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

Over the past 20 years housing and appropriate accommodation for people with disabilities has been a constant issue. Housing that can be adapted or purpose built to meet the accessibility needs of people with physical disabilities is a well - known deficit. However, having a home which meets more than just basic physical needs is an essential for all people, including those with disabilities. People with intellectual disability or autism often need high levels of support to meet their social, employment, and daily living functions, which may differ from those people with physical needs, particularly when the young person has communication difficulties, which impact on their capacity for self - advocacy.

In Australia there are around 13,000 people with Down syndrome and despite the availability of maternal screening in the first trimester of pregnancy, and the resultant possibility of early termination, the population of people with Down syndrome continues to grow. http://www.downsyndrome.org.au/down_syndrome_population_statistics.html

Gradually society is changing to recognise the contribution and potential for meaningful lives for people with Down syndrome, acknowledging their capacity to learn skills, work in paid positions, form meaningful relationships and to live independently. As people with Down syndrome are now living longer, due to improved medical and early intervention services, and a generally improved standard of living, so the need for longer term supports, in the community, is on the rise.

One of the topics of most concern to families is accommodation. Parents of a 35 to 40 year old with Down syndrome are usually ageing themselves, and they would like to see their son or daughter living out of home, either independently or with the supports they need to achieve a good life. Many individuals have developed the skills needed to live more independently, in a unit or house, with family, friends or informal community supports, or funded supports. They have a greater level of control and self - determination and overall their life is more in line with that of most people in the general population.

However, there are still a significant number of people who require supported residential care, with paid and trained staff and possibly higher ratios of attendant care support. This type of accommodation is well known to be expensive, staff and schedule driven, rather than person centred and resident controlled, and often institutionalised and bureaucratic in its management. There have been recent shifts in the way that community residential care is managed, with efforts being made to a more person centred approach, but this is still a work in progress.

People who have Down syndrome have a high chance of acquiring age related health conditions, including dementia, in midlife – around 35 to 50 years – often with a more rapid onset and deterioration in cognition, than the general population. Although only about 50% of people with Down syndrome will have the signs and symptoms of Alzheimer's Disease, in their later life, almost 100% of people with Down syndrome will have the plaques and tangles in the brain, that are associated with this type of dementia. Diagnosis is often difficult due to existing cognitive and language deficits and there are other conditions which may have similar impacts on the person's functioning, for example: hypothyroidism, depression, hearing impairment, visual impairment, pain associated with arthritis, urinary tract infections, diabetes, may all cause changes in behaviour, cognitive function, social interaction and communication. It is important that these are explored and treated, before diagnosing with dementia.

https://fightdementia.org.au/about-dementia-and-memory-loss/about-dementia/types-of-dementia/down-syndrome-and-alzheimers-disease

In terms of housing and accommodation though, a diagnosis of dementia is often a precursor to admission to aged care facilities at a much younger age than in the general population. The level of supports provided in family or independent living situations, or community residential units (CRUs), are often inadequate to manage the changing needs of this group of people. In many instances the person will be unable to continue their employment or day service, due to the changes in behaviour and cognition, so occupation out of home becomes more difficult. Staffing a CRU 24 hours a day becomes more expensive, particularly as the person's condition deteriorates and active overnight care is required. Similarly in the person's own home or with family, the levels of care and support needed cannot be managed within current disability or aged care funding models. Therefore, residential aged care is often the only choice. Some CRUs are working towards an "ageing in place" model of care but this too is a work in progress. Palliative Care within residential services is a tricky area, as staff can have difficulty dealing with the impending death and the protocols in Government funded housing usually don't allow for non-active treatment. Clients are, therefore, transferred to hospital or hospice care and this can be distressing for the individuals and their families.

Aged care facilities are generally not equipped to appropriately manage the needs of younger people with intellectual disability and dementia. This is apparent on a number of levels:

1. Aged Care staff are often untrained and unfamiliar with intellectual disability and associated communication needs.
2. Staff ratios in aged care are usually low, so meeting individual needs is a struggle. Care is regimented and scheduled and subject to restrictive OH& S procedures
3. Medication is often used to manage troublesome behaviour, with a resultant sedating effect on the individual.
4. The older residents are often unfamiliar with and intolerant of some of the behaviours or communication styles associated with intellectual disability, and younger people with disability can be shunned or even bullied, within aged care. The younger person can create distress for the older residents also.
5. The young person can become quite isolated within this type of accommodation, due to these communication issues
6. Depression and a more rapid progression of the dementia often results
7. The capacity of aged care services to meet the social needs of younger people is diminished, particularly where there are only one or two younger residents. Lifestyle coordinators struggle to meet the individual social needs of the elderly residents, let alone those of younger people. Someone with a higher need for active pursuits, different music preferences, use of technology, community access needs, and TV show preferences, often struggles to have these needs met in aged care facilities, especially in situations where shared rooms and no private living space are the norm.

The existing TAC and other compensatory arrangements have enabled individuals with acquired disability - through traffic accidents or medical negligence - to benefit from individual choice in accommodation, which meets their support needs. For those who have congenital or non-compensatory disabilities, the levels of funding at best, have been ad hoc. Now, with the introduction of the NDIS, there is potential for people with intellectual disability to be better supported in an individual way, particularly when it comes to choice in where, how and with whom the person lives.

While the cost of paid support is an ever increasing commodity, there is also the issue of bricks and mortar to appropriately meet the accommodation needs of individuals. Congregate care, such as a CRU or aged care facility, has cost savings but individual needs and choice are limited. There are other models of accommodation such as in The Netherlands, which are based on "the village" idea, which reflects "normal community life" and may, therefore, reduce confusion and distress in individuals. http://gizmodo.com/inside-an-amazing-village-designed-just-for-people-with-1526062373

In discussions with families supporting a younger person with dementia, the prospect of seeing them accommodated within aged care is extremely daunting but there are few options. Families often say they would like to have the services and supports to care for their loved one at home or if this is not possible to sustain, then the option of a home which better meets the divergent physical, intellectual and social needs of a younger person to those of an older person, would be preferred. The recommendation from many of families would be for a communal "village" type arrangement, of individual units connected to a community hub/living space. Each unit would have a bedroom, bathroom, kitchen and living room, so individuals could have privacy and a sense of ownership and self -management of their home, but staffing support, activities and company could be provided through communal areas, if desired. Residents could move to this village in their younger years and have the independence to access the community and their employment or day services. Activities could be organised which are age appropriate and chosen and planned by residents. As the residents age, the level of staff support could increase as needed, with the possibility of ageing in place, rather than moving to an aged care facility. Staff who are specifically trained in dementia care could then be provided.

Ultimately though, the issue of accommodation is about choice, control, privacy and dignity and having meaningful lives as valued members of the community. Most of us benefit from this experience in our lives. Unfortunately for people with intellectual disability these benefits are rarely realised, despite deinstitutionalisation, social role valorisation, the recognition of human rights, the Disability Act 2006, inclusion and other social changes designed to benefit people with disability. If there is no actual change to the options for younger people, then community models of care are just rhetoric.

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