

SUBMISSION TO SENATE INQUIRY ON RESIDENTIAL CARE FOR YOUNG PEOPLE WITH SEVERE DISABILITIES

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Invitation to Visit Greystanes Disability Services

I am writing to invite the Senate Standing Committee on Community Affairs to visit Greystanes Disability Services to assist the Committee in its inquiry on residential care for young people with severe disabilities.

About Greystanes Disability Services

Greystanes Disability Services (Greystanes), based at Leura NSW, provides support and assistance to young people with severe intellectual and multiple disabilities who have complex health needs. Historically these services were provided in a forty bed institution called Greystanes Children's Home, staffed principally by nurses. This institution was devolved over a number of years and now Greystanes supports its clients in community based living arrangements, such as group homes located in the Blue Mountains and Nepean areas. Our group homes are ordinary but accessible houses located in ordinary streets and neighbourhoods. Our front line support staff are Disability Support Workers and our service includes a small mobile health team consisting of nurses and allied health staff. Greystanes strongly believes that a person's chronic and complex health needs should not prevent them from living and enjoying a full life in the community.

Health needs of the People Greystanes Supports

Greystanes currently supports twenty nine people ranging in age from 20 to 42 years. These people have multiple physical disabilities and severe/profound intellectual disability, as well as complex health needs. A significant number also have visual and hearing impairments. Their health needs typically relate to a range of conditions such as epilepsy, dysphasia, cerebral palsy and osteoporosis. A number have cardiac, renal or lung disease. The majority of



the people we support have specialist dietary needs with a number having enteral feeding via a PEG, all have movement and positioning needs as well as communication and sensory requirements. Many are frail and susceptible to respiratory illness. All require 24/7 support for all their daily needs.

Service Design

In planning the devolution of Greystanes Children's Home it was recognised that the mainstream health system was not properly resourced to meet the particular needs of people with intellectual disability who have complex health needs. It was for this reason that Greystanes established its mobile health team. This lack of capacity within the health system sadly still exists, as highlighted in the NSW Council on Intellectual Disability (NSW CID) submission to the Committee.

The Greystanes mobile health team, which has expertise in supporting people with intellectual disability, consists of nurses, physiotherapist, speech pathologist and dietitian. This team complements the mainstream health system and specialist intellectual disability health services by:

- Working closely with each person's family, GP and medical specialists;
- Coordinating and monitoring each person's health care plan;
- Intervening early to avoid preventable illnesses;
- Training and mentoring Disability Support Workers in health related matters;
- Reducing hospital admissions and achieving shorter hospital stays; and
- Working with health related bodies and inter agencies to improve the responsiveness of mainstream health services for this group of very vulnerable people.

A major concern for Greystanes and specifically for the people we support, is the need for our mobile health team to continue to operate and be funded following the rollout in our region of the National Disability Insurance Scheme.

An Engaged and Meaningful Life

Greystanes has adopted Person Centred Active Support (PCAS) as the framework for how staff work with and assist the people they support. Research has demonstrated that people with severe intellectual disability can spend eighty percent or more of their daily awake hours disengaged and not involved in any meaningful activity, and that disengagement is a leading cause of challenging behaviour. PCAS is about the skills and capacity of staff and the service in enabling engagement of the person with a disability in meaningful activities and relationships. This is an evidence based approach that focuses on ensuring people, no matter their level of intellectual disability, spend their time engaged in meaningful activities and relationships and experience choice and control as valued members of their community. Greystanes has

produced a brief DVD about how we provide person centred supports in our community living program. To see the DVD click here: [Greystanes active support](#)

NSW CID Submission

The NSW CID submission to the Committee highlights a number of key service deficiencies and the need for the full implementation of the National Disability Insurance Scheme and enhancement of health services for people with disabilities. Both of these initiatives require maintenance of some key positive functions of State and Territory disability services systems.

Greystanes Disability Services fully supports the NSW CID submission to the Standing Committee.

John Le Breton

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