

Neurodegenerative Disorders Project - Report Number 6

**AN INVESTIGATION INTO THE HOME SUPPORT NEEDS OF
ADULTS LIVING WITH MULTIPLE SCLEROSIS,
HUNTINGTON'S, PARKINSON'S AND
MOTOR NEURONE DISEASES**

PROJECTIONS OF UNMET NEED

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GLOSSARY

ACRONYM	DESCRIPTION
AHDA WA	Australian Huntington's Disease Association of Western Australia
ALS	Amyotrophic Lateral Sclerosis
DSC	Disability Services Commission
HD	Huntington's Disease
IADL	Instrumental activities of daily living
MND	Motor Neurone Disease
MNDAWA	Motor Neurone Disease Association (Western Australia)
MS	Multiple Sclerosis
MSS WA	Multiple Sclerosis Society of Western Australia
NC	Neurological Council
NDD	Neurodegenerative disorder(s)
Neuro	Neurodegenerative
NSU	Neurosciences Unit, WA Department of Health
PD	Parkinson's Disease
PWA	Parkinson's Western Australia
QLD	Queensland
UK	United Kingdom
VIC	Victoria
WA	Western Australia

PROJECT REPORTS

There are six reports and an Executive Summary for this project:

Report 1: Client and Carer Survey Results

Report 2: Client and Carer Interviews

Report 3: Case Studies

Report 4: Data Linkage 2006

Report 5: Key Issues and Unmet Needs - Health, Allied Health and Service Provider Perspectives

Report 6: Projections of Unmet Needs

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1 INTRODUCTION

The project is an investigation of the home support needs of people in Western Australia with one of four neurodegenerative disorders (NDD) – Multiple Sclerosis (MS), Motor Neurone Disease (MND)¹, Parkinson's Disease (PD) and Huntington's Disease (HD). There are a number of components in the project including the development and analysis of a linked database, a summary of the characteristics of participating organisations' members and clients 1996 – 2006, a postal survey of clients and carers, interviews with clients, carers and providers, client case studies and projections of the gaps in home care support for people with NDD as the Western Australian population increases and ages.

This report summarises the results of the projections component of the project. The starting point for these projections is a discussion of current estimates of incidence and prevalence rates for each disorder. The annual incidence rate is the frequency of new cases of each disorder in a population in a year. Few studies report this rate although some studies might report the average or exact number of new cases of a particular disorder in a given year or over a period of time for a certain jurisdiction.

The annual prevalence rate, which is most often reported in Australian and international studies, is the proportion of a given population in any one year (or at a point in time) who have the disorder. Generally, this refers to people who have had a formal diagnosis of the disease as a primary condition or, in some cases, a secondary condition. As reported in NDP Report No 1 – Client and Carer Survey, this definition of the prevalence rate may be unreliable. On one hand, some people being treated for a particular neurodegenerative disorder may not have had their condition formally diagnosed. If these individuals are not identified in medical databases (such as those maintained for hospital admissions, Medicare returns, pharmaceutical benefits and community care), then the disorder prevalence rate will be underestimated.

On the other hand, some individuals may be misdiagnosed as having a particular neurodegenerative disorder due to the inexact nature of diagnostic testing. Wade (1997) reports that “the number of patients referred with ‘possible multiple sclerosis’ probably exceeds the true incidence of multiple sclerosis by a factor of five”. Including possible cases will result in the prevalence rate being overestimated. The extent of under- or over-estimation of the numbers of individuals with the disorder at any one time or in a particular year is uncertain. Issues of under-diagnosis and misdiagnosis are particular problems in the determination of prevalence rates for PD (Access Economics, 2007).

The only one of the four neurodegenerative disorders in this project in which the diagnosis is incontrovertible is HD². Moreover, predictive testing prior to the onset of obvious symptoms can determine whether someone at risk (that is, has a family history of HD) is gene positive (Goldberg, Telenius, & Hayden, 1994). Included in the estimation of the HD prevalence rate are only people who have obvious symptoms of and have been diagnosed with HD³.

Reported prevalence rates should therefore be treated cautiously. Nonetheless, the incidence and prevalence rate estimates reported here give some idea of the impact of these disorders in Australia and overseas.

¹ In northern America, this disorder is known as Amyotrophic Lateral Sclerosis (ALS).

² Note that MND, MS and PD can all be diagnosed via post mortem examination.

³ There is some new evidence (Rosas, *et al.*, 2008) that HD manifests from birth and that, in the lead up to the onset of traditionally recognised symptoms, for example, chorea, all individuals who are gene positive for HD will have some, albeit subtle, symptoms.

In Section 2, the methodology describes how the published prevalence rates are included in the derivations of the estimated disorder population in Western Australia in 2007 and the projected disorder population in 2021.

Tables 1 to 4 summarise incidence and prevalence rates reported in a number of studies in various Australian and overseas locations for each of the four neurodegenerative disorders. In Table 1, prevalence rates for MND are shown to range from 1.7 per 100,000 (Emard, Thouez, & Gauvreau, 1995) to 10 per 100,000 (Krivickas, Shockley, & Mitsumoto, 1997). The median value across the nine studies that reported prevalence rates is 3.5/100,000. There do not appear to be any consistent differences between rates reported in studies undertaken in the northern and southern hemispheres. No studies report different rates for males and females.

Incidence rates for MND range from 0.4/100,000 in Italy (Emard, Thouez, & Gauvreau, 1995) to 2.4/100,000 in Scotland (Forbes, Colville, Parratt, & Swingler, 2007). As with the prevalence rates, these incidence rates are also very low. Prevalence is not much greater than incidence because average survival time is low. Shaw (1999), in her discussion of MND pathogenesis, pointed out that, with no treatments to slow the progression of the disorder, the average survival time of three years has not changed over time.⁴

Table 1: Incidence and Prevalence Rates for MND

Incidence Rate	Prevalence Rate	Year of Data	Country of Study	Source
n.a.	8/100,000	n.a.	London, England	Turner (2001)
n.a.	1.8/100,000	2002	Australia	cited in Kristjanson (2003)
n.a.	6/100,000	2002	Australia	cited in Kristjanson (2003) ^a
n.a.	10/100,000	n.a.	US	Krivickas, <i>et al.</i> (1997)
n.a.	2.25/100,000*	n.a.	Scotland	van Teijlingen, <i>et al.</i> (2001)
2/100,000	n.a.	n.a.	UK	Shaw (1999)
2.4/100,000	n.a.	1989-98	Scotland	Forbes (2007)
1.0/100,000	3.5/100,000	1980	Spain	Emard (1995)
0.4/100,000	1.7/100,000	1984	Italy	Emard (1995)
1.6/100,000	3.7/100,000	1989	Norway	Emard (1995)
n.a.	1.9/100,000	1989	Poland	Emard (1995)
1.9/100,000	n.a.	1976-86	England	Emard (1995)

Note: ^a The prevalence rate stated in this reference was used as the base case for MND in Section 3.

Unlike studies of MND, studies giving prevalence rates for MS show differences based on geographic location – in general, the closer to the equator, the lower is the prevalence rate. Thus, Asia and South America have rates under 5/100,000 (Sadovnick & Ebers, 1993) and Tasmania and New Zealand have high rates, 76 and 69 per 100,000 (Compston, 1990), respectively.

⁴ See NDP Report No 4 – Data Linkage 2006, for MNDAWA member survival times between 1996 and 2006.

The Australian study by Access Economics (2005) examined prevalence rates reported around the world, including those reported in previous Australian studies. The latter show a range of prevalence rates ranging from 18.2 persons per 100,000 for Newcastle, New South Wales, in 1961 to 80.9 persons per 100,000 in southern Tasmania in 2002. They concluded that prevalence had increased, and would continue to increase, over time although they could not clarify whether this reflected better diagnostic techniques, migration of people from high risk populations (for example, northern Europeans settling in Australia), longer survival rates (due to, for example, improved treatments) or increased incidence. Access Economics estimated that there would be a 3.5 percentage point difference between the growth of the Australian population (14 per cent) and the MS prevalence rate for Australia (17.5 per cent) between 2005 and 2020.

Table 2: Incidence and Prevalence Rates for MS

Incidence Rate	Prevalence Rate	Year of Data	Country of Study	Source
n.a.	30/100,000 (high risk)	n.a.	Northern Europe	Sadovnick and Ebers (1993)
n.a.	30/100,000	n.a.	Northern USA, Canada, Southern Australia, New Zealand, Worldwide	McKeown <i>et al.</i> (2003)
n.a.	5/100,000	n.a.	Asia and South America	Sadovnick and Ebers (1993)
n.a.	5-25/100,000 (medium risk)	n.a.	Southern Europe, Southern USA and Northern Australia	Sadovnick and Ebers (1993)
n.a.	Under 5/100,000 (low risk)	n.a.	Asia and parts of South America	Sadovnick and Ebers (1993)
2.4/100,000	59.1/100,000	1996	Newcastle, Australia	Barnett <i>et al.</i> (2003)
n.a.	40/100,000	n.a.	Milan, Italy	Solari <i>et al.</i> (2005)
n.a.	36.5/100,000	n.a.	New South Wales, Australia	Hammond <i>et al.</i> (1988)
n.a.	69/100,000	n.a.	Southern New Zealand	Compston (1990)
n.a.	76/100,000	n.a.	Tasmania	Compston (1990)
n.a.	79.12/100,000 41.14/100,000 (males) 116.52/100,000 (females)	2005	Australia	Access Economics (2005) ^a
n.a.	51/100,000	n.a.	Germany	Emard (1995)
5.0/100,000	200/100,000	1985	US	Emard (1995)
n.a.	2.0/100,000	n.a.	India	Emard (1995)
n.a.	15/100,000	n.a.	Israel	Emard (1995)
n.a.	2.0/100,000	n.a.	Japan	Emard (1995)
n.a.	2.0/100,000	n.a.	Mexico	Emard (1995)
n.a.	80/100,000	n.a.	Norway	Emard (1995)
n.a.	23/100,000	n.a.	New Zealand	Emard (1995)
n.a.	70/100,000	n.a.	Czechoslovakia	Emard (1995)

Note: ^a The prevalence rate stated in this reference was used as the base case for MS in Section 3.

The median value for MS prevalence rates for the studies in Table 2 is 33.25/100,000⁵.

The Australian study by Barnett, *et al.* (2003) reported an incidence rate for MS of 2.4/100,000 which is much lower than the reported incidence rate for the US of 5.0/100,000 (Emard, Thouez, & Gauvreau, 1995). Unlike the incidence and prevalence rates for MND which are similar, the incidence and prevalence rates for MS are disparate. This is because individuals with MS have longer survival times – 42 years for MS (median survival time reported by McLeod, Barnett, Macaskill, & Williams, 2007) compared with 3 years for MND (Shaw, 1999).

Table 3 shows that prevalence rates for HD range from 5/100,000 (Williams, Schutte, Evers, & Forcucci, 1999) to 15/100,000 (McGarva, 2001). In WA, the prevalence rate for HD was estimated by Pental in her study commissioned for AHDA WA (2000) at 7/100,000 in 2000. No incidence rates have been reported for HD in the studies identified in Table 3.

Table 3: Incidence and Prevalence Rates for HD

Incidence Rate	Prevalence Rate	Year of Data	Country of Study	Source
n.a.	5/100,000	1995/1996	Australia	Williams <i>et al.</i> (1999)
n.a.	10/100,000	2007	Western Australia	Doyle (2008)
n.a.	10/100,000	n.a.	UK	McGarva (2001)
n.a.	15/100,000	n.a.	Fife, Scotland	McGarva (2001)
n.a.	7/100,000	2000	Western Australia	Pental (2000) ^a

Note: ^a The prevalence rate stated in this reference was used as the base case for HD in Section 3.

The prevalence rates for PD are shown in Table 4 at different ages – 1,000 in 100,000 people at age 65 years rising to 2,000 in 100,000 people at age 80 (Kristjanson, 2003). The study by Access Economics (2007) showed slightly higher PD prevalence rates for males compared with females. Prevalence rates across all ages and both genders range from 160/100,000 (Kristjanson, 2003) to 370/100,000 (Vickers & O'Neill, 1998). PD incidence rates are rarely reported. However, Access Economics (2007), in their review of other studies, reported age-specific rates ranging from 10/100,000 for those aged 45 to 54 years to 790/100,000 for the population aged 85 years or older.

⁵ In the calculation of the median prevalence rate, Sadovnick and Ebers' (1993) medium risk rate of 5 to 25 per 100,000 is included as 15/100,000 and their low risk of under 5/100,000 is included as 5/100,000. The gendered rates reported by Access Economics (2005) are excluded. Note that the average prevalence rate for MS for the twenty studies listed in Table 2 is 44.486/100,000 (s.e. = 10.3). The distribution is highly skewed (k = 6.15) and the range is from 2/100,000 to 200,000.

Table 4: Incidence and Prevalence Rates for PD

Incidence Rate	Prevalence Rate	Year of Data	Country of Study	Source
n.a.	160/100,000	2002	Australia	cited in Kristjanson (2003)
n.a.	1,000/100,000 @ age 65	2002	Australia	cited in Kristjanson (2003)
n.a.	2,000/100,000 @ age 80	2002	Australia	cited in Kristjanson (2003)
n.a.	370/100,000	n.a.	US	Vickers and O'Neill (1998)
10/100,000 @ ages 45 – 54 ^a 790/100,000 @ age 85+	269/100,000 ^b 277/100,000 ^c (males) 260/100,000 ^d (females)	2005	Australia	Access Economics (2007) ^e

Notes: ^aPD has also been diagnosed, albeit rarely, at younger ages. ^bThe number of Australians with PD in 2005 is estimated at 54,700 people (Access Economics, 2007); Australian population in 2005 is estimated at 20,328,600 people (Australian Bureau of Statistics (ABS), 2005). ^cThe number of Australian men with PD in 2005 is estimated at 28,100 (Access Economics, 2007); the proportion of men in the Australian population is 99/199 (49.7 per cent) (Australian Bureau of Statistics (ABS), 2005). ^dThe number of Australian women with PD in 2005 is estimated at 26,600 (Access Economics, 2007); the proportion of women in the Australian population is 100/199 (50.3 per cent) (Australian Bureau of Statistics (ABS), 2005). ^eThe prevalence rate stated in this reference was used as the base case for PD in Section 3.

2 DATA AND METHODOLOGY

In the following sections, the data used to generate the projected hours of unmet need⁶ for home care support and the methodology used in this process are described. Summarily, key parameters are taken from ABS and postal survey data (see NDP Report No 1 - Client and Carer Survey). The methodology section describes a base case scenario with unchanged prevalence rates and current values of parameters. An alternative scenario with different prevalence rates in 2021 for each of the four disorders is also presented.

2.1 Data

WA population data are taken from estimates for Western Australia by the national statistician, the Australian Bureau of Statistics, for 2007 (Australian Bureau of Statistics (ABS), 2008) and projections for 2021 (Australian Bureau of Statistics (ABS), 2006). Population growth over this period is not expected to be uniform as the age profile will change due to population ageing. Indeed, some population estimates suggest a turning point in population size in the first half of the twenty first century as declining fertility and immigration impact on population birth and growth rates, respectively (ABS Series B and C assumptions).

⁶ (Ohlin, 1999) in her appraisal of unmet need in disability services refers to the (then) National Disability Advisory Council definition of unmet need - people who need a service and can't get it, people who may soon need a service and people who aren't getting a service who are similar to people who are. In this project, unmet need is defined from the gap between what respondents reported as their currently weekly hours of service and what they considered their needed weekly hours of service. If they reported current and needed hours were the same, then there is no unmet need or gap in support. However, where needed hours of service exceeded current hours of service, then there appeared to be a gap in, or unmet need for, home care support.

Prevalence rates for 2007 are based on the latest estimates for Australia for each disorder - Kristjanson (2003) for MND, Access Economics (2005) for MS, Doyle (2008) for HD and Access Economics (2007) for PD.

Although Emard (1995) reported incidence rates for a number of countries, these were all in the northern hemisphere. For reasons discussed in Section 1, country of residence appears to be an important predictor of rates, especially for MS. In the absence of knowing the number of new cases per year, the estimates in Section 3 assume that any growth in incidence is reflected in the growth of prevalence rates, where this has been previously acknowledged. Incidence rates per se are not included in the calculation of unmet need for home care support.

Two parameters used in the projections have been obtained from the postal survey of clients and carers (see NDP Report No 1 - Client and Carer Survey). The first of these is the proportion of respondents who reported receiving home care support services⁷. The postal survey results showed that between 14 and 36 per cent of respondents with a neurodegenerative disorder need some home care support. For example, 14.41 per cent of females with MS require home care support as do 35.98 per cent of females with PD. About 32 per cent of people with MND and HD require home care support.

The second parameter from the postal survey that is used in the projections is the average hours per week of unmet need for home care support services. Both parameters are disaggregated by disorder and, for MS and PD, by gender. Some people needing home care support are getting the hours of service they need. That is, they do not have an unmet need. Others are getting fewer hours than they need, hence they have an unmet need. For the purposes of the estimations in Section 3, unmet need is averaged across both groups.

2.2 Methodology

Table 5 summarises the derivations of unmet need for home care support in 2007 and 2021. The estimations are calculated for each disorder. The key parameters in the derivations are the prevalence rates and the WA population sizes in 2007 (estimated at 2,105,783 people (Australian Bureau of Statistics (ABS), 2007)) and 2021 (projected to be 3,164,510 people (Australian Bureau of Statistics (ABS), 2006)). As mentioned in Section 2.1, the proportions of each of the disorder populations who received home care support, as well as unmet need in hours of service per person, are taken from the postal survey results.

The assumptions underlying Table 5 projections are that, between 2007 and 2021:

- the disorder prevalence rates do not change;
- the proportions of each of the disorder populations receiving home care support do not change; and
- the weekly hours of unmet need per person in need do not change.

Table 6 shows unmet need for home care support if expected changes to prevalence rates by 2021 occur. The assumptions related to these changes are:

⁷ For the purposes of these projections, home care support refers to personal care (including meal preparation), domestic assistance, social support (including in-home respite) and gardening and home maintenance.

- For MND, an increased prevalence rate from 6/100,000 in 2007 to 8/100,000 in 2021 due to increased survival as a result of better treatments, earlier diagnoses, etc. Shaw (1999: 1121) cautions that “if neuroprotective treatment prolongs patients’ survival, we must ensure that they consider the quality of this extra life to be acceptable”. It is to be expected that contributing to this quality includes timely and appropriate support in the home.
- For HD, the prevalence rate remains at 7/100,000. There is no WA evidence, or indeed international evidence, that predictive testing has impacted on HD incidence rates. Whilst Pandal (2000) assumes that the HD prevalence rate will increase due to “cultural influences over the HD population that may affect choices/options regarding having children, etc” and “the increase in life expectancy of people with HD due to medical care and other factors”, she does not change her use of the current rate of 7/100,000 for 2021.
- For MS, an increased prevalence rate between 2007 and 2021 (Access Economics, 2005) due to increased survival rates and better diagnostic testing together with changes in the age profile of the Australian population. The MS population will increase by about 10.4 per cent over the period 2005 to 2020 (pg 23); and
- For PD, an increased prevalence rate between 2007 and 2021 (Access Economics, 2007) for reasons including demographic ageing and excluding changes in risk factors and effects on survival rates of improved treatments. Access Economics expects that the PD population in 2025 will be 1.8 times the PD population in 2005 (pg 27).

The hours per week and per year of unmet need are costed using 2007 unit costs for home care support services. A comparison of annual costs for 2007 and 2021 is shown in Table 7.

3 PROJECTIONS OF UNMET NEED FOR HOME CARE SUPPORT TO 2021

As summarised in Section 2, Tables 5 and 6 show the derivations of unmet need for home care support in 2007 and 2021 for each disorder and, for MS and PD populations, by gender. In the tables, prevalence rates for 2007 - selected from Tables 1 to 4 - are listed in Column 2. These rates for 2007 are applied to the Western Australian population in 2007 to give the size of each disorder population in 2007 (Column 3) – 7,600 people, three quarters of whom have PD. The smallest group is those with MND – less than two per cent of the NDD population.

Note that the disorder population profile is different to the disorder population profile from the postal survey. This comparison is shown in Appendix 3. For example, 36 per cent of the survey respondents had PD compared with 74 per cent of the estimated disorder population in 2007. About 5 per cent of the survey respondents had MND whereas less than 2 per cent of the disorder population in 2007 has MND. The differences in profile are common to selection bias in group membership. In the main, the survey respondents are members of disorder support agencies whereas the disorder population comprises members and non-members.

The proportions of people needing home care support (Column 4) are applied to the disorder populations. These give the numbers of people needing home care support for each disorder, and by gender for people with MS and PD (Column 5). Four in every five people who need home care support have PD.

Unmet need per person (Column 6) ranges from 0.59 hours per week for respondents with HD to 2.30 hours per week for female respondents with MS. Applying these averages to the numbers of people with home care support needs (Column 5) gives unmet need in hours per week for 2007 (Column 7). Thus, total unmet need for home care support for people with NDD is about 2,200 hours per week in 2007.

For the estimations of unmet need in 2021 shown in Table 5, the prevalence rates for 2007 (Column 8) are applied to the projected population figure for Western Australia in 2021 (Australian Bureau of Statistics (ABS), 2006). This gives the disorder populations in 2021 (Column 9). The disorder population is thus expected to grow by 25 per cent between 2007 and 2021.

The number of people needing home care support in 2021 (Column 10) is derived from the proportion of people needing home care support⁸ in each disorder population (Column 4). Finally, home care support in 2021 totals 2,800 hours per week (Column 11). This is derived from the number of people needing home care support (Column 10) and the number of hours of support they need on average per week (Column 6).

A similar process for deriving unmet need for home care support applies in Table 6. However, in this table, the prevalence rates assumed for 2021 are different to those in 2007, except for HD. The changes are explained for each disorder as follows.

MND studies that comment on future prevalence of this disorder mention increased survival rates and fewer home care support needs due to improved treatments especially in the early stages of the disorder. Hence the prevalence rate is likely to increase. In Table 6 it is assumed that the MND prevalence rate will increase from 6/100,000 to 8/100,000. The disorder population for MND remains low at 212 individuals in 2021 – less than one per cent of the WA population and about 1.5 per cent of Western Australians with a NDD.

The population of people with MS is also thought to be affected by rising prevalence rates. For example, Access Economics (2005) estimates that the MS population will increase by about 1.2 per cent per annum or 17.8 per cent over the period from 2005 to 2020. When applied to the MS population in 2007 of 1,666, this growth rate results in an MS population size of 2,170 by 2021 as shown in Table 6. This compares with the projected MS population size of 2,101 in 2021 shown in Table 5.

Table 5 shows that the PD population is expected to grow from 5,665 to 7,144 people between 2007 and 2021. This growth reflects only the growth in population. Access Economics (2007) argues that growth in the WA population as well as the ageing of this population will result in an increase of 3 per cent per annum in the PD prevalence rate between 2005 and 2020. This means that, by 2021, the PD population in WA could be as high as 11,447 as shown in Table 6.

For HD, a prevalence rate of 7/100,000 is used for 2007 as well as for 2021, as this is not expected to change over this period. The growth in the disorder population from 147 in 2007 to 186 in 2021 is based only on the growth in the WA population.

⁸ Note that these estimates are not based on clinical assessment (in contrast to Wade, 1997 who argues that estimating need requires an assessment by an experienced clinician).

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Table 5: Projections of Unmet Need for Home Care Support to 2021

Disorder	Gender	Prevalence rate (per 100,000) 2007 ^a	Disorder population in WA, 2007 ^b	Proportion having home care support ^c (%)	Number of people needing home care support, 2007 ^d	Unmet need per person in need 2007 ^e (hours per week)	Unmet need 2007 ^f (hours per week)	Prevalence rate 2021 ^a	Disorder population in WA 2021 ^g	Number of people needing home care support, 2021 ^h	Unmet need 2021 ⁱ (hours per week)
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
MND	All	6.00	126	32.14	41	0.94	38.17	6.00	159	51	48.14
MS	Males	41.14	438	15.04	66	2.10	138.33	41.14	549	83	173.32
	Females	116.52	1,213	14.41	175	2.30	402.09	116.52	1,540	222	510.53
	All	79.12	1,666	14.47	241	2.25	542.44	79.12	2,101	304	684.14
HD	All	7.00	147	32.00	47	0.59	27.83	7.00	186	59	35.10
PD	Males	278.00	2,960	21.68	642	1.26	808.46	278.00	3,708	804	1,012.97
	Females	260.00	2,707	35.98	974	0.84	818.16	260.00	3,437	1,237	1,038.83
	All	269.00	5,665	27.62	1,565	1.03	1,611.49	269.00	7,144	1,973	2,032.46
All NDD	All	n.a.	7,604	n.a.	1,893	n.a.	2,219.93	n.a.	9,591	2,388	2,799.85

Notes: ^a From Tables 1 to 4; prevalence rates from highlighted studies. ^b The number of people with each disorder in 2007 is estimated from the prevalence rate applied to the estimate of the WA population for 2007 (Australian Bureau of Statistics (ABS), 2007) – 2,105,783 persons; 1,064,600 males and 1,041,183 females. ^c From postal survey data (see NDP Report No 1 - Client and Carer Survey). This proportion includes only respondents who reported receiving any combination of personal care, housework, social support and gardening and home maintenance services in the home. ^d Column 3 x Column 4. ^e From postal survey data (see NDP Report No 1 - Client and Carer Survey). Calculated only for those respondents who reported receiving any combination of (unpacked) personal care, housework, social support and gardening and home maintenance services in the home. ^f Column 5 x Column 6. ^g The number of people with each disorder in 2021 is estimated from the prevalence rate applied to the estimate of the WA population for 2021 (Australian Bureau of Statistics (ABS), 2006) – 2,655,884 persons; 1,333,891 males and 1,321,993 females. ^h Column 9 x Column 4. ⁱ Column 10 x Column 6.

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Table 6: Projections of Unmet Need for Home Care Support to 2021 Using Revised Prevalence Rates

Disorder	Gender	Prevalence rate (per 100,000) 2007 ^a	Disorder population in WA, 2007 ^b	Proportion having home care support ^c (%)	Number of people needing home care support, 2007 ^d	Unmet need per person in need 2007 ^e (hours per week)	Unmet need 2007 ^f (hours per week)	Prevalence rate 2021 ^g	Disorder population in WA 2021 ^h	Number of people needing home care support, 2021 ⁱ	Unmet need 2021 ^j (hours per week)
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
MND	All	6.00	126	32.14	41	0.94	38.17	8.00	212	68	64.19
MS	Males	41.14	438	15.04	66	2.10	138.33	42.76	570	86	180.15
	Females	116.52	1,213	14.41	175	2.30	402.09	120.17	1589	229	526.52
	All	79.12	1,666	14.47	241	2.25	542.44	81.72	2170	314	706.62
HD	All	7.00	147	32.00	47	0.59	27.83	7.00	186	59	35.10
PD	Males	278.00	2,960	21.68	642	1.26	808.46	446.00	5,949	1,290	1,625.12
	Females	260.00	2,707	35.98	974	0.84	818.16	417.00	5,512	1,983	1,666.12
	All	269.00	5,665	27.62	1,565	1.03	1,611.49	431.00	11,447	3,162	3,256.47
All NDD	All	n.a.	7,604	n.a.	1,893	n.a.	2,219.93	n.a.	14,015	3,603	4,062.38

Notes: ^a From Tables 1 to 4; prevalence rates from highlighted studies. ^b The number of people with each disorder in 2007 is estimated from the prevalence rate applied to the estimate of the WA population for 2007 (Australian Bureau of Statistics (ABS), 2007) – 2,105,783 persons; 1,064,600 males and 1,041,183 females. ^c From postal survey data (see NDP Report No 1 - Client and Carer Survey). This proportion includes only respondents who reported receiving any combination of personal care, housework, social support and gardening and home maintenance services in the home. ^d Column 3 x Column 4. ^e From postal survey data (see NDP Report No 1 - Client and Carer Survey). ^f Column 5 x Column 6. ^g Prevalence rates changed as follows. For MND, increased prevalence rate from 6/100,000 to 8/100,000 in 2021 due to increased survival (better treatments, earlier diagnoses, etc); for HD, decreased prevalence rate from 7/100,000 to 6/100,000 due to uptake of predictive testing resulting in fewer offspring of HD families; for MS, increased prevalence rate of 10.4 per cent between 2007 and 2021 (Access Economics, 2005); and for PD, increased prevalence rate of 3 per cent per annum between 2007 and 2021 (Access Economics, 2007). ^h The number of people with each disorder in 2021 is estimated from the prevalence rate applied to the estimate of the WA population for 2021 (Australian Bureau of Statistics (ABS), 2006) – 2,655,884 persons; 1,333,891 males and 1,321,993 females. ⁱ Column 9 x Column 4. ^j Column 10 x Column 6.

As summarised in Section 2.1, Tables 5 and 6 use parameters from the postal survey related to the proportions of disorder populations having home care support and the weekly hours of unmet need for this group. An alternative method of estimating unmet need in 2007 and projecting unmet need in 2021 can be derived from the, smaller, proportions of disorder populations having gaps in services and the, greater, weekly hours of unmet need for this group. Hence, Appendix 1 estimates unmet need for home care support using figures related only to the number of people with an unmet need together with their (higher) average hours of unmet need. As expected, the weekly hours of unmet need in 2007 (Column 7) and 2021 (Column 11) shown in Appendix 1 are approximately⁹ the same as in Table 5.

Tables 5 and 6 show that unmet need¹⁰ for home care support may rise from about 2,200 hours per week in 2007 (Column 7 in Tables 5 and 6) to just over 4,000 hours per week in 2021 (Column 11 in Table 6).

Table 7 translates weekly unmet need (Column 2) to annual figures (Column 3) and then applies hourly unit costs (Column 4) to obtain the extra cost of providing services to eliminate the gaps in home care support (Column 5). There are no published unit costs for Western Australia hence the HACC unit cost for personal care in Victoria has been used. There are two cautions to the use of this figure. First, this is the rate for personal care which is higher than that for domestic assistance (\$26.80 per hour) and in home respite (equivalent in some respects to this project's category of social support - \$27.69 per hour) and lower than that used for property maintenance (equivalent to this project's category of gardening and home maintenance - \$38.98 per hour).

A second concern with the use of the Victorian unit cost figure in Table 7 is that it is not necessarily representative of unit costs funded under the HACC program. Different rates apply to different States for a number of reasons, one of which is that costs of living differ across the country. For example, in Western Australia, the resources boom has put pressure on the prices of consumables and labour. Distances between homes in both urban and regional areas also contribute to differences between States.

WA, which has a relatively low population density, is recognised by the Commonwealth Grants Commission as having higher infrastructure and delivery costs compared to other States. This expenditure disadvantage (above average cost of service provision) relates to the higher costs of meeting community service obligations for utilities such as water and power and services such as transport and health (WA Department of Treasury and Finance, 2002).

Within States, unit costs may differ between providers and, for large providers, between regions or services. In the main, these differences reflect the different unit costs of providers, which, to some extent, reflect the economies of scale that are present in the sector. However, in a service industry such as community care, qualitative differences in care delivery (related to level of care and clinical governance) may also affect costs. Note that costs can also influence the delivery of care.

⁹ Small differences are due to summing rounded numbers.

¹⁰ See Appendix 2 for a comparison of met, unmet and total need for home care support by disorder in 2007.

Unit costs can also differ because of differences in hours of operation, different staff Award rates and staffing mix, billable hours (for example, including or excluding time taken for care workers to travel between homes), complexity of care and training requirements¹¹. Any of these differences may increase service delivery costs for one provider relative to another. In addition, depreciation and consumables¹² can differ from one provider to the next. The WA Department of Health is looking into this issue of determining unit costs for the HACC program. The unit cost for 2007 used in Table 7 should thus be considered indicative only.

Table 7 shows that the annual cost of meeting the gaps in home care support is about \$3.5 million (in 2007 dollars) in 2007. This represents about 2.3 per cent of the total WA Home and Community Care¹³ (HACC) 2007/2008 budget of \$153 million (WA Department of Health, 2007a). The annual cost is expected to rise to, at most, \$9.8 million in 2021 (\$6.5 million in 2007 dollars).

Table 7: Costs of Additional Home Care Support, 2007 and 2021

Year	Number of people needing home care support	Unmet need (hours per week)	Unmet need (hours per year)	Unit cost of home care support ^{ab} (\$)	Total cost of unmet need per year (\$)	Extra cost per person with NDD (\$)
	(1)	(2)	(3)	(4)	(5)	(6)
2007	1,893	2,219.93	115,436.36	30.63	3,535,816	1,867.84
2021 (i) ^c	2,388	2,799.85	145,592.20	46.33	6,745,287	2,824.66
2021 (ii) ^d	3,603	4,062.38	211,243.76	46.33	9,786,923	2,716.33

Notes: ^a The unit cost of personal care HACC rate of \$30.63/hour in 2007 is used. This unit cost is taken from the published unit costs for Victoria (Department of Human Services Victoria, 2008). ^b Assumes an inflation rate of 3 per cent per year. ^c From Table 5. ^d From Table 6.

¹¹ As well as funding based on unit costs, there is also block funding being granted for certain services types in other States making benchmarking of unit costs difficult. For example, some States, excluding WA, provide post acute care under HACC.

¹² Medical consumables, such as dressing products and intravenous pumps, are expensive and not provided by some organisations.

¹³ “The HACC program is a key provider of community care services to frail aged and younger people with disabilities and their carers. The HACC program is a joint Commonwealth State and Territory initiative under the auspices of the Home and Community Care Act 1985. It provides services to support people who live at home whose capacity for independent living is at risk” (WA Department of Health, 2007b: 43). “The Australian Government also jointly funds community care with the states and territories through the Home and Community Care program (HACC) which provides services to people with disabilities, as well as to older people. HACC services for older people generally assist people with lower levels of care needs than those who receive residential care and community care packages. HACC assists older people to defer or avoid the need for residential care or community care packages” (Department of Health and Ageing, 2006: 3).

Included in Table 7 are the numbers of people needing home care support in 2007 and 2021 (Column 1). The extra cost per person is, thus, \$1,800 in 2007, rising with inflation only to \$2,800 in 2021 (Column 6). The alternative per person cost in 2021 is \$2,700 with both inflation and changed prevalence rates (Column 6). At the 2007 unit cost of \$30.63, the 2021 per person extra cost is \$1,798 (changed prevalence rates) or \$1,867 (constant prevalence rates).

The total cost of home care support for people with NDD is about 3.3 times the cost of the gap or unmet need. Appendix 2 shows this derivation. In 2007, the total cost of HACC-type support to people with NDD living at home is estimated at around \$12 million. This is 7.8 per cent of the HACC budget for WA in 2007.

4 DISCUSSION AND CONCLUSIONS

Adults with neurodegenerative disorders who want to remain at home face increasing needs for support as their functioning and mobility deteriorate. This process can be quite short. This is the case for most people diagnosed with MND who have, on average, three years from diagnosis to death. Alternatively, functioning might reduce at a much slower rate. This is common for people with PD. In most cases, increases in the provision of services tend to lag behind the increased need for support. In many cases, the limits of funded services are reached whilst care needs are at a relatively low level. Thus, as the disorder progresses, unmet needs for home care support increase at an increasing rate. As a result, those that have the greatest need are the most disadvantaged.

The alternative to remaining at home is for these people to be institutionalised at the point at which the level of service for which they are eligible is seriously insufficient for their needs. However, residential care for this group, particularly those who are younger and have young families, has been shown to be unsuitable as an option (see NDP Report No 5 - Key Issues and Unmet Needs: Health, Allied Health and Service Provider Perspectives). Few facilities exist in the metropolitan area, and none in the country, that can satisfactorily accommodate this group. Their needs for specialised equipment, clinical management and personal care mean that they are too resource-intensive to be housed in aged care facilities. Neither are high care wards at tertiary hospitals appropriate.

The projections for 2021 provided in Section 3 show that, without changes to current funding models of home care support, unmet need will grow in response to population growth. This growth is likely to be exacerbated by increased disorder prevalence which is influenced, *inter alia*, by population ageing. This is particularly so for Parkinson's Disease (Vos, Goss, Begg, & Mann, 2007: 24).

Filling the gaps in home care support for people with neurodegenerative disorders is likely to increase the current HACC budget by about 2 per cent per year, assuming that this budget is progressively increased by cost inflation appropriate to community care expenditure items. Compared with options for residential care and hospitalisation, neither of which are necessary or satisfactory, increasing support in the home in a flexible and timely manner is preferred by carers and the professionals and care workers that support them.

REFERENCES

- Access Economics. (2005). *Acting positively: Strategic Implications of the economic costs of Multiple Sclerosis in Australia* (Report for Multiple Sclerosis Australia). Canberra, ACT: Access Economics Pty Ltd.
- Access Economics. (2007). *Living with Parkinson's Disease: Challenges and positive steps for the future* (Report for Parkinson's Australia). Canberra, ACT: Access Economics Pty Ltd.
- Australian Bureau of Statistics (ABS). (2005). Population by Age and Sex, Australian States and Territories, June 2005, Cat. No. 3201.0. Retrieved 5 May, 2008, from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/7030CEE75D8A9F0ACA257242001B1C87?opendocument>
- Australian Bureau of Statistics (ABS). (2006). Population Projections, Australia, 2004 to 2101, Cat. No. 3222.0. Retrieved 5 May, 2008, from <http://www.abs.gov.au/ausstats/abs@.nsf/mf/3222.0>
- Australian Bureau of Statistics (ABS). (2007). Population by Age and Sex, Australian States and Territories, Dec 2007, Cat. No. 3201.0. Retrieved 5 May, 2008, from [http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/6F9CDA7774E409B0CA2573AE0017F78C/\\$File/32010_jun%202007.pdf](http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/6F9CDA7774E409B0CA2573AE0017F78C/$File/32010_jun%202007.pdf)
- Australian Bureau of Statistics (ABS). (2008). Australian Demographic Statistics Cat. No. 3101.0. Retrieved 5 May, 2008, from <http://www.abs.gov.au/ausstats/abs@.nsf/81d2945d3269ee5cca25709a00138ffb/6949409dc8b8fb92ca256bc60001b3d1!OpenDocument>
- Barnett, M. H., Williams, D. B., Day, S., Macaskill, P., & McLeod, J. G. (2003). Progressive Increase in Incidence and Prevalence of Multiple Sclerosis in Newcastle, Australia: a 35-year Study. *Journal of the Neurological Sciences*, 213, 1-6.
- Compston, D. A. S. (1990). The Dissemination of Multiple Sclerosis. *Journal of the Royal College of Physicians of London (now Clinical Medicine)*, 24, 207-218.
- Department of Health and Ageing. (2006). *Aged Care in Australia*. Canberra, ACT: Commonwealth of Australia.
- Department of Human Services Victoria. (2008). Home and community care: Unit prices for 2007 - 08. Victorian Home & Community Care (HACC) Program Manual. Retrieved 10 June, 2008, from http://www.health.vic.gov.au/hacc/downloads/pdf/unit_price2007-08.pdf
- Doyle, M. (2008). Prevalence rates for HD in Western Australia, 2007. Perth.
- Emard, J.-F., Thouez, J.-P., & Gauvreau, D. (1995). Neurodegenerative diseases and risk factors: A literature review. *Social Science and Medicine*, 40(6), 847 - 858.
- Forbes, R. B., Colville, S., Parratt, J., & Swinger, R. J. (2007). The incidence of motor neuron disease in Scotland. *Journal of Neurology*, 254(7), 866 - 869.
- Goldberg, Y. P., Telenius, H., & Hayden, M. R. (1994). The molecular genetics of Huntington's disease. *Current Opinion in Neurology*, 7, 325 - 332.
- Hammond, S. R., McLeod, J. G., Millingen, K. S., & al, e. (1988). The Epidemiology of Multiple Sclerosis in Three Australian Cities: Perth, Newcastle and Hobart. *Brain*, 111, 1-25.
- Kristjanson, L. (2003). *Assessing the Extent to which Existing Models of Supportive Care Service Delivery meet the Needs of People living with Multiple Sclerosis, Motor Neurone, Parkinson's and Huntington's Diseases and their Families* (Summary Report of Phase I). Perth, Western Australia: Edith Cowan University.
- Krivickas, L., Shockley, L., & Mitsumoto, H. (1997). Home Care of Patients with Amyotrophic Lateral Sclerosis (ALS). *Journal of Neurological Sciences*, 152(Supp 1), S82 - S89.
- McGarva, K. (2001). Huntington's Disease: Seldom Seen - Seldom Heard? *Health Bulletin*, 59(5).

- McKeown, L. P., Porter-Armstrong, A. P., & Baxter, G. D. (2003). The Needs and Experiences of Caregivers of Individuals with Multiple Sclerosis: A Systematic Review. *Clinical Rehabilitation*, 17, 234 - 248.
- McLeod, J. G., Barnett, M. H., Macaskill, P., & Williams, D. B. (2007). Long-Term Prognosis of Multiple Sclerosis in Australia. *Journal of Neurological Sciences*, 256, 35-38.
- Ohlin, J. (1999). *Unmet Need in Disability Services: Shortfall or Systematic Failure?* Retrieved from <http://wopared.parl.net/library/pubs/CIB/1999-2000/2000cib06.htm>.
- Pendal, N. (2000). *The future of services for the Huntington's community: An analysis of the current and future accommodation, respite and day-centre needs for people with Huntington's Disease in Western Australia* (Report). Perth, Western Australia: The Australian Huntington Disease Association (Inc.) WA.
- Rosas, H. D., Salat, D. H., Lee, S. Y., Zaleta, A. K., Pappu, V., Fischl, B., et al. (2008). Cerebral cortex and the clinical expression of Huntington's disease: complexity and heterogeneity. *Brain*, 131(4), 1057 - 1068.
- Sadovnick, A., & Ebers, G. (1993). Epidemiology of Multiple Sclerosis: a Critical Overview. *Canadian Journal of Neurological Science*, 20, 17-29.
- Shaw, P. J. (1999). Science, medicine, and the future: Motor neurone disease. *British Medical Journal*, 318(7191), 1118 - 1121.
- Solari, A., Ferrari, G., & Radice, D. (2005). A Longitudinal Survey of Self-Assessed Health Trends in a Community Cohort of People with Multiple Sclerosis and Their Significant Others. *Journal of the Neurological Sciences*, 243(1-2), 13 - 20.
- Turner, M. (2001). The treatment of motor neurone disease. *The Practitioner*, 245, 530 - 538.
- van Teijlingen, E., Friend, E., & Kamal, A. (2001). Service Use and Needs of People with Motor Neurone Disease and Their Carers in Scotland. *Health and Social Care in the Community*, 9(6), 397 - 403.
- Vickers, L., & O'Neill, C. (1998). An Interdisciplinary Home Healthcare Program for Patients with Parkinson's Disease. *Rehabilitation Nursing*, 23(6), 286 - 299.
- Vos, T., Goss, J., Begg, S., & Mann, N. (2007). *Projection of Health Care Expenditure by Disease: A Case Study from Australia*. Brisbane, QLD: Centre for Burden of Disease and Cost-effectiveness, School of Population Health, University of Queensland and Australian Institute of Health and Welfare.
- WA Department of Health. (2007a). *Home and Community Care Program: Western Australian Program Plan 2007/2008* (Annual Plan Report). Perth, WA: Aged Care Policy Directorate.
- WA Department of Health. (2007b). Key Performance Indicators Certification Statement. Retrieved 5 June, 2008, from <http://www.health.wa.gov.au/publications/documents/annualreports/2007/DOH/DOH%20Part%20-%20-%20Key%20Performance%20Indicators.pdf>
- WA Department of Treasury and Finance. (2002). Western Australia's Submission to the Commonwealth Grants Commission 2004 Review. Retrieved November, 2003, from www.treasury.wa.gov.au/TreasuryPublications/CGC_WA_Submission_April_2002.pdf
- Wade, D. T. (1997). Epidemiology of disabling neurological disease: How and why does disability occur? *Journal of Neurology, Neurosurg Psychiatry*, 63(Supp 1), 11 - 18.
- Williams, J. K., Schutte, D. L., Evers, C. A., & Forcucci, C. (1999). Adults Seeking Presymptomatic Gene Testing for Huntington's Disease. *Journal of Nursing Scholarship*, 31(2), 109-114.

Neurodegenerative Disorders Project – Report Number 6 – Projections of Unmet Need

APPENDIX 1: UNMET NEED FOR HOME CARE SUPPORT, 2007 AND 2021 FOR PEOPLE WITH UNMET NEEDS ONLY

Disorder	Gender	Prevalence rate (per 100,000) 2007 ^a	Disorder population in WA, 2007 ^b	Proportion with unmet home care support needs ^c (%)	Number with unmet home care support needs, 2007 ^d	Unmet need per person in need 2007 ^e (hours per week)	Unmet need 2007 ^f (hours per week)	Prevalence rate 2021 ^g	Disorder population in WA 2021 ^h	Number with unmet home care support needs, 2021 ⁱ	Unmet need 2021 ^j (hours per week)
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
MND	All	6.00	126	16.07	20	1.89	38.37	6.00	159	26	48.4
MS	Males	41.14	438	10.53	46	3.00	138.36	41.14	549	58	173.35
	Females	116.52	1,213	6.99	85	4.73	401.11	116.52	1,540	108	509.29
	All	79.12	1,666	7.73	129	4.21	542.20	79.12	2,101	162	683.84
HD	All	7.00	147	8.00	12	2.38	28.07	7.00	186	15	35.40
PD	Males	278.00	2,960	11.06	327	2.47	808.51	278.00	3,708	410	1,013.02
	Females	260.00	2,707	18.90	512	1.59	813.50	260.00	3,437	650	1,032.91
	All	269.00	5,665	14.32	811	1.98	1,606.11	269.00	7,144	1,023	2,025.67
All NDD	All	n.a.	7,604	n.a.	972	n.a.	2,214.75	n.a.	9,591	1,226	2,793.31

Notes: ^a From Tables 1 to 4; prevalence rates from highlighted studies. ^b The number of people with each disorder in 2007 is estimated from the prevalence rate applied to the estimate of the WA population for 2007 (Australian Bureau of Statistics (ABS), 2007) – 2,105,783 persons; 1,064,600 males and 1,041,183 females. ^c From postal survey data (see NDP Report No 1 – Client and Carer Survey). ^d Column 3 x Column 4. ^e From postal survey data (see NDP Report No 1 – Client and Carer Survey). ^f Column 5 x Column 6. ^g The number of people with each disorder in 2021 is estimated from the prevalence rate applied to the estimate of the WA population for 2021 (Australian Bureau of Statistics (ABS), 2006) – 2,655,884 persons; 1,333,891 males and 1,321,993 females. ^h Column 9 x Column 4. ⁱ Column 10 x Column 6.

APPENDIX 2: MET, UNMET AND TOTAL NEED FOR HOME CARE SUPPORT, 2007

Disorder	Prevalence rate (per 100,000) 2007 ^a	Disorder population in WA, 2007 ^b	Proportion having home care support ^c (%)	Number of people needing home care support, 2007 ^d	Current services per person (hours per week) ^e	Current need (hours per week) ^f	Unmet need (hours per week) ^g	Total need (hours per week) ^h	Unmet need as a proportion of total need (%) ⁱ
	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
MND	6.00	126	32.14	41	4.49	184.09	38.17	222.26	17.17
MS	79.12	1,666	14.47	241	4.54	1,094.14	542.44	1,636.58	33.14
HD	7.00	147	32.00	47	4.42	207.74	27.83	235.57	11.8
PD	269.00	5,665	27.62	1,565	2.45	3,834.25	1,611.49	5445.74	29.59
All NDD	n.a.	7,604	n.a.	1,893	n.a.	5,320.22	2,219.93	7540.15	29.44

Notes: ^a From Tables 5 and 6. ^b From Tables 5 and 6. ^c From postal survey data (see NDP Report No 1 – Client and Carer Survey). ^d Column 2 x Column 3. ^e From postal survey data (see NDP Report No 1 – Client and Carer Survey). ^f Column 4 x Column 5. ^g From Tables 5 and 6. ^h Column 6 plus Column 7. ⁱ Column 7 / Column 8 expressed as a percentage.

APPENDIX 3: COMPARISON OF SURVEY AND ESTIMATED DISORDER POPULATIONS, 2007

Disorder	Disorder Population ^a		Survey Population ^b	
	Number	Percentage	Number	Percentage
MND	126	1.6	56	5.2
MS	1,666	21.9	608	56.3
HD	147	1.9	25	2.3
PD	5,665	74.5	391	36.2
All NDD	7,604	100.0	1,080	100.0

Notes: ^a From Column 3 in Tables 5 and 6. ^b See NDP Report No 1 – Client and Carer Survey.