BRIGHTwater

Submission to the Senate Standing Committee on Community Affairs – Briefing Paper

The adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

Introduction

The Brightwater Care Group is one of the largest providers of residential care in Western Australia employing more than 2,100 staff and providing care to over 2,500 Western Australians across 23 facilities located from Joondalup to Mandurah as well as a variety of community and at home care services. Although often recognised for its services to people who are ageing, Brightwater has also been providing specialist rehabilitation, transition and accommodation services to people with a neurological disability for over 20 years.

Within its suite of services Brightwater delivers a number of specialist services that support younger people with complex disability. These include:

1. *Additional Care Subsidy Scheme - additional services provided within existing Residential Aged Care Facilities*

   The purpose of the Additional Care Subsidy Scheme is to fund existing and prospective nursing home residents who, because of their complex and high cost care needs, or their age, require care that is above that or unavailable through normal Commonwealth funding arrangements or outside the current boundaries of normal State Government funding. Many of these people are under 65 years of age and live in an aged care facility due a lack of suitable accommodation able to support the complex nature of their care needs.

2. *Long Stay Younger Persons Program (LSYP) – transitional support and interim accommodation for people with complex disability unable to discharge from the metropolitan hospital system (Model of Care – Appendix 1)*

   Funded by the Health Department of WA, this program developed as a result of large numbers of people under the age of 65 in metropolitan hospitals who had complex disability but were medically fit and ready for discharge. Due to the complexity of their care needs they remained as inpatients for lengthy periods whilst their carers, clinicians and service providers engaged in protracted negotiations to find a suitable pathway out of acute care. This resulted in acute care beds being used as interim accommodation to the detriment of other patients needing inpatient care.

   High level of care in interim accommodation within the LSYP Program allows younger disabled clients to adjust to their medical condition, optimise their physical and psychological functioning and maximise their ability to enter long-term supported accommodation or to return home with community support. During the period of interim accommodation, individuals are supported to develop a planned exit strategy to access long-term supports to meet their assessed needs.

3. Oats St Rehabilitation Program – slow stream rehabilitation in a home-like, community based residential environment

The Oats Street Program provides a residential and community based rehabilitation program for people with a diagnosis of neurological disability, due to acquired brain injury (ABI). The program has a strong focus on Cognitive Rehabilitation Therapy and goal directed individualised outcomes.

While the program aims to maximise functional ability, it also focuses on identification and development of appropriate long-term accommodation.

Accommodation Services for People with Huntington's Disease – a continuum of support services for people with Huntington's Disease including two shared community houses, Ellison and Kailis House, for people with mid and end stage presentation.

Both Ellison and Kailis House, funded by the Disability Services Commission, are part of a larger continuum of care for people with Huntington's Disease. This continuum also supports people to live in their own homes while others may choose to live in a Brightwater residential aged care facility. The aim of the continuum is to provide people with a choice of accommodation options, enable them to plan for the future degeneration associated with the progressive nature of the disease and to be provided support commensurate with their needs

4. Accommodation for People with Severe Disability Related to Acquired Brain Injury (Endeavour House) – shared supported living in a high care environment conducive to supporting people with brain injury who have extremely complex care and health needs.

Endeavour House supports people with an acquired brain injury whose severity of injury prevents them from effectively and spontaneously interacting with their immediate environment. All people living at Endeavour House have both high support needs requiring the availability of a multidisciplinary team and high health care needs necessitating access to 24 hour nursing staff. This facility is situated in the local community and aims to provide people living there with a healthy and stimulating lifestyle.

The very nature of the programs outlined above plus the many years that Brightwater has been providing these services means that the organisation has a comprehensive level of understanding, knowledge and expertise in supporting younger people with complex needs. Many of these services are unique to Western Australia and assist people in linking to and transitioning between the health and disability sectors.

Response to Specific Questions

1. The estimated number and distribution of young people in care in the aged care system in Australia, and the number of young people who require care but are not currently receiving care

Figures from the Productivity Commission, Report on Government Services 2014 indicate that of 18,904 people in residential aged care in WA in 2012/13, 498 were people of non-indigenous background aged between 0 – 64 with an additional 22 people of indigenous background aged between 0 – 49.

Additional tables from the report the show the following:

Year	Non Indigenous 0 - 49	Non Indigenous 50 - 64	Indigenous 0 - 49	Total
07/08	18	137	-	155
08/09	8	148	10	166
09/10	16	142	6	164
10/11	10	141	7	158
11/12	5	127	6	138
12/13	15	128	6	149

Table 1 Number of people under the age of 65 admitted to residential aged care in WA

Year	Non Indigenous 0 - 49	Non Indigenous 50 - 64	Indigenous 0 - 49	Total
07/08	75	538	-	613
08/09	46	494	21	561
09/10	49	497	18	564
10/11	42	505	19	566
11/12	35	488	18	541
12/13	41	457	22	520

Table 2 Number of people under the age of 65 in residential aged care in WA

Brightwater's own figures demonstrate that approximately 10% of all people living in its residential aged care facilities are under the age of 65.

Sex	0 – 49 years	50-54 years	55 – 59 years	60 – 64 years	Total 0 – 64 years
Female	3	6	10	16	35
Male	5	6	6	16	33
Total	**8**	**12**	**16**	**32**	**68**

Table 3 Number of people under the age of 65 in Brightwater residential aged care (total population 681)

Whilst individual diagnoses are varied and many are also impacted by additional health and mental health related conditions, the predominant disabilities for people under 65 years living in Brightwater's aged care facilities are dementia, brain injury and neurodegenerative impairment. The table below indicates the percentage number of people under 65 in each diagnostic group. It should be noted that some people are represented in more than one diagnostic category.

Sex	Brain Injury	Neurodegenerative Impairment	Dementia	Congenital Disability
Female	27.5%	27.5%	39.0%	< 1.0%
Male	47.0%	< 1.0%	40.5%	15.5%
Total	36.5%	16.0%	40.0%	11.5%

Table 4 Percentage of people in each diagnostic category Under 65 years living in Brightwater Aged Care

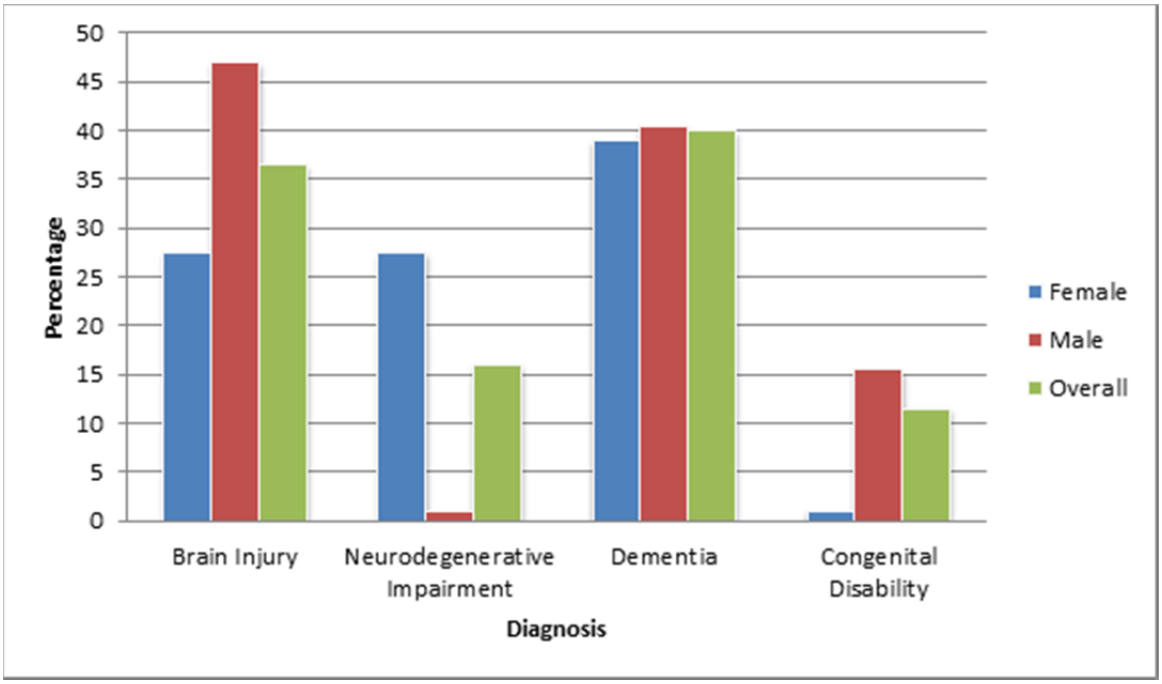


Figure 1 Percentage of people in each diagnostic category Under 65 years living in Brightwater Aged Care

2. Short- and long-term trends in relation to the number of young people being cared for within the aged care system

Figures from the Productivity Commission, Report on Government Services 2014 would indicate a reducing trend for the rate of people in WA under the age of 65 per 10,000 people admitted to residential aged care.

Year	Non Indigenous 0 - 49	Non Indigenous 50 - 64	Indigenous 0 - 49	Total
08/09	2.2	142.3	38.4	33.5
09/10	4.3	132.6	22.8	32.2
10/11	2.6	128.0	26.2	30.4
11/12	1.3	111.8	22.2	26.0
12/13	3.6	106.5	21.9	26.6

Table 5 Rate of people aged 0 – 64 admitted to RAC in WA per 10,000 population

Availability of figures regarding the numbers of people discharged back home from residential aged care is limited and what figures are available show that once someone is admitted to residential aged care the likelihood of discharge home is slim.

Year	0 - 64
07/08	19
08/09	15
09/10	Not Published
10/11	9
11/12	11
12/13	<10

Table 6 People in WA under the age of 65 who have left residential aged care to go home

Of concern if we are to continue to accommodate people under the age of 65 with complex needs in residential aged care are current trends in bed availability. Aged Care Financing Authority (ACFA) estimates that $31 billion will be needed over the next decade to fund the construction of new or to rebuild existing aged care homes to

accommodate an additional 76,000 older Australians. If we then apply Western Australia's 10% ratio of total beds to this figure, approximately seven to eight thousand new residential aged care beds will be required in this state alone.

In recent years, Western Australian residential aged care providers have been reluctant to build new or expand existing aged care facilities due to the high cost of building when compared to diminishing returns on investment. Hence there is currently a shortage of beds in WA. Encouragingly, more recent trends show that aged care beds are likely to increase as a number of providers applied for and received increased places in the December 2014 ACAR round. It should be noted, however, that seven to eight thousand beds is a large shortfall and it is doubtful that this demand will be met in the next 10 years. This will mean that demand will outstrip supply and service providers will be able to cherry pick who they offer places to. It is likely that younger people with complex and challenging needs will miss out.

3. The health and support pathways available to young people with complex needs

Since 2006 funded initiatives in both the disability and the health sectors have impacted on accommodation outcomes for people under 65 years of age who have complex support needs. These include:

- The Young People in Residential Aged Care Program (YPiRAC) was in operation from 2006 – 2011. WA's agreed target figures for this program were:
  - Objective 1 (accommodation of people already in RAC) – 43
  - Objective 2 (prevention of people moving into RAC) – 30
  - Objective 3 (alternative support for people in RAC who have no other option – 10.

  Figures demonstrating the actual outcomes of this program would appear to show limited success in achieving the main goal of the program – reducing the number of people under the age of 50 living in residential aged care. One table contained within the Productivity Commission, Report on Government Services 2014 shows the number of YPiRAC service users in WA over the years from 2007 – 2011 to be:
  - 07/08 – 44
  - 08/09 – 92
  - 09/10 – 94
  - 10/11 – 85.

  The same report indicates that YPiRAC totals under the defined objectives were:
  - Objective 1 – 20
  - Objective 2 – 27
  - Objective 3 – 38.

  These figures seem to show that although the final 10/11 figure of 85 people being YPiRAC service users is correct, only 47 were provided with accommodation outside of residential aged care. The remaining 38 were provided with other services such as equipment and recreational support whilst continuing to live in residential aged care.
- Brightwater Discovery Way (an LSYP program) opened in June 2008. Since that time it has had 53 admissions including the current 12. Interestingly, the number of people under 65 in residential aged care in WA in 07/08 was 613 dropping to 561 in 08/09 and stabilising at 564 and 566 for the next two years. Of these we know that 20 relocated under the YPiRAC program from 2008 to 2011. It can be hypothesised that the additional reduction can be attributed to reduced numbers transferring into residential aged care from hospital due to the introduction of the LSYP program.

A total of seven clients in the Discovery LSYP program has discharged into residential aged care. At least four of this seven relocated to aged care due to desire by family to have them live close to them and no funding from Disability Services Commission (DSC) being available to enable this to happen.

- In November 2011 a further seven beds for people with acquired neurological disability were added to the LSYP program. It was intended that the seven beds would be co-located with the Oats St Rehabilitation program along with a further eight LSYP beds (15 in total) on completion of a rebuilding program at the Oats St site. This co-location and further increase in LSYP bed numbers occurred in February 2013.
- In 11/12 (after the addition of the initial seven LSYP beds) the number of people in residential aged care under 65 decreased to 541. In 2012/13, following the opening of the final eight LSYP beds, the number of people in residential aged care under 65 years decreased further to 520. The Oats St LSYP program has had a total of 27 admissions since November 2011 with the 15 beds currently fully occupied. In addition, metropolitan hospitals are now more likely to wait for a vacancy to arise for a person accepted into the LSYP program rather than admit them directly into residential aged care.
- Since the inception of the first LSYP program in 2008 there has been a gradual reduction in the number of people per 10,000 population in WA admitted to nursing homes from 33.5 in 08/09 to 26.6 in 12/13.
- Within the Perth metropolitan hospital system the number of patients defined as "long stay" has reduced since the inception of the LSYP program. Long stay is defined as those patients with complex needs who are aged between 18 and 65 years and whose acute care certificate has expired. Figures for long stay patients before, and then after the commencement of the first LSYP program were as follows:
  - Sept 2007 = 18 long stay inpatients
  - Dec 2008 = 19 long stay inpatients
  - July 2010 = 14 long stay inpatients
  - Feb 2011 = 11 long stay inpatients.

4. The appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities

Brightwater has considerable experience of supporting people under the age of 65 years in residential aged care. Four of Brightwater's residential aged care facilities are funded by the Health Department of WA under the Additional Care Subsidy Scheme. This funding is in addition to Federal aged care funding, complementing it to offer additional services to people with complex care and support needs living within existing residential aged care facilities. The scheme provides for extra direct care staffing, further hours of Allied Health and specialised equipment including electric wheelchairs, communication devices, beds and showering equipment.

Prospective nursing home residents, who are recognised by Aged Care Assessment Teams as having complex and high cost care needs which are unable to be met by nursing homes through normal Commonwealth funding arrangements, can be referred to Brightwater for priority listing. Of the 184 people currently funded through this scheme, 50 are aged from 0 – 64 years.

The complex nature of their support needs, coupled with the difficulty in accessing funding packages and accommodation options that appropriately meet those needs, means that all 50 people under 65 years currently supported by this scheme had little or no choice but to accept a place in residential aged care. Whilst the Additional Care Subsidy Scheme for the most part meets the basic needs of the under 65 population it by no means provides specialised support in keeping with what are often complex

diagnoses. Nor does it provide an environment both physically and socially that is relevant to this age group. In addition community access, unless provided by family or friends, is either limited or non-existent.

Whilst, at times, there can be a benefit to older residents having some young residents at a facility this only seems to be when there are larger numbers of young residents and they are more able to interact with each other. For the most part younger people in residential aged care have expressed feelings of confusion at living with older people, guilt that their families are feeling unhappy about them living there, sadness at a loss of independence and lack of common interests with their fellow residents. Older residents also express a range of emotions including frustration with the younger residents, fear when they are exposed to challenging behaviours and sorrow for the younger people who are in their nursing home.

Family members, whilst describing a sense of relief at having a safe and secure environment for their relative to live in, often express heartbreak that they have no other choice.

It is of concern that despite a joint protocol (see Appendix 2) developed in 2009 between the WA Disability Services Commission (DSC) and the Health Department of WA (HDWA) requiring that all disability options be exhausted before anyone under 65 years of age is admitted to residential aged care the discharge directly from hospital to aged care for this age group continues. Of equal concern is that although each of these people requires a letter from the DSC Aged Care Coordinator indicating that DSC is unable to provide funding support at this point in time, there is no formal recording of who these letters are being issued for. Unless formal application is made to DSC through its Combined Application Process (CAP) on behalf of the individual they are not registered at all with DSC. Often a CAP is not completed from the hospital because discharge to aged care is seen as completing the discharge process.

The resulting outcome is that many people under the age of 65 admitted to residential aged care have little or no further opportunity to move into a more age appropriate community based living option. In an attempt to counteract this problem HDWA has directed that all ACATs completed for people under 65 years of age be valid for only 12 months with a requirement that they be reviewed by the ACAT team at the end of that period.

Brightwater also recognises the need to review younger people admitted to residential aged care to identify improvement in their functional ability and potential for rehabilitation. Sometimes that potential is not evident for months or even years post discharge so it is essential that people are supported to continue to make gains whilst in residential aged care and then offered opportunity for more intensive rehabilitation where relevant. Detailed below are the de-identified case studies of two people who have transitioned from Brightwater's residential aged care services into Brightwater Oats St rehabilitation facility.

Julia (Born 1959)

- Right middle cerebral artery aneurism September 2010.
- Admitted to Residential Aged Care (RAC) December 2010.
- Past History of alcohol abuse possibly related initially to unmanaged post natal depression.
- When admitted to RAC it was thought that she would either die or make little recovery thus she has never been referred to a neurologist or neuro-rehabilitation physician.
- Admitted to Oats St March 2014.

- On admission:
  - Required a standing hoist to transfer
  - Used a manual wheelchair with customised insert supports
  - Was fully dependent on assistance for showering/dressing
  - Had moderate expressive language difficulties, significant difficulty with reading comprehension of more than single sentence and could only write her name.
- Now:
  - Walking independently in shared house
  - Independently preparing small meals
  - Requires some limited assistance with showering/ dressing particularly lower limbs
  - Has set up a library in the Learning Centre and writes short precises of the books she has read for the other clients.
- Where to now for Julia? She is continuing to make strong gains and has potential to move into supported, community based accommodation. While she will still need some funded care support Julia will not require 24/7 care and support to meet her basic needs.

Mary (Born 1952)

- Sub arachnoid haemorrhage with massive cerebral oedema, decompressive craniectomy September 2011.
- Dense left hemiplegia and severe left neglect.
- Admitted to Coorabel Adult Rehab service (Sydney) October 2011.
- Admitted to RAC (Sydney) January 2012.
- At request of friends in WA reviewed by Oats St team May 2012.
  - Dependent all activities of daily living
  - Required full assistance for all mobility
  - Considered to have “attention seeking behaviour”
  - Had little contact with others and spent most of her time in her room
  - RAC concerned with her behaviour and considering referral for transfer to mental health services.
- Transferred to Brightwater RAC with aim of facilitating transfer to Oats St August 2012.
- Admitted to Oats St March 2013.
- On admission to Oats St:
  - Severe issues with food absorption, vomiting
  - Low weight (36kg)
  - At strong risk of dying
  - Showed limited awareness of her surroundings, this was further impacted by severe left inattention
  - Poor communication with others.
- Now:
  - Remains fully dependent for most self-care and mobility
  - Eats independently with supervision
  - Highly engaged with her environment and others – chatty with opinions on everything!
  - Healthy at an appropriate weight
  - With support of friends visited family in Singapore in March 2014.
- Where to now for Mary? She will continue to need high care with monitoring of health but has no disability funding and is at risk of returning to RAC.

5. Alternative systems of care available in federal, state and territory jurisdictions for young people with serious and/or permanent mental, physical or intellectual disabilities

As described above in the introduction, Brightwater operates a number of service streams that are alternate or complementary to Residential Aged Care in WA. It is important to recognise that not only are most of these services unique to Western Australia but also to understand the contribution that each one makes to improving outcomes for people under the age of 65 with complex support needs, particularly those with neurological disability.

- Additional Needs Subsidy Scheme

  This scheme has been well described under Question 4. While it does not address the problem of young people living in residential aged care it does provide them with improved staff levels and expertise, access to specialised equipment and, for many with complex care needs, is the only accommodation option available for long term care and support.

- Long Stay Younger Persons Program (LSYP)

  Since its inception in 2008 the LSYP program has admitted over 70 young people with complex needs resulting from disability from Perth metropolitan hospitals. Without this program many of these young people would have either remained in hospital or discharged directly into residential aged care. In addition the LSYP hospital liaison team has been able to work directly with hospital Social Workers and Discharge Coordinators to identify alternative discharge options for people not able to be admitted into the program. Key advantages of LSYP are:

  - Identification directly within the metropolitan hospital system of young people at risk of aged care admission
  - Direct intervention to address individual issues related to care and support that are impacting on the person's ability to obtain funding and long term care
  - A focus on long term care and support that will be sustainable into the future to prevent breakdown of support option and further hospital admission.

- Oats St Rehabilitation Program

  Oats St Rehabilitation Program has operated within the Western Australian community since 1991. From that time until now it has supported over 250 people with an acquired brain injury to achieve improved levels of independence and thereby greater choice over their long term accommodation options. For many this has meant moving to residential aged care is no longer necessary.

  Brightwater Care Group has demonstrated through Social Cost Benefit Analysis of the Oats St Program (ACIL Tasman 2010) that effective and timely rehabilitation of people with brain injury can result in a 4:1 reduction of care support costs over a person's lifetime. Whilst focused primarily on savings through reduced long term costs of care, the report also provided insight into reducing the burden of disease through increased productivity not only of the individual themselves but also for family carers.

- Accommodation Services for People with Huntington's Disease

  The advantage of specific services for people with complex needs related to neurodegenerative disability is strongly evident through the outcomes achieved at Brightwater Ellison and Kailis Houses. Standardised outcome measurement of people with Huntington's Disease living in these specialised shared accommodation options is demonstrating that, even for those with severe

physically degeneration, participation in their immediate environment and adaptation to the disease process is maintained and, for some, improving. The resulting reduction in behavioural incidents is significant to the point that they are almost non-existent.

The knowledge gained by staff working in these services is being used not only to support Brightwater's residential aged care facilities that are also providing care and support for people with Huntington's Disease, but it is also being shared with the Huntington's community both in WA and in other states.

It is important to recognise that many people admitted to Brightwater Ellison and Kailis are transferred from residential aged care services that are no longer able to meet their needs. In addition some have been admitted from mental health hospitals where they have been transferred either from aged care or other hospitals.

Of concern for both of these services is the level of uncertainty that an individualised funding model brings to their financial viability. Apart from the risk of the service experiencing more than one vacancy at a time due to participant death or relocation, viability is further exacerbated by:

- Care and support needs that increase and decrease throughout the progress of the disease requiring the service to be responsive to those changes while still meeting the needs of other participants
- A participant population that, due to cognitive changes caused by Huntington's Disease, often does not identify with requiring care and support until they have reached a crisis point resulting in emergency rather than planned admission to services.

- Accommodation for People with Severe Disability Related to Acquired Brain Injury (Endeavour House).

Young people with complex needs, in particular those with high risk of requiring medical intervention, are often admitted to residential aged care due to the availability of nursing support and the inadequacy of disability support funding to finance the level of care support required.

Although all of the 18 people who live at Endeavour House are medically stable this is only due to both the 24 hour oversight of Registered and Enrolled Nurses and interventions by therapy staff that enable the service to maintain each person's health and wellbeing. Included in the model of service is tracheostomy and gastrostomy care, dysphagia and nutrition management, postural care and support, pressure management and maintenance of skin integrity, continence care, contracture prevention and medication management.

Aside from supporting residents to remain healthy and well, staff at Endeavour House also ensure they are assisted in accessing the community, maintaining and developing relationships, communicating and interacting with others and living a life of their choosing.

It has been evident since the opening of Endeavour House in 2000 that when it has no vacancies, which is generally the case, individuals looking for accommodation that provides this high a level of support are often admitted to aged care. It has also been evident that although the cost of living at Endeavour House is high (currently $162,718pa plus resident fee) the cost is greatly diminished when compared to an individualised living option due to the shared living arrangement.

6. The options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities

From 1995 to 2000 the West Australian government, with some assistance from the Federal Government, funded the Young People in Nursing Homes Project (YPINH). The intent of this program was to relocate people aged between 18 and 65 years from large government funded nursing homes into shared and individual accommodation options. The YPINH program saw nearly 100 people, most of whom had acquired neurological disability, move from institutionalised care into smaller, community based living.

Advantages of YPINH were that:

- Accommodation, even shared housing, was designed and built, in accordance with individual need.
- Staffing was rostered and trained to meet the specific needs of the people living in the houses.
- Families were more comfortable visiting, and thus often more likely to visit people living in more discrete accommodation models.
- Interaction with and integration into the community was more seamless and much more targeted to individual preferences.
- Ability of the individual to influence and dictate how their care was provided was much greater.
- Opportunity existed for each person to be involved in normal household tasks and interactions.

A disadvantage of YPINH was that, once completed, there wasn't any additional funding to continue the program meaning that those who came after the initial program was completed, had to wait for a vacancy to occur in one of the houses or to receive an individual funding package through the Disability Services Commission Combined Application Program (CAP). The downfall of this system is that the extreme time frame for an individual to obtain funds through the CAP system (often this could take years) does not match with the fast throughput of an acute hospital. For people with complex needs related to acquired disability this has meant that discharge into residential aged care has once again become a key option for long term accommodation.

Whilst the old state government funded nursing homes may not have been a good environment for young people with disabilities they were always the fall-back for people who had nowhere else to go. In addition they offered care and support that had been developed specifically around their complex needs including specialised services such as seating and positioning, tracheostomy management, management of challenging behaviours and understanding of neurodegenerative disability. This removal of a guaranteed discharge option has resulted in the following consequences:

- Rapid discharge into residential aged care for people with severe impairment from acquired neurological disability.
- Fewer opportunities for acute rehab with a cherry picking of those with the most potential.
- Fifty has become the new 65 with little or no disability funding for people over the age of 50 and higher risk of entering RAC – approximately 8.8% of all people in Brightwater residential aged care are aged from 50 – 64 years.
- People with brain injury at higher risk of homelessness or entry into the justice system.

7. What Australian jurisdictions are currently doing for young people with serious and/or permanent mental, physical or intellectual disabilities, and what they intend to do differently in the future

Western Australia's Disability Services Commission (DSC) has operated under an individualised funding model for over 10 years. This model has proven to be successful for people with mild to moderately severe disability who are either able to make decisions independently or are well supported by family in making those decisions. It offers them choice and control over living and care arrangements and interfaces well with outcomes based contracting arrangements which ensure that service providers assist all participants to develop personal goals around long term living and future aspirations.

Unfortunately this individualised funding arrangement has transitioned into a belief at government level that this should also mean that the only "normal" living arrangement is for people to live alone or with family. For people with complex disability the downfalls of this premise are:

- Funding amounts for people who require 24/7 support, including the support of more than one care worker, are often so great that they are precluded from receiving funding at all. Transfer from hospital to residential aged care will be the outcome for people with complex care needs who are unable to attract support funding.
- Risks for people who have health and medical needs related to their disability are increased in a living arrangement where the only staff that can be funded are disability support workers.
- Social isolation is a well researched and well documented risk for people with acquired brain injury who are often unable to form and retain social relationships. Living alone with the only visitors being family (where available) and paid support workers further exacerbates this issue.
- People under the age of 65 with newly acquired disability, often have already, prior to acquiring their disability, developed independent lives away from their parents, who in turn are beginning a lifestyle without children at home. Regardless of how much these parents love and care for their child, they are in our experience, often reluctant to take on the role of long term carer.

There is enormous potential to utilise the outcomes based contracting model to offer service providers the opportunity to take responsibility for building better services through more effective use of funding. This has been Brightwater's experience in working with the Department of Health where the Department and the organisation have collaborated together to develop strong service outcomes that are aimed at improving services for people with complex needs. In addition the contract outcomes are aimed at meeting the Department of Health's requirement to reduce admissions and length of stay in metropolitan hospitals.

A joint approach with organisations experienced in providing services for people with complex needs and DSC could result in the development of a range of accommodation options that are both relevant to individual needs and responsive to the demands caused by the number of people requiring high levels of support. There is little evidence at this point in time that DSC recognises the relevance or importance of collaborating with service providers. Such an approach is fast becoming essential if we are to capitalise on the gains made through YPRAC and the introduction of the Health Department funded LSYP program.

8. The impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation

As the NDIS trial only commenced in Western Australia in July 2014 it is difficult to comment on the impact of the NDIS on young people in residential aged care. It is encouraging that the trial Perth Hills NDIA has taken a proactive approach in interacting with Brightwater's LSYP and Oats St Rehabilitation programs to prevent the young people in those programs who are eligible for the NDIS from going into aged care. There is a strong sense from the NDIA that its aim is that no people from the NDIS trial area will go into a nursing home. The challenge to fulfilling this aim will not be the availability of funds but the critical shortage of both accessible and shared housing arrangements.

Brightwater would also caution that during both YPINH (1995 – 2000) and YPRAC (2006 – 2011) it was evident that younger people already living in aged care, and their families, are reluctant to seek alternative, more age appropriate accommodation unless that accommodation is tangible and offers the same level of care, particularly nursing and allied health.

9. State and territory activity in regard to the effectiveness of the Council of Australian Governments' Younger People in Residential Aged Care (YPRAC) initiatives in improving outcomes for young people with serious and/or permanent mental, physical or intellectual disabilities, since the Commonwealth's contribution to this program has been rolled into the National Disability Agreement and subsequent developments in each jurisdiction

It is Brightwater's observation that the Western Australian government and DSC's efforts to address the growing issues with providing long term care and support for people aged between 0 - 64 years with complex care needs has been sporadic and uncoordinated. During the COAG YPRAC initiative DSC initially tried to identify people in residential aged care and develop individual solutions for this group. Over half chose to remain in their existing aged care accommodation and in Brightwater's observations it was clear that this was due to a lack of viable alternatives.

Funds for the at-risk group became an adjunct to the existing Combined Application Process (CAP) funding round. Even the target of 30 people set for the at-risk group was not met. This could easily have been achieved through collaboration with the health system simply by identifying and funding people with newly acquired disability. Attachment of the funding to the CAP round meant it could only be accessed every five to six months meaning it would never meet the discharge requirements of the more "fast track" hospital system.

Due to strong lobbying by Brightwater, YPRAC did result in the establishment of two community house models – Kailis House and a cluster housing option using a block of six villa units to accommodate people with an acquired brain injury. Unfortunately attachment of the YPRAC funds to the CAP round meant that identification of appropriate people to fill vacancies in a timely manner was impossible and it took over twelve months and two years, respectively, for these services to be fully occupied. Even now only half of the people living in these houses have YPRAC funding with the remainder having standard accommodation support funding (ASF) and one lady being privately funded. This arrangement puts both of these accommodation services at risk should an individual with accommodation support funding leave the service particularly in the current system where funding is not guaranteed for people with disabilities.

At least two houses were opened in regional Western Australia (Broome and Kalgoorlie). These areas have previously had few options for young people with complex needs other than residential aged care or permanent units attached to local

hospitals. Unfortunately the home for two people in Broome is struggling both in care delivery and funding. This is due to a lack of expertise in supporting people with neurological disability and through a lack of additional people being funded to fill the beds in this shared accommodation arrangement. The service currently has funds to support consultancy and education of staff in supporting people with neurological disability.

During the state election in 2013 a small amount of YPINH funding was promised. Some of this funding was released with the CAP round in the middle of 2014 with the expected final total amount to be $9 million released over the next f years. Ultimately this will equate to $3 million in recurrent funding by the final year. There is no indication as to how these packages will continue to be funded at the end of the four years.

Conclusion

While the YPRAC and LSYP initiatives have had some success in reducing the number of young people entering residential aged care, it is still evident that there is no clear long term care and support pathway for young people with complex needs related to acquired disability in WA. This is particularly evident for those people with co-existing health and mental health issues and those with changing needs (e.g. neurodegenerative disease). Within the separate systems of Health and Disability in WA there are no formal linkages to identify people with newly acquired disability and coordinate opportunities for their long term care and support.

Brightwater often forms the conduit between the two sectors, not only to provide opportunities for individuals directly but also in advocating and educating across the health and disability sectors for this client group.

Whilst transitional (LSYP) and rehabilitation programs (Oats Street) have success in reducing the cost of long term care, the ability of people to identify and have funded long term accommodation and support is limited. As such even discharge back into the community from these programs is fraught with difficulty and usually requires innovative, individualised solutions around funding, housing and care and support.

The reliance on residential aged care as the only fall-back position for young people with complex needs is neither appropriate nor relevant. Mainstream aged care facilities are poorly resourced and equipped to manage complex physical and behavioural challenges and has resulted in this state in specialised funding being injected into the system by the Health Department . There are limited accommodation options that cater for people with high care needs and with the introduction of individualised funding through NDIS and an increase in demand through population growth the situation is certain to escalate to crisis point with residential aged care again being the fall back.

In Brightwater's experience, consideration should be given to a range of support and accommodation options for younger people with complex needs. For example, Brightwater provides accommodation and support for younger people living with Huntington's disease. Given the changing needs of this diagnostic group a block funded approach which allows a service provider to allow for and be responsive to these changing needs.

Jennifer Lawrence
GM Disability, Research & Risk

Janet Wagland
Manager Services for Younger People

February 2015

Government of **Western Australia**
Department of **Health**
Aged Care Policy Directorate

Disability Services Commission

Department of Health and Disability Services Commission

Joint Protocol to Guide the Assessment and Support of Younger People with a Disability

1. Introduction.

Aged Care Assessment Teams are responsible for assessing and approving access to all Commonwealth funded aged care services. This includes frail older people and younger people with high or complex needs.

Younger people with disabilities under the age of 65 years are eligible for assessment by an Aged Care Assessment Team. However, approval for aged care services should only occur where it is demonstrated that all disability service options have been exhausted and there are no other services that are more appropriate to meet the person's needs.

When a younger person with a disability is at risk of requiring either permanent or respite care in a residential aged care facility or a community aged care package, Aged Care Assessment Teams and the Disability Services Commission have a commitment to work together with the person with a disability and/or their family/carer to determine the best way to meet that person's individual support needs. (See Appendices 1 and 2 for descriptions of the roles of Aged Care Assessment Teams and of the Disability Services Commission).

This protocol describes processes to be adopted across all Aged Care Assessment Teams and the Disability Services Commission. It is expected that local level processes will be developed jointly by the local Aged Care Assessment Teams and Disability Services Commission staff to support working collaboratively to achieve the best outcomes for younger people with disabilities and their families and carers.

The Commission has established a Disability and Aged Care Coordinator to support this initiative. This person is contactable on telephone 9426 9696 or 1800 998 214 or email: acatreferral@dsc.wa.gov.au.

The Disability and Aged Care Coordinator will confirm if a younger person is within the Commission's target group and will liaise with relevant Commission and/or disability funded agency staff to support the implementation of the joint protocol in the most timely, efficient and responsive manner.

2. Purpose.

This protocol is designed to ensure that the Commission and Aged Care Assessment Teams collaborate in planning the support of people in the target group who are seeking Commonwealth funded aged care services or who are inappropriately placed in residential aged care facilities.

3. Principles.

3.1 Aged Care Assessment Teams and the Disability Services Commission undertake a person-centred approach to supporting and responding to individual needs in a timely manner, acknowledging that the demand for services often outweighs available resources.

3.2 Aged Care Assessment Teams and the Disability Services Commission will work together to achieve the best outcome for the person and their family/carer, and respect their choice of option.

4. Target group.

The focus of the protocol is people under the age of 65 years (under the age of 45 years for Aboriginal and Torres Strait Islander people) who are within the target group for the Disability Services Commission and who may require access to Commonwealth funded aged care programs.

To be eligible for specialist disability services that are either provided or funded by the Disability Services Commission, a person must be a permanent Australian resident living permanently in Western Australia and meet the following:

- Age – less than 65 years (or under the age of 45 years for Aboriginal or Torres Strait Islander people) when the disability manifests. [ATSI people who are aged between 45 and 65 should also be considered for Commission services if/when their care requirements meet that of the target group.]
- Diagnostic Group – having an intellectual; sensory; physical; neurological or cognitive impairment or a combination of those impairments.
- Permanency – the disability is permanent or likely to be permanent.
- Adaptive Functioning – having a substantially reduced capacity for communication, social interaction, learning or mobility and have an ongoing need for support services.

People who require palliative care or who have a primary psychiatric disability are not eligible for Commission services. Further, the Commission does not provide or fund specialist dementia programs or services.

5. Referral pathways to Aged Care Assessment Teams for younger people with disabilities.

People under 65 years of age with disabilities may or may not be known to, or in contact with, the Disability Services Commission. There are therefore two different pathways through which younger people with disabilities may be referred to the Aged Care Assessment Team (refer to appendices 3 and 4 – referral pathways flow charts).

5.1 People with disabilities who are known to or in receipt of services through the Commission.

These people may be in receipt of Local Area Coordination, Accommodation or Specialist Services.

5.1.1. Steps for the Disability Services Commission to take before making a referral.

Prior to contacting the Aged Care Assessment Team, the Local Area Coordinator, Accommodation Services or Statewide Specialist Services staff will ensure that discussions have been held with the person with a disability, their family or carer and current support providers and that all possible alternative care options have been explored and documented. The matter will also have been discussed with the relevant supervisor or manager, and the Commission's Disability and Aged Care Coordinator.

When all options have been explored and there is no appropriate option available in the disability sector to meet the support needs of the person with a disability, a written referral will be made to the Aged Care Assessment Team.

5.1.2. Making a written referral from the Commission to the Aged Care Assessment Team.

A referral of a younger person with disability from the Commission to the Aged Care Assessment Team will include details of the planning process that has been undertaken with the person and/or their family/carer, the options that have been explored and why there are no facilities or supports available that are more appropriate to meet the needs of the younger person with a disability.

The referral will include, with the consent[1] of the consumer, the provision of a copy of any application for support under the Combined Application Process (if available) and a completed Disability Services Commission referral form, to the Aged Care Assessment Team (refer to appendix 5).

This information will be accompanied by a signed letter from the relevant Commission Director confirming that all options have been exhausted and that there is no alternative option available.

5.2 People with disabilities who are not known to the Commission or whose primary relationship is not with the Commission.

Some younger people with disabilities referred to the Aged Care Assessment Teams may not be known to the Commission, or have never had contact with the Commission. This can occur when someone:

- has self-referred or been referred by a health professional;
- has only been in contact with another service provider (for example, Home and Community Care);
- has recently acquired a disability;
- has a disability that has required a hospital admission, either due to the progressive nature of the condition or a situation, such as a fall, that has exacerbated it; and/or
- has chosen not to contact the Commission.

[1] Consent means signed, informed consent from the person themselves, a close family member or guardian

5.2.1. The Aged Care Assessment Team is in receipt of a direct referral of a younger person with a disability, with no information from the Commission.

The Aged Care Assessment Team will explore the reasons for the referral, the level of need, and any risk or urgency factors. They will also explain to the referrer that referrals would usually come from the Commission once all other options have been explored. This may result in the Aged Care Assessment Team:

- advising the referrer that all alternative accommodation and care options need to be explored through the Commission prior to an Aged Care Assessment Team assessment; and
- requesting that the person or their family member, or carer, contact the Disability Services Commission for further assistance; or
- contacting the Commission's Disability and Aged Care Coordinator on the person or family's behalf (with their written consent[2]), to discuss the referral and determine if the person's needs and requested service model fall within the scope of eligibility for Commission services and capacity to provide.

Where the person is likely to meet eligibility requirements for Commission services, the Commission will follow up with the person, their family or carer as per the protocol and advise the Aged Care Assessment Team:

(i) if an option can be developed, in which case there is no requirement for an Aged Care Assessment Team assessment, or

(ii) if the Commission has no timely and/or appropriate options, the Commission will:
  - outline the planning process that has been undertaken with the person and/or their family/carer;
  - document the options that have been explored; and
  - identify why there are no other facilities or supports available that are more appropriate to meet the needs of the younger person with a disability.

Where a younger person with a disability has already had contact with the Aged Care Assessment Team, then any relevant information held by the Aged Care Assessment Team, with the person's consent, should be provided to the Commission to reduce duplication and help streamline the assessment and referral process (See appendix 6 - guide for information required for a referral to the Commission).

6. Assessing a younger person with a disability.

Once the processes outlined above have been completed, the Aged Care Assessment Team may accept the referral for assessment. This acceptance suggests that it is likely that the person may need care through a Commonwealth funded community aged care package or in a Commonwealth funded residential aged care facility, as no other care options are currently available to meet the person's current type and level of need.

With the consent of the younger person with a disability, the referral information from the Commission will include all relevant planning and assessment information available to the Commission in order to reduce duplication and streamline the assessment process for the person with a disability and their family/carer.

[2] Consent means signed, informed consent from the person themselves, a close family member or guardian

In general, best practice in assessing a younger person with a disability would involve a joint assessment between the Aged Care Assessment Team, Disability Services Commission and/or the Commission funded service provider to adequately inform the recommendations in order to canvas all relevant care options, along with their suitability and availability.

7. Urgent matters.

Aged Care Assessment Teams will be guided by their existing priority system in responding to a referral that has not been initiated or examined by the Commission. This will also depend on the level of need, risk and urgency of the person's situation. A joint assessment by the Aged Care Assessment Team and the appropriate Commission Local Area Coordination staff may be arranged via liaison with the Commission's Disability and Aged Care Coordinator.

8. Disability Service Commission's planning for, and review of, a younger person's support needs.

Further to a younger person being assessed and approved for Commonwealth funded care options under this protocol, the Commission will identify eligible persons for which Commonwealth funded aged care services are considered a "temporary arrangement".

The Commission will engage in ongoing planning and review of the person's support needs and alternatives for their care to secure a more appropriate option. This may include an application for Commission funding or consideration for an appropriate Commission funded vacancy when one is available under the Combined Application Process.

9. Conflict resolution.

Where issues arise in relation to this protocol and/or issues pertaining to younger people with disabilities accessing appropriate services, the following resolution path is followed:

1. The local ACAT Coordinator and the Commission's Disability and Aged Care Coordinator.

If not resolved:

2. Department of Health, Aged Care Assessment Program - Senior Project Officer and Commission's Principal Policy Officer (aged care portfolio).

If not resolved:

3. Director - Aged Care Policy Directorate and Director - Policy and Strategy, Disability Services Commission.

10. Other considerations and linkages.

The protocol for "People with Disabilities Transitioning from Disability Services Commission Accommodation Services to Residential Aged Care" is to be referred to in the instances when a younger person with a disability has such existing Commission services.

11. Protocol review process.

This protocol will be reviewed regularly throughout the 12 month implementation period and then on an annual basis following document ratification from all parties.

*This document is available in alternative formats on request from Disability Services Commission.

Appendix 1

Aged Care Assessment Program

The Aged Care Assessment Program (ACAP) is a national program funded by the Commonwealth and State governments. There are 16 (Aged Care Assessment Team) ACAT's in Western Australia.

The core objective of ACAT is to comprehensively assess the needs of frail older people and facilitate access to available care services appropriate to their care needs. Selected ACAT team members are authorised as Commonwealth delegates under the Commonwealth Aged Care Act 1997 to approve people for Commonwealth funded aged care services. The decision to accept a person recommended for care by an ACAT rests with the provider of the Commonwealth funded aged care service.

The ACAT target group is frail older people, that is, people over the age of 70. Indigenous people are included in the ACAT target group from age 50. Younger people with disabilities are assessed by ACAT when no other more age appropriate services are available. The ACAP Operational Guidelines state that younger people with disabilities are eligible for care in residential aged care facilities if they require the intensity, type and model of care provided in such facilities and no more appropriate service is available.

The ACAP Operational Guidelines set out the core requirements and responsibilities of ACAS.

The guidelines are available at:
http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-acat-secure-guidelines.htm

Appendix 2

The Disability Services Commission

The Disability Services Commission both provides and funds services for people with disabilities. Permanent Australian residents with a severe or profound disability, where the disability manifests before age 65, can apply for services and/or funding for services. The Commission does not provide services for people requiring high levels of nursing care and does not provide specialist dementia programs. Care for people with a primary Psychiatric condition is provided through the Health Department.

Local Area Coordinators or Commission funded service providers can assist people with disabilities and their families and carers to identify and apply for appropriate services. Local Area Coordination support is available in Perth and throughout all regional areas of Western Australia. Local Area Coordinators assist people with a disability to plan, organise and access supports and services which enhance their participation in and contribution to their local community. They are based in local communities, enabling them to build and maintain effective working relationships with individuals and families in their local area. Local Area Coordinators also contribute to building inclusive communities through partnership and collaboration with individuals and families, local organisations and the broader community.

The Disability Services Commission provides assistance to people with disabilities and their families and carers through funded service providers and uses the Combined Application Process (CAP) to provide Accommodation Support Funding (ASF), Intensive Family Support (IFS); and Alternatives to Employment (ATE) to eligible families and people with disabilities. Applications through CAP are considered on an individual basis by an Independent Priority Assessment Panel (IPAP). Funding is recommended on the basis of relative priority need and available resources and is provided on an individual basis.

- **Accommodation Support (ASF)**

ASF refers to funding that is provided to support people with disabilities to live in the community in a home environment. Arrangements include shared care or individual arrangements, with funding provided for the provision of personal care or support.

- **Intensive Family Support (IFS)**

This program aims to support people with disabilities to live with their families and to support families in their caring role. It has two separate approaches: providing support to families in critical and urgent need of support to care for their family member with a disability; and, focusing on early intervention and strengthening family support. Funding is available for a range of supports, include personal care, in home and out of home respite and domestic support.

■ **Alternatives to Employment (ATE) support.**
The ATE program provides funding for people with disabilities who require an alternative activity to paid employment so that they can develop skills and participate within their community.

■ **Community Aids and Equipment Program**
The Community Aids and Equipment Program (CAEP) provides a range of aids and equipment to assist people with disabilities to live safely at home. Funding is provided for home modifications; for example, installing a ramp to improve accessibility to the home; and for loaning equipment; for example, providing a wheelchair or communication device.

Specific programs for young people, at risk of, or in Residential Aged Care

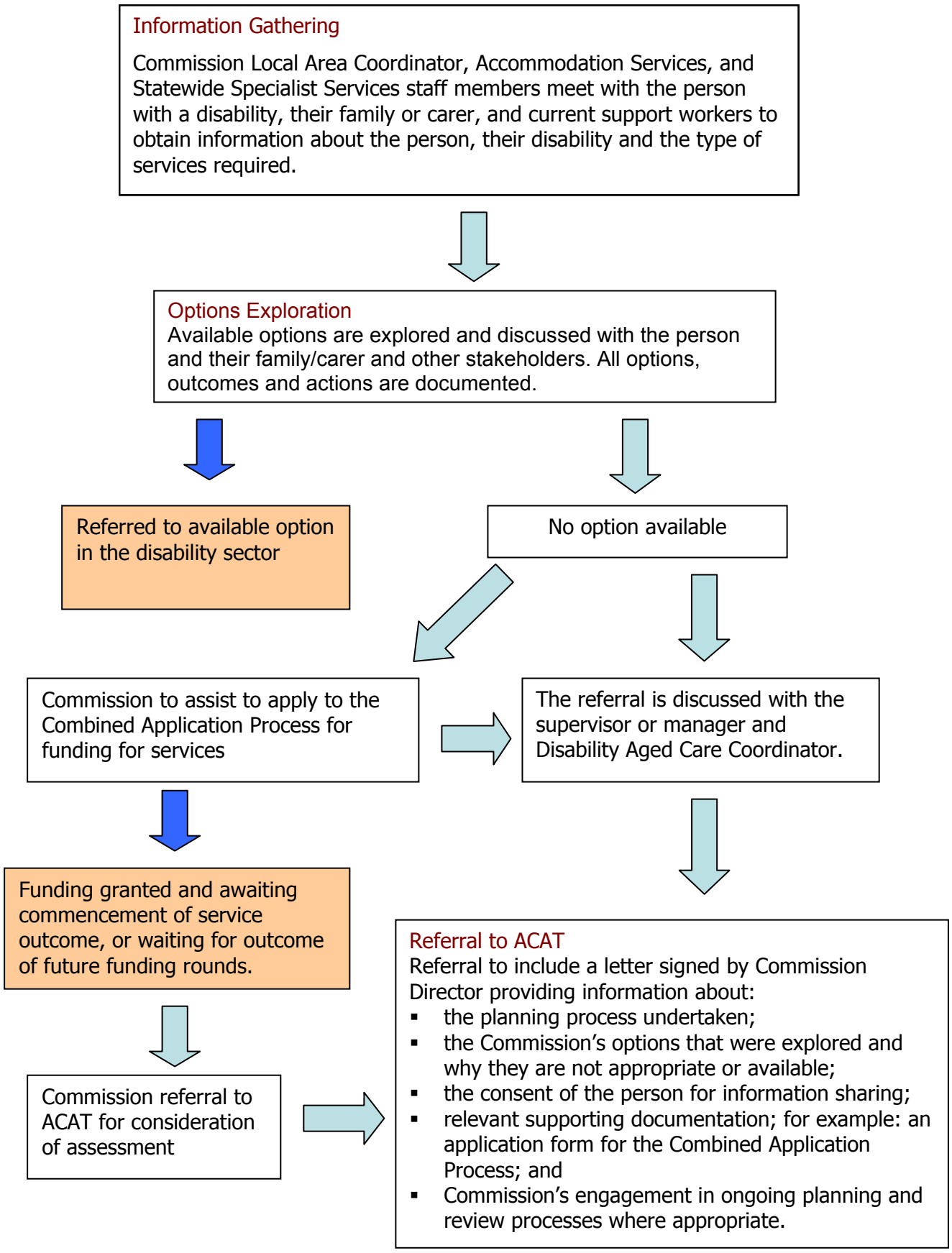
- **The Young People in Nursing Homes Program**
  The Young People in Nursing Homes Program currently supports eighty six younger people with a disability to live in the community. Vacancies occur at a rate of approximately two vacancies per year. Priority access to these beds is decided through CAP.

- **Young People in Residential Aged Care (YPRAC)**
  The Younger People in Residential Aged Care program (YPRAC) is jointly funded by the State and Commonwealth governments under a bilateral agreement. Funding available under the program is anticipated to support a total of 73 people over the four years 2006 – 2010. Initial priority is focused on people who are under 50 years of age.
  The program has three key elements:
  - the transfer of younger people with a disability currently inappropriately accommodated in residential aged care into more appropriate accommodation with a target of 43 people by June 2011;
  - redirection of younger people with disabilities at risk of inappropriate admissions into residential aged care, with a target of 30 people by June 2011; and
  - enhancing the delivery of specialist disability support services to younger people with disability for whom residential aged care remains the only available suitable supported accommodation option. These in-reach packages may include services such as, but not limited to, allied health therapy, day programs, equipment, transport and social outings. The target for this element is 10 people.

- **Rapidly Degenerating Neurological Conditions Pilot Program**

  This pilot program was designed to address the needs of a small group of individuals in Western Australia, with rapidly degenerating neurological conditions who require supports such as: personal care and postural, nutritional and airway management (excluding people who are ventilator dependent) to continue living in their own home. A Rapidly Deteriorating Neurological Condition is one that is anticipated to progress from time of diagnosis to requirement for full 24 hour care within a maximum of three to four years. The program is not designed to respond to the needs of individuals who are experiencing a period of rapid change during the end stages of a long term (beyond 4 years) condition, or to provide palliative care.

Appendix 3 People with disabilities who are known to the Commission



Appendix 4 People who are not known to the Commission:

Referrals
Referrals are received from GPs, Hospital Doctor or Social Worker, Medical Specialist, self referral by the younger person themselves, their family, carer, community worker, or community agency.

Referral to the Commission from all other sources

Referral received by Commission
To LAC, Statewide Specialist staff member or the Disability and Aged Care Coordinator.

Eligibility for Commission services determined.

Person eligible for Commission Services:
- Information gathered
- Options explored

See continuing referral pathways from appendix 3.

Person not eligible for Commission services:
Refer to ACAT

Referral to ACAT
Referral to include a letter signed by Commission Director providing information about:
- the planning process undertaken;
- the Commission's options that were explored and why they are not appropriate or available;
- the consent of the person for information sharing;
- relevant supporting documentation; for example: an application form for the Combined Application Process.
- Commission's engagement in ongoing planning and review processes

Referral to ACAT (see 5.2.1 of protocol)

Referral received by ACAT
1. Determine ACAT eligibility
2. Determine priority:
- Urgent: Follow existing priority systems (see 7 of protocol).
- Non urgent: Gather information regarding diagnosis, social circumstances and whether request is for residential or community support.

Eligibility
Examine eligibility for Commission services (see part 4 – Target Group of Protocol).

Not Eligible
If not eligible for Commission services, progress to ACAT assessment.

Eligible
Contact the Disability and Aged Care Coordinator to initiate follow up by the Commission

The person is referred to the Commission:
- by ACAT. If possible, obtain consent for release of information for referral to the Commission; or
- referral source is asked to make direct contact with Commission.

Appendix 5

Referral by the Commission of a younger person with a disability to the Aged Care Assessment Team.

Referring person:
Title
Role
Agency Contact Details:
Phone:

Name of referred person
Date of Birth:
Address:
Phone No:
Next of Kin/Contact:
Is a legal guardian appointed?
Details:

Reason for Referral:
[Brief history of the person and summary of their condition]

Details of Planning Undertaken:

Options explored and why they are not suitable or available:

Consent obtained **Yes** ☐ **No** ☐

Attached:

- Combined Application Process (CAP) application form, if appropriate.
- Signed letter from a Director of the Disability Services Commission.

Signature _____ **Date** _____
Disability and Aged Care Coordinator

Appendix 6

Guide for information required for a referral to Disability Services Commission by an Aged Care Assessment Team

Referring person:
Title
Role
Agency Contact Details:
Phone:

Name of referred person
Date of Birth:
Address:
Phone No:
Next of Kin/Contact:
Is a legal guardian appointed?
Details:

Diagnosis/Disabilities, please list

Is the person likely to meet Commission diagnostic criteria?

Reason for the referral; provide a brief history of the person

Signature _____ **Date** _____

Attach:

- a signed consent form; and
- copies of relevant assessment reports

Please send completed forms addressed to the Disability and Aged Care Coordinator at the following address:

Disability and Aged Care Coordinator
Disability Services Commission
PO Box 441
West Perth WA 6872

Fax number: 9322 1397

email: acatreferral@dsc.wa.gov.au

Enquiries about providing referral information and signed consent should be directed to the Disability Aged Care Coordinator on telephone 9426 9696 or 1800 998 214.

MODEL OF CARE FOR LONG STAY YOUNGER DISABLED PATIENTS IN METROPOLITAN PUBLIC HOSPITALS

INTRODUCTION

The main objective of this paper is to provide a framework for a model of care for interim accommodation and related services for Long Stay Younger Disabled Patients (LSYDP) in metropolitan public hospitals. For many of these clients there are limited options when they are medically fit and ready for discharge. Consequently, they remain as inpatients for lengthy periods whilst their carers, clinicians and service providers engage in protracted negotiations to find a suitable pathway out of acute care. This results in acute care beds being used as interim accommodation to the detriment of other patients needing inpatient care.

Following the acute care phase, many younger disabled clients and their families would benefit from the option of age-appropriate interim accommodation with a high level of nursing and personal care, with access to lifestyle rehabilitation services and to specialised medical / psychiatric care as needed.

A high level of care in interim accommodation will enable younger disabled clients to adjust to their medical condition, optimise their physical and psychological functioning and maximise their ability to enter long-term supported accommodation or to return home with community support. During this period of interim accommodation, clients will need a planned exit strategy to access long-term supports to meet their assessed needs.

Some younger disabled clients will continue to need a high level of 24 hour nursing care necessitating admission to age-appropriate residential care. Admission to an aged care facility is seen as an option of last resort rather than an option, which is currently activated immediately following acute care.

At present, there are no clearly funded options or pathways for younger disabled clients to access age-appropriate interim accommodation, which provides a high level of care when medically fit and ready for discharge. This program is designed to address this unmet need and free up acute care beds for other patients requiring hospital intervention.

FOUNDATION FOR THE MODEL OF CARE

The Operational Directive "*Care Awaiting Placement Program and Other Transition Care Options for the Elderly*" (OD 0043/07) provides a standardised foundation for all transition options in Western Australia. This foundation remains relevant and applicable to LSYDP in metropolitan public hospitals. It is acknowledged that this target group has additional care needs, which require consideration whilst they are in the LSYDP program.

PRINCIPLES AND MINIMUM STANDARDS

The following principles and minimum standards apply in caring for clients who are eligible to enter the LSYDP program:

- The processes and policies are administered with compassion and take into account the individual needs of the client and their carer or family.

- The client and their carer or family are provided with sufficient information in a form that fosters understanding and awareness of expected stages of care. This includes information on the alternate pathways of residential care planning if returning home is no longer an option, or accessing community support services where the plan is to return to their usual place of residence.

- The client and their carer or family have unencumbered access to appropriate staff including social workers to assist them through the process of arranging appropriate long-term care.

- The client and their carer or family understand and are able to assert their right to compliment or complain and to have their complaints dealt with promptly and impartially.

- A clearly defined Care Pathway is available for use and reference by health service staff at all points in the continuum of care. The Care Pathway is the foundation for information delivery to all stakeholders in the care of the client.

MODEL OF CARE

LSYDP program is fully state funded and designed to provide interim accommodation and related services to younger disabled clients who are inpatients in a metropolitan public hospital and are medically fit and ready for discharge. Entry into the LSYDP program should be considered after all other care alternatives have been extensively explored.

The typical client referred to the program will be offered a range of services depending on their assessed needs. The client service delivery options include funding to access interim accommodation and related support services with a focus on lifestyle rehabilitation. Support services include medical care, nursing and personal care, allied health services and any other relevant community services to assist clients to transition into appropriate long term care options.

Provider of Care

Interim accommodation and related services will be provided in an age-appropriate setting and may be extended to community living if and when appropriate. The interim accommodation will be licensed under Department of Health guidelines.

Care and Services

The LSYDP program will provide a mix of staff and services to address the individual needs of clients. Staff will have appropriate training and skills to manage the care of younger disabled clients.

A case management approach to client care will be undertaken. The client will initially receive a high level of care on entry, to meet additional care needs and to support adjustment to the new environment. It is anticipated that the care and support will reduce overtime to a level that will enable the client to return home with community support or enter appropriate long-term supported accommodation with other service providers including Disability Service Commission.

A designated coordinator from Royal Perth Hospital, Sir Charles Gairdner Hospital and Fremantle Hospital will be responsible for liaising with the coordinator of the LSYDP program. The designated coordinator from each of the above mentioned tertiary hospitals will also be the contact person for the secondary hospitals in their Area Health Service.

The LSYDP program will nominate a coordinator to liaise directly with the designated hospital coordinator regarding referrals, admission and case management of clients.

The LSYDP program will identify a Case Manager to assist the client, their carer and family prepare, locate and move to appropriate long-term supported accommodation or to return home with community support.

The LSYDP program will manage the purchase and provision of medical care (including psychiatric services) and any other relevant support services.

Management of the Program

This metropolitan initiative will be program managed by the Aged Care Policy Directorate (ACPD).

The Service Provider in accordance with the contractual obligations will carry out the operational management of the program.

Access Priority

Access to this program is dependent on the assessed needs of the client, the capacity of the program to meet those needs and care arrangements negotiated between the LSYDP program coordinator and the designated coordinator of the tertiary hospital.

The LSYDP program coordinator reserves the right to make the final decision on client entry to the program.

Target Group

- Current inpatient at a metropolitan public hospital;
- Ongoing medical condition which may include psychiatric co-morbidities;

- Patient must be deemed medically fit, psychiatrically stable and ready for discharge;
- Expiry of the acute care certificate;
- Age range from 18 – 65 years inclusive;
- Patients with complex care needs including those with tracheostomies;
- Patients currently receiving compensation will be considered if extenuating financial circumstances can be demonstrated; and
- Ventilated patients are excluded.

Target Timeframe

Case by case assessment will determine the client's readiness to leave the LSYDP program. The anticipated length of stay is 18-24 months.

Roles and Responsibilities

Transferring Health Service

It is the responsibility of the transferring Health Service to ensure that:

- The transfer to the LSYDP program has been planned and action has commenced prior to the client transferring to the program. This should be coordinated via the nominated LSYDP program coordinator and the designated coordinator at the relevant metropolitan tertiary hospital.
- The Service Provider has access to all relevant information including health records prior to the client entering the LSYDP program.
- A comprehensive hand-over will be prepared by the designated hospital coordinator. This handover will have addressed the specialist needs of the client, any family issues of concern and any outstanding outpatient and medical appointments.
- Technical nursing skills, experience and competencies that may be needed to care for the person will be included in the hand-over.
- Any behavioural symptoms will have been accurately defined in this assessment and strategies to managing these behaviours including maintaining the safety of others will have been communicated to the LSYDP program.

- The client has a legal guardian or advocate if they are unable to give informed consent.

- The client, their family and carer are clearly informed of the interim or transitional nature of the LSYDP program, of fees and charges and of their rights to compliment and complain about the service.

- The most appropriate means of transfer of the client from the acute unit to the LSYDP program will be determined by the assessed needs of the individual client. The Transferring Health Service is responsible for the transport of the client to the LSYDP program, which includes ambulance transport. Where required, the client may be accompanied by a carer, family member or a hospital staff member to ensure a smooth transition from the acute setting.

- If the client requires acute medical care following their transfer, the client will be readmitted to the original referring public hospital in a timely manner.

- Referrals and entry into the LSYDP program is maintained and reported monthly to ACPD.

Service Provider

It is the responsibility of the Service Provider to ensure that:

- The client, their family and carer are fully informed about the goals of the LSYDP program.

- The client, their family and carer be provided the opportunity to be involved in the achievement of those goals.

- The client, their family and carer are clearly informed of the interim or transitional nature of the LSYDP program, of fees and charges and of their rights to compliment and complain about the service.

- If the client requires acute medical care, they will be transferred to an acute care facility, preferably to the referring public hospital. The client will be responsible for the cost of ambulance transport to the acute care facility.

- Upon the client exiting the LSYDP program, ongoing care plans will be provided to the client's GP and other relevant services.

- Maintain adequate records of clients and ensure that evaluation criteria are recorded and reported monthly to ACPD.

Coordinating Referrals

The nominated coordinator from the LSYDP program will:

- liaise with the designated coordinator from Royal Perth Hospital, Sir Charles Gairdner Hospital and Fremantle Hospital regarding potential referrals.

- coordinate and prioritise appropriate referrals from metropolitan public hospitals to the LSYDP program.

Referral protocols and templates will be developed as a part of the implementation phase of the project.

Follow-up Care

A general practitioner (GP) will manage the client's medical care during their participation in the LSYDP program. This can be the client's usual GP or a GP facilitated by the Provider. The GP is responsible for assessing and referring the client for appropriate specialist medical care and rehabilitation services.

EXIT STRATEGY FROM THE LSYDP PROGRAM

An exit strategy from the LSYDP program is an essential component of meeting the long-term needs of this target population.

Clients in the LSYDP program will be individually assessed to manage their exit into long-term care options.

It is expected that this target population will be given priority access to other accommodation and community services provided by Home and Community Care, Disability Services Commission (DSC), Mental Health Services, Aged Care Assessment Teams and other service providers to facilitate transition out of the LSYDP program.

For the purposes of Disability Services Commission Combined Application Process funding, clients in the LSYDP program are deemed to be homeless and accorded the same priority to access funding through DSC.

EVALUATION AND REPORTING

LSYDP program reporting is used to determine the maintenance and potential expansion of the program. They are also used to inform the longer term planning strategies especially towards supporting the increase of age-appropriate residential care beds and packages with the Disability Services Commission, Australian Government and other stakeholders relevant to the target group.

It is also expected that the LSYDP program will collect relevant data and report on performance measures to assist the Aged Care Policy Directorate of the Department of Health to evaluate the efficiency and effectiveness of the LSYDP program.

The LSYDP program is required to maintain reporting (in relevant formats) as per contracted arrangements. This includes:

a) Monthly
Referrals, Admissions, Discharge, and Length of Stay information.

b) Monthly
Attendance at meetings with metropolitan hospitals and ACPD.

c) Quarterly:

Details of client/family survey indicating the level of satisfaction of the service;

Details of unforseen circumstances that may have taken place at the LSYDP program, which affects, directly or indirectly, clients of this service; and

Adhoc reporting as requested in relation to gaps in services, barriers to services and reasons for declining referrals.

d) Yearly:

The Model of Care for LSYDP in metropolitan public hospitals be reviewed after 12 months of operation.

Reporting templates to be developed as a part of the implementation phase of the project.

MANAGING COMPLAINTS

Clients and their family and carers have the right to complain and to have their complaints dealt with promptly and impartially. All Health Service sites are required to have a complaints management process.

Complaints related to a patient's stay in hospital or to their transfer to the LSYDP program need to be initially managed by the transferring health service and then referred to the Office of Health Review if the complaint cannot be resolved.

Complaints regarding the LSYDP program need to be initially managed by the LSYDP program and then referred to the Office of Health Review if the complaint cannot be resolved.

LINKAGES TO OTHER POLICIES AND PROGRAMS

- Home and Community Care Program
- Protocol between the Disability Services Commission and the Department of Health Aged Care Assessment Team
- Care Coordination for Rehabilitation of People with Acquired Brain Injury (ABI) – unpublished
- Department of Housing and Works

- Community Disability Housing Program guidelines