

Submission to inquiry into National Disability Long-term Care and Support Scheme

As Carers of our intellectually disabled brother, we would like to express our views as to the issues facing our family, and many others in the same situation, at the lack of permanent accommodation options.

After our mother died 21 years ago, we took over the care and responsibility of all aspects of our brother's life. At the time, our Father was aging and unwell and we were raising young families.

Our brother was working with a local Provider. He was working in the print room, not the Sheltered workshop. As we felt it was in the best interests of our brother, and with our Father becoming unwell with early dementia, we needed to consider permanent care and accommodation for him. Under the guidance of the Provider, it was recommended we place our brother in to residential care. Initially he was in a house with very disabled people, however, it was decided by the Provider he would be shifted to another house, where he would not require the same level of care. Unfortunately, the carer in charge of the house was totally unsuitable for this role. Our brother's mental health deteriorated so badly, he suffered a breakdown. As this residential care became a health & safety issue, he was returned under our care. As a result of this experience, he was unable to return to his work. We would not contemplate this form of care now or in the future, and believe carers need to be suitable for this position with adequate training provided.

As mentioned earlier, we have dedicated 21 years to our brother's complete care, with sourcing information and connecting to Agencies without any guidance or assistance.

We are at a stage where we require permanent care and accommodation for our 57 year old brother. Unfortunately, there is nothing available. Our brother would be most suitable for a hostel-style accommodation, similar to aged-care. He was in respite in an aged-care facility recently, and settled well. The care was excellent. He enjoyed the contact with staff, residents and activities. It must be understood a 57 year old intellectually disabled person, is not at the same capacity as a 57 year old person with full health. Unfortunately, we cannot access this facility for permanent care due to his age.

In summary, our submission is:

- Urgent need to increase accommodation available to disabled, both intellectual and physical. Our many years of experience and dedication believe HOSTEL accommodation, run similarly to Aged Care, would be an excellent solution to this serious issue. The wide-spread contact with staff, other residents and activities allows the residents to be part of a community environment.
- Carers need to be provided with more support and information to maximise the resources available.
- We believe that the medical profession are not always equipped with the necessary skills to meet the medical and subsequent emotional needs of the disabled or elderly. In our opinion there is a great need for some training of medical staff in this area.

- We are currently working with Uniting Care, an agency for DHS, and they have informed us they have 60 clients, and 37 looking for accommodation with no prospects in the near future.
- Awareness by DHS to understand age-appropriate accommodation – a 30 year old have different needs to a 57 year old.
- Carers employed in positions run by DHS, need to have adequate training to ensure that the health & safety of residents is paramount. We have found this area to be of a great concern from our personal experience.

Our brother has come from a loving and caring home, and we are desperate to see him in an environment suited to his needs. Disabled people have human rights as other citizens within Australia and we, as a developed country, have an obligation not to discriminate against their special needs. Thank you for this opportunity to express our views on behalf of those who do not have voice in our community.

Susan McLean and Helen Spellman
Carers