Helping Younger People with Disability in Residential Aged Care Programme

‘A continuum of care’: Summary report of public submissions about support and accommodation for younger people with disability

Australian Government Department of Families, Community Services and Indigenous Affairs
Helping Younger People with Disability in Residential Aged Care

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DISCLAIMER:

The Department of Families, Community Services and Indigenous Affairs has compiled ‘A continuum of care’: Summary report of public submissions about support and supported accommodation for younger people with disability (the report) on the basis of information provided by individuals or groups in response to a formal Request for Information advertised in the media on 15 July. All information sources, including quotes, used in this report have been de-identified with the respondent’s permission.

The Australian Government will provide funding to the States and Territories to develop models for Support and supported accommodation for Younger People with Disability in Residential Aged Care as part of the Australian Government’s contribution to the Council of Australian Governments’ Health Services package. The Australian Government does not have any vested interest in what models the States and/or Territories develop, nor any models proposed by the States and/or Territories.

The Australian Government accepts no responsibility for the accuracy or completeness of any material contained in this publication. Additionally, the Australian Government does not endorse any of the views, comments or proposed models included in the report.
1 Background

On 10 February 2006 the Council of Australian Governments announced a new Programme to assist younger people with disability living in residential aged care throughout Australia. The Programme’s initial target group is people aged under 50 years.

In March 2006 there were approximately 6,500 younger people with disability in residential aged care, including 1,000 people aged under 50 years.

With Australian Government funding of up to $122 million over five years, and up to $122 million from the states and territories, the new Helping Young People with Disability in Residential Aged Care Programme focuses on:

- moving younger people with disability from residential aged care into more appropriate forms of accommodation
- diverting younger people at risk of admission to residential aged care into more appropriate forms of accommodation
- providing disability support services to those younger people with disability who cannot be moved from residential aged care.

2 About this report

As part of the Government’s commitment to provide better support and accommodation for younger people with disability, the Department of Families, Community Services and Indigenous Affairs, issued a public Request for Information on 15 July 2006.

Advertisements requesting information about the issues were placed in all national newspapers and 78 public submissions were received.

This summary report highlights the main issues raised by a range of respondents, including industry peak bodies, service providers and individuals.

The report does not endorse ‘preferred’ service delivery models or particular views. It is simply designed to share information and encourage discussion about suggested options for future support and care arrangements.

3 Responses to the Request for Information

In response to the Request for Information the department received 150 enquiries and 78 submissions. Of the submissions, 71 were from organisations and seven were from individuals. Four national bodies responded. The other respondents were state, territory or community based (see Table 1).

There were 64 submissions from disability service providers (17 also provided health care services), three from peak organisations, and two from advocacy organisations.

Fifty-six organisations were ‘not-for-profit’ and seven were ‘for-profit’. Of these organisations, eight were aged care and accommodation service providers.

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Most submissions (70) discussed direct service delivery; and the others (8) provided specific feedback on the Request for Information process or expressed concern about the current situation for younger people with disability in residential aged care.

Three submissions focused on services to families and carers, but most submissions did include families and carers as a central feature of their models. Only one submission covered the need to develop training materials for families, carers and other stakeholders.

Table 1: Responses to the Request for Information by state and territory

<table>
<thead>
<tr>
<th>Head Office</th>
<th>Number of responses</th>
<th>Existing and proposed service provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>State or Territory Location</td>
<td>Organisations</td>
<td>Individuals</td>
</tr>
<tr>
<td>NSW</td>
<td>28</td>
<td>25</td>
</tr>
<tr>
<td>VIC</td>
<td>27</td>
<td>26</td>
</tr>
<tr>
<td>QLD</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>WA</td>
<td>4</td>
<td>3</td>
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<tr>
<td>SA</td>
<td>6</td>
<td>6</td>
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<tr>
<td>TAS</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>ACT</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>NT</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>78</td>
<td>71</td>
</tr>
</tbody>
</table>

* A number of submissions did not identify their existing nor proposed area of service provision.

4 Elements of proposed models

Most submissions identified service delivery and support models based on the individual. However, some submissions noted particular aspects of support and supported accommodation for people with a specific disability.

Thirty-two submissions included models that could be applied generally, and others suggested model elements specific to people with Multiple Sclerosis, Acquired Brain Injury, Huntington’s Disease, and Spinal Chord Injury. (See Table 2.).
### Table 2: Suggested model elements by disability type

<table>
<thead>
<tr>
<th>Type of disability</th>
<th>Number of responses</th>
<th>Suggested models</th>
</tr>
</thead>
<tbody>
<tr>
<td>All types of disability – general</td>
<td>32</td>
<td>Safe care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Specific case management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Individual planning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Time allowed for rehabilitation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Access to appropriate information and review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Coordinated care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Flexible funding</td>
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<tr>
<td></td>
<td></td>
<td>Individually tailored care packages</td>
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<td></td>
<td></td>
<td>Independent living</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Access to specific therapeutic expertise</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Well-trained and informed carers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Therapeutic, vocational, leisure and recreational needs met</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Varied housing options, allowing choice and maximising independence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provide equipment appropriate to person’s changing care needs</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>9</td>
<td>No waiting lists</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Individual care package</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Continuous care service structure</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assessment and review monitoring</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Case managers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Choice of provider</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Improved education and information for clients and families</td>
</tr>
<tr>
<td>Acquired Brain Injury</td>
<td>21</td>
<td>Person centred approach</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Long term stable outcomes achieved</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Care needs assessment – holistic – based on a person’s health needs, skills, preferences, relationships and experiences.</td>
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<tr>
<td></td>
<td></td>
<td>Advocacy support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Flexible supports and supported accommodation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accommodate changing life circumstances and choices</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stakeholder involvement in decision making</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Able to access specialist clinicians for therapy</td>
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<tr>
<td></td>
<td></td>
<td>Availability of transition programmes</td>
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<tr>
<td></td>
<td></td>
<td>Option of aged care residential – last resort</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rehabilitation services</td>
</tr>
<tr>
<td>Huntington’s Disease</td>
<td>5</td>
<td>Continuity of care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Case management</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accommodation specialising in Huntington’s Disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Independent living</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Additional funds to cater for high food intake and food supplements</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Age appropriate personnel</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Recreation choices</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Close proximity to family and friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Involvement of stakeholders in decisions and planning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transition services from home to alternative accommodation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Skills for new carers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provide a ‘home away from home’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Monitor and respond to needs and expectations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Community integration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Skilled and patient staff</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provide easy access to specialists</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Structured diversion activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Provide time and flexibility to meet people’s specific needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Support stakeholders throughout the terminal illness</td>
</tr>
</tbody>
</table>
4.1 Policies, planning and services for individuals

Over 50 per cent of submissions emphasised that all Programme development and responses should include individual and person centred practices. Respondents identified the need to involve younger people in residential aged care in decisions made about alternative support and accommodation. Support was also widespread for services that are flexible and take account of individuals’ changing needs over time. As well, individual funding packages need to be targeted and well structured, particularly for people with progressive conditions.

‘A package of care that can grow to meet a person’s changing needs over time. Once a package is allocated, the individual would be able to draw down on a range of services – a suite of services available in HACC and Disability Services and could even include aged care (for respite or emergency accommodation) and palliative care.’

4.2 Legislation and the National Disability Standards

One-third of the submissions referred to the National Disability Standards, and others included information relating to the Disability Services Act 1986; the Disability Discrimination Act 1992 and other related state and territory legislation.

Almost all of the submissions mentioned the National Disability Standards in their model descriptions. Many respondents also included details of their own quality systems.

‘Legislative provisions may need to be made to ensure that potential … providers have services that are accountable under the Disability Services Act. It would not be appropriate for services supporting young people in nursing homes to be accountable to the Aged Care Act 1997. Such services must also be accountable to the other legislation as outlined.’

Common views included the need to achieve a balance between the interests of key stakeholders and value for money.

‘The attitudes and opinions of residents and families will be a key performance indicator of quality and culture, and will actively monitor and respond to these as part of ongoing performance evaluation.’

‘While current funding levels frequently compromise the implementation of service principles and values particularly in terms of the least restricted alternative, much can and needs to be done to address individual needs, promote independence and control and enhance quality of life.’

4.3 Supported accommodation models

Submissions included suggestions for accommodation options, and several commented on existing residential choices for younger people with disability. Submissions also discussed non-residential accommodation options including private ownership, private rental, and social and family housing.
Thirty per cent of respondents included information about private provisions; community housing; cooperatives and housing associations; as well as the need for crisis housing. The majority of models referred to associated issues such as the importance of purpose built housing; assistance for housing modifications; and other types of support needed by people with physical disabilities.

Many submissions strongly emphasised the need for a ‘continuum’ of care. Models highlighted the importance of individuals being central in the planning and development of accommodation options. They also argued that a range of accommodation options should be available to give people choices, so they can move to different types of accommodation if their situation changes.

‘In the best possible circumstances, supports and supported accommodation available should be flexible enough to provide the person with real choice. For example, the choice to move to accommodation with attendant care, to move home with adequate home modifications, to move to a cluster setting with company’.

‘Any innovative method … should have the characteristics of flexibility and responsiveness to changing individual needs and choices. Given that many young people in nursing homes will require some level of care over the course of their lifetime, the flexibility has to extend to accommodating changing life circumstances, choices and needs over long periods of time’.

Other issues were raised in relation to accommodation for younger people with disability.

‘Involve the potential residents and families in the planning, design of new residential settings or the renovations of old ones …’

‘Integrate the residents and the setting with the surrounding community and its services …’

‘Accommodation … should be provided within reasonably close proximity to the family of the resident’.

‘Supported accommodation is a … place to live not just being cared for – stimulation not just sustaining life and accommodation is family friendly that allows and supports the interaction between individuals their family and friends’.

‘Residents are supported to live as independently as possible with continuing community access and choice and control over decisions as long as they are able to do so.’

‘Accommodation should be safe, secure and supportive.’

Several submissions stressed the importance of separating tenancy management and support. As well, respondents identified the need to spell out tenants’ rights and responsibilities in shared tenancy arrangements and housing managed through partnerships (that is, partnerships between cooperative and service organisations). Other principles relating to young people’s housing were also raised.
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‘Housing should be
- Dispersed among the general housing of the community
- Of a size and grouping that conforms with community norms of housing’.

Some responses discussed why residential aged care accommodation is unsatisfactory for young people with disability. The majority of respondents preferred alternatives to residential aged care for this group, and many held strong views about residential aged care as the option of last resort. Some submissions suggested setting up accommodation that is attached or linked to residential aged care facilities.

Respondents also highlighted the importance of the local and affordable transport, appropriate equipment, and clinical care to support any housing option.

Models included several common types of living arrangements. An outline of these options is provided in the following pages.

**Living alone with support**

Living alone with support was seen by most respondents as the ultimate outcome for individuals with disability, and submissions identified aspects of models to support this. The aspects included the early intervention to prevent ‘higher levels of care’ and/or further regression; organised transitional accommodation; and adequate support or a ‘package’ that could be expanded to address changing needs.

Respondents considered ways to support individual choice, the option for emergency accommodation; and alternatives that provide a ‘continuum of care’ in a community setting. Submissions also highlighted options to improve independence and reduce isolation.

‘The desire to live in a home of your own, and not in institutional care, has been central to the disability rights movement for over 40 years. There are some organisations that have been founded on that very principle, by individuals who were going to be inappropriately housed in aged care facilities’.

‘The amount of care and supervision provided is commensurate to each person’s individual level of need and may be varied as these needs change’.

‘It is important to acknowledge that some individuals with disabilities prefer to stay in their own home. Support services need to be available to ensure these individuals are able to continue living in their homes effectively and safely’.

Many respondents considered that a number of assumptions are made about people with ‘complex needs’, ‘high care needs’, or challenging behaviours. Disability service providers said that with the right planning, effort and service mix it was possible for people in all these categories to live independently.
On many occasions we have been told that the individual concerned has “high support needs” or “complex medical requirements” that facilitate the need to reside in an aged care facility. One example of people with “high support needs” successfully living in the community can be found in a program that supports over 15 people who are ventilator dependent to live in their own home. Despite the high cost of care it is still substantially cheaper than hospital care.

Living with family

Respondents raised issues about living at home with family, and many identified the steps that lead to the move from the family environment into residential aged care. Early intervention strategies and access to respite and flexible support were identified as strategies to prevent the shift away from the family home.

Submissions also highlighted the need for transition support if younger people are to return to the home. This should involve developing a transition plan that incorporates rehabilitation and appropriate levels of support. Respondents also noted that some people may need to re-engage with their families and communities, and that clinical services, counselling and life skills training should be provided as well as a range of disability supports.

Emphasis was placed on the need to educate clients and their families about their condition, particularly in the case of degenerative conditions. They should fully understand the progression of the condition, the impact it will have on the client and individual family members and the support that is available from the wider community through each phase.

For people who have been living in an aged care facility for some time, the transition home and the increased level of responsibility can be both daunting and traumatic. It may be that some will require a gradual introduction into a new programme starting with short respite stays. The person will eventually leave the nursing home and stay … in transitional accommodation. Prior to this final transfer, the applications for housing, personal care services, equipment etc. must be in place.

Another issue raised by many was the lack of information for individuals and families about supported accommodation options, and in particular information for people who suddenly acquire a disability.

While options for accommodation support may be available for people with disabilities, their carers lack clear and consistent information on how to access such support. This often leads to people giving up, or not applying for support they may be entitled to. This issue is often stronger for people with acquired disability who have not had natural entry into the system in childhood.

Shared living arrangements

Respondents considered a range of shared living arrangements including with:
- other people with disability in a house, block of units, block of motel style units, or purpose built group residences
Helping Younger People with Disability in Residential Aged Care

- other people without disability in a shared tenancy arrangement, when the co-tenant often provides some level of support, an informal relationship, and a link to the community
- other people with and without disability in a village setting, cooperative arrangement, or cluster housing developments.

The suggested sizes of group homes varied. However, most respondents thought four to eight people in a home with onsite 24 hour support is the model most likely to give tenants more independence and individual privacy.

Respondents suggested that shared living models should reflect individual needs; provide choices; take account of gender and cultural needs; involve families; offer safety and security; be affordable; and be located in a community setting.

Examples of shared living arrangements

‘A group home includes private and communal areas, good access and surrounds, hydrotherapy pool on-site (also used by public), vehicle for transport, on-site physio and equipment and an adequate staff ratio means that families can be assured of excellent personal care for their loved one. Seven residents live here with respite offered.’

‘Six purpose built fully accessible two bedroom units, two of which would be joined by a “motel style unit” for staff. One of the aims of this project is for people to be able to live with family, partners/friends therefore it would be unlikely to be fully occupied by people with disability.’

‘Proposed model based on the cluster housing style, with six motel style rooms that would include bathroom facilities (disabled access). These rooms would be attached to a common kitchen area and would also include a common lounge room and laundry. The staffing attached to the service would be ultimately dependent on need; however the model will be adjacent to a currently staffed 24-hour service, with a stand up night shift thus reducing staffing costs.’

‘Up to ten units in close proximity to each other with a carers unit amongst cluster of units. Intercom systems and buzzers in each unit connect to the carers unit. Entertainment area for individuals to have parties or barbecues. Individuals have their own bedroom and privacy.’

‘A shared house where the house is shared by person with disability and another person who provides companionship, shares the preparation of meals and provides limited assistance in exchange for accommodation. This situation would also need to be supported with brokered services for the person with a disability. This enables increased social networks, autonomy and independence and the development of a meaningful relationship’.

‘A suggestion includes a range of options for people including funded in home care, respite care, short-term crisis accommodation, independent living units in a village style accommodation.’
Larger group living arrangements.

Several submissions outlined features of existing group facilities that have large numbers of people (20 to 100 residents). Several models include beds for people with specific disabilities and respite beds, and transitional arrangements for people receiving rehabilitation. These models also cater for a range of ages. Some are part of hospital settings or existing residential aged care facilities.

In submissions that opposed large group living arrangements, a range of issues was raised, for example:
- limited scope for ‘individual needs to be met’ and reduced ‘home like’ provisions
- less capacity for family involvement, and community involvement and community integration
- safety and security concerns
- constraints on providing age appropriate, cultural and gender relevant responses
- concerns about ‘a high level of care’ unnecessarily provided for all residents.

Examples of larger group living arrangements.

‘A forty-five bed, high level residential care facility. This facility includes large individual rooms. 24/7 nursing care, annexed to an Aged Care Facility. There is no recreational space.

‘A thirty-bed high level residential care facility. Patient centred model of care. There is no recreational space.’

‘A twenty-one bed residential on hospital grounds. This is a complex care facility providing time limited, high level residential care. All referrals to this facility since 2000 have been for a 2-year “transition” type program, encompassing low-intensity rehabilitation to facilitate discharge to either community, or to mainstream residential care. This facility includes “slow to recover” funding where applicable and supports individually tailored therapy.’

‘A facility with five houses and thirty independent units. Included in this are seventy-nine Commonwealth funded aged care beds (high and low), Twelve Transport Accident Commission (TAC) beds (ABI) Seventy-eight unfunded beds which are either contracted for short-term rehabilitation or offered privately.’

4.4 Disability support services

A third of the submissions advocated a ‘continuum of care’ for younger people at risk of entering or who want to leave residential aged care. The range of services needed include disability, clinical and generic services.
Examples of providing a continuum of care

‘An example of one proposal is a four level continuum of care service model. This ranges from comprehensive support in the community utilising existing systems, community living units, specialist residential and respite facilities and existing residential aged care services. It includes an holistic approach to care and identifies appropriate accommodation and support options following assessment to identify individual requirements. These services could be provided through partnerships between existing service system providers and/or individual initiatives by organisations. Overarching all services is a regionally based therapy team, providing care assessments and consultative therapy services.’

‘This proposal includes packages to support people in the early stages of diagnosis of a deteriorating neurological condition. The packages we propose would need to be put in place in the early stages of one’s illness if the full benefits possible are to be obtained. We envisage these packages would include support from the time of diagnosis, through the process of education and information to matters relating to managing medication. Families would be included in the process of adjustment and plans put in place to better manage the progress of disability.’

‘This model allows for the possibility of pooling care so that where a number of people require assistance one or more carers can provide a service to those people without the travelling time.’

Most submissions supported direct service delivery. However, some specified extra support such as a programme to coordinate service delivery or broker services; a mobile outreach programme to provide emergency or ad hoc services; and a research programme to foster contemporary service delivery approaches.

Individuals and families raised several other issues, for example, the importance of providing timely services in dignified and respectful ways, allowing time for people with disability to prepare for and adapt to new arrangements, and making sure services have the capacity to respond to individual needs.

‘The thing that makes a difference is the staff’s attitudes. The staffing has to be at a level that allow individual attention like being able to spend 30 minutes feeding someone orally, who is peg-fed and has swallowing difficulties.’

‘There are degrees of support that are required at various stages of the disease (MS), including community care, respite, allied health support and residential care.’

Some respondents stressed issues that relate to specific disabilities, for example, the need to cater for extra meal times and higher food intake and food supplements for people with Huntington’s disease. Other submissions noted that individual choice and individual planning and coordination of services are essential across all services. (For suggested service delivery elements, see Table 2.)

Across submissions a common thread was that some people only had access to one service or one type of service. Submissions recommended that services should respond
to all of an individual’s needs, rather than one or just a few - for example, if a person needs a Home and Community Care service to assist them to shower, they may also want help to participate more in their community.

Coordinating care options was a consistent call in many submissions, particularly because a range of disability, clinical and generic supports are needed. Several respondents were concerned about the lack of joined up services and local policies. These submissions claimed that uncoordinated and inflexible services were often the reason why individuals could not remain in the supported accommodation they had chosen.

‘A single point of access should be established for ease of access to the confusing array of available community services.’

4.5 Clinical care

Submissions that included models of supported accommodation also covered strategies and related service options for clinical care. Many respondents noted that although clinical care will vary for each individual, it needs to be available in the early transition phase and remain part of the service mix. In particular, a third of the responses included the need for access to therapy services.

While some respondents suggested that clinical services could be brokered when they are needed, others simply recommended increasing the number of services available.

There were also diverse views about the location of clinical services. For instance, some submissions proposed models of shared living in group home arrangements and congregate care and suggested that clinical services should be offered on site. However, others said this would not respond to all individual needs; limited people’s choices, and continued the practice of applying ‘a high level of care’ to everyone, whatever their situation.

Early identification of clinical care needs was coupled with the need to provide information to families, individuals, carers and service providers. As well, clinical care should be timely and accessible and matched with the rehabilitation and progressive care needs of younger people with disability.

In the early phases of a younger person’s diagnosis, it was noted that coordinating appropriate clinical care, or even understanding what was available, was very confusing and a significant challenge for individuals and their families. In particular, this is difficult for people who have not already used clinical therapy and disability services – for example, for people with an Acquired Brain Injury or people diagnosed with a progressive condition.

‘Opportunity to access specialist clinicians for therapy to increase skills, to prevent secondary complications and manage activity limitations. Clinical specialist services includes but is not limited to rehabilitation specialists, clinical psychology services, neuro-psychological assessments, case management, physiotherapy, speech pathology, occupational therapy and social worker services.’
A few respondents identified problems accessing specialist clinical support in rural and regional areas, and some suggested how this could be overcome.

Since the clients using this service have a combination of physical cognitive disability and some level of social disadvantage, most will have limited mobility, and will be unable to access services at a distance from their home. Members of an outreach team could also troubleshoot new problems with a view to preventing hospital admission if possible. The outreach team would provide specialist input and peer support to regional and rural service providers, mainly through consultancy and telehealth links.

4.6 Associated supports

Some models of supported accommodation included the need for timely, affordable and appropriate equipment and transport, and suggested linking these within individual plans to underpin supported housing options.

Submissions also included a range of policies and practices to support individuals in their chosen accommodation, for example by:

- maintaining governance mechanisms that involve stakeholders
- ensuring the issue of access is considered across all environments, especially in people’s chosen accommodation
- providing support that is integrated with the availability of necessary equipment
- offering a taxi subsidy or other transport allowances, and take account of the transport needs of people with disability and their families in rural and regional areas

‘Availability of appropriate (accessible, cost effective) transport is crucial for people with disabilities to enable them to meet their individual goals and prevent isolation.’

‘Depending on transport and rural/metropolitan location a vehicle fitted out for wheelchair access may be required. Wheelchair taxis are in very short supply in the … regional location.’

‘Equipment purchased or hired is based on the residents/clients individual needs and is assessed for suitability by the staff and Allied health team. Current equipment includes, however, is not limited to lifting equipment; electric beds; shower trolleys; commodes; wheelchairs – manual and electric; wheelchair weight machine; gastrostomy pumps; suction equipment; oxygen equipment and concentrators; nebuliser pumps; tilt tables; plinth table; leg weights; exercise bikes; spa; voyager system.’

4.7 Respite

‘Access to quality respite is a dire need to enable families to continue their caring role’.

A third of the submissions referred to respite as part of the mix of services offered to families and individuals with disability.

Family respondents claimed that, for some, the availability of timely, appropriate, locally based respite would have prevented early entry into residential aged care or other residential facility for younger people with disability.
'Respite assists in reducing pressure on families, and in preventing admission to long-term facilities. It may also help encourage those who are now institutionalised to look at other options, after they have spent time away from their present residence.'

Respondents put forward a number of ideas about respite options.

**Examples of respite options**

'The proposal seeks to offer carer’s some respite and also offer the person living with a deteriorating neurological condition such as MS, the opportunity to be a part of their community. It will offer them the chance to plan and then participate in activities on a regular basis in the … metropolitan area and close regions. It is planned that partnerships will be developed with other organisations such as the … zoo and local council libraries.

'It is planned that six beds will be available for us to use for respite for approximately nine months of the year and two beds will be available for our clients all year. The respite we will provide will include planned and unplanned (emergency), and will be mainly for short term stays.'

Respite in the form of day tours 'is a social program designed with the participants input and is run according to their needs and finances – it provides respite to carers and a social program for younger people in nursing homes.'

**4.8 Case management and assessment**

Case management, assessment, monitoring and review make up the centrepiece of service responses across half of the suggested models.

'Specialised case managers would execute the plans and monitor client needs and service quality'.

'Timely and appropriate individual needs assessment and planning is crucial. The process needs to have the capacity for ongoing review to take account of changing needs, confidence and capacity. It needs to take into account all relevant stakeholders to provide a full picture of the individual’s history, aspirations and potential.'

'A needs assessment must include a rehabilitation component (speech therapy, vision therapy, physiotherapy, communication training) and equipment required e.g. communication devices. It must also address the emotional needs of the person, likes and dislikes, community participation etc. Any case management offered must not be time limited.'

Some submissions saw case management as a precursor to developing individual plans. However, most considered that case management was needed as an ongoing resource and could assist in better coordinating service options available to each individual.
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‘The preliminary step prior to an investigation of service options. An assessment based only on care needs is insufficient. Any assessment undertaken would need to include holistic measures of a person’s health needs, skills, preferences, relationship and experiences.’

‘Linking of assessment, planning and service design builds on a continuity of care philosophy with the service provider following the individual through the various phases, rather than the individual being handed over at the end of each discrete phase.’

A number of submissions also included the benefits of case managers working with families. They said that this usually helps in developing informal relationships and support around the individual, particularly in the early stages when people are at risk of entering a residential aged care facility.

Most proposals suggested regular reviews of assessments. This was considered particularly important for people with progressive conditions because their needs and choices change over time. However, a few proposals expressed concerns about unnecessary assessments, especially when a person’s situation and disability are stable.

‘Funding should be put into service and accommodation support, which is developed from one thorough assessment. Clients should not have to undergo unnecessary repetitive needs assessments.’

Several submissions focused on one or two case management aspects of the ‘continuum of care’.

‘The model is based on a case management framework, with a case manager working closely with the younger person with a disability and his/her family to comprehensively assess and plan for their needs, desires and aspirations in the process of moving from a residential care facility or to divert them from placement in residential care. Case management involves working across many boundaries and systems. Case managers understand how each system interacts and ensure a match between available resources (both formal and informal) and client needs, providing support in the most cost effective manner, while maximising independence wherever possible. All support/services are coordinated and implemented by the case manager who acts as the one contact for the person with a disability and his/her family and therefore reduces the complexity of the process for the younger person and his/her family.’

4.9 Stakeholder involvement and support

Respondents overwhelmingly noted the importance of individuals and often their families being involved in the planning, development, delivery and review of all areas of the ‘continuum of care’.

‘Needs of the client are assessed and plans are developed based on what they and their family want’.

Submissions from family members, individuals and many organisations pointed out that involving individuals and families means that support is tailored to the choices people
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make; ensuring informal relationships with friends and families are maintained; and providing more effective safeguards for individuals.

‘The involvement of families is a prime consideration in the promotion of a person’s well-being. It is important … to support families for the purpose of either preserving or reunifying the family unit wherever these goals are consistent with plans developed to achieve the person’s safety from harm.’

‘Family and friends participation in the client’s everyday life is considered a vital necessity for ongoing health and wellbeing of the individual. Where applicable family are consulted and involved in the care planning process and are informed of health deterioration and changes made to care and or treatment. Family and friends are welcomed into the facility and relationships fostered between carers and family members to establish a trust and rapport. Counselling services are available for family and friends as required to assist them in the adjustment to a new environment on admission and to provide them with ongoing support regarding stressful situations that may occur due to health deterioration of their loved one, grief and loss or other outside influences that may be affecting the way they are coping and feel.’

Two submissions focused on people from diverse cultural backgrounds. Both emphasised the need for close involvement of individuals, and often their families, in making choices. One of the submissions identified a model of supported accommodation for Indigenous people, which included close involvement and close proximity to the individual’s and family’s community. The other submission highlighted the value of services that are culturally appropriate and respond to the cultural needs of the person and their family.

Respondents considered the effects on people with disability if they decide to move from metropolitan aged care facilities back to their own communities in regional areas. In cases like this, all the stakeholders need to be involved in the transition.

‘Families, who live in rural and remote regions, in their bid to obtain service delivery for their child with a disability sometimes place their children in the more major centres around Queensland [sic]. Therefore it will be important to include families in the decision making process if clients are to be relocated geographically.’

4.10 Transition arrangements

Twenty-three submissions included a transition service option or suggested that transition services were crucial in assisting people to re-enter the community. As well, 10 of the submissions noted that information for individuals, families, carers and other decision makers was important throughout the process of transition from residential aged care.

‘Merits of transition arrangements are noted as:
• Reducing the amount of dislocation and relocation of families
• The ability to provide ongoing slow stream rehabilitation;
• The provision of time to allow for appropriate care planning and home modifications to occur before the person returns home; and
• The establishment of the care partnership between the family and the service sector.’
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As with all other parts of the ‘continuum of care’ transition, submissions mentioned that approaches will differ at different phases of a person’s entry or re-entry into new supported accommodation, and that these approaches need to be aligned with various support and housing options.

There needs to be ‘Community based transitional rehabilitation programs so people with high care needs can access this program to increase the skills and introduce the supports required to move from nursing home care or hospital acute care to the community.’

‘It is anticipated that a transitional phase may be necessary for some people to facilitate a graduated move from residential care when the younger person needs assistance to adapt to living within the community’.

‘The transitional phase would be of limited duration (possibly 3–6 months) and involve a graduated process while still being in a “protected environment”. The type of process being considered is the linking to community activities for say, a day per week; the building of supportive relationships (family, neighbours, friends) which will provide support and assistance when the person lives in the community; provision of support to family while transition is taking place; provision of services and equipment to assist the transition; assistance with budgeting; planning/cooking nutritional meals; rehabilitation support; counselling linking to medical services and provision of other services that are required. This process may be graduated and extended to staying in community housing with supports for short periods once the younger person feels confident enough to try this. With review and adjustment to the person’s changing needs, this will enable the further step of full-time community living. A transitional phase could also address any supplementary services/supports required.’

4.11 Cross programme and cross agency collaboration

Twenty-three submissions noted the importance of cross agency involvement and said that local protocols, as well as ‘back pocket’ protocols, help to ensure a smoother alignment of service delivery.

Many submissions highlighted the frustrations and difficulties in aligning services across the service mix (clinical, disability and aged) to ensure seamless responses for individuals and their families. They argue that protocol arrangements, as well as jurisdictional flexibility, are essential to improving responses to the needs of younger people with disability, particularly people with progressive disabilities who may eventually need palliative care.

‘The full suite of services is currently operating in the HACC/disability/aged care spectrum, but the journey through the sectors is not linear or even accessible at present. This package will require back of house protocol arrangements between various jurisdictions and funding programs, however that is entirely possible.’
4.12 Community integration

In one form or another, organisations and individuals identified the need to ensure continued community connections for younger people with disability. Some expressed strong concerns that younger people in residential aged care facilities can become isolated and lose relationships and life skills that are usually associated with community integration. Ten submissions referred to specific strategies that could improve community integration. These included community development strategies and dedicated staff to promote the involvement of individuals and their families in community life.

Some submissions also said that existing congregate care options do not provide opportunities for community integration, seldom have recreational spaces, and often have policies or practices that limit family and community connections.

Individual respondents particularly noted that the heightened ‘service’ environment in aged care and other congregate settings meant that people lost the skills to relate to others apart from those providing the care. They also commented that social isolation affected people’s ability and readiness to improve their health.

Examples of strategies and outcomes to improve community integration

One submission proposed that self-funding people with disability employ private companions to help them participate in community, small group and individual activities, and to take them on holidays. ‘An example is one 53 year old e.g. from being bed bound, aphasic and totally withdrawn to being up and about, sometimes able to utter words, learning to use a cd player and responding with joy to activities of interest.’

‘In circumstances where the person chooses to reside in a facility then community disability support services are accessed and links with family and friends supported to improve the quality of life for the person and reduce the overall impact of living with frail and elderly people in their final years.’

‘It is necessary to … provide reasonably close proximity to family of the resident, such that the travel distance is not an impediment to either the resident visiting family, or alternatively family and friends visiting the resident.

‘Integrate the residents and the setting with the surrounding community and its services; incorporate well-trained community volunteers into the operations of the setting via a structured program.’

‘In one case example, support by a music therapist allowed a client to increase his capacity to communicate through the use of sounds rather than eye blinking.’

‘Model coherency – it ensures that the right program is being offered by the right people to the right people in the right way and that this is consistently so. The … project operates by working with the individual and family to identify their individual interests and potential groups/interests they might wish to be linked to build up confidence and establish their role within this community. The worker also assists the community group to identify the best way to respond to the individual’s needs.’
4.13 Rehabilitation

Many submissions stated that rehabilitation could assist people to re-enter the community in the post acute phase of their injury or diagnosis; re-engage with family and community; and re-establish a life in alternative supported accommodation. Whatever the circumstance, submissions indicated that individual rehabilitation phases could differ in time and intensity.

Twenty-nine submissions identified models that include a rehabilitation phase with internal rehabilitation strategies and external or brokered rehabilitation for younger people with disability.

Also noted was that rehabilitation for some people with progressive conditions may need to occur at several points in the ‘continuum of care’.

Examples of rehabilitation approaches

‘There is however emerging evidence that slow stream, contextualised rehabilitation can assist these people to increase their level of independence and reduce accommodation and support costs in the longer term’.

‘Example: Establishment of a small, slow stream rehabilitation-focussed transitional community accommodation facility (T-CAF) for people with very severe ABI. The length of stay would be up to four years’.

‘For some people after a severe TBI the skills they require to live with others have been damaged and living alone with support is the best and only option.’

4.14 Information and advocacy

Several submissions stressed the need to make ongoing information and advocacy services available to individuals and their families.

‘Support for the person and their family in the decision making process to determine accommodation options and the preferred living arrangements. An advocacy role in negotiating and providing appropriate long term care and accommodation options as an alternative to residential aged care services where these services are available and meet the wishes and needs of the client.’

5 Resourcing

Over 80 per cent of submissions included comments and information about funding for models of supported accommodation. Funding levels varied according to the approach suggested. Costings depended on the type of supported accommodation model;
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individual needs; funding sources; capital funding for buildings and/or refurbishments; location; equipment; and staffing and human resource arrangements.

Many respondents suggested that some of the initial government programme funding be set aside to evaluate new services set up to support younger people with disability.

‘These proposed changes are considered to be more complex than the current prioritisation system with no clear evidenced based benefit to the person or their family. Process evaluation will need to be implemented at the same time and funding made available for such research’.

‘We recommend that evaluation methods be developed and implemented to assess the outcomes of each of the models of support and supported accommodation.’

Some submissions also recommended that a proportion of the programme funding be set aside for ‘crisis situations’.

‘At present a number of younger people reside in aged care services or are at risk of entering such services because their high level of physical and personal care needs cannot be funded. The program will need to factor the prevention component into the program. A suggested way is to allocate a certain amount of the block funding for crisis management’.

5.1 Funding

Possible funding arrangements were mostly designed to ensure long term viability, and some submissions included support for a specific target group and, more generally, for young people with disability at risk of entering or in residential aged care.

Possible savings were identified for individuals when a number of people share some parts of the support, especially when they live alone or with their family. However some respondents claimed that the savings are not as high for people in congregate care.

Specific areas of savings for people living alone and with family included providing informal, unpaid support and reducing capital funding and/or maintenance costs. As well, some respondents identified savings when people’s skills increase and demands for service support lessen.

Most respondents costed ‘continuum of care’ approaches, mostly because they say these promote greater choice. At the same time, these approaches offer more value for money because the funding is targeted at specific needs.

Some of the proposed models suggested in house clinical support. Others identified savings by using existing networks of clinical support for low levels of care.

Submissions included various ways of co-locating supported accommodation for younger people with disability - for example, with a residential aged care facility and in some cases, sharing resources.
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“This model is based on up to four houses built on one block of land next to an Aged Care Facility. The houses would be staffed to support the residents in their daily living. Significantly, the houses would be staffed to provide age appropriate recreation … the co-located Aged Care Facility would resource the four houses. The direct care resources provided would include laundry, meals and nursing staff. The synergies would include management, fire alarm, sharing staff, training, telephone and insurance’.

5.2 Partnerships

Savings were suggested by allocating tenancy management to an external party or partner organisation.

Examples of partnerships

‘A housing company and a not for profit organisation have developed a supported accommodation site of 13 independent living units for people with an ABI or other neurological disability. The project is designed for people who are in receipt of … disability support funding … or Transport Accident Commission (TAC) funding, and who require moderate levels of support. The site incorporates 2 respite beds for people with Multiple Sclerosis. Capital funding has been raised through a number of sources including government and charitable grants (50%), resident (mixed equity) contributions, loan funds (housing organisation) and support provider contribution (not for profit organisation) (42%) in return for title. The housing company will provide the tenancy management and the not for profit organisation will provide the support. Refurbishment and modification funding through shared contributions by both organisations (85%), resident contribution (7.5%) and the Slow to Recover Program (7.5%). Operating costs, short and long-term maintenance is funded through accommodation charges (rent) paid by the residents.’

5.3 Individual needs

Individual planning and person centred approaches were central to most submissions, with the majority preferring individual support packages. Some respondents claimed this reduces overall costs because the funding is targeted directly to specific needs.

‘The support model for this service is funded through individual support packages – with funding attached to the individual not the service’.

‘A minimum 34 hours of attendant care funding is required for tenants to be considered for placement, enabling the resident to access 24 shared supervision and support, plus 3 hours per week individual planning assistance. Community access, day placement, rehabilitation and recreational/leisure options are not included in the support model; however, residents are given the opportunity to pool individual support to access recreation and leisure options. Individual funding agreements vary according to individual need. The average support cost per person is $58,615 per annum, including rehabilitation services funded through the Slow to Recover Program in addition to the minimum funding requirement.’
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‘Individualised funding is the preferred option however in the light of limited resources strategies to make the best use of resources may involve some sharing or pooling of resources. Some examples of or suggestions for sharing of resources include:

- People living in close proximity pooling support services to enable flexible use of resources.
- Town houses/units (no more than four) on one site with staff unit to enable 24 hour access to support.’

‘Individuals need to have the opportunity to administer their own package of funds or to choose the organisation they would like to administer the funds.’

Several responses pointed out that costs could change as an individual’s needs change.

‘For people with Huntington’s Disease … recognise and validate the need for variation in the maintenance costs for each resident where this arises from the inherent nature of the disease – this would apply, for example, to the extra catering costs for residents … who require a high food intake and food supplements.’

Other organisations favour block funding.

‘That funding for this cohort be by way of block funding to relevant organisations during the transition and establishment of innovative models of support until program stabilisation is evident and sustaining patterns of service delivery emerge. In addition this organisation noted … that the yearly block funding reflects the actual CPI increases in real terms.’

5.4 Funding sources

Other options for funding arrangements included funding for capital or refurbishment costs for supported accommodation facilities. Generally, the respondents wanted recurrent funding from government for support and clinical care.

‘Capital funding for each development is separate from recurrent support and is to be sourced through partnerships with not for profit community housing providers.’

Some respondents suggested a mix of funding from various levels of government and government agencies.

‘Our organisation (Residential Aged Care provider) believes (as with other current models to date), that the most cost effective means of running such a program would mean that Aged Care provides top-ups to places and Disability Services also contribute additional funding to support the disability needs. Overall the Commonwealth funding covers the accommodation and care component but, in terms of providing that additional support, the … disability … state programs would be required to do that’.
The Transport Accident Commission (TAC) ‘will be a primary fund provider for many of our proposed permanent clients. Other compensable clients such as work cover, and private insurance recipients may also be expected as permanent residents.’

‘There is a clear need to develop workable and viable options for people who have received, and continue to receive, compensation funds for their catastrophic injuries. Considering alternative ways to supplement the actual compensation fund itself … is one recommendation. This option requires the injection of funds from government, with the emphasis on extending the overall lifespan of the individual’s compensation funds.’ The respondent suggests early injections of government funding, together with compensation funds, could pay for the appropriate level of care, reduce the need for high level care, and at a minimum lessen the chance of premature admission to residential aged care).

Several submissions included the option of client contributions towards operational and maintenance costs, although the amounts were minimal.

5.5 Equipment

Some responses included equipment as an extra cost to the individual and/or their family. Others suggested coordinating equipment which would be offered at ‘no cost’ or ‘minimal cost’ to people with disability.

5.6 Staffing/human resources

All of the responses that proposed supported accommodation models included information about the staff required to maintain the support. Options included:

- staff to coordinate services, often from external agencies - for example, therapy, specialist clinical support, equipment, transport, hairdressing, and recreation
- nursing and other support staff, including in-home support workers and for recreation or leisure activities
- staff to support individuals, families and carers
- ancillary staff – for example, for grounds maintenance and the kitchen
- ongoing training for staff
- human resource management staff

While most respondents provided costings, there were many variations in the support model because of individuals’ needs and different types of accommodation options. Some respondents also mentioned that the mix of external and internal support could vary in rural and remote areas where some external services may not be available. Staff training was also a key consideration in the budgets.

To support people with a progressive disability and people with high clinical care needs, it was suggested that nursing staff and clinical support coordinators (registered nurses) should be a key part of service responses, and that skilled staff should be available to support people in and out of their accommodation.
‘After consulting with service providers currently providing similar service it would appear that if the service supported eight residents, there would be a requirement for two registered nurses each working an 8 hour shift per day and two assistant nurses per shift.’

‘Complex medical clients would need a model with … nursing staff … managing the clinical care. The registered nurse could work across several homes or be employed jointly by a number of service providers with homes in the same geographical area as a care co-coordinator. Registered nurses wages are $28 per hour. Enrolled nursing (EN) wages are $19 per hour. Certificate 4 EN’s can administer medication. Assistant in Nursing (AIN) wages is $16 per hour. (All these are flat rates with no penalties or shift loading)’. (This option relates to a specific model and State).