Huntington's Community Connect:
Gap Analysis Report summary

Huntington's Victoria received NDIS funding to create a national online peer-to-peer forum called Huntington's Community Connect.

The first stage of the project focused on collecting information and community feedback to help inform the development of the online forum. This information has just been published as a gap analysis report, with a focus on the following areas:

1. The national prevalence of Huntington's Disease (HD), that is, how many people are diagnosed with the disease in Australia. They looked at published evidence and asked HD clinics and genetics services across the country.

2. How the impacts of HD are described, and the relevance of the Huntington's Victoria Social Impact Domains to describe the things that matter to the Huntington's community

3. What services and support members of the Huntington's community and HD health professionals use and need. They also asked what gaps and challenges exist and how peer connection might help.

4. Recommendations for creating and rolling out the Huntington's Community Connect peer support program.

2. Huntington's Victoria Social Impact Domains framework

Huntington's Victoria's Social Impact Domains have been developed as a framework to identify and measure what matters to the HD community. The research confirmed the relevance of these domains and explored the relationship of this framework to others, such as COAG and the National Disability Insurance Scheme Outcome Framework.

The feedback was gathered through focus groups. Domains were described as either being about risks and safety orabout social inclusion. Risks and safety topics included housing stability and economic sustainability. Social inclusion included health and symptom management, physical wellbeing,emotional wellbeing, and building resilient relationships. All focus groups participants agreed that each of these domains was relevant.

3. Supports and services

We conducted three focus groups. The first was with health professionals, the second was with community members who are gene positive, and the third was with community members who are gene negative and supporters of people with HD. Here is a summary of the main findings:

Who supports us?
Support is drawn from informal supports such as family and friends, semi-formal supports such as online peer-support groups and support workers, and formal supports, such as medical professionals.

Being knowledgeable and insightful were the top attributes of informal and semi-formal supports and of formal services which are not HD-specific (such as local medical services).

Trustworthiness, availability and geographic coverage were the top attributes of formal support services specific to HD (such as genetics counsellors).

What kind of support do we need?

Support needs to adapt and reflect the trajectory of Huntington's Disease.

Support might be emotional, such as having people stand with you; educational, such as advice about options; physical, such as actual help to physically manage; or it might be advocacy, such as working with others to make systems better.

The community accesses a range of systems and services: international (online support groups), national (NDIS, My Aged Care), state/ territory based (HD associations), regional (health networks) and local (local councils and community facilities).

People want more local support but recognised that given the rarity of the condition that regional networks were more likely.

Knowledge sharing can be empowering: the power of collaborating and sharing information and experiences was described as valuable and energising. The community described a feeling of 'strength in numbers'.

Peer support is seen as a creative way to work together to wrap supports around the person, across regions and across services.

Gaps and challenges

The main gaps and challenges the community is facing with supports and services are outlined below:

Geographic gaps

Across Australia, the quality and availability of services and supports is inconsistent. There are some great services available, but they do not cover all geographic areas.

Changing needs

Different supports are needed at different stages of the disease. There are challenges with getting the right information, approach, and reactions at the right time. People from the Huntington's community were very clear that there is a right and wrong time for certain types of information. The professional community agreed, suggesting, 'Lived experience needs to be mapped around stage of illness'.

Support system complexity

The system of formal, semi-formal and informal supports is complex and keeps changing. It is extremely important for the community to have access to experienced people who can advise how the system works.

Innovation gaps and opportunities

We found that some new supports are simply not accessible to many people. For example, the smart technologies and concierge-style supports in new Specialist Disability Accommodation settings cannot be delivered at home or in other forms of residential care.

Intersectionality gaps

There is an absence of intersectional services and support; for example, indigenous-focused services.

4. Recommendations

The report made a number of recommendations in implementing Huntington's Community Connect, including that:

·the service is constructed with clear roles and support structures

·the community is made aware of the relationship between peer support and other forms of support

·the service provides clear links to other resources by subject and region.

·the service should be monitored closely to make sure processes are being followed. This monitoring should continue ongoing.

The service should be opt-in and flexible according to individual needs.

What comes next?

Huntington's Victoria will now use this report to start work on implementing Huntington's Community Connect.

The community-based steering committee will continue to guide this process and will be discussing the report in detail.

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