



24 March 2015

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

Dear Ms Radcliffe,

**Re: Submission to the Senate's Inquiry into the adequacy of existing residential care arrangements for young people with severe physical, mental or intellectual disabilities in Australia**

Thank you for the opportunity to appear before the Committee on 11<sup>th</sup> March at its hearings in Melbourne to discuss Wesley's submission.

Wesley notes the interest from the Committee on the impact that the full rollout of the National Disability Insurance Scheme (NDIS) will have for clients of our neurological service. Wesley firmly supports the NDIS and believes it will provide greater choice and control for people with a disability. However, as we noted at the hearing, people with Huntington's disease have complex support needs and these need to be fully understood when preparing for full scheme rollout. In particular, Wesley believes that the use of health services is a reasonable and necessary support for people with Huntington's. We urge a review of the rules about the use of health services under NDIS to ensure that there is clarity about how these rules will be interpreted in the future.

Wesley wishes to raise some further issues with the full rollout of the NDIS that will be important when planning for the needs of people with complex neurological disabilities.

**Training:**

It is not clear if staff training will be funded under the NDIS.

As stated in our submission, clients with neurodegenerative conditions, in particular Huntington's disease (HD), are at significant risk of aspiration pneumonia.

To manage this risk, all new staff commencing employment at Wesley Neurological Support Services receive training from the program speech pathologist, who has specialist knowledge of the complications arising from HD. In addition all staff are mandated to do refresher training at least annually. Furthermore, we have a number of mandatory training topics that are not only

critical in managing risks to client's health and wellbeing, but also staff safety. Currently, the cost of this training is covered under the block funding model.

**Aids and equipment:** Wesley understands that the NDIS will provide aids and equipment required by clients. To adequately meet client's needs, equipment needs to be provided in as timely a way as possible. Currently, clients can wait up to 2 years for equipment. This can mean that by the time it arrives, the piece of equipment is no longer suitable, because the client's condition and care needs have changed over that time. This is especially the case for a progressive neurological disability like Huntington's disease. This results not only poor in outcomes for the client, but it is also a significant waste of resources. For example, a client at WNSS waited 2 years for a custom built chair; it cost in excess of \$11, 000. It was funded by SWEP and the client. When it arrived, the client had progressed in his illness to the point that the chair was no longer suitable. The delay, and lack of suitable equipment, meant that the client was unable to visit his wife at their home.

**Support for carers:**

Wesley acknowledges that family members or friends will continue to play an essential role in meeting the care needs of people living with a disability. It is critical that carers be supported through adequate respite provision, both in-home and in residential and day care. This must be given serious consideration. This requires respite programs to be adequately funded to avoid carers' fatigue, family breakdown and potentially complex clients being abandoned in the acute sector, and thus rendered homeless

The NDIS provides a significant improvement in the mechanisms to ensure that quality care is provided to people with a disability. However, the Committee has an opportunity to ensure that transition to the full scheme will completely address the complex needs of people with progressive neurological conditions, such as Huntington's disease.

We look forward to the Committee's report and recommendations.

Yours sincerely

Kelly Stanton  
General Manager – Services  
Wesley Mission Victoria.