# Effective housing and support models for people with Huntington's disease

## Report 1: Interviews with professionals

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Please note that these are preliminary findings and are correct at the time of publication.
Full findings will be published following completion of the project.

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# Executive summary

## Background

Huntington's disease (HD) is a genetic neurodegenerative disease that affects global executive functioning and includes cognitive, physical and psychiatric symptoms. Housing and support needs of people with HD change as the disease progresses. In Australia, Specialist Disability Accommodation (SDA) is a range of National Disability Insurance Scheme (NDIS) funded housing designed for people with extreme functional impairment or very high support needs. Supported Independent Living (known as SIL) is an NDIS funded support that provides help and/or supervision of daily tasks. Despite the presence of funding for housing and support in Australia, people with HD often end up living in residential aged care (RAC) facilities, even when aged under 65 years. Although the Australian Government has set targets to ensure that no people under the age of 65 years are living in RAC by 2025 (DSS, 2020), it remains unclear what housing and support models are effective for people with HD. It is particularly important to understand how NDIS funding can support people for the duration of their lives and avoid admission to RAC. In the absence of an evidence base, the aim of this research was to explore professional perspectives on the effectiveness of housing and support models for people with HD.

## Method

Qualitative interviews were conducted with 17 professionals who had expertise in housing and support for people with HD and supplemented by input from a stakeholder reference group. Interview participants were recruited from Australia, the Netherlands, Belgium, Denmark, Switzerland, Scotland, and New Zealand. Interview participants had a variety of backgrounds, including service providers, academics, clinicians (physiotherapists, occupational therapists, psychologists, psychiatrists, neurologists, nurses), social workers and NDIS support coordinators. Interview questions focused on the housing and support models that exist for people with HD in the country they were based, evidence of their effectiveness and opportunities to further improve housing and support.

## Findings

Five overarching themes related to effective housing and support models were identified:

1. Housing and support considerations
2. Access to housing and support
3. Types of housing and support
4. Effective elements of housing and support
5. NDIS supports

There are a number of important considerations for the housing and support needs of people with HD including the young age of people with HD, complexity of symptoms, the need for flexible and responsive support and consideration of family dynamics.

The housing and support experiences for people with HD are characterised by a lack of choice, discrimination, long wait times, and poor quality care. Whilst several different housing and support models exist internationally, they tend to only support small numbers of people and thus most people with HD, even if young, end up living in RAC. Most participants reported that RAC is not an appropriate environment for young people with HD, not only due to not being age appropriate but also because the staff ratios and staff expertise were not adequate for people with HD.

HD-specific facilities were reported to be effective by some participants. Whilst there was recognition that it made sense to have people with HD together with staff who have expertise in HD, some participants felt that diagnosis should not dictate where someone lives. Some opposed the idea that housing should be based on diagnosis and suggested that it should be based on the person's needs.

Across housing types, there were several key elements of effective housing and support models. These included support for families; accessible physical design and location; staff with expertise in HD; person-centred support and flexibility to support changes in functioning.

Whilst the introduction of the NDIS has been beneficial for people with HD, interview participants reported that the NDIS is not fit for purpose for people with progressive neurological conditions. Problems included long wait times for funding for SDA, home modifications and disability supports, finding housing and support that accepts people with HD, and concerns with the quality of care provided by some support providers.

## Implications

RAC is not a viable housing option for people with HD. Shared HD specific housing and support models can be helpful; however, housing and support arrangements should be based on the individual's needs and preferences rather than diagnosis. Housing and support models should incorporate support to remain living with family for as long as possible/desirable (including allied health, disability supports and home modifications).

Where disability housing and supports are required, these need to be physically accessible, geographically located near close others and include support staff who have expertise in HD. Both housing design and disability supports must be sufficiently flexible to meet the individual's changing needs as the disease progresses. For this to occur, funding needs to be made available responsively and flexibly to avoid extended hospitalisation and/or RAC admission when an individual's current living situation becomes untenable. In order to assist people with HD, there should be funded peak disability services who specialise in progressive neurological disease to provide training, consultation, mentoring and supervision to services delivering housing and supports.

# Background and aim

Huntington's disease (HD) is a fatal genetic neurodegenerative disease. The disease is rare, affecting up to 7.5 per 100,000 in European, American and Australian populations (Rawlins et al., 2016). It affects global executive functioning and includes cognitive, physical and psychiatric symptoms that worsen progressively. The general age of onset is 30-50 years (although it can appear earlier or later) and the prognosis from age of diagnosis to death is approximately 17-20 years. Due to the complex nature of HD, people typically require various supports including housing, nursing and disability support workers. They require support from a specialised multidisciplinary team including neurologists, psychiatrists, occupational therapists, psychologists and speech therapists.

The National Disability Insurance Scheme (NDIS) is an Australian Government scheme that funds costs associated with living with disability (NDIS, 2021a). The scheme entitles people, referred to as "participants", with permanent and significant disability and are aged under 65 years to funding for any "reasonable and necessary" support needs related to their disability (NDIS, 2021b). Funding is allocated to the individual, and the individual or their guardian chooses which providers supply the funded goods and services. Specialist Disability Accommodation (SDA) is a range of NDIS funded housing designed for people with extreme functional impairment and/or very high support needs. Supported Independent Living (known as SIL) is an NDIS funded support that provides help and/or supervision around daily tasks including personal care.

With 945 NDIS participants with HD in March 2021, this cohort comprises a small proportion of (0.21%) people receiving NDIS supports (NDIS, 2021b). As a proportion of the general population who are NDIS participants, the rate for people with HD is very low at 3.9 people per 100,000 nationally, although the rate varies between states and is greater in South Australia and Tasmania (6.5 and 9.3 per 100,000 respectively) (NDIS, 2021b). Most NDIS participants with HD are aged between 55-64 years (35%); however, 31% are aged between 45-54 years, 16% are aged between 35-44 years and 8% are aged 34 years or below (NDIS, 2021b). Ten percent of NDIS participants with HD are aged over 65 years (NDIS, 2021b). Seventy nine percent of NDIS participants with HD are gauged to have "low level functioning" compared with the broader NDIS cohort at 27% (NDIS, 2021b). There is a roughly even gender distribution with 52% of NDIS participants with HD identifying as female, 47% as male and 1% as other (NDIS, 2021b). Sixty nine percent live in major cities, 30% in regional areas and 1% in remote and very remote areas (NDIS, 2021b).

In Australia, people with HD often end up living in residential aged care (RAC) facilities, even when aged under 65 years. Recognising the inappropriateness of aged care for young people with disability, the Australian Government has set targets to ensure that no people under the age of 65 years are living in RAC by 2025 (DSS, 2020). Whilst there are housing facilities specifically for people with HD internationally, there are very few places available in Australia (capacity for 62 people with HD nationally: Australian Huntington's Disease Associations, 2020).

With few possible housing and support models for people with HD, it is important to understand the effectiveness of the models and who they work best for. It is particularly important to understand how NDIS funding can support people for the duration of their lives and avoid admission to RAC. A scoping review of the international literature was conducted to understand the most effective housing and support models for people with HD. This scoping review demonstrated that although there were 7 studies in the area of housing and support for people with HD, overall, there is a lack of specific literature identifying effective housing and support models or choice for people with HD. Although there is a lack of published research, there are several housing and support models for people with HD internationally that would be useful to explore. In order to do this, new qualitative research was conducted with professionals who had expertise in housing and support for people with HD. In addition, qualitative interviews were also conducted with people with lived experience of HD (these are reported in a separate report).

The aim of this research was to explore professional perspectives on the effectiveness of housing and support models for people with HD, including national and international researchers, clinicians, academics and service providers.

# Method

## Participants

Ethics approval for the study was obtained from La Trobe University ethics committee. Potential participants included professionals who had expertise in housing and support for people with HD. Potential participants were identified through a number of activities: 1) experts already known to the research team; 2) experts identified by Stakeholder Reference group members and Lived Experience Reference group members and 3) through authors identified from a scoping review of the literature. Potential participants were emailed an invitation to take part in the study, along with the plain language statement and consent form. If they were interested in taking part, they returned the consent form to the researchers and a time was organised to conduct an interview.

## Data collection

Interview questions focused on the housing and support models that exist for people with HD in the country they were based, evidence of their effectiveness and opportunities to further improve housing and support. Interviews were conducted with 17 people with expertise in housing and support for people with HD supplemented by input from the reference group. Interview participants had a variety of backgrounds, including service providers, academics, clinicians (physiotherapists, occupational therapists, psychologists, psychiatrists, neurologists, nurses), social workers and NDIS support coordinators. Interview participants were recruited from Australia, the Netherlands, Belgium, Denmark, Switzerland, Scotland, and New Zealand. The interviews were conducted from February to August 2021 over Microsoft Teams or telephone and generally lasted for 30-60 minutes. Participants were offered the opportunity to be named in the report or remain anonymous.

## Data analysis

The interviews were professionally transcribed and read by 2 researchers. Thematic analysis was used to analyse data from the interviews. This method was selected to identify, analyse and report patterns within data (Braun & Clarke, 2006; Braun et al., 2018). Two researchers read through the transcripts and identified possible codes. Transcripts were then re-read to examine the suitability of these codes to the data more broadly. The codes were used to generate broader themes.

# Results

Five overarching themes related to effective housing and support models were identified:

1. Housing and support considerations
2. Access to housing and support
3. Types of housing and support
4. Effective elements of housing and support
5. NDIS supports

These themes and subthemes are described below.

## Housing and support considerations for people with Huntington's Disease

This theme depicted the complex symptom, psychiatric and social sequelae of HD and how the fluctuating interplay of these factors influences housing and support needs over time. Sub themes focus on the young age of people with HD, complexity of symptoms, the need for flexible and responsive support and consideration of family dynamics.

### Housing and support needs to be appropriate for people who are young

The symptoms of HD are unique and complex and need to be considered in any housing and support model. Notably, people are often young when they develop symptoms and may have families and important meaningful roles that need to be considered in housing and support models.

> *"People who have HD are young, and they're engaged in all sorts of activities…it's so different from what you see when you go into an aged care facility."* **(1)**

> *"[A gap exists for young adults requiring] a physical set up where family still want to stay together as a unit and there is just – like, there is nothing available that allows people to stay together as a family unit when they're requiring SDA type options. That is a real gap."* **(14)**

Young people that have tested gene positive or who are learning about HD from recent family diagnosis require support. An initiative currently being developed called the "Huntington's Disease Network of Australia" involves technology to make an HD registry. One participant reported that the registry will be helpful in monitoring the housing needs of families with HD, including the prevalence and the geographical distribution.

> *"Understanding where you are is going to be really important, and to do that, building up the registry and then mapping, it's called, in fact it's called a Map HD Registry. Because a big part of what we want to do is understand where are these people… [in cities as well as regional and rural areas]... we really want to understand the disbursement. And how we need to address [and] get services out to those people, and how to make sure that they have what they need..."* **(1)**

Knowledge of where people with HD and potentially gene positive family members live will identify where support for diagnosis, intergenerational trauma and vicarious trauma is needed.

## Housing and support for complex physical, cognitive and psychiatric symptoms

HD includes physical, psychiatric and cognitive symptoms although the presentation of these is unpredictable, varies between people, and changes significantly and rapidly over time. Physically, at early stages of the disease people may have lots of energy, they may be impulsively mobile and have a high risk of falling. At the later stages of the disease, they may be unable to get out of bed. There are other physical symptoms including difficulty with swallowing and the risk of aspiration that must also be considered in support options and require clinical oversight.

> *"So they're very, very high risk for things like aspiration, because of the swallowing difficulties… very high risk for injury because of the chorea and just flinging their bodies around and injuring themselves on different equipment and things like that."* **(2)**

Cognitively, the ability of people with HD to process information typically decreases and cognitive impairments need to be understood by those supporting them. Participants reported that these cognitive impairments mean that people with HD need information presented to them slowly and time given time to respond. Participants felt that environmental adaptations, such as anticipating and responding to needs quickly, need to be implemented to reduce the risk of behaviours of concern. Without accommodating these cognitive changes, behaviour can become challenging.

> *"And examples are as simple as slow down, one thing at a time, if they want something, hurry up because they for neural reasons can't wait….So if you don't accommodate that stuff you see aggressive behaviours."* **(12)**

> *"...one of the challenges if you look at the Huntington's disease population compared to the other intellectual/motor disability group, which I suppose is a mixture of cerebral palsy and acquired brain injury, as a group on similar age, with similar needs, the problem for Huntington's disease is not so much that they have more motor, cognitive, or behavioural problems. It's just that it's a dynamic disease and these people are changing."* **(8)**

Participants reported that psychiatric symptoms and subsequent behaviours can also be difficult for people to manage. People can develop mental health disorders including depression, anxiety and psychosis. They can also present as angry and aggressive or withdrawn and apathetic. Participants said that people with HD can have a desire to be in control, yet conversely face a great deal of loss of control with the disease.

> *"It's one of the most debilitating things for people with HD and for their families - that they can have temper outbursts and be a bit unpredictable. Or they can be apathetic and inert, and not do anything."* **(1)**

> *"So there's also a huge psychiatric component with the disease with people developing sort of schizophrenia and delusions and all sorts of psychiatric disorders as well. So very, very complex in that area."* **(10)**

> *"One of my patients got out a butcher knife, because he was frustrated with his wife. And he wasn't that kind of guy."* **(1)**

## Housing and support needs to be flexible and responsive

Due to the progressive and unpredictable nature of HD, housing and support needs can change over time and can change quickly. Participants reported that this means that a housing and service model needs to be flexible and responsive to those changes. One of the biggest challenges in housing and support models for people with HD is that they may be suitable at one point and quickly become unsuitable, meaning an alternative model needs to be found promptly. Similarly, people with HD may need rapid support with well-informed allied health assessments or equipment. Such rapid support was perceived as being unavailable with alarming consequences for safety.

> *"We've had times where we're really worried about him and we need him to get assessed. And you're having to wait days for somebody to go out and see him."* **(19)**

> *The rapid rate of deterioration was illustrated by a person with HD who "was in a unit on his own. He did get food, he was walking around and he used to drive you mad with conversations, 'Hey, hey, can I tell you something? Can I tell you something?' Now he can't even get out an effective grunt, you know, he's constantly grunting. He can barely walk. He's unable – you know, unable to successfully feed himself and he's and he's 27 and that level of deterioration over 15 months is incredible."* **(21)**

## Family dynamics

Participants described many family considerations and dynamics that can impact on housing and support for people with HD. These included fractured relationships, marital breakdown, and differences in opinion on housing and support models. Many people with HD may have already cared for relatives with HD and seen multiple generations and different housing experiences. There is often intergenerational trauma as a result of multiple family members having had HD. For a significant number of people with HD, who have no family support system, they live alone without informal carers. Some family relationships may become fractured due to aggression or violence and safety may become an issue. For others, relationship breakdowns with significant others separates a person with HD from their children.

> *"Because there is quite a high incidence of breakdown in relationships in Huntington's disease, so quite often people are relatively isolated."* **(4)**

> *"In Huntington's Disease…the families themselves may not share the same opinions… families doesn't just mean parents it can be siblings, children. They are often very complex, and it could be that there are different opinions about what might happen and then that adds further complexity."* **(7)**

Nonetheless, for many families, the preference remains to have housing and supports that can keep a family unit together:

> *"...one mum with [children] in their 20s is going to have to move to out of home care because they're not going to get the funding to set up the home in the way that enables having enough carers, enough support in. She wants them to stay together as a family but it's not going to happen."* **(14)**

> *"...we would like to change, I think when we have people living here when they have children, small children and maybe a husband or are divorced. It would be so nice if the family could come here, you know and stay."* **(5)**

# Access to housing and support for people with Huntington's disease

Participants described a number of factors that encapsulate the housing and support experience for people with HD including lack of choice, discrimination, long wait times, and poor quality of care.

## Lack of choice

In terms of understanding the most effective housing and support models, many participants referred to the lack of choice around housing and support. One participant **(14)** said "the lack of anything is actually the biggest issue." Generally, participants felt that people with HD are given 1 option, and if their current housing is unsuitable, they have little choice but to take what they are offered. Without an alternative, people may be stuck in hospitals or hostels or living in situations that are inappropriate and unsafe.

> *"So I think very few people with HD actually get the choice about where they are going to go at that stage of their lives anyway which is sad."* **(4)**
>
> *"They're sitting homeless on our ward because there isn't anywhere else. Sometimes I'm managing them at home knowing that they're living with such high level of risk that the rest of us would not feel comfortable with it but the only other option is then to get them admitted to a hospital and no hospital wants to take them."* **(14)**
>
> *"...there are very few, sort of, fit for purpose, residential options for people with HD, in Australia. There are, in fact, relatively few around the world as well."* **(1)**
>
> *"I think the challenge overall for everyone and anyone - regardless of if it's in the community or moving from aged care out - is that where the participant's family want the [person to live], there's not places available. You try to explain that, you know, the more affluent the area, the more expensive it is; the [disability housing] providers are just not there..."* **(15)**

In addition to a lack of choice is the insecure nature of housing in which a person with HD is placed. Change can be difficult for people with HD adding another layer of complexity for securing permanent, suitable housing.

> *"I've had several experiences not that long ago with people with Huntington's disease who have developed significant psychiatric issues and their accommodations been at risk."* **(7)**
>
> *"So that – you have two problems there. One is that people with Huntington's don't like change, and two, it's progressive. So if we're going to put him in a forever home, it has to be high dependency."* **(19)**

### Discrimination

A number of participants from Australia referred to people with HD having limited housing options due to discrimination against them. This was discussed in relation to RAC as well as NDIS funded arrangements. This was more prevalent when people had behaviours of concern or positive behaviour support in their funding.

> *"Some providers say "Oh, he's got behaviour – he's got behaviour support provided in his plan. Oh, that's no good."* **(21)**

> *"It's the same with aged care as well... I think it is so hard to get anyone that's prepared to, you know, take them in. Ultimately they're the provider, they can make the decision however they like – you don't have any grounds to appeal it."* **(14)**

> *"I think these guys with Huntington's disease just get put in the 'too hard' basket, because they usually have a terrible reputation for behaviours that aren't any control of their own."* **(19)**

> *"Some wouldn't even go any further than looking at the application because they'd seen Huntington's, seen progressive, degenerative, and just went, 'No way, we're not taking that on.' My biggest thing with HD has been around providers not really willing to take on anyone who may pose some level of behaviour or restricted intervention required."* **(21)**

> *"The problem with Huntington's disease, that label is so large, so stigmatised and so huge and full of fear, people see the label before they see the individual. And for my guys, they need to see an individual with a swallowing problem, with a cognitive problem where the response time is much slower – with a movement disorder. You know, that's what needs nursing and nurturing. Whereas we've just got this bloody label and I hate it."* **(11)**

Inflexibility and discrimination is reflective in RAC business models, for example,

> *"there's are certain image or culture that they're trying to promote and attract to the nursing home. And I guess Huntington's disease doesn't necessarily fit with the sort of people they're trying to market the nursing home to. I can think of one or two occasions where … the nursing home have said that this is not our image.* **(9)**

> *"Ultimately they're the provider, they can make the decision however they like, … you don't have any grounds to appeal it, you don't have any opportunity to question it, you're just told no, you haven't been successful."* **(14)**

### Long wait times

Within Australia, participants referred to the long wait times for housing and support funding to be approved. The process and timing of getting funding and finding accommodation was difficult to manage.

> *"And I think [housing and support], that process is ridiculous. You just wait forever and ever and ever. And I think, also, with [housing and support], you can't look for a property until you get the approval back for what category that the participant is eligible for... then it takes another 12 weeks to get the roster of care approved, and then it's just all backwards."* **(15)**

> *"It [wait times] just varies. I've had people that take six weeks, and I've got four at the moment waiting… I think they're ranging from three months now to four months."* **(15)**

Even if the NDIS funding process is smooth, the availability of housing stock is limited. People may have to move away from family or services to where disability housing is located.

> *"I think the challenge overall for everyone and anyone...is that where the participant's family wants the person [to go], there's not places available… the [disability housing] providers are just not there. It's too expensive to build, so hence the fact that they're all on the sort of fringes of [capital city]."* **(15)**

> *"...we've spoken with a couple of providers that are setting up new things that have talked about potentially doing a purpose build for that. You know, these young people – well, it won't even – I mean, they might not even be alive for that – you know, long enough to make that worthwhile but, you know, I do think that that is another – another real gap."* **(14)**

> *"There is an investor that lives locally that's building SDA and SIL accommodation, and so we've been flagged for one of those properties. But it's going to take 12 to 18 months for that to be built now."* **(19)**

## Poor quality of care

Some participants reported that they knew people with HD who were living in unacceptable or inappropriate housing and support models, yet nothing was being done to change it. This could be because there were no other options; however it could also be that because people with HD are perceived as complex and consequently a lower standard of care is provided. Participants referred to people with HD being forced to live in poor conditions, and when describing a client's housing, 1 participant said, "I wouldn't put my dog there" **(19)**.

> *"I think they think, 'oh, that's just [Bob]. He's been like it forever. Just leave him. He'll be okay.' Like, and it's not fair to live with psychosis - but because his unit is dirty, and he's scary to talk to sometimes when he's like that, it's just easier to leave him in the corner – but it p\*\*\*es me right off!"* **(19)**

Reflecting on past concerns, 1 participant discussed the need to be selective when allowing people to reside in housing:

> *"we're very much involved who would come into that house because to manage that risk, you know, there were instances at [facility] with sexual assault in the past and, you know…so, you need to be really mindful who's sharing that space"* **(20)**.

Participants discussed negative experiences and substandard quality of care for people with HD. Poor quality care was sometimes provided because staff did not have sufficient training or experience in HD. Other times, it appeared to be about services that are focused on money rather than providing high quality care.

> *"You know, the [supported] accommodation is terrible – even though they've got funding for her for 24-hour care she doesn't get taken out anywhere. They have no structure, no routine... We did a review with her the other day and she said...some workers won't even give her a drink, so that, you know, she gets upset and frustrated."* **(14)**

> *"My pool of providers for Huntington's is quite small; and not to say that there aren't some great ones out there - there might be - but I'm pretty reluctant. I've just had a really bad experience with a [disability support] provider - not the [housing] provider, but the [disability support] provider - who really put my client at harm."* **(15)**

# Types of housing and support models

A number of housing and support models were identified across the various countries and they varied depending on the national health and disability system. More resource-intensive specialised models were evident in countries such as Denmark, Netherlands and Belgium, reportedly reflective of high taxes and health insurance. As 1 participant said, "everything depends on national healthcare systems dramatically."  In Scotland and Australia, participants referred to individualised disability funding including the NDIS.

> *"In Denmark we have a welfare system. We pay a lot of money in taxes. So, we have equipment and chairs and beds for Huntington's, we can buy a lot of beds in Denmark."* **(5)**
>
> *"We've got fairly good healthcare services in Switzerland, because we have mandatory health insurance."* **(13)**
>
> *"I think in the Netherlands, we just have a lot of luck with the health system -the money that's provided."* **(6)**

There were different housing and support models for people at different stages of the disease, although some international models were designed to be accessible across disease stages. In the early stages of the disease, generally people remain at the family home or living on their own for as long as they can until some sort of crisis prompts a change. As support needs increase, most people move into RAC or a nursing home where they can stay for the rest of their lives. A smaller number of people move to a HD-specific facility where they can also stay for the remainder of their lives. Participants discussed the following housing and support models:

- Living with family
- Supported living (small groups)
- HD-specific facility
- RAC/nursing home

## Living with family

Most participants suggested that living with family is possible during the early stages of HD depending on family support, and paid supports being available. Whilst for some people, it is possible for them to stay living in the family home as their disease progresses, this is reportedly rare and very challenging and more likely in families that have multiple generations living in them and more people to assist with care. To enable people to stay living at home, there needs to be a lot of support for carers. In New Zealand, supports are available to enable people to live at home for as long as possible, if that is their choice. Living at home for longer is more likely if carers get some respite during the day, as it can be very demanding.

> *"So we're very passionate that we keep people at home for as long as possible, supporting their caregivers...and we have individualised funding over here. So I can send kind of like up to – well, up to 60 hours plus of care going into an individual's home... So that's for those people that do want to [provide care to remain at home], have the health literacy and have the support networks around. And we can do that and involve palliative care 'til the very end."* **(11)**

> *"...some families somehow manage, and that you know, and I've seen it where people, like a partner will give up a couple of years of their lives to just every day like make sure the person is, you know, bathed, and fed, and – you know. But boy, what a hard way to go, you know. And you just, you know, you don't, you know, it's very meaningful obviously for people to be able to do that for another person. But it also just – so demanding, um, so you'd certainly like for them to be able to have some respite - or being able to have some professional support so that maybe they didn't have to bathe them, you know so that person – could sit down and eat their meal."* **(1)**

In one situation, a married couple who wanted to remain in the family home requested funding through the NDIA for home modifications.

> *"[They] wanted some funding for a housing assessment so that we could then direct those home modifications around his needs…"*

The funding for home modifications was refused resulting in an advocate lodging a complaint stating the case should be handled by a complex planning team. **(21)**

### Supported living (small groups)

Participants mentioned a few one-off cases where people with HD were living in small groups. One Australian service, which recognised the need for young people with HD to move out of RAC, built their own property to support a person with HD and upskilled their staff to be able to support them. Other participants referred to one-off models, where 2 or 3 people with disability live together and have staff support.

> *"We had a contact from a support coordinator who had a client named [Jane] who had lived in a dementia ward for six years, from when she was 40. And we said, 'Look, as soon as this house is finished, if [Jane] would like to live there, she's welcome.'"* **(3)**

Another concern related to how accepting housemates were of a person with HD.

> *"I can see that putting [John] in with someone else at times, depending on his paranoia and stuff like that, could be quite traumatising for people."* **(19)**

> *"...if we could get someone that purpose-built place, you know, that I could put – that I could encourage, you know, a couple of people, three/four, whatever you put in your purpose build, you know, to live together who have similar sorts of needs, would that make a difference? You know, can we then get the people that are actually going to be the right people to support that and would that work?"* **(14)**

One participant reflected on the experiences of a housemate of a person with HD in SDA:

> *"he doesn't particularly like [Billy]. I think the other guy tends to stay in his room a fair bit - you know, because, you know, [Billy], you know – he spills food everywhere and, you know, his – coffee gets flown around the house and, you know, it's all of those big movements and sudden movements and impulsive movements that this other poor fellow, he's got an acquired disability – and he's in a wheelchair and I think he feels quite – you know, not unsafe but [Billy] has fallen on him, [Billy] has hit him unintentionally and - you know, it's quite a small environment for two people in with wheelchairs and, you know, it's big – big equipment, it's not little equipment."* **(21)**

## HD specific facilities

Participants referred to a number of HD specific facilities, including those in Denmark, the Netherlands, Belgium, Australia and Scotland. These models were quite different to each other in terms of their funding and staffing, although they all provided nursing and allied health support for people with HD. The residents were either all people with HD or mostly people with HD, as well as people with other neurological conditions. Staff in these facilities had expertise in HD and this was cited as a strength of the models. They tended to have a small number of placements available in each site and had long waiting lists and thus were not an option for most people with HD.

There were varied perspectives on the appropriateness of HD specific facilities. Whilst there was recognition that it made sense to have people with HD together with staff that have expertise in HD, some people felt that diagnosis should not dictate where someone lives. Those who had seen the abolishment of asylums in previous years opposed the idea that housing should be based on diagnosis. Rather it should be based on the persons' needs.

> *"[HD specific place] is okay. It's in the country and the staff are lovely and they are now very experienced in looking after people with HD. But I hate it, I hate everything about it. I hate the fact that we have bundled all of these people together, just because they have the same condition."* **(4)**

> *"And the entry into there is a diagnosis of Huntington's. And that's what I disagree with. So you could be juvenile HD. You could be late onset HD. You could be HD with lots of movements, HD with lots of psychiatric problems, no movements. So to me it's not tailored to that individual's needs."* **(11)**

> *"We've moved beyond congregating them together and integrating them and I think the principles and the reasons are the same. If you have one person with a short fuse, it just makes no sense to put them in a group of people who everybody or most of them have a short fuse."* **(12)**

A further problem with HD specific facilities cited by participants was that these models result in a group of staff with expertise in HD but only helping those in the facility. This further adds to the specialisation of HD and means that health professionals in the community do not develop the skills to support people with HD and feel that it is beyond their expertise.

> *"We are never gonna be able to fund or sustain funding for 800 purpose-built facility beds for people with HD, nor should we. Everybody, nurses, doctors should all be trained when the students and registrars are, it should be the same as any other long-term condition."* **(11)**

> *"The more we say there needs to be specialist units, the more we emphasise this is so different. And as a nurse looking after somebody with late-stage Huntington's disease, it's doable, it's clinically no more challenging than late-stage Parkinson's or Motor Neurone Disease or any other brain disorder. But people are just still afraid of it."* **(11)**

Placing people with HD together provides the benefits of being cared for by trained multi-disciplinary teams but it does perpetuate beliefs and practices such as: 1) the lack of trained staff or access to multi-disciplinary teams in rural or remote areas, 2) the inevitable need to move away from your home community; and 3) housing options based on diagnosis rather than individual needs and preferences.

> *"If it is a social worker or a family member looking somewhere, they are going to go to the place which appears to have the specialist… be the specialist option 'cause they think that might deliver care for the person which they are looking after. So I think very few people with HD actually get the choice about where they are going to go at that stage of their lives anyway which is sad. And of course, the other thing about places like [named facility] are that they tend to be nowhere near where people have lived so their community, their friends, that all gets lost…"* **(4)**

Participants also discussed the relationships and dynamics of having people with HD living together. Participants reported that having people with HD living with other people with HD can work well, and residents can provide support and connection to each other. However, participants also reported that it can be confronting to live with other people with HD and see people at later stages of the disease and it can be overwhelming dealing with others' behaviour and symptoms.

> *"I think it works quite well, because there's a lot of acceptance of each other...we do talk about the things happening with other people, if people allow us to talk about it, and it does give a connection. They also see things and say, "I wouldn't want that," or "I would want that, as well," so that's good. So it's both good and bad."* **(16)**

> *"So what's sometimes hard is that some people are very noisy and loud, and others are very sensitive to sound and stuff like that, so those are challenges, but I think that the benefits of having specialised care and having acceptance of each other is more than the adverse effects."* **(16)**

> *"They do develop a bond and they actually become quite protective of each other. There is targeting, there is aggression.  I've seen a resident try to set another resident on fire. I've seen a resident fill the urn up with hot water and tip it over another. So, that's where I'm talking about the safety aspect."* **(20)**

Participants referred to the HD specific models summarised below:

### Denmark

There are a few HD-specific facilities models in Denmark. One of them is in a regional area. The facility accepts anyone with HD including those that may have been forced to leave other facilities. They are well resourced and have 10 staff to support 18 patients. They have a multidisciplinary team on site including occupational therapists, physiotherapists and psychologists. Each resident has their own large apartment and there is also shared space to socialise with the other residents. They have all the equipment that they need for the residents including HD beds and chairs. They also have a wellbeing space and a focus on holistic wellbeing. The program reportedly focuses on supporting and maintaining people's identity, even as their functional abilities decline. They also focus on maintaining communication and allowing people to be able to express their choices. They use a particular program to assist people to regulate emotions through co-regulation with staff (i.e., staff managing their effect in turn supports affect regulation in people with HD). They reportedly have very low incidence of physical aggression and find that residents provide support to each other. The only change participants would like to see to improve the model is more space to allow residents' families to stay the night.

### The Netherlands

There are several HD-specific facilities in the Netherlands. One of the facilities caters for people with HD who can live at home while accessing multidisciplinary care via an outpatient clinic. Alternatively, the provision of day treatment is offered; people with HD can access treatment as needed. As the disease progresses, there is an inpatient residential service for 24 people. They have a multidisciplinary team consisting of occupational therapists, physical therapists, speech therapists and dietitians with expertise in HD. The facility was redeveloped 2 years ago and now includes a large private space, a shared space, and an outdoor space. They are described as being person-centred and activities are developed to suit the residents. People at different disease stages live together.

### Belgium

Participants referred to an HD-specific housing and support model that has room for 27 people, most of whom have HD. They also provide respite care during the day for people with HD still living in the community. Residents have their own large space and there is also a communal area. They focus on activities that are directed towards younger people, along with person-centred care and supporting the resident to have choice and control in the way they live their lives.  Residents can draw on allied health professionals through their own personal budgets although there are also some allied health staff on site. They report few behaviours of concern. This model could reportedly be improved by better integration with the community, such as a buddy program.

### Australia

In Australia, participants referred to a housing and support model in Western Australia, New South Wales (NSW) and Victoria. These services are now being funded through NDIS Supported Independent Living. The model in Western Australia includes 2 houses for people with HD. One house is for people at the early stages of the disease (for 6 people) and the other house is for people at a later stage of the disease and includes palliative care (for 12 people). People can transition from 1 house to the next as needed. The model is focused on staying independent and engaged with the community for as long as possible. People have their own room although the space is not large and there is a shared communal space. According to participants, this model could also be improved by having some space for families to spend time together.

The HD specific service in Melbourne, Victoria has transitioned from being an HD-specific service to approximately a third of the residents having other neurological conditions such as Multiple Sclerosis. To live within this service, people need to have funding for disability support workers in their NDIS funding. There are 3 houses that house up to 10 people and a fourth that houses up to 6 people. This model sits between the health and disability systems where they provide 24-hour nursing support and also disability support workers. Allied health professionals are organised at an individual level dependent on people's NDIS capacity building funding. They have a young cohort of residents and focus on age-appropriate activities and engagement in the community. Changes that could reportedly improve this service would include smaller houses (around 4 residents) and changes to the physical design to have more of a homely feel rather than a hospital feel. It is noteworthy that there is tension between health (state funding) and disability (federal funding).

The service in Sydney, NSW is an HD-specific arm within an aged care setting and is an NDIS provider within aged care. It has more staff than a typical aged care facility but residents rely on their NDIS funding for activities and allied health supports. There is a division of costs between aged care and the NDIS. HD-specific beds, which would normally fall under NDIS, were the responsibility of aged care.

*Scotland*

In Scotland there is 1 facility located in the country that is HD-specific. It has capacity for 18 people with HD. Staff focus on person-centred care and are very experienced in HD. Its regional location means it can be difficult to recruit staff. There is another service in Scotland that is a combined housing association and nursing home model; this model cares for people through to the end of life. Residents have their own apartment including a bedroom, living room and kitchen allowing people with HD to live independently. Nursing care, housing and social support staff are available to support people with complex needs as required, plus residents can utilise the facilities and care available at the onsite residential nursing home. Staff work hard to integrate residents into the local community and community groups come to the village. In addition, there is a community cafe. This model, considered a hub and spoke model, can be replicated by nursing homes with adjacent land suitable for building small units on. Independent living located near a residential facility share the same multidisciplinary, HD-trained staff team. Residents are provided with flexible care that meets their current and future needs.

When discussing the best aspects of these international models, participants placed emphasis on adaptive models that allowed for the progressive deterioration caused by HD.

## Residential aged care/nursing home

Most participants reported that RAC is not an appropriate environment for young people with HD, although often the only option. Generally, there are only 1 or 2 people with HD in the facility. There are concerns that the ratio of staff to residents and level of care and supervision is not sufficient for people with HD. As such, participants cite that residents have falls without adequate supervision and that their mental health can deteriorate.

> *"Aged care facility is no place for a person who's not old...it's particularly inadequate for people who are connected to the world in so many different ways."* **(1)**

> *"I've worked on getting three (people with HD) out of aged care into the community - and the aged care certainly is the worst, especially around the fact that, you know, you've got one to seven staff through the day, and then maybe one to 15-20 at night, which makes it quite complex for Huntington's clients, as they tend to have irregular sleep patterns.* **(15)**

> *"If we are full? Yeah, then they come to elderly homes, it's the same. And they often come to a department with dementia. It's awful…it's awful. And then they sometimes move from there to our place. 'Cause they get very, very, angry."* **(5)**

In situations where there are no available places at specialised HD centres, people with HD may be placed on a waiting list but enter RAC while they wait. For others, being close to family limits their choice. In some situations, the family member is making the decision to remain in RAC.

> *"And there are also a lot of people in nursing homes for the elderly. We are only one house that's specialised and, yeah, for some people it's far away from where they live and they want to stay near their family, and so they stayed in nursing homes closer by."* **(16)**

> *"...we have some clients who are still in our residential aged care services. We've got one lady who is in one of our aged care facilities who is under 65… and we've worked with her husband, and have continued to do so, but he doesn't want her to move because he just likes that location…but we're now in the process of really pushing the NDIS to see if we can get additional supports around her care within aged care because, you know, her care needs are beyond what aged care funds."* **(2)**

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*"And then having that - shift the participant's family members' thinking is quite difficult too, how they are pretty old school and like the idea of aged care, and that's what they know and that's what - how they've, you know, worked with their family members who have gone into aged care in the past. So they don't want to move out of that thinking."* **(15)**

*"I think in the end, it was just, kind of, deemed that it was easier to leave her in a nursing home, because there'd be less restrictive practices in play, and all that kind of stuff. Because of, you know, however nursing homes do it. I don't think they have as much accountability. So – yeah, which is, which is unfortunate… It certainly wasn't her coordinator who made that decision. It was the daughter who made it, because I think she just got sick to death of hearing how hard work her mum's going to be."* **(19)**

# Effective housing and support models

In terms of understanding the most effective housing and support models for people with HD, it is evident that "one size does not fit all", with the most effective housing and support models depending on a number of individual and family characteristics. Much of the discussion around the effectiveness of housing and support models is based on perceptions of how models appear to be working, as there is a lack of data on effectiveness of models for people with HD.

## Not 'one size fits all'

There are a number of factors that can impact on the success of housing and support models for people with HD. There is not 1 ideal housing model, rather housing and support is highly dependent on the individual and their family and their needs and preferences, as well as how the disease impacts on their functioning and quality of life. The most effective housing and support model may be influenced by a range of characteristics such as age, gender, HD symptoms, finances, location, life commitments and family and support. As highlighted earlier, there are benefits and downfalls to living individually versus in HD-specific facilities once supported housing is required. Similarly, whilst some cited HD facilities where people move to different sections of the property as their care needs increase (i.e., from low care to high care) as beneficial, others also highlighted the bonds formed between residents and potential distress caused by moving locations even within the same facility.

> *"I think part of the challenge is that because the way that Huntington's affects people is so different, it affects them at very different times in their lives. It affects you know people with very different family circumstances… the presentation... the package of symptoms people have is so different... there isn't a one size fits all."* **(4)**

> *"I think every person with Huntington's disease and their families has to find a solution, which fits in with a number of factors. Those factors relate to the person with Huntington's, their age, their gender, the degree of cognitive impairment, the degree of motor impairment, the degree of behavioural disturbance. And that's so different for every person."* **(7)**

## Lack of data

Unfortunately, there is a lack of data on the effectiveness of housing and support models. Whilst services may monitor progress of an individual, or conduct satisfaction surveys, there is little available evidence. Participants were able to report on perceived outcomes for particular cases. For example, a service provider that developed a property for a person with HD reported that her health had improved moving into disability housing from when she was in aged care.

> *"So look, one particular property is – has worked out really well. What we've noticed for [Jenny] though is the change in her health. Okay. So she appears happier. … She's put on weight. Which is really, really significant. And just the access to her family…now, they come into this beautiful house and you know, spend some time with their mum."* **(3)**

In some of the HD-specific facilities, families completed satisfaction surveys. Although these are only analysed and reported internally, participants reported that the findings were positive and that residents and carers are satisfied with the service. Another indicator of a service being effective was low episodes of violence or behaviours of concern.

> *"Every three years we do a survey with our clients, and also with their families. …. we get good results, people are happy living here. They especially appreciate he care - they all have one caregiver who is mainly responsible for them."* **(16)**

> *"We have very very low violence for more than, nearly two years now, we haven't had any episode of violence at all."* **(5)**

## Elements of effective housing and support models

Several key elements of effective housing and support models could be identified from the interviews. These could be grouped within the following areas:

- Support for families
- Accessible physical design and location
- Staff with expertise in HD
- Person-centred support
- Flexibility to support changes in functioning

### Support for families

Support for families is important for effective housing and support, particularly to enable the family member to stay living at home as long as possible, if that is their preference. Participants stressed the importance of family members having the opportunity to connect with other families with HD and to have the opportunity for respite to support them to maintain their role.

> *"There's a lot of courageous family members and spouses who care for these people at home for a long time –and probably with all sorts of burnout. I think supporting those as much as possible will delay the need for residential care."* **(8)**

> *"There are monthly activities where families come together and they have picnics outside, and kind of have HD just as part of life."* **(1)**

There is acknowledgment that families play a key role in securing housing and support and supporting successful transitions. NDIS support coordinators may also play this role. Within residential care, it is also important that families are supported to get the information and help they need. They often end up supporting training staff about the needs of their family member. Residential facilities should provide the space for families to spend time with their family member to encourage the maintenance of family and social relationships.

> *"I think when we have people living here when they have children, small children and maybe a husband or are divorced. It would be so nice if the family could come here, you know and stay."* **(5)**

> *"So it's those sorts of spaces where people, families can spend time together... to be able to keep the family connections happening in a safe environment."* **(2)**

Support for families can also take the form of education, counselling and understanding needs.

> *"And, you know, make sure that the other participants that we have up here are being, you know, connected and supported with information. And particularly my – the two new girls that I have because one of them in particular she just started deteriorating and they've had no – apart from their appointments at [hospital] they've had no information provided or counselling provided – and they've watched their father die, they've now – their youngest brother is, you know, no longer functioning in any way, shape or form and he would usually have and I would find that frightening as a 30 year old."* **(21)**

> *"... there are just some questions and they think they're not symptomatic yet, could also be true, send a case manager to their homes, to home visits just to keep in touch. Just to start a dialogue."* **(6)**

## Accessible physical design and location (physical design, location, community inclusion)

There are a number of important elements that need to be considered in relation to the physical design and location of housing and support. Participants reported that the physical design needs to be accessible and allow for changing accessibility needs as the disease progresses, allowing people to be as independent as possible. One service provider designed a house to be accessible as they would for other people with a mobility impairment.

> *"Make the doorways wide, make the hallways wide. I want a completely flat bathroom and I don't want a bath in it, because I want to have a shower bed in there."* **(3)**

Participants reinforced design features that could assist people with HD, including accessible showers and large, strong furniture **(19)**; assistive technology to increase level of independence **(2)**; wide doorways that fit a HD bed and climate control for each individual room **(20)**; sensors to detect movement **(6)** and, ceiling tracks to facilitate lifting and movement **(3)**.

People with HD need space for either moving around if they are able and also for equipment in later stages of the disease. People with HD need to be able to move around inside and feel safe. In shared housing, people need their own space for their bedroom, kitchen and bathroom but also a communal space where they can connect with other residents, if they choose. In addition, the house may also need high impact wall lining and protected windows due to involuntary movement and impulsive behaviours.

> *"Because, those residents that like to run, it's good that they have more room to run inside. But we can't really – you know, allow them to go out."* **(13)**

> *"But there is still also a large amount of communal area, because we notice when people get sicker, some people tend to stay in their rooms all the time and want no stimulation- and others, they are afraid in their room or feel lonely, or they have to be in the communal area all day. So you have to have both, so people can be here in all stages of the disease and feel comfortable."* **(16)**

> *"Their house [disability housing] was flagged as the highest level however it isn't. He's gone through so many walls because it was just usual plasterboard."* **(21)**

> *"We did things like we put laser items on the windows, cause they would smash the windows, you know, and that just meant if they did that, that's okay but you're not going to get hurt."* **(20)**

Gardens and outdoor space were reported to be particularly important for emotional regulation and quality of life. People with HD need space to be on their own when desired and still within a safe space.

> *"And I think even aggression levels got lower because people can go outside – leave their apartments."* **(6)**

> *"And it's just a life choice to go outside, to see a garden. To see the sun. To see that kind of thing. I think people need it. So that's a big improvement."* **(6)**

> *"Having a quiet room, a sensory room, where they can get away from that stimulation if they need to but having them scattered throughout the property. Having a main central room is ideal, and an outdoor area is ideal, allowing them to have that quiet time, but having the workers be able to be with that person..."* **(15)**

> *"I think it's important, too, that there's a bit of an outside area where people can be, and relax, and also several different spaces, so that not everyone has to sit together during the daytime, inside and outside; because they get annoyed with each other easily, so if everyone has to group together all day that's not a good thing."* **(16)**

Participants said that the location of services and the ability to remain close to family, services and community was important. Often these connections have to be sacrificed in order for people to attend an HD specialist service as they are only available in a few areas. Alternatively, people may prioritise location over the preferred service and attend their nearest facility even if not HD specific.

> *"We are only one house that's specialised and for some people it's far away from where they live and they want to stay near their family, and so they stayed in nursing homes closer by."* **(16)**

> *"But I think you know, keeping people as much in proximity to their families is really important."* **(1)**

Location becomes an important consideration when planning HD-specific services or housing. Several participants discussed the geographical dispersion of people with HD. When designing an HD specialist centre with multidisciplinary teams, it may not meet the needs of those residing in rural or regional locations.

> *"...even if you told me, that we've built this wonderful new facility… in wherever… that's gonna cater the needs of anyone and everyone with Huntington's you are still going to have this problem of geography and closeness to home and person's preferences and families preferences etc."* **(7)**

> *"The HD population is sparse, and we're spread all over the country. Dedicated facilities outside of urban areas, seem really very difficult. Because you don't want to take a person with HD and then move them 300 kilometres…"* **(1)**

> *"...clients with HD are scattered over… in little pockets, as it is a family disease, and they tend to stay in that same sort of area."* **(15)**

## Staff with expertise in HD (multidisciplinary team, staff training, accommodation for cognitive challenges, responsive support)

The staff supporting people with HD consistently appeared to be the most important element of effective housing and support. Participants highlighted a need for there to be a multidisciplinary team of clinicians supporting the person with HD, including specialised nurses, occupational therapists, physiotherapists, psychologists, speech therapists, dietitians, social workers as well neurologists and psychiatrists. Models that worked well could draw on a team that was available to quickly respond to someone's needs.

> *"If there was a change to someone's posture when they were in a seat, they could get a physio and the OT over within a day to two days."* **(17)**

Staff needed to be trained and have expertise in HD. Participants reported that for day-to-day support, in addition to disability support workers, there needs to be clinical oversight to respond to sudden changes and to be able to manage complex symptoms. It can be particularly challenging for disability support workers to manage psychiatric symptoms and deal with behaviours of concern. There needs to be stability in staff for residents and a consistent staff member. Changing staff can be very disruptive for a person with HD and the transition needs to occur gradually.

> *"There needs to be a clinical input as well...for example, with nurses that can do quick assessment and rapid response and planning  – to a sudden change...it's very, very hard on people with a Cert IV with minimal training and minimal understanding of what's happening who are confronted with people with behaviours, quite complicated behaviours at times... it's a very, very big ask I think for a disability support worker in this workplace."* **(10)**

> *"A lot of their staff are very poorly trained in behavioural support...–they'll just say to him "no", rather than saying "yeah, sure you can, just give me half an hour".  So, you know, it really inflames potential situations."* **(21)**

Training needs were discussed by several participants in particular, the need to upskill staff to meet demand.

> *"...we've created more [housing] and we've created more jobs for, you know, people supporting people with disabilities but now anybody without any qualification can work [in the sector]…it is around the staff and training as much as what the type of accommodation is..."* **(14)**

> *"I know that with the rollout of the NDIS, the sector is largely unskilled."* **(3)**

> *"I think it's such a complex disease process that there aren't many other providers that kind of have the expertise who can kind of wrap up the whole lot and provide the services."* **(2)**

Understanding the cognitive challenges that people with HD face and accommodating for those challenges is key to effective support. These include slowing down conversations and allowing time for processing and ensuring that people's needs are met early as possible. Staff working in HD-specific facilities often have this understanding and skill.

> *"But the one single unifying thing to me is how well the people who provide the direct care accommodate challenges in thinking. And examples are as simple as slow down, one thing at a time, if they want something, hurry up because they for neural reasons can't wait. Those are the most essential principles and the places that do well train and supervise their staff and put it in their culture."* **(12)**

> *"...my priority is to hire someone and to train on that area. To get used to the routine and the behaviour of the resident. And I ensure that they are like only working on that area and not on other places… Because behaviour management's so important that the consumers or resident knows who are their carer."* **(18)**

## Person-centred support (person-centred, holistic care, control, meaningful activities)

Housing and support models that were reported to work well were person-centred and holistic in their approach. Staff spent time getting to know the person and their personality and preferences. People were able to furnish their housing with their own belongings. Staff tailored activities to be suitable for that person. Activities were flexible and this allowed the person to have control and choice. Staff focused on people's identity and maintained that focus even as the disease progressed and people became less able to articulate their preferences. There was also recognition that meaningful activities are important, irrespective of the housing and support model.

> *"Wherever they are...if they're living on their own, then they may need some help structuring their activities to be able to live a productive, interesting life."* **(1)**

> *"And I guess when having support workers that are able to do more person-centred activities or are able to take the person with HD out of a facility and go and you know go to the movies, or engage in the community in another way."* **(9)**

> *"And keep focussed on people's identity and respect it you know; we have some young people here. And we have one of them, he has always bought Adidas training clothes. So of course, you know we don't buy Nike...You know we have some women and they have always worn mascara and you know we try to give them mascara every day. It's important."* **(5)**

> *"We actually set up the multi-purpose room as a dress shop for one of the young girls and she would come over with some money and she would go shopping there. But it didn't matter if she destroyed the room."* **(20)**

> *"...it's a matter of getting the [disability support] provider to put in the roster of care around accessing the community in their community more, like taking them out, bringing them back home, going and visiting or having Sunday lunch, or going to the beach, or doing whatever that may look like once or twice a week. And then they can still visit, and it still gives them that sense of, "Okay, we're still connected." And it's putting that as a plan, an action plan, together and helping them identify that."* **(15)**

Maintaining connections to the community and activities within the community was emphasised in the Scottish model. Although Covid-19 has limited current activities, participants discussed what had been effective in the past.

> *"We funded the music. But you really noticed a change in their presentation going from that every Friday with [musician] to nothing. Yeah, so unless they – a couple of residents they would join together and that's something else, they pooled their resources."* **(20)**

Equine visits:

> *"They'd go once a week and it was done under a psychologist. The intensity - from the horse was - between the – we had a resident who was non-verbal, non-ambulant and we took her to equine and she started – not – it wasn't coherent, but she was trying to talk and she was trying to touch the horse. And she had – hadn't moved and I was like, 'oh my god.'"* **(20)**

> *"...we do a lot of activities. What people would like more of, we are doing quite well, but it's very important to people to be engaged in their care, to be asked about what you want, and we focus a lot on that but it's still something people say it can be more and more."* **(16)**

> *"But pre-COVID, we have some activities, we take them to join the main activities with other residents. Or the residents here, we go onto – to their unit to join their community. So that's how we [did] before. Now it's – yeah, it's good as well. And then yeah, they have their own bus trip, you know."* **(18)**

Participants stressed that the promotion of control and choice and driving one's own care is very important, particularly as people with HD face such a loss of control with the disease. Furthermore, as people are young, they want to be their own agents. To be effective, services need to allow people to be self-determining.

> *"I've always felt it's a disease that people feel so out of control when they have it... if you remove even more of their control it just compounds issues and results in people getting angry and frustrated...so where we can we support people to maintain that level of control and choice."* **(2)**

> *"They want to drive their own care, they want to do it the way they want to do it, they want to select what they think is the most appropriate for them. And that's different to a person in aged care."* **(1)**

> *"And its main focus is to give people as much control over their own life as possible, so we don't have any fixed programs or mandatory things, or - I think that's important to look for what does a person want? And of course, you have to sometimes make some restrictions or guide something, but for the main part we go with - with their flow."* **(16)**

Some participants referred to the benefits of services focusing on holistic wellbeing and quality of life, including a music water bath, movement garden, sensory space and wellbeing room. One service focused on counselling and residents supporting each other to live with HD.

> *"We had [counselling] once a month. And people who don't have their voice anymore, we know them so well that when we look at their eyes, we can see if they are sad or if they are happy. And we talk about the pain and the fear of this disease... and how we cope and live our best life."* **(5)**

One participant referred to the effectiveness of a palliative model, in contrast to a medical model. The palliative model was more person-centred and the person's needs were placed at the centre. It was about "having a life worth living and dying with dignity the way the person wanted" **(20)**. The participant reported that with the palliative model, a lot of behaviours were reduced.

> *"We were always told we would never stop this person self-harming. Once we sat down with them and said, "What is it that you want?" And we listened to them, they stopped, they actually stopped. We managed that behaviour. We implemented some strategies. They got to live with their cat. Previously her boyfriend was not allowed to come over, from the previous management. We allowed him to, with the consent of the other residents."* **(20)**

### Support during disease progression (palliative care, supportive transitions)

There were clear differences in the length of time that a housing and support model could be useful. Whilst the HD-specific models were able to provide palliative care, other models could only be a short-term option. Participants reported that most people with HD would need to move into a facility as the disease progressed and that change could be particularly hard for people with HD. This can be exacerbated if it is also difficult to find a place that will accept the person with HD. For those in a HD facility that could provide palliative care, this also raised additional issues about people with HD experiencing the loss of other residents. Often there was the opportunity for people with HD to be supported when losing other residents.

> *"You know, I think a lot of these group homes, the staff are probably generally not trained for the palliative stage of these conditions. And I think it's pretty inevitable in most of those NDIS or similar funded group homes with carers, that they're generally not going to be able to manage people towards the end."* **(8)**

> *"And when we have somebody who is dying, they visit each other, sometimes they sit and we talk about it. I think it's very hard. But it's very important to make a good end every time, thinking before going to the church, we have an open coffin, and we talk and we sing, and you know telling stories. And everybody around. So, we try to celebrate and say goodbye to a life together."* **(5)**

> *"... is important, you know, to do more work around the dying period, and um, you know, people are taking an interest in that quite a bit now they – not a, you know, not enough but I think we will see some improvements in end-of-life care as well."* **(1)**

# How the NDIS supports people with HD in Australia

Whilst participants reported benefits and a positive impact of NDIS for people with HD, there was recognition that the NDIS is not fit for purpose for progressive neurological conditions. As reported earlier, there were problems with wait times for funding for specialist housing and disability supports, and problems with the quality of care provided by some support providers. Participants also reported that NDIS processes can be frustrating for people advocating for people with HD.

## Increased availability of funding

Participants spoke about the benefits of the NDIS and the opportunity it provided for increased support for people with HD, including equipment and allied health. The NDIS was reported to be an improvement from the previous disability services model. Being able to have a disability support worker help someone with HD be included in their community was recognised to be valuable and less available with previous models.

> *"Yeah, so I think that the NDIS is sort of the best thing to happen for people with Huntington's. It has meant that we've got equipment in nursing homes, which has never been possible previously. And it means that people are living at home for longer. Access to allied health, which is something, again, that we've never had in such an ongoing, intensive way."* **(9)**

> *"It's more about individuals getting a community support person to – to help them do certain things. And a lot of our clients do. They go out on outings, even if it's just to drive to the local park or you know, whatever. A lot of them are back into the footy this year and had assistance going to the football."* **(10)**

> *"Within three months he went from being homeless on the riverbank into [disability housing] and funded appropriately."* **(21)**

## Not 'fit for purpose'

Despite being an improvement on the previous disability model, participants reported that the NDIS was not 'fit for purpose' for people with progressive neurological conditions. The main reasons noted were that the NDIS was not responsive enough to the (sometimes urgent) changes that people experience. NDIS planners and Local Area Coordinator (LAC) staff were not necessarily aware nor have a sound understanding of HD anosognosia (i.e., lack of insight into one's own illness) or the unpredictable and impactful behaviours of concern.

> *"We've had people downgraded from high to moderate care, standard care in their funding packages even when they are getting worse. They have no concept of this disease process at all and they are not responsive enough to the changes…so basically the NDIS is not performing when it comes to meeting the needs of this client population."* **(2)**

> *"NDIS is not as fit for purpose as people with progressive neurological disorders would like. They, you know, they get offered a lot of – but you know, the data shows that they get offered a lot of services that they don't take up."* **(1)**

## Frustrating NDIA processes

Participants referred to the difficulty in helping people with HD navigate the NDIS, not only in terms of the long wait times but the lack of a central contact for people. This is particularly frustrating and difficult when the needs of a person with HD are complex, inexorably increasing, and can change rapidly and unpredictably. Furthermore, participants reported that planners do not have a good understanding of HD and the needs of people with HD.

> *"So it really, really depends. Plus there's no-one that you can actually directly talk to. You ring the 1800 number and all you get is someone there to say, 'I'll put that in the file and I'll get someone to call you,' and then no-one calls you. So you're sort of sitting in limbo 24/7 with clients who are generally - with Huntington's - always in and out of crisis."* **(15)**

> *"The planners that have no idea about Huntington's. They're not seeing the bigger picture, when all plans should be individualised… Then they say, 'Don't compare a participant to another participant', but you're seeing way too many discrepancies between plans, and I find that just horrendous."* **(15)**

> *"I had one planner say to me, "Oh, we just need to give him some more capacity building and then you'll be able to drop back on his one on one - but you know, there is no capacity building because it's degenerative."* **(21)**

> *"The turnaround time for equipment is abysmal. And by the time a person with a degenerative condition gets their equipment, it's no longer suitable."* **(20)**

Support coordinators and allied health professionals who have expertise in the area of HD and advocate for the person with HD reported that their recommendations are not taken seriously and this objectivity questioned. Furthermore, given the complexities in finding housing and support models for people with HD, participants reported that the NDIA does not provide sufficient time for support coordinators to assist with this process. One participant said, "No, 40 hours is not enough for a client that you're trying to find housing for." **(19)**

> *"A lot of support coordinators are not that educated either, but they should be acknowledging, say, myself who is a social worker, who has a clinical background, who can understand, who specialises in HD; look at my sort of reports, my recommendations. They're not looking at that, they're totally skimming that and thinking that I'm in it for the money, when I'm not."* **(15)**

> *"...for something like Huntington's, I really believe that experienced planners – as soon as they see that diagnosis it should be an experienced planner that does it - because the – the risk of deterioration for somebody who's not receiving adequate supports is so high."* **(21)**

# Discussion

HD is a unique disease that encompasses a diverse symptom profile comprising physical, cognitive and psychiatric symptoms that fluctuate and worsen as the disease progresses. Accordingly, housing and supports must be flexible and responsive to meet the needs and preferences of individuals with HD and their close others. This includes education and support early on to support people to remain living at home for as long as possible, and fit for purpose funding, housing and support models once an individual can no longer remain at home. This qualitative investigation of international HD housing and support models highlighted important strengths and areas needing development for supporting this cohort to live outside of RAC.

According to the participants, the experience of housing and support for people with HD is often characterised by lack of choice, delays in funding and inadequate development of appropriate housing, discrimination and poor quality of care as people are forced to live in unsafe conditions and are at risk of neglect and physical assault. Lack of choice and drawn-out funding decisions placed people at risk of extended hospitalisations and admission to RAC. There was an almost universal consensus that RAC was not a suitable option for people with HD due to their often younger age, lack of resourcing and expertise within the RAC facility and lack of opportunity for people to engage with meaningful age-appropriate activity.

Where HD specific housing models exist, participants highlighted strengths and weaknesses associated with the grouping of people based on diagnosis, siloing of health professionals and risk of institutionalisation. Some participants described the benefits of HD specific shared living options, such as a shared understanding of living with HD, provision of support between people with HD and the availability of expert health and disability personnel. However, others felt that there would never be enough availability of these facilities to meet the needs of the entire HD population. This meant that many people did not have access to this kind of housing, and there was a risk that having the HD expertise centralised in certain facilities would detract from broader expertise across the health and disability sectors. Similarly, there was not a consensus on whether people housed in HD facilities should move through various sections of the same facility based on changing care needs or remain in the same section for the duration of their stay.

The below factors emerged across the qualitative interviews relevant to housing and supports that meet the needs and preferences of people with HD.

## Education and support

Family members and informal caregivers require early and ongoing education about the physical, cognitive and psychiatric sequelae of HD. This includes communication, personal care, motivation and Positive Behaviour Support. Such supports may improve the capacity of family members to support the individual with HD to remain living at home for longer where this is their preference. Given the incidence of psychological trauma in people with HD and their family members, psychological supports should be provided as part of the disability support package.

Regarding disability and nursing supports, there was a strong consensus highlighting the importance of staff with expertise in HD to manage the complex physical and behavioural needs of those living with HD. This included a need for training, mentoring and ongoing supervision for staff as well as good organisational skills in those rostering staff. Positive Behaviour Support interventions for both family members and paid disability and health staff require sufficient time in the assessment phase as well as provision of training and on the ground support to implement behaviour support plans. Such investment in health and disability support staff may result in improved quality of life for people with HD and less turnover in staff.

## Housing needs and preferences

There was a consensus that there is no "one size fits all" approach that will meet the housing needs of people with HD. Key needs and preferences emerged that ranged from physical attributes of housing through to considerations that support psychological wellbeing. For those living at home, timely access to equipment, home modifications, education and skilled support staff were necessary to maintain an individual's informal supports to keep caring for the individual at home.

Where supported housing was necessary, participants identified robustly built environments that can withstand property damage due to behaviours of concern and uncontrolled movement. Housing needs to have sufficient space for freedom of movement, the introduction of new/additional equipment as an individual's needs change, physical access (e.g., wide doors, no stairs) and the necessary fittings for equipment such as ceiling hoists. Participants highlighted the importance of a person having their own self-contained space (e.g., own bedroom, bathroom and kitchen facilities) even if living in a shared support model.

In shared support models, lower density of residents was preferable and a match between residents in terms of stage of disease and personality was important, where possible. Some participants suggested that it was beneficial for people with more advanced HD to progress through different parts of the same facility as their disease progressed to mitigate the confronting nature of people earlier in the disease trajectory seeing people with worse symptoms. Others felt that moving through the facility may be traumatic, and threaten bonds formed between residents. In all proposed models, space for family and friends to visit and spend the night are important for the ongoing inclusion of informal support networks.

Location emerged as an important component, with participants emphasising the importance of availability of housing that is accessible to people's families and pre-existing communities. Outdoor spaces and an overall "homely" feel rather than a clinical feel were other considerations presented as important for supporting the psychological wellbeing of people with HD. Regarding disability and nursing supports, there was a strong consensus highlighting the importance of staff with expertise in HD to manage the complex physical, emotional and behavioural needs of those living with HD. This included a need for training, mentoring and ongoing supervision for staff as well as good organisational skills in those rostering staff.

## Funding

HD is a unique disease and housing and support models need to be able to support people who are young and recognise the roles that the person has, their complex physical, cognitive and psychiatric symptoms, provide flexible and responsive care and support for families. Early in the disease trajectory, or when a person continues living at home, allied health and disability supports should be included in an individual's NDIS plan to maximise the sustainability of this living arrangement. As the disease progresses, housing, allied health, health and disability supports, and support coordination are essential components of an individual's NDIS plan and often need to be implemented quickly. The NDIS was described as being not fit for purpose for people with HD who often experienced rapid changes in their symptoms and, hence, housing and support needs. To adequately support people with HD to live an ordinary life, the NDIS processes need to be streamlined, responsive and flexible to reduce the risk of lengthy hospitalisations and/or admission to RAC for people under 65 years of age. Participants highlighted that people with HD should have a central point of contact within the NDIS, and that specific planners with HD expertise are necessary given the unique disability support needs of this cohort.

# Implications

People with HD require housing and support options aside from aged-care that include nursing and disability support. In order for people with HD to remain living at home for as long as this is feasible, and for supported living options to be appropriate throughout the course of the disease, it is recommended that the below be incorporated into people's housing design, funding and support plans.

### Housing

**Accessible and robust:** For people with HD to be able to move into housing where they can remain for the course of living with the disease, there is a need for housing that is robust as well as accessible for people with high physical needs. This ensures that as an individual's care needs change, necessary equipment and accessibility aids can be introduced.

**Location:** Housing options should be available in metropolitan, regional and remote areas so that people can live close to their families, friends and communities. The Huntington's Disease Network of Australia (HDNA) is currently leading the development of a mapping registry to identify the geographical locations of people with HD throughout Australia to better guide clinical care and support services across metropolitan, urban, regional, and remote areas.

**Built design:** Gardens and outdoor space are important for wellbeing and facilitate visits from families and friends. In shared models, people should have their own self-contained spaces with options for communal areas. Architecture principles of the built design influencing wellbeing should be incorporated into the planning. Housing should be accessible and allow for deterioration in functioning and incorporate light and green space.

**Social integration:** A wealth of research demonstrates the positive health and psychological benefits of maintaining social connections, and the negative consequences of isolation (Haslam et al., 2018). Housing should be built with family and friends in mind. The built design should be homely, comfortable and have indoor and outdoor areas for close others to visit, spend time and stay the night if they wish. Location wise, housing should be in an area that is easy to reach, close to existing communities and within close proximity to community facilities such as cafes, shopping centres, parks and cinemas.

### Staff expertise

Multi-disciplinary teams of allied health professionals, readily available to provide care are ideal but limited to HD facilities and small services that are not equipped to provide support to the broader population of people living with HD. To enter an HD-specific facility, there are long wait times and few places available. Geographically dispersed, multidisciplinary teams are needed to service needs of small group housing to meet the needs of people with HD wanting to remain in their communities or close to families in order to maintain connectivity. At present people with HD are often required to move to the services thus distancing themselves from community/family. The registry under development will aid in geographical planning.

As the disease progresses, HD specific facilities may be more appropriate. Design features from overseas (in particular, Denmark, Netherlands and Scotland) and alternate housing models where individual housing is supported by a nearby facility employing specialised multidisciplinary teams can help inform best practice. Huntington's Disease Associations (HDAs) typically have strong connections and knowledge of people with HD and an understanding of the experiences of family caregivers. The involvement of HDAs in planning housing solutions would be beneficial.

### Training needs

As noted above, greater investment is needed to provide more staff education and training but the need for training extends beyond support staff.

**NDIS**: Planners and LAC staff require training regarding the complexity of people with HD, the rapid changes that can occur, and consequently the requirement for flexibility and timely adjustments.

**Support coordinators:** There is a need for more support coordinators to be trained in the complexities of supporting people with HD and the associated navigation of health, disability and housing sectors. Digital education resources may provide a baseline of foundational knowledge for support coordinators and NDIS personnel that can be built upon by mentoring and supervision from professionals with HD expertise.

**Support workers and allied health:** Staff located in specialist HD facilities are often well-trained but those outside of these services are typically ill equipped to adequately support people with HD. There is a need for training, educational resources and mentoring to be available for support staff and allied health professionals to better support people with HD. Rather than a "one off" training session, this will require foundational training and ongoing supervision from others with expertise. Overall, there should be an investment in staff training and developing expertise in HD in terms of physical, cognitive and psychiatric symptoms as well as Positive Behaviour Support.

**Family caregivers**: There is a need to not only support caregivers, but to provide them with training and practical skills in managing the complexities of supporting someone with HD. This needs to be tailored to individuals and include topics such as Positive Behaviour Support, personal care and sourcing equipment, and housing and supports through the NDIS. Investment in supporting people with HD should include an investment in building the capacity of family and caregivers. This includes funding for psychological therapies.

### NDIS funded time/support

NDIS processes need to be streamlined, responsive and flexible so that an individual's changing needs can be met in a timely manner. The below are essential components of NDIS plans that allow people with HD to live in the community safely and with dignity.

**Housing:** Where supported housing is required, people with HD should be funded for specialist housing that is both robust and fully accessible so that they can remain living there for the entire course of their disease rather than returning to hospital or RAC when their support needs increase. Funding should be provided in line with an individual's needs and preference (i.e., living alone, with family/friends and/or with others with HD).

**Support coordination:** Due to the complexities surrounding HD, there is a need for an increased level of specialist support coordination to be included and accessed as needed in people's NDIS plans. Funding for support coordination needs to be made available rapidly when an individual's needs change to support the navigation of NDIS, housing and health/disability support sectors.

**Nursing and disability support staff:** These supports are important earlier in the disease process to sustain family members' ability to provide care and support to the individual with HD at home for longer. Due to the physical, cognitive and psychiatric symptoms of HD, there is a need for nursing and disability support staff to be made available at a quantity recommended by the person with HD's allied health professionals (e.g., occupational therapist, registered nurse). NDIS planners should follow the recommendations of these allied health reports.

**Caregiver support**: Informal caregivers require support in understanding and navigating the NDIS. When supporting an individual to remain living at home, they require funding for training from allied health professionals (including Positive Behaviour Support) as well as access to psychological therapies such as counselling to manage psychological trauma associated with HD and caregiver burden. This is especially important in this population as many caregivers have previously supported other family members with HD, experienced family breakdowns and may themselves also be gene positive. Inclusion of ample funding for support work and respite may allow people with HD to live at home for longer if that is their wish.

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