Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia
**Brief Introduction**

The heightened community expectations for equal rights for all Australians and access to services based on individual choice has increased the priority on maintaining and supporting a person’s engagement, independence and connection with their local community. This principally relates to appropriate community access for individuals together with aged appropriate accommodation options. The development and implementation of reforms including the Younger Persons in Nursing Homes Initiative and the National Disability Insurance Scheme (NDIS) were in direct response to community needs. As an advocacy and service delivery body, Huntington’s Victoria (HV) has responded positively to these reforms by working in partnership across all jurisdictions in order to continue to meet the specific needs of the Huntington’s disease (HD) community. Unfortunately, despite the best intentions of all key stakeholders those living with Huntington’s disease and its unforgiving progression continue to be inappropriately placed in aged care facilities. This is due to a lack of alternative age appropriate residency options, and staff that are sufficiently skilled to meet the specific needs of community members affected by Huntington’s disease.

**What is Huntington’s disease?**

Huntington’s disease (HD) is a fatal genetic neurodegenerative disease that results in brain cell death. The disease affects global executive functioning inclusive of cognitive, physical, emotional, behavioural and psychological symptoms. As the brain cells die, people with HD can experience:

- Involuntary movements,
- Impaired physical coordination and balance
- Loss of mental flexibility
- Compromised thinking skills and processes
- Limited attention span and memory difficulties
- Difficulties with swallowing
- Impaired verbal communication
- Problems in planning, organising and executing tasks
- Personality changes
- Mental disorders experienced can include: anxiety, anger management issues, depression and mood disorders, amongst others.

As the Huntington’s disease progresses, mental health deterioration can occur. According to the American Psychiatric Association, the repercussions of mental health issues impact the person directly affected by the disease and those who care for them, “It is well established that psychiatric symptoms are common in Huntington’s disease. In fact comparison with other research suggests that suicide rates in Huntington’s disease remain higher than those found in other medical and neurodegenerative diseases” (Critical Periods of Suicide Risk in Huntington’s disease American Psychiatric Association, 2005: 3-19)
There is no cure for Huntington’s disease but limited medical interventions are available to minimise and assist in the management of symptoms. It is commonly agreed that the general age of onset is between 35 - 55 years, however over the last 3 years Huntington’s Victoria has noted and experienced an alarming escalation of onset amongst those aged 16 - 29 years. The juvenile form of Huntington’s disease presents during early childhood and/or adolescence and is more rapidly progressive. Each child born of an affected parent has a 50% chance of inheriting Huntington disease. Once diagnosed with Huntington’s disease prognosis is generally between 15 - 25 years.

The impact of Huntington’s disease
Upon the onset of symptoms, a client deteriorates rapidly both physically and mentally. Huntington’s disease has a direct and indirect impact upon the person affected and family members/carers including extensive psycho-social and economic ramifications. One of the most devastating traits of Huntington’s disease is its entrance into people’s lives during their young adulthood, when personal development and creating one’s life is a priority (i.e. university studies, career establishment, entering relationships, creating a home and family). The prevalence of this disease and the associated costs of health care, medications, aids, equipment, uncertain employment status or enforced early retirement is an extra burden on top of a young adult’s day-to-day financial situation. The financial costs coupled with qualitative costs such as the vital provision of ‘informal’ care provided by carers/family is a shock to the system. Additionally, HD community members face financial challenges that are as a result of their disabilities impending upon their ability to work and earn income. Therefore, vital needs such as medical treatments, daily living expenses, and family expenses are unachievable.

Carers are an important part of the provision of service to people with HD whether they are living at home or in care. Due to the high complex care needs of HD and its rapid progression, carers often need to reduce or cease their own paid employment. As a result of the heredity nature of the disease, carers grieve for the loss of family members across generations, often many within the one family unit. Children, adolescents and siblings witness firsthand the devastating impacts of HD with the knowledge that their future will be impacted by the disease in one way or another. Children and adolescents often provide the role of carer for a parent and/or sibling resulting in the associated social impacts:

- Frequent interruption of education thus less social involvement with peer group
- Truancy leading to poor academic performance
- Adolescents are time poor therefore unable to participate in work force
- Reduced income earning potential over the lifetime
- Child’s safety at risk due to reduced supervision
- Episodes of mental health issues as a result of stresses performing parental roles whilst their own future is unknown

Community Need
Huntington’s disease clients’ needs are ever changing due to the progressive nature of the disease, which places continuous and ongoing demand for suitable services and
accommodation options. Huntington’s Victoria recognises the complex dynamics of the current fragmented and multi-layered service sector environment and the innate difficulties in trying to establish a coordinated process across the health, mental health, and disability systems. Huntington’s Victoria would like to take a coordinated approach with Government and advocacy bodies across service sectors in addressing the needs of all individuals.

Whilst some patterns of the disease are discernible across the population of people affected, each experience is utterly unique, unpredictable and complex. Those affected by Huntington’s disease require constant monitoring, service planning, service coordination and advocacy (Research and Development program: A Scoping Paper, AHDA VIC Inc, April 2004:8)
A. The estimated number and distribution of HD persons in care in the aged care system in Australia, and the number of HD persons who require care but are not currently receiving care.

Whilst there is no existing national registry for Huntington’s disease, below are the estimated number of Huntington’s disease affected Victorians in aged care:

There are currently 20 Victorians under the age of 65 living with Huntington’s disease awaiting placement in care.

B. Short and long-term trends in relation to the number of Huntington’s disease (HD) persons being cared for within the aged care system.

Individuals affected by Huntington’s disease strive to maintain their independence as well as remain living in their own home, but frequently, they cannot achieve this goal. As a result of both physical and cognitive decline, people experience an increase in their care needs, which cannot be sustained at home with the support of formal and informal supports. Despite the number of disability accommodation options increasing over the years there is still a trend towards young people with HD entering residential aged care prematurely. This can be explained by:

- An increase in diagnoses: It is now estimated that 1 in every 10,000 people will have HD with many more currently at risk. A greater number of people affected with inevitable symptoms eventuating is creating increased demand upon insufficient supply of care and appropriate accommodation options.
- An increase in the number of younger people becoming symptomatic in their 20’s and early 30’s. Typically, the disease progresses more rapidly in younger people, therefore these young people will require a high level of care when they are young people and...
well below 50 years of age. Limited formal (professional carers/supports) and informal (family and friends) supports combined with insufficient disability housing options without immediate access results in clients resorting to support through the aged care sector.

- Due to HD being hereditary, family members fulfilling the carer role often become Huntington’s Victoria clients. Every child of an affected parent has a 50% risk of inheriting Huntington’s disease, and it is not uncommon for multiple generations to be affected simultaneous. This means that the burden of care cannot remain within the family system, therefore support is outsourced to residential settings; sometimes earlier than usually required or expected to avoid adverse outcomes.

- The HD community is also often financially and socially disadvantaged due to reduced capacity to participate in the work force; this includes both Huntington’s disease clients and their carers/family members. Consequently, individuals do not have the financial resources to fund in-home supports, forcing them to rely on residential aged care to ensure that care needs are met.

- Vacancies for HD clients are minimal due to the majority of disability accommodation being utilised by young people with mainstream intellectual disabilities such as Prader Willi syndrome or Down syndrome. Consequently, the disability accommodation sector cannot respond to HD clients need within a timely manner.

C. The health and support pathways available to HD persons with complex needs.

The needs of Huntington’s disease clients span across a range of health and community sectors. Persons affected by HD often require a range of supports that are supplied by different service systems. Persons affected by HD often struggle to receive essential care and services as a result of the little collaboration between various agencies including local government, health, mental health, and disability. Observing the need for collaboration, Huntington’s Victoria has created working partnerships with Royal Melbourne Hospital (RMH) and the National Disability Insurance Scheme (NDIS).

- Collaborative Model of Care between HV and RMH:
  - Continuity in client care.
  - Regular assessments to ensure supports are in response to current needs of client.
  - Timely access to support services.
  - Build capacity of local generic services to meet the needs of people affected by HD.
  - Reduce significant risks to clients that could impact on their ability to remain in the community.

- Collaborative protocol between HV and NDIS:
  - Access to HV support services.
  - Link with HD specialist services ensuring continuity in client care.
  - Access to education on HD in response to current client needs.
  - Localised service sector capacity building.
D. The appropriateness of the aged care system for care of HD persons with serious and/or permanent mental or physical capabilities.

The prospect of entering care well before the age of 40 years of age is very real and distressing prospect for the HD community. When discussing the appropriateness of aged care for this group, questions raised are regularly, “can and does aged care meet the care needs of HD residents”?

The answer is multifaceted. The aged care system does have the skilled staff and appropriate staffing ratios to attend to the medical and physical aspects of Huntington’s disease. However, aged care is geared towards the older generations and therefore the skill set of staff, the structure of the aged care system, as well as social activities held within these settings are generally not engaging or connecting with the young demographic affected by Huntington’s disease.

People with Huntington’s disease often require a balance between mainstream and secure (dementia) units. Cognitive changes that include perseveration, disinhibition, impulsiveness, and the need for instant gratification are commonly not well managed within mainstream residential units. Staff in aged care facilities are often time poor and are not trained to manage a resident affected by Huntington’s disease.

Staff are also confronted by caring for a person that is close to their own age or younger. This experience for staff can be emotional and challenging, with some staff finding it difficult to continue caring for HD residents. A common symptom of Huntington’s disease is severe behavioural changes that can be challenging for a staffing group to that do not have specific training to manage successfully. Huntington’s Victoria recognises the need for standardised training and provides education sessions upon request to alleviate staff distress through strategies. Without individual facilities seeking training, staff are not briefed on the specific symptoms and behaviors unique to Huntington’s disease.
E. Alternative systems of care in federal, state and territory jurisdictions for HD persons with serious and/or permanent mental, physical or intellectual disabilities.

There are no existing systems of care tailored to Huntington’s disease Australia wide. In Victoria, there have been two specific programs that Huntington’s Victoria is utilising to meet the needs of their community. Clients based in Victoria are fortunate to have access to the following state based supports not offered in any other state or territory:

- **Individual Support Packages (ISP)**
  ISPs are funds allocated to a person to meet their disability related support needs and prevent early admission into the aged care system.
  A person with Huntington’s disease can wait for up to 2 years before being considered for allocation of an ISP. Due to the progressive nature of HD, this timeframe is unrealistic and often results in early admission into aged care.

  There are limited packages available in Victoria specifically for people with HD. These packages are allocated for the duration of a person’s life regardless of location. Whilst the ISP system is a useful resource, Huntington’s Victoria find it is limited by funding, waiting lists, and fragmented approach region to region. Without a centralised screening process and management body, clients are disadvantaged by their geographic location with respect to allocation of ISPs.

- **My Future My Choice**
  My Future My Choice provides accommodation housing for younger people who possess high, complex care needs and are at risk of entry to aged care.

  This initiative has now been amalgamated into mainstream disability accommodation. This initiative met short term accommodation needs for the HD community, however there are no longer vacancies for new clients or staff training needed to provide appropriate care due to insufficient funds.

- **Mainstream Disability Accommodation**
  Mainstream disability accommodation is an alternative for Huntington’s disease clients that do not have high level care needs. Mainstream disability accommodation is structured to manage people with intellectual disabilities. This accommodation option does not meet the majority of our clients needs as it is focused on the more physical aspects of disability. Huntington’s disease clients have progressive needs that are unable to be met in this environment.

  Individuals with Huntington’s disease have specific care needs that require expert knowledge and specific training. Currently, the Arthur Preston Centre in East Burwood is the only facility explicitly for Huntington’s disease affected people; however they possess just 20 beds. Huntington’s Victoria has a successful collaborative working relationship. The facility is effective at managing clients whose symptomology is a combination of physical, medical and cognitive issues; however disability trained staff struggle with matters relating to behavior management and psychiatric presentations. Without sufficient funding mainstream disability
accommodation are unable to access initial and ongoing Huntington’s disease training.

F. The options, consequences and considerations of the de-institutionalisation of HD persons with serious and/or permanent mental, physical or intellectual disabilities

Not applicable.

G. What Australian jurisdictions are currently doing for HD persons with serious and/or permanent mental, physical or intellectual disabilities and what they intend to do differently in the future.

There are no existing systems of care tailored to Huntington’s disease Australia wide. In Victoria, there have been two specific programs that Huntington’s Victoria is utilising to meet the needs of their community. The introduction of the NDIS in the pilot region of Barwon has enabled a shift towards a system that is committed to an integration of services that meet the specific individual needs of the HD client. Huntington’s Victoria has worked collaboratively with NDIS to develop a protocol between the respective agencies to ensure that all persons affected by HD receive a consistent approach to care. Whilst Huntington’s Victoria is fortunate to have NDIS support the HD client, it is our collective hope that this evidence based protocol will be implemented Australia wide.

One challenge Huntington’s Victoria continues to face is engaging with the mental health system despite numerous attempts. The psychiatric symptoms of Huntington’s disease is recognised in the diagnostics and statistical manual of mental disorders (DSM-5), however on presentation to a mental health service this is not recognised as a criteria for treatment.

H. The impact of the introduction of the National Disability Insurance Scheme on the ability of HD persons in aged care facilities to find more appropriate accommodation

The introduction of NDIS and its ability to provide timely services to people with HD has been long overdue and is much welcomed by the disability service sector. The NDIS centralised approach to care has enabled a more responsive and appropriate method to meeting the needs of the client.

Unfortunately, the introduction of NDIS did not alleviate the need for more age appropriate accommodation. Whilst the NDIS has been successful in empowering the HD client to continue living in their existing home within their community, there remains an vital need for age appropriate accommodation.
I. State and territory activity in regard to the effectiveness of the Council of Australian Governments’ Younger People in Residential Aged Care initiatives in improving outcomes for HD persons with serious and/or permanent mental, physical or intellectual disabilities, since the Commonwealth’s contribution to this program has been rolled into the National Disability Agreement and subsequent developments in each jurisdiction

Since the roll out of the National Disability agreement, the Younger People in Residential Age Care Initiatives has ceased to develop.

The purpose built My Future My Choice homes continue to be a vast improvement on the mainstream disability accommodation options. This initiative has enabled young people with HD to continue to live in the community who would have otherwise entered residential aged care.

As discussed in previous submission criteria, the challenges currently faced directly relate to the highly complex needs of the Huntington’s disease affected client. Ongoing issues experienced by Huntington’s Victoria include: disability staff not skilled in areas relevant to Huntington’s disease management, non-existent mandated training, and insufficient availability of beds in age appropriate accommodation.

Since the amalgamation of My Future My Choice into the mainstream disability accommodation program, the commitment to keep young people out of aged care facilities has significantly diminished as a key priority of the Department of Human Services.