

Submission
No 237

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Organisation: Huntingtons NSW & ACT

Date Received: 9 August 2018

INQUIRY INTO THE IMPLEMENTATION OF THE NATIONAL DISABILITY SCHEME AND
THE PROVISION OF DISABILITY SERVICE PROVIDERS IN NEW SOUTH WALES

Portfolio Committee No. 2 – Health and Community Services

Introduction:

Huntington's NSW & ACT represents people with Huntington's disease (HD), their families and carers and those at risk, gene positive or gene negative for HD.

HD is a genetic (autosomal dominant) neurodegenerative disorder that results in prolonged and disabling behavioural, cognitive and motor changes. Each child of an affected person has a 50% chance of inheriting the gene for HD. The average age of onset is between 35 and 45 years of age and it affects both men and women. Life expectancy is about 15 to 20 years after symptoms appear.

In NSW there are approximately 600 people with HD of which 76% are under the age of 65. Consequently, there are 456 people with HD who could be participants in the National Disability Insurance Scheme (NDIS).

Most frequently long-term carers for people with HD are:

- still in the workforce, caring for a relative with HD as well as dependent children;
- retired from the workforce to care for relative with HD, with or without dependent children, and experiencing substantial reduction in income;
- people "at risk" for HD (siblings and offspring) spending their 'well years' caring for affected relatives or
- caring for, or have cared for, more than one family member over more than one generation, e.g., women caring for their husbands and children simultaneously.

These factors can significantly impact carer mental health and can lead to higher burnout levels.

We are aware that people with HD in NSW are receiving support services through the NDIS and it is acknowledged that the NDIS does not provide funding for carers. The benefits of the NDIS for carers results from or is a consequence of improved services provided to the person with HD. Carers still require specialised knowledge about their caring role and such information and education about HD is not available from generic carer services. It is best provided by organisations with experience and expertise such as HNSWACT.

Up until 30th June 2018, support for carers of people with HD, and particularly those in rural and remote NSW, was provided by this organisation with a grant from the NSW Department for Disability Services. Because this grant has been discontinued HNSWACT is no longer able to support geographically and socially isolated carers of people with HD in rural and remote NSW.

Recommendation: For the NDIS to satisfactorily support people with HD, their families and carers it is recommended that the NSW Department of Disability Services reconsider providing funding for carers of NDIS participants, particularly those in rural and remote areas. Caring for carers of people with HD will complement the NDIS and ensure that carers receive the education, knowledge and information required to undertake their caring role.

Robyn Kapp OAM
Executive Officer
9th August 2018