

An investigation into the home support needs of people living with **Neurodegenerative Disorders**

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- Two in three are clumsy
- Three in four have some degree of weakness in their arms and/or legs
- Four in five have compromised balance
- About half have difficulty with their eyesight
- Seven in ten have muscle spasms, tremors or involuntary movements
- Nine in ten people with NDD experience fatigue/tiredness
- Many experience pain and/or bladder incontinence
- Many experience heat intolerance, particularly those with Multiple Sclerosis
- Many experience lapses of concentration, difficulty remembering and/or sleep disturbance

In addition to symptomatic difficulties, the four neurodegenerative (NDD) disorders of interest, Huntington's, Parkinson's, Multiple Sclerosis and Motor Neurone Disease are similar in that:

- They can reduce lifespan as well as decrease health-related quality of life;
- They cause deterioration in functioning and mobility to the extent that patients may need help with all activities of daily living, particularly towards the end of life
- They require varying levels of clinical care in the home

Research Methods

- Collaboration with 11 support agencies and home care service providers, as well as academic support from Curtin University of Technology
- A postal survey (n = 1,050)
- Interviews with survey respondents (n = 49)
- Case studies of interviewees (n = 4)
- Summaries and linkage of organisation data (n = 10)
- Interviews with health and allied health professionals and care workers of home care support organisations (n = 11)
- Estimations and projections of the gaps in home care support, 2007 and 2021

Key Findings

- In 2007, there were an estimated 7,600 adults with a NDD living at home in WA
- 41% reported receiving one or more home care services, the likelihood of receiving services increasing as dependency increased
- For those receiving assistance with activities of daily living, 51% reported needing more help
- The size of the gap between what was received and what was needed, varied between disorder and the stage of the disease, the gap becoming larger as the needs of the individual increased
- The average gaps per week were:
 - 4.7 hours of personal care
 - 1.4 hours of domestic assistance
 - 3.2 hours of social support
 - 1.3 hours of gardening and home maintenance
- Filling these gaps represents little more than 2% of the current HACC budget

- Funding programs do not provide for the levels of case management required or facilitate the provision of the flexible and timely care required to meet the sometimes rapidly changing needs of individuals living with NDD, and their carers
- Other significant gaps in services are in transport, respite and age appropriate and NDD specific supported accommodation or residential options
- The financial burden on the family, associated with meeting the needs of people living with NDD and trying to ensure their own and their carers' quality of life, can be considerable

Policy implications

- Home care services to support the everyday living activities of people with NDDs need to be quantitatively increased and qualitatively enhanced
- NDD specific funding is needed for individualised packages of care support is needed. These packages should not be means tested and should be able to: include case management; be flexible in the quantity and type of services provided at any point in time; as well as, increase over time as dependency increases
- A greater variety and number of disorder specific supported accommodation options for respite and emergency and permanent placement need to be developed

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- HACC Budget excluding NDD extra home support (97.8%)
- NDD extra home support (2.2%)

