Submission

to the Joint Standing Committee

on the National Disability Insurance Scheme (NDIS) Inquiry

into the current Scheme implementation

and forecasting for the NDIS

Huntington's Australia

On behalf of:

Huntington's New South Wales & Australian Capital Territory
Huntingtons Queensland
Huntington's South Australia & Northern Territory
Huntington's Tasmania
Huntington's Western Australia

Opening statement

People living with Huntington's disease are an ideal example of where the issue of service interface comes to a pointy and sometimes nasty head.

Huntington's disease (HD) is a genetic neurological condition that affects the brain and nervous system. It can cause three types of symptoms including:

- Involuntary movements, which can lead to problems with balance, walking and functioning
- Cognitive (or 'Thinking') symptoms, which can reduce a person's memory impacting their ability to plan and multi-task; as well as impacting their ability to reason
- Behavioural symptoms, which can be seen as personality changes and/or actions that are out of character.

Each person with HD is affected differently.

HD symptoms commonly appear in a person between the ages of 30 and 50, but it is possible for them to appear at any age. There is currently no cure.

People living with Huntington's disease thus have a progressive "disease" which will almost invariably mean they qualify for the NDIS. When they become NDIS participants they risk losing access to e.g. health services. In theory NDIS covers nursing needs, but this is often not understood by NDIS planners and others responsible for reviewing, determining and signing off on Participants' plans.

Individuals with rare diseases such as HD rely on an array of services from both the disability care and health sectors to meet their needs. It is well documented that having a rare disease creates specific challenges as the health and disability care systems are focused on detecting, treating and managing diseases that affect a large number of patients (Jackson, 2019 [1]). The system is not geared towards meeting the unique, complex and multi-system needs of people with rare diseases (Jackson, 2019). The problem is that this line between health and disability services is artificial, especially for people with HD whose disability is caused or exacerbated by their condition and morphs and changes with the degenerative nature of the disease progression. This artificial delineation between health and disability services

[1] Jackson, A 2019, *Disability and rare disease: towards person centered care for Australians with rare diseases*, apo.org.au, https://apo.org.au/node/263806

also fails to promote care integration that can best support the complex needs of people with HD (Community of Practice Framework, 2017 [2]). People with HD who are NDIS Participants require seamless pathways, including shared care pathways and initiatives between health and disability sectors by enabling a better coordinated approach between organising NDIS supports alongside of developing care plans in partnership with Participants, their carers and medical/allied health professionals resulting in improved outcomes for people with HD.

As of 31 March 2021 there were 945 active NDIS Participants with a primary disability of Huntington's disease (HD). There were a further 24 Participants with another disability also living with HD.

Responses to questions

- The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:

  i. the availability of support outside the NDIS for people with disability (e.g. community-based or 'Tier 2' supports),

For people with Huntington's disease the NDIS should have been a godsend. For many it has improved their quality of life markedly but for others it has been a mixed blessing.

In particular the overlap of multi-disciplinary services required to adequately support someone with Huntington's disease has been a real challenge between health-funded supports and NDIS-funded supports. As many people with late-stage Huntington's disease live in residential aged care (even though around 50% of them are under 65 years of age), there can be a three-sided conflict between NDIS supports, health supports and aged care supports.

[2] Huntington's WA 2017, *Living well with Huntington's Disease: Community of Practice Framework, Huntington's Western Australia*, July, https://www.huntingtonswa.org.au/about-us/living-well-with-huntingtons-disease-community-of/.

ii. the future of the Information, Linkages and Capacity Building grants program;

The ILC program is a crucial component of the various mechanisms to develop the NDIS and the capacity of agencies supporting those accessing NDIS services.

Over the life of the ILC, various iterations of grant rounds have delivered funding for a mixed foundation of activities. It would be of great value to review how well previous rounds were targeted in relation to need and to evaluate the impact of those grants.

Due to the competitive nature of the ILC grant rounds, many worthy proposals do not get funded. In some senses, this approach potentially discriminates against smaller cohorts, or those with only or largely volunteer staffed organisations compared to better funded agencies or those who can afford to hire professional grant writers.

Advance notice of funding cycles would help level the playing field. We could start preparing grant applications without the sense of crisis when the closing date is only a few weeks after a funding round is announced.

- The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;

As part of Huntington's WA (HWA) annual survey in 2020, over 40% of HWA clients receiving NDIS packages told us the current system was not meeting their complex health and disability care needs and that NDIS planners and coordinators often lack vital expertise to offer the support required for this complex and challenging disease, leading to a failure of incorporating key support recommendations in plans resulting in reduced outcomes for HD clients. HWA clients also reported having experienced a deterioration in the support they receive under the NDIS along with incurring significant out-of-pocket costs just to receive some of their most basic needs.

Consideration also needs to be given to the inherent risks and liabilities in regard to HD Participants sharing accommodation with other individuals with disability. There is extensive research on the short and long-term impacts on physical, psychological, and social well-being of individuals who experience witnessing the decline and eventual death of another person.

Significant adverse physical and psychological well-being, poorer mental health and social functioning occur up to four years following bereavement, with less socially active individuals experiencing a longer deterioration in physical and psychological

health. Furthermore, evidence suggests that the experience reduces the impacted person's satisfaction with their own health (Liu WM, Forbat L, Anderson K, 2019 [3]). This poses a significant liability and risk on those entities and government bodies entrusted to provide care for individuals placed into co-sharing accommodation arrangements with HD clients, as these individuals are more likely to experience lasting negative and enduring consequences experienced by witnessing the decline and eventual death of their housemate who has HD.

- The reasons for variations in plan funding between NDIS participants with similar needs, including:

i. the drivers of inequity between NDIS participants living in different parts of Australia

The key concern our community faces is the lack of knowledge or understanding of the complexity and unpredictability of HD. In theory it would make an enormous difference if the complex care streams promised in 2017 were generally available to this client group and to all with complex progressive neurological conditions. There is no hope of being able to ensure every person involved in the NDIS plan of a person with HD has a good understanding of the disease, but some hope of achieving this if everyone with HD was referred through to a complex care team, or better still a progressive neurological team.

ii. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding

Inconsistent decision-making within the NDIA is a plague for our community. The lack of access to the promised complex needs pathway has not helped improve the situation for many people with HD.

Furthermore, it has been fairly commonly reported over the past 12 months or so that people with HD are having the funding in their plans REDUCED on review, even though they are suffering from a progressive disease which means that they are almost inevitably MORE DISABLED than at the last review.

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[3] Liu, W-M, Forbat, L & Anderson, K 2019, 'Death of a close friend: Short and long-term impacts on physical, psychological and social well-being', in I Papousek (ed.), *PLOS ONE*, vol. 14, no. 4, p. e0214838.

iii. measures that could address any inequitable variation in plan funding

The promised complex care stream could be of great benefit to people with HD. It is not a realistic expectation that all LACs and Planners should have a solid understanding of this or other complex or rare diseases. However it is important to note that simply measuring presenting levels of disability will often not produce the right outcome in the case of HD as people affected by this disease commonly have anosognosia, a lack of insight which impairs their ability to understand or perceive their illness or level of disability. Also HD is unpredictable with severity of symptoms varying from day to day and in particular presentation of behavioural issues often temporarily controlled or minimised in “interview” type settings.

Thus, the approach of simply measuring assessed disability may very well lead to inequitable plan variations and funding and support outcomes.

- The ongoing measures to reform the scheme including:

i. the new early childhood approach, including whether or how early intervention and other supports intended to improve a participant’s functional capacity could reduce their need for NDIS funding, and
ii. planning policy for personalised budgets and plan flexibility;

Personalised budgets and plan flexibility are good in theory but can fall down when people with HD are required to live in group homes. If supports are shared between three or four people and one of these participants receives a reduction in their supports, there are often negative resource consequences for the other members of the household whose needs may not have changed.

iii. and

- Any other related matters.

People with progressive degenerative neurological diseases continue to be eligible for the NDIS but continue to feel like a square peg in a round hole due to the wording of the NDIS Act and Objects which clearly does not appropriately consider the needs of this small but significant cohort.

We re-iterate our view of the need for a review of the wording of the NDIS Act and Objects so as not to exclude people with disability caused by progressive disease.