

April 2015



Submission in brief to Community Affairs References Committee

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

About Anglicare Australia

Anglicare Australia is a network of over 40 independent local, state, national and international organisations that are linked to the Anglican Church and are joined by values of service, innovation, leadership and the faith that every individual has intrinsic value. Our services are delivered to one in 40 Australians, in partnership with them, the communities in which they live, and other like-minded organisations in those areas. In all, almost 13,000 staff and more than 7,500 volunteers work with over 600,000 vulnerable Australians every year delivering diverse services, in every region of Australia.

Younger people in residential aged care

Thank you for the opportunity to make a contribution to this inquiry. The Anglicare network provides care and support across a number of areas that intersect with this inquiry's terms of reference.

This submission offers some evidence of the accommodation of young people with disability in network aged care residences with the Anglicare network. The problems that face those residents, and the challenge for staff in providing appropriate support and opportunities, are well documented. The reality of course is that in many instances there is simply no other choice.

Some of the Anglicare network members provide accommodation and care for people living with profound disability in specialist facilities. Anglicare Tasmania runs a number of disability housing and supported living services, as does Samaritans Foundation, based in Newcastle. Some of the Anglicare network's larger providers work separately with both people with disability and the aged, and thus look to accommodate people with disability in specialist accommodation rather than take them into their aged care facilities.

We have received specific feedback from specialist aged care provider Benetas, based in Melbourne, and Anglicare Southern Queensland, based in Brisbane. It is essentially offering a snapshot of their

accommodation of younger people with disability in residential aged care and some reflection on the issues they face.

We trust it will assist you in this inquiry.

Anglicare Southern Queensland

Anglicare Southern Queensland (ASQ) is a large social service provider caring for people across the life course. It has 647 residential aged care beds and of those 47 are presently occupied by 'younger persons' under 65 yrs old. [See breakdown (a) below.]

Many of these residents have been accommodated from a younger age and have aged in place, while others have been cared for by families in community before discovering suitable accommodation was not available when the family could no longer care.

Issues identified by ASQ include:

- the extra needs regarding age relevant activities and resources, noting
 - many existing residential aged care activities are based on the experience of older generations (usually the radio-agers), whereas these younger people are either Baby Boomers or even Gen Y, and require different memory games, music, etc
 - the sexual needs of a younger person are more apparent, and they are more likely to develop or want to maintain special relationships
 - more generally, there are additional needs regarding age appropriate company, access for visitors and quiet visiting areas/spaces
- the greater range of health care issues and the need for broader knowledge by staff, including various diagnoses not usually encountered in older residents
- that there are also complexities around the ACAT approval process, cost shifting and consequent impact on younger residents' opportunities. The ACAT approval of course is the first step towards accessing residential aged care, which is Commonwealth funded. While many such residents may remain on the register of need for state disability services, their priority changes as they are determined as 'accommodated'.

Benetas

Benetas is a large Victorian provider of aged care services established in 1948. It provides aged care support to over 4,000 older people, and has 1,314 beds for residential care.

Of the 1,224 clients Benetas accepted to residential care from 2010 to 2014 (at a median age of 85), 36 were aged under 65. Requests for admission of younger people are uncommon. They generally relate to disability or illness, but not trauma-induced brain damage. [see

breakdown (b) below].

Anecdotal reports from residential managers are that there are a growing number of requests for admission for younger clients with mental health issues, including alcohol and drug related disease processes.

Expanding on comments provided by ASQ, Benetas makes the point that this is a very specialised area of care, given client age, co-morbidities, mental health problems, and sometimes challenging and violent behaviours. Allocating an aged care bed for such a client is often the last resort, which simply reflects the very limited alternatives available.

In short, Benetas recognises aged care services are not designed for this cohort. The issues relate primarily to the lifestyle needs of younger people in relation to service choice, and here are many cultural, lifestyle and sexuality considerations around providing care for people in these circumstances, which Benetas is not well placed to provide.

For self-evident reasons, many of the services Benetas provides are age specific, and whilst adequate physical care may be able to be provided, lifestyle options and personal support suitable for younger people are not.

Finally, Benetas made the point that the aged care workforce is neither trained nor educated to meet the needs of this age group, nor are providers geared to provide relevant services.

In addition to workforce development, there would need to be specific funding to enable providers to provide innovative service models to meet these needs. Accepting a resident for admission knowing that their needs are not able to be adequately met is unconscionable.

Anglicare Australia would be happy to explore these or other specific issues relating to younger people in residential aged care settings with its members. We trust this brief collation of information will assist the committee in its deliberations.

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Breakdown (a) ANGLICARE SOUTHERN QUEENSLAND		
YOUNG PERSONS LIVING IN RESIDENTIAL AGED CARE FACILITIES		
Aged care facility	Resident no. and Age range	Diagnosis on Entry
Abri	1 x 40 – 50 1 x 50 – 60 7 x 60 – 70	1 x CVA 1 x intellectual disability 1 x dementia 1 x alcoholic depression 1 x epilepsy 1 x Parkinson's/dementia/depression 1 x depression/chronic fatigue 1 x psychotic depression/Parkinson's 1 x OCD/dementia
E M Tooth	1 x 65 – 70	Acquired brain injury
Kirami	1 x 60 – 65 1 x 65 - 70	Front temporal dementia
Neilson Home	1 x 45 - 50	Younger onset dementia
	3 x 60 – 65 3 x 65 – 70	1 x alcohol related dementia; Korsakov psychosis 1 x dementia & schizophrenia with associated psychoses 1 x Parkinson's disease 1 x psychoses, depression, paranoia 1 x Huntington's disease 1 x Multiple Sclerosis
Meilene Court	1 x 65 - 70	Severe dementia
St John's Home for Men This is a home for men who are homeless or at risk of being homeless and also those with mental health conditions.	8 x 50 - 60	1 x family unable to care for 1 x schizophrenia 1 x intellectual disability (family unable to care for) 1 x dementia 1 x alcohol dependence, depression, affective disorder 1 x schizophrenia, alcohol dependence 1 x cognitive impairment, dementia 1 x dementia, depression
	10 x 60 – 65	1 x CCF, COPD, Gord 1 x intellectual disability, schizophrenia affective disorder 2 x depression, dementia 1 x dystonic reaction, depression 1 x schizophrenia, depression 1 x paranoid schizophrenia, depression 1 x schizophrenia 1 x dementia Korsakoff's 1 x Alzheimer's, bipolar disorder
Symes Thorpe	1 x 60-65 1 x 65-70	1 x Korsakoff's Disease/MS 1 x Cerebella degeneration/Oedema
Symes Grove	1 x 60-65	1 x Epilepsy

St Martin's	6 x 60-70	1 x schizophrenia 1 x dementia 1 x sub-arachnoid haemorrhage 1 x profound intellectual disability 1 mental retardation 1 x Downs Syndrome & dementia
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Breakdown (b) BENETAS

YOUNG PERSONS LIVING IN RESIDENTIAL AGED CARE FACILITIES

DEMAND FOR RESIDENTIAL CARE FOR YOUNGER PEOPLE

The demand for admission to residential aged care for people aged under 65 years is relatively uncommon. Over the five year period 2010 to 2014 inclusive, Benetas accepted 1,224 clients for permanent admission to residential care. The median age of these clients was 85 years and the median length of stay was 420 days. These age data are shown in Figure 1 (below).

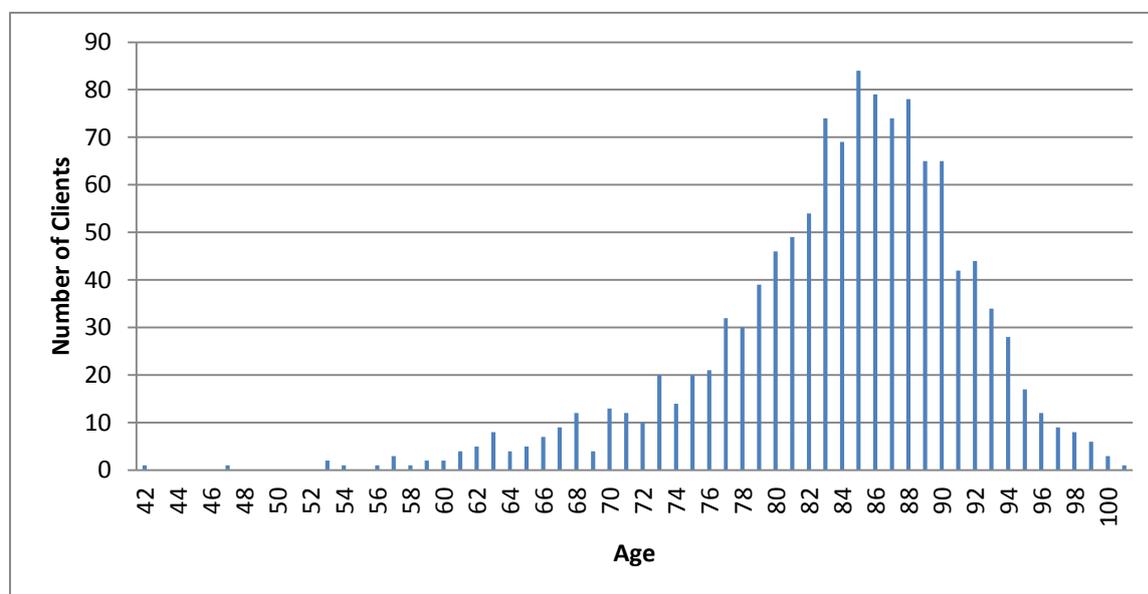


Figure 1: Age range of clients admitted to permanent residential care 2010-2014.

However, during this period there were 36 clients admitted to residential aged care that were aged under 65 years. These clients ranged in age from 42 to 64 years. The detailed profiles of age admissions are shown in Table 1 (below).

Age	Clients	Age	Clients	Age	Clients
41	1	49	0	57	3
42	0	50	1	58	1
43	0	51	0	59	2
44	0	52	0	60	2
45	0	53	2	61	4
46	1	54	1	62	5
47	0	55	0	63	8

48	0	56	1	64	4
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Table 1: Detailed age profile of clients admitted to permanent residential care 2010-2014.

To assist the committee, the records for these younger clients' admission have been examined in detail and the de-identified and aggregated data describing the reason for admission have been collated. Please note that three records could not be retrieved for this analysis.

Principal Reason for Admission	Frequency
Cognitive Impairment (not dementia)	8
Stroke	6
Multiple Sclerosis	5
Dementia	4
Multi-morbidity	3
Psychiatric condition	3
Mobility restriction	2
Palliative care	1
Other condition	1
Data unavailable	3
Total	36

Table 2: Reasons for admission of clients admitted to permanent residential care 2010-2014.

It is worth noting that in addition to the principal reason for admission, most clients had multiple chronic conditions that exacerbated the difficulties of their primary reason for admission. Perhaps surprisingly, the most common reason for admission was cognitive impairment of a non dementia cause. Many of these clients had lifelong intellectual disability or had acquired a cognitive impairment following a medical illness. None of these cases reported an acquired brain injury of traumatic origin.

LENGTH OF STAY

Most residents had a length of stay of less than 700 days (i.e. less than two years). The range of length of stay is shown in Figure 2 (below). Specific data on length of stay for clients aged under 65 years is not available.

