the Microboard are not “attached” to the settings in which the person lives, works, volunteers, or recreates.

Microboards have enabled people requiring supports to realise their hopes and aspirations, including significant and meaningful community interaction, employment, independent living and meaningful and intimate personal relationships.
Keyring

“The essence of a Keyring network is that it consists of 8-9 members who have a disability and who each have their own home (usually a public housing rental flat), dispersed throughout an ordinary local neighbourhood. Support is constructed on a number of levels:

- from the input of a local community living volunteer (who has a rent free place to live among the other homes and in return provides 10 hours support each week to network members - for example, keeping in contact with members, assisting with any tenancy issues, making community connections);
- mutual support among network members (for example, each member is required to share their skills and support other members, monthly meetings where the network gather);
- reciprocal connections with neighbours and local community groups (for example, giving and receiving hospitality, looking out for neighbours and being involved and contributing to community events);
- specialist support and advocacy from paid community living support workers (for example, assistance to move in and learn new skills); and
- a level of overall coordination, planning and after hours support from a network manager.

The Keyring approach builds on the strengths and contributions of each network member, each of whom sees themselves as ‘members who own Keyring’ rather than ‘service users.’ The model is very intentional about mapping out the key resources and opportunities in each community, and the community living volunteer and project staff have very good local knowledge which is used to connect people to their community, based on their interests and possible contributions. The developers of the model acknowledge that the model has advantages and limitations and is not for everyone. Its strength however, is the intentional focus on relationships, connections, contribution and mutual support. This model works well for people with intellectual disabilities and reasonably good independent living skills, who might otherwise be quite socially vulnerable. The model also operates at a low cost per person due to the significant use of mutual and community supports rather than just paid specialist disability supports”\textsuperscript{122}. There are also cases cited where significant savings have been achieved over time where service users have significantly reduced support hours, or in some cases no longer required support hours through a combination of skill acquisition, increased community participation and acquisition of informal or alternate supports\textsuperscript{121}.

“Approaches to Co-Housing (Good Neighbour, Co-resident, Teaching Families)

Similar to the Keyring model described above, there are a number of examples of projects where people with disabilities can be supported in their own homes with the assistance of a ‘good neighbour’, live-in housemate/co-resident or a teaching family.

The ‘Good Neighbour’ program (Midwest Community Living Association) has been operating for several years and has been identified in a number of state and national reports as an example of innovation. A site visit was also made to the program in December 2007 and the following key features were identified: the person lives in their own home (unit) and support is constructed from a combination of a ‘good neighbour’ (who lives in an adjoining unit, and in exchange for subsidised rent, the ‘good neighbour’ provides a small amount of daily checking in to see how the person is

\textsuperscript{122} Community Living Concept Plan Stage 1 Report: Innovative examples, alternative pathways and partnerships, and a new framework for community living for people with disabilities in Western Australia. Disability Services Commission WA August 2008 p 16-17

\textsuperscript{121} \url{http://www.keyring.org/site/KEYR/Templates/Generic3col.aspx?pageid=244&cc=GB}
getting on plus some practical support as needed), ongoing family involvement, Local Area Coordinator support and community connection, plus oversight by the Manager of the Community Living Association and the addition of any additional formal supports as required. This ‘layered’ style of support was observed to provide both emotional/social and practical support for a woman who would otherwise have been vulnerable on her own in the community, and importantly created an ideal opportunity for mutual support. For example, the ‘good neighbour’ commented how the support went both ways, as the woman herself was a good neighbour and looked after her unit and pet when she herself was away. Like Keyring, this approach presents as well suited to people with disabilities with good skills but who might otherwise be quite socially vulnerable, and operates at a low cost per person.

There are many variations to this theme, including what are sometimes called ‘homeshare’ or ‘co-resident’ arrangements where live in students or others provide a first level of support and companionship, involving varying levels of subsidised rent and/or payment. Experience has shown that this type of approach can support people with high support needs to still have their own homes and personalised support, through this ‘layering’ of various types of informal and formal support.”

Another approach to co-housing is a variation on the model known as “Teaching Families”.

This model was established to assist those who had been previously living in Large Residential Centres in one state of the USA to transition into the community.

Duplexes are set up to be wheelchair friendly. An internal door linking the two duplexes is included in the design. Two care-givers (usually a couple) and their immediate family occupy one duplex, and up to 3 people with a disability occupy the other. Residents have constant supervision and support even at night. Care-givers are recruited and screened by the disability service provider and must undergo a certification process including intensive training in care giving, ongoing consultation with clinical and program experts (including health-care and behavioural experts) and regular formal quality evaluation and feedback designed to improve the quality of life for the person supported. It is a condition of employment that care-givers are re-certified annually. Care-givers provide most of the support for the people in the adjoining home and are responsible for ensuring their needs are met, including hiring and supervising a small team of assistant teachers to provide support on the weekends and other times the care-givers are not available.

The Extended Family Teaching Model (EFTM) has one or sometimes two adults with developmental disabilities reside in the host family’s home. These arrangements are designed to be long term and originate from an existing positive relationship. The EFTM hosts receive the same training, support, certifications and evaluations as the Training Family care-givers.

124 Community Living Concept Plan Stage 1 Report: Innovative examples, alternative pathways and partnerships, and a new framework for community living for people with disabilities in Western Australia. Disability Services Commission WA August 2008 p 59
125 http://www.cco-ca.org/about.html; http://clokansas.org/pages/FTMAIN2.html
Jay Nolan Community Services (JNCS) is a not for profit community organisation established in 1975 by members of the Autism Society of Los Angeles, to provide care for people with autism and other disabilities in a group setting. In 1992 as the result of a number of identified challenges, JNCS changed its philosophy and the way it delivered services. JNCS began delivering individualised support to people to enable them to live in their own homes, obtain employment and live the way the individual wanted to live.

Although the move to providing individualised supports was only initially offered to those who expressed an interest in having more individualised supports, the interest and willingness to engage in this model of service delivery was embraced by other individuals as they came to see the results, which lead to 90% of all individuals in group homes moving into the community with individual supports. The remaining 10% changed service providers, as they or their families had concerns about this model of support.

JNCS now provides Community Facilitators who assist the families of children with a disability by providing the intense supports necessary to enable the child to remain at home as long as possible. JNCS also provides Alternate Family Placements when the child can no longer remain at home.

JNCS also has a Supported Living Services which offers individualised supports. There are five principles of this service

- A home of one’s own
- Choice and self-directed
- Relationships
- Community Membership
- Flexible, Tailored Supports

“It starts with JNCS employees learning about an individual and their hopes, dreams, desires as well as any needs for assistance and support. This is the discovery process. Family members, friends, co-workers and other important stakeholders provide their insight and reflections. This discovery process allows us to develop an Individual Support Plan, which is our “agreement” with the person and his/her family on developing a personalized action plan.

Each individual receiving services from Jay Nolan Supported Living works with a Circle of Support comprised of the person being supported, family, friends, associates, allies, and other community members the individual chooses. The circle of support uses a holistic approach to develop a person-centred plan that helps the individual achieve their dreams.

Decisions made by the individual as well as the circle members include deciding which support staff to hire or terminate, what individualized day-to-day support is appropriate for the individual, what back-up and emergency support is needed, and many other decisions, which comprise the individual support plan. This model maintains the individual’s control over his/her life. The circle of support meets every four to six weeks depending on the person’s choice. The circle meetings are facilitated by the individual or a circle member of their choice.”

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126 http://www.jaynolan.org/index.php
127 http://www.jaynolan.org/supported_living.php