

Neurodegenerative Disorders Project - Report Number 5

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

**KEY ISSUES AND UNMET NEEDS - HEALTH,
ALLIED HEALTH AND SERVICE PROVIDER
PERSPECTIVES**

by

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ACRONYMS

ACRONYM	DESCRIPTION
A&E	Accident and Emergency Department
ACAT	Aged Care Assessment Team
ACSA	Aged and Community Services Australia
ADL	Activities of daily living
AHDA WA	Australian Huntington's Disease Association of Western Australia
ALS	Amyotrophic Lateral Sclerosis
CAEP	Community Aids and Equipment Program
Centrelink	Federal agency for the management of social support
DSC	Disability Services Commission
GP	General Practitioner
HACC	Home and Community Care
HD	Huntington's Disease
Homeswest	State agency for the provision of public housing
IADL	Instrumental activities of daily living
MND	Motor Neurone Disease
MNDAWA	Motor Neurone Disease Association (Western Australia)
MPT	Multi purpose taxi
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
PEG	Percutaneous Endoscopic Gastrostomy
PWA	Parkinson's Western Australia
QLD	Queensland
RBD	REM sleep behaviour disorder
REM	Rapid eye movement
SUN	Services and needs assessment instrument
TUSS	Taxi users' subsidy scheme
UK	United Kingdom
VIC	Victoria
VOC	Volatile organic compounds
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 BACKGROUND

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 to the project including the development and analysis of a linked database, an analysis of member and client characteristics 1996 – 2006, a postal survey of clients and carers, interviews with clients and carers as well as with health and allied health professionals and service providers², and case studies.

The purpose of the project is to provide home and community care providers, planners and policymakers with information that will enable them to better understand the current and future home care support needs of individuals (and their carers) living with NDD in the community. To this end, the quantitative and qualitative outcomes from the analyses of the survey, interview and membership/client data are amalgamated. With an understanding of the key issues related to unmet needs, better funding and planning can eventuate.

Interviews with professionals and providers will provide another perspective relevant to discerning the natural progression of the disorders and their affect on individuals and their carers. Moreover, professionals and providers can provide insights into how these are translated into the need for services to support quality of life and the ability to remain living in the community.

This report summarises the key issues arising from interviews with providers. In the remainder of this background section, five studies using surveys of and/or interviews with providers of services to individuals having any or all of these disorders are summarised. In Section 2, the interview process is described. The interview material is summarised in two sections. Section 3 summarises the specific key issues and unmet needs that all providers have experienced in their attempts to provide appropriate and timely services to individuals and their families. Section 4 raises some additional issues that some providers commented on. The conclusions are found in Section 5.

The literature search for the project found five studies of the home support needs of people with NDD in which providers were surveyed or interviewed. In Australia, the studies by Dawson, *et al.* (2004) and Kristjanson (2003) included semi-structured interviews with health care workers dealing with people with HD and with people with any of the four neurodegenerative disorders (MS, MND, PD and HD), respectively. In the United Kingdom, De Broe, *et al.* (2001) conducted a postal survey with MS specialty nurses and Hughes, *et al.* (2005) held semi-structured interviews with professionals supporting people with MND. Finally, Kersten, *et al.* (2000) used both phone and face-to-face interviews with professionals caring for people with MS in five European countries³. Highlights of each of these studies are as follows.

Dawson, *et al.* (2004) reported, *inter alia*, on semi-structured face-to-face interviews in Western Australia, Victoria and Queensland with a total of seven health care workers - a social worker, an occupational therapist, a nurse consultant, a doctor, two care co-ordinators and a support worker - with a range of specialty experience with HD of between one and twelve years.

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

² In this report, health and allied health professionals and providers of home care services are referred collectively as 'providers'.

³ Belgium, Estonia, Greece, Italy and United Kingdom.

The authors did not report specific comments, nor did their discussion refer specifically to responses made, by these health care workers. However, two of the key findings in Dawson, *et al.* appear to have been informed explicitly by interviews with these workers. First, they reported that, ideally, support for people with HD should come from a competent and consistent team of support workers who are familiar with and trusted by the family (pg 127). Second, they reported that financial difficulties for families caring for someone with HD are considerable and may result in a crisis approach to care, including premature institutionalization (pg 129).

The study by Kristjanson (2003) surveyed support agency members, carers, and care and health care workers. The response rate for care and health care workers was 13.1 percent (n = 17). The study had a number of findings which, unlike the Dawson, *et al.* (2004) study, were directly attributable to semi-structured face-to-face interviews with providers.

In relation to practical support, Kristjanson (2003) stated that “*health care professionals acknowledged that many carers were elderly themselves and were not strong enough to provide heavy care*” (pg 28) and that “*equipment provision in a timely fashion (is) an art form*” (pg 28). A second finding related to the impact of a neurodegenerative disorder on children. “*One health care professional believed that children ten years and over seemed to be more accepting of the deterioration and were often willing to participate in caring (even becoming)... a primary carer*” (pg 29).

Another finding in the Kristjanson (2003) study was that health professionals agreed with member and carer concerns that some providers had inadequate or inaccurate information, particularly in acute health care settings, in relation to particular disorders (pg 30). Other findings were related to what the health professionals were able to discern from patients and their families in relation to disease progression (such as some carers being afraid to ask about the end stage of the illness or being uncertain about how to ask questions about their stage of care) and palliative care (for example, people with MND coming to terms with their disorder and preparing for a supported death).

A literature review of studies that evaluated the effectiveness of MS nurse specialists in the United Kingdom (De Broe *et al.*, 2001) found only one study that fulfilled the review search criteria. This study by Kirker, Young and Warlow and published in *Clinical Rehabilitation* in 1995 found that “*GPs ... reported finding the nurse to be helpful with their MS patients, and 40% of the GPs stated they would purchase the services of an MS specialist nurse if their practices became fundholding*” (De Broe *et al.*, 2001: iii)⁴.

Another UK study, by Hughes, *et al.* (2005), examined the lives and experiences of people with MND living in three boroughs in London. The authors used semi-structured interviews with people with MND, carers of people with MND and health, social and palliative care professionals providing care for people with MND. The latter were recruited from professionals registered with the specialist MND service in London, the MND Care and Research Centre at King’s College Hospital.

⁴ The general practitioner fundholding scheme was introduced in the UK in 1990. It allows GPs who meet certain criteria to purchase health services directly for their patients. It has led to improvements in services to patients and made GPs more aware of the cost implications of their spending decisions (National Audit Office, 1994-1995).

In their findings, Hughes, *et al.* (2005) refer to professionals' views of the coping strategies and life quality of their patients. Quoting from an interview with a community-based health professional with six year's experience in caring for people with MND, the authors report:

"I think people feel that they struggle to have a quality of life, to find enjoyment, the basic things. I mean, not being able to just speak to people, not being able to eat, physically wasting away. I think people really, really struggle with it ... and I think, often the person that we see is not the person that they were before MND, and most families will say that. I think, when you're in a situation where you can't do even the most basic things for yourself, that must change your personality" (pg 69).

Regarding coping strategies, Hughes, *et al.* (2005) provide a quote from a hospital-based health professional also with six year's experience in MND:

"You can have denial, you can have depression, you can have anger, you can have acceptance, you can have apathy, you can have someone who wants everything ... and every single emotion can be displayed in an MND patient" (pg 69).

Importantly, the authors also report a need to prioritise people with MND because *"of the nature of the disease and (its) rapid progress"* (pg 69), a view expressed in another interview with a social service professional with twelve years experience in MND.

In addition to asking questions about the lived experience of people with MND, Hughes, *et al.* (2005) also asked about the provision of services. One of their results was that professionals recognize that the plethora of information provided to individuals and their carers can be confusing (pg 69). Individuals, carers and professionals all concurred that the low incidence of MND meant that therapists and GPs, who do not specialise in MND or other NDD, do not have sufficient exposure to the disorder and therefore have incomplete knowledge (pg 70), a finding in Kristjanson's (2003) Australian study. Hughes, *et al.* (2005) argued that this could be remedied through *"better coordination and information exchange between professional teams"* (pg 71). For example, some professionals commented to the authors that *"services should be restructured to reduce demarcation between providers to enable professionals to follow-up their caseload between hospitals and the community. These changes were understood to improve coordination and consistency of care"* (pg 71). In addition, some providers suggested in their interviews in the Hughes, *et al.* (2005) study that improved education and training was needed for their colleagues (pg 71).

A final study of the home support needs of people with NDD that utilised telephone and face-to-face interviews with providers is a study by Kersten, *et al.* (2000) aimed at piloting *"an international services and needs assessment instrument (SUN) for people with multiple sclerosis and their carers and to pilot this in (six) countries of the European Community"* (pg 42). The instrument had three parts. The first and second parts were directed at the person with MS and their carer, respectively. The third part was intended for the key health or social care professional nominated by the care recipient. When discussing their questionnaire design, Kersten, *et al.* noted that the questionnaire finishes with a request to all participants to list the five most important unmet needs in order of priority. In addition, all three categories of participants were asked to comment on what they perceived as the unmet needs of the carers. Of interviews with 137 people with MS, 111 health professionals completed the appropriate sections of the instrument.

The results of the Kersten, *et al.* (2000) study revealed that professionals in all five countries estimated fewer unmet needs than suggested by individuals and their carers. For example, the unmet needs of care recipients in the UK was estimated to average 2.3 by professionals and 2.9 by individuals with MS (pg 46). In Greece the estimates of mean number of unmet needs were closer – 3.5 by professionals and 3.6 by individuals (pg 46). Kersten and her colleagues concluded, using information from all three types of participants, that:

“the SUN needs assessment schedule is a practicable tool for the identification of unmet needs for people with multiple sclerosis and their carers across European countries... (It) can be used for research purposes and in a clinical setting. (However) country - specific issues must be considered in international comparisons of patients’ and carers’ needs”. (pg 47).

The Kersten, *et al.* (2000) study was interesting in that it attempted to quantify the perceived differences in estimates of unmet need between different types of participants. However, whilst they showed that estimates from providers were, on average, lower than estimates from care recipients, it is unclear whether the unmet needs overlap. That is, were the 2.3 unmet needs identified by providers a subset of the 2.9 unmet needs identified by individuals? Another problem with this study was that it did not distinguish between the size of need for individuals reporting the same type of need. For example, two respondents each reporting one need for more complementary therapy would each be recorded as having one unmet need. Yet one of these respondents might need two extra therapy sessions each week and the other only requires one extra session per month. That is, Kersten and her colleagues did not take into account the size of these needs in their enumeration. By comparison, the present project goes one step further by asking, in addition to what the need is, how much extra servicing is required.

Despite their limitations, the five studies discussed here provide useful information from provider viewpoints to complement the views and experiences of people living with NDD and their carers. Reference to these studies is made in Sections 3 and 4 in relation to similar or different findings from this project’s interviews with providers.

Provider input to the present project emphasised the type of services that may be missing from current home care support and how these might be accessed and delivered in a more timely and appropriate way. This input did not specifically estimate hourly amounts of services that needed supplementing although many providers commented on unrealistic ceilings to existing service provision.

Important to the questions about what support and how much support is needed, is recognition that there is a fine balance between providing too much or too little support. For example, Karol and Giles (2008) use Lawton’s (1989) model of environmental gerontology to demonstrate the trade-off between the demands of the environment, such as housing modifications, and personal competence which may be measured in terms of mobility. That is, people whose personal competence, in one or in a number of areas, is low require an environment that does not expect much of them, whereas more competent people would be less challenged by, and therefore more responsive to, higher demands from their environment. Accordingly, providing too much support (demanding less effort than they can exert) is as detrimental as over-stimulating an individual (demanding more from them than they are capable of doing) (M.P. Lawton, 1989). However, determining the competency of an individual who has a neurodegenerative disorder may be difficult at any one time or over time. Most providers interviewed for this project acknowledge this trade-off in their estimations of unmet needs.

In the next Section, the process of obtaining the views and experiences of providers is described. A summary of the roles and objectives of each of the providers or provider groups is provided elsewhere (see NDP Report No 4 – Data Linkage 2006).

2 INTERVIEW PROCESS

Earlier in this project, at the client and carer interviews, individuals were asked which health and allied health professionals they saw and which providers of home care services they used. Lists of neurologists, other specialists, general practitioners, allied health professionals, home care support agency workers and other professionals were compiled. From these lists, and following discussion within the Steering Group⁵, an interview schedule was determined. Included were interviews with neurologists and metropolitan-based general practitioners (GPs), Parkinson's nurse specialists, Neurosciences Unit social workers, Neurological Council regional nurses and metropolitan care co-ordinators, the multi-disciplinary care team at the MS Society, MNDAWA care advisors, representatives of the Silver Chain palliative care team and Silver Chain regional managers.

The selection of interview participants was intended to reflect the range of services available to people with each of the four neurodegenerative disorders in both metropolitan and country areas. Some interview participants provided support to only one of the four disorders, for example, MNDAWA care advisors. Other participants provided services across the four disorders, such as Neurological Council.

Similarly some participants provided services in either the metropolitan area or the country regions. (See Attachment D for a map of Western Australia showing Home and Community Care (HACC)⁶ regions). Other interviewees provided services in both metropolitan and country areas.

Just as the organisations involved in this project are not an exhaustive list of all organisations providing care to people with NDD in Western Australia, the selection of provider interview participants is not inclusive of all care workers from these organisations. Neither are the neurologists and general practitioners who participated in interviews necessarily a complete or representative collection of those professionals with patients diagnosed with NDD. However, it was not considered necessary to ensure representativeness of these participants. Rather the results of the interviews were expected to be illustrative of the expertise and experience of providers (see Cohen, Kahn, & Steeves, 2002 for their take on the representativeness and communication of qualitative research results in nursing research). In this way, the semi-structured interviews provide another perspective to inform the project's primary objective of identifying the gaps in home care support for people with NDD.

⁵ The Steering Group has representatives from the thirteen organisations involved in the Neuro project. The key roles of this group are to oversee the conduct of the research and co-ordinate their own organisation's involvement in the project.

⁶ The HACC Program is a joint Commonwealth, State and Territory initiative which funds basic maintenance and support services to help frail older people and younger people with disabilities to continue living at home. These services are managed through State and Territory health authorities via recurrent funding for existing services with an annual competitive application process for growth funding (that is, any additional services or services in a new HACC region).

The interview process evolved slightly between the first interview in early February and the last interview in late March. Nine interviews were held altogether. The interviews that were held earlier on in the interview schedule began with a semi-structured interview questionnaire (see Attachments A, B and C for the interview questionnaire, information sheet and consent form, respectively). Interviews held later on used the questionnaire and referred to responses given in earlier interviews. Initially, the later interviews provided more comprehensive information than the earlier interviews. However, draft individual (or group) interview summaries, together with early drafts of a combined interview summary, were circulated to all participants for correction, deletion and addition. This enabled all participants, in particular those who gave interviews early in this process, to compare their own responses to issues and problems raised by other groups/professionals with a view to adding their different experiences or to confirm their similar understanding.

Note that, whilst particular clients were discussed in interviews as exemplars of difficulties and issues related to the support of people with NDD, this report and the interview summaries preclude reference to particular cases.

The interview summaries highlighted common themes between providers in relation to the unmet needs of people with NDD living at home. These themes are discussed in the next Section. Some other issues which were raised by one or more providers but which were not of general concern to all providers are discussed in Section 4.

3 KEY ISSUES AND UNMET NEEDS

From a provider's viewpoint, people with NDD have three important and inclusive needs if they want to remain at home as their ability to undertake activities of daily living⁷ deteriorates in the face of the progression of their disorder. These are clinical management of their disorder and its symptoms (and any other health issues), home support (including services, transport, equipment, housing modifications and assistive devices), and respite (whether or not they have a carer).

Regarding the first of these needs, this project did not specifically examine the clinical management of these disorders. However, providers raised characteristics of symptom control that might affect home support and respite. First, providers might find, in the course of their contact with a client, some aspect of the clinical management plan is not working effectively and that this is impacting on the ability of the client to access respite or signalling a need for more personal care. In some cases, care advisors might suggest individuals seek GP or neurologist appointments.

A second aspect of symptom control relates to co-morbidities. For some people with NDD, their symptoms may be confounded by frailty associated with old age. Some individuals may have other chronic illnesses, such as diabetes or high blood pressure, or other health issues with which to contend. In some of these cases, there are additional avenues of support. For example, people with PD who have dementia can access services through Parkinson's WA as well as via Alzheimers' Association of WA.

⁷ These include both Activities of Daily Living (ADLs) (Collin, Wade, Davies, & Horne, 1988) and Instrumental Activities of Daily Living (IADLs) (M. P. Lawton & Brody, 1969).

A final aspect of the clinical management of a disorder noted by some providers is that some people with NDD (and/or their families) are in denial about their disorder and its life-limiting effects. This can prevent them from seeking help from health professionals, from the disorder-specific support agency or from home care service providers in the early, or even middle, stage of their disorder. They may be slow to seek help or to investigate the availability of and access to support or medical treatment. Providers are aware that, if this attitude persists, then a crisis situation may develop to the detriment of the wellbeing of the individual and their family. This may be exacerbated by the breakdown of family structures, which increases the strain on, and reduces the care available to, individuals. Providers, particularly care workers of disorder-specific support agencies, and social workers from NSU in the case of people with HD, may then need to fast track access to services and other supports. Given provider experiences with long lead times in implementing home care support services in the home, this is not an easy task. Moreover, the supports are likely to be less effective than would have been the case if earlier interventions had been obtained.

Before summarising key issues and unmet needs, it should be noted that providers agree that their clients have varying competencies in relation to accessing the health and community care systems. At one extreme are people living alone who have few financial resources, no family or friend networks, and no ability to negotiate the application processes, including interpreting the eligibility rules, for home care support. At the other extreme are individuals who are good with problem solving and are resourceful. In some cases, it is the carers (often life partners) who have these skills. In these cases, individuals or carers can co-ordinate many sources of support. Providers find that, generally, in the latter cases, their support for the family is collaborative. In the case of people with few resources, however, provider support is more complex and necessarily leading.

Regarding the important needs of home support and respite, providers are of the same mind - that provision of home care support for people with NDD and their families within the existing framework of disability and aged care funding and resources is inadequate and often also inappropriate. As a result, providers are frustrated in their attempts to do their jobs well, and the well-being of carers and maintenance of the life quality of care recipients are compromised. In the following Sections, the key issues underlying the shortcomings of current arrangements are discussed with reference to unmet needs for support in the home.

Note that the following discussion also includes reference to literature that uses terminology that is different to that used by providers in interviews but that reflects common usage within the aged, disability, health and community care sectors. Terms such as 'case management' and 'person-centred' are defined where necessary and discussed where appropriate.

3.1 Choreography of Care

'Choreography of care' is a well worn phrase (see, for example, Dawson et al., 2004; Kristjanson, 2004) that precisely describes the complexity of service provision that is necessary for people with NDD. What it doesn't necessarily convey is that this care is most effective when the precise needs and circumstances of an individual at a point in time are accommodated. This corollary means that the provision of care to any individual is unique. The reasons for this are clear. Not only can physical, psychological/psychiatric and cognitive difficulties related to their disorder differ, but individuals can also differ in terms of pre-morbid personalities, co-morbidities, their experiences with the health and community care systems, and their networks of family and friends.

Where they are at in the progression of their disorder is another difference. That is, as highlighted by all providers who were interviewed, a one-size-fits-all approach to providing a 'choreography of care' to individuals with NDD is not appropriate. In this regard, one provider commented that their home care support services are "*necessarily flexible to accommodate the unpredictable course and the complexity and uniqueness of each individual's experience*".

Some generalisations can be made about home care support needs. People who are more mobile and have fewer physical difficulties need less support and people who are in the palliative phase of their disorder need more services in the home as well as assistive devices and housing modifications. However, these motherhood statements are not useful for defining the delivery of specific services, etc, to particular clients in the home. Some examples of how needs may differ are as follows. Whether someone needs extra personal care time when their functioning declines may depend on how much extra physical help they can expect from their carer, or, indeed, whether they have a live-in carer. Different types of hoists are available for people depending on their transfer needs and who is assisting them in the home. The exact types of housing modifications will depend on the structure and fittings of the existing home as well as where the client lives and what family and friend networks they have.

This heterogeneity of needs suggests that home care support should be individualised and the best way to do this is via case management⁸. As Dawson (2004: 129) argues, "*a case management approach is likely to be most useful in catering for the differences among individuals*".

The experiences of all providers reflect this approach, albeit in different ways. For example, providers in different country areas seemed to have access to different facilities or to have different ways of organising services. Depending on these differences, regional providers are able to obtain more or less services, etc, for their clients. Importantly, most metropolitan and country providers are able to compare notes within their care teams (across areas) and so can attempt to locate like services, etc, within their own locale. Through the interview process and the review of interview summaries, providers interviewed for this project became aware of other funding, services and support that could supplement the resources they usually used.

Whilst case management is an agreed ideal by providers, in most cases the role of case manager is adopted by providers on a *de facto* basis. That is, most providers fulfil the role of case manager for those clients who need it, irrespective of whether funding rules or job descriptions specify it. Only in the case of NSU social workers is the role of case manager included formally in the provision of their services to people with HD and their families.

⁸ Case management is defined as "a method of managing the provision of health (and community) care to members with high-cost medical conditions. The goal is to coordinate the care so as to both improve continuity and quality of care and lower costs" (Koongstvedt, 2001). Case management involves locating funding, coordinating services, undertaking post acute care follow-up, etc, as well as providing counselling, advocacy and patient education in a timely and suitable manner.

Some providers advocate on behalf of their clients with employers, government agencies such as Centrelink and Homeswest, the Independent Living Centre and other government or non-government agencies or private organisations or landlords, regarding changed financial circumstances or the need for changes in the workplace or modifications to the home. This assistance can also extend to liaison within the health and community care systems, especially for clients who are living alone and/or whose cognitive abilities preclude them from effectively communicating.

The type of networking that occurred during the provider interview process for this project, mentioned earlier, is evident across services supporting people with the different neurodegenerative disorders. For example, the care team from MSS WA often meets with other providers, such as health professionals in hospitals or other service providers, to case manage hospitalised clients prior to their discharge. AHDA and NSU share the support of people with HD and their families. The community support officer of the AHDA specialises in counselling and advocacy and NSU social workers provide broader case management assistance. Care advisors at MNDAWA and the health and allied health professionals that provide services through the MND Clinics ensure collaborative support for people with MND. As with other providers, the PWA nurse specialists provide professional development to all providers to ensure that the care given to people with PD is informed, current and appropriate. Without shared information (to be discussed in the Section 3.2), these collaborations would be ineffective.

It is prudent to point out that the effectiveness of informal and formal collaborations between providers of services is reliant on trust and commitment by professionals from various discipline or educational backgrounds and diverse experiences. Often it also depends on personalities. In her study of interprofessional healthcare teams in Sweden, Kvarstrom (2008) found that “difficulties related to the team dynamic ... arose when team members acted towards one another as representatives of their professions, ... when the members’ various knowledge contributions interacted in the team, and ... (in relation) to the influence of the surrounding organization. The perceived consequences of the difficulties, beyond individual consequences, were restrictions on the use of collaborative resources to arrive at a holistic view of the patient’s problem, and barriers to providing patient care and service in the desired manner” (pg 191). None of the interviews with providers of home care support to people with NDD in Western Australia suggested that these difficulties had arisen in their collaborations. Instead, the providers reported that the teamwork was instead enhanced by the over-riding frustrations with state and federal bureaucracies and their funding models - a case of joining forces against, or in spite of, a common adversary.

Some providers report that a collaborative role can include being the lead organisation in the management of home care support for particular individuals. The cross-provider group, which provided the impetus for the current project, investigated multi-servicing of people with NDD and recognised the need for collaboration including the potential for different organisations to take the lead with different clients (Silver Chain, 2003). Providers recognise that whilst the community care sector is notionally competitive, each organisation in Western Australia has a uniqueness to offer to particular clients in particular settings. Hence, as examples, Brightwater is the lead organisation in the care of people with HD and the primary palliative care team in the metropolitan area is based at Silver Chain which is the largest of the community care providers and has a longstanding nursing and palliative care capability.

Without provider involvement of various kinds and at various levels, a ‘choreography of care’ that is timely, flexible and appropriate to the individual, would be, at best, difficult for the individual or their family to organise and, at worst, impossible. Hence, a collaborative and person-centred⁹ approach to home care support for people with NDD that encompasses these ideals is preferred by all providers.

3.2 The Need for an Up-To-Date and Comprehensive Person-Centred Database

If individuals are obtaining home care support for themselves, or with the help of providers, such as their disorder-specific support agency, then there are forms to fill in and eligibility rules to comply with. The organisations providing the funding or resources will need to assess the initial need and, usually, review changing needs. For some individuals, there are thus many occasions when they are providing information about themselves, their circumstances and their needs. Given the degenerative nature of their disorders, it would be expected that some, but not all, of this information will change over time. It might also be expected that past and current information can both be used to inform decisions regarding current and future home care support.

Some providers feel that the continual request for information from this group of people is too onerous and that there should be a central clearing house or database. The type of information would be clinical (medication dosages, times, etc), care needs and preferences, contacts for carers and providers, ACAT assessment decisions, DSC funding programs, next of kin information, history of respite experiences, forward bookings for respite or hospital, equipment loans and requests, etc. Ideally, the information should be updated continually by providers. Hill (2007) concurs that sharing an individual’s records will make it easier for providers to coordinate care for the individual. In an ideal world, Hill envisages “joint health and (community) care teams with dedicated case management, through a single expert case manager, 24 x 7 service contact and an information system that supports a shared health and (community) care record” (p 14).

One provider suggested that such a shared database could be constructed so that subsets of the information are available to care workers on a need-to-know basis. To illustrate, the neurologist may want to ensure that the care in the home comprehends the medical needs of a patient, for example, an MND patient with a supra pubic catheter needing access to in-home nursing for catheter maintenance. Another example is a home care support agency being able to inform relief or new care workers of the specific needs of a client with NDD (such as how to position the client in bed or a wheelchair, the client’s ability to transfer, the types of assistive devices in the home and whether or not the client has a live-in carer, including how physically and cognitively competent they might be). This information would be useful also for the respite service, whether in-home or residential, to more effectively support the client and their family.

⁹ Person centred-ness can be applied to planning (Circles Network, 2008), service delivery and information management (Hill, 2007). It is a process of life planning for vulnerable individuals, such as the frail aged and disabled, that is based around the principles of social inclusion and the social model of disability (Circles Network, 2008). Social inclusion is affirmative action to change the circumstances and habits that lead to (or have led to) the inability of society to keep all groups and individuals within reach of what is expected as a society or to realise their full potential (Power & Wilson, 2000). Note that the social model of disability is an alternative to the traditional medical model – the former sees the problems of people with disabilities as stemming from significant barriers in the social and built environment and the latter which sees the problems of disabled people as arising from their physical impairments (Sim, Milner, Love, & Lishman, 1998).

The importance of an information repository, also recommended by Kristjanson (2003), was seen by providers as being particularly useful in the event of a crisis. For instance, if there is a need for emergency respite when the carer is suddenly hospitalised, then up-to-date information on the client's care needs is vital. Whether or not individuals and carers could also update or access the information was not raised by providers. However, carers are more likely to know the subtleties of care routines and the importance of these to the wellbeing of the care recipient, so their input is likely to be important for obtaining appropriate care in a respite facility. Some people keep photographic accounts of their needs¹⁰ which are particularly useful to care workers who are new to the home or care workers working in residential facilities that cater for respite.

Such comprehensive information sharing is not a new concept. In the UK, under the National Service Framework for Older People, introduced in 2001, a Single Assessment Process (SAP) (UK Department of Health, 2008) across health (in particular hospital) and community care was trialled in the south east of England prior to adoption across all jurisdictions. The Framework and the SAP were seen as “an attempt to elevate standards of assessment (and) to facilitate information sharing between health and social care in order to improve efficiency and lead to more effective care” (Dickinson, 2006: 365). However, experience with the SAP trial found that front-line practitioners were reluctant to engage with the process, to work together or to share assessments (Dickinson, 2006: 365). It was generally recognised that the cultural shift underlying this sharing requires more time than the trial period had allowed.

In Warwickshire, in the east midlands of England, concerns over the lack of coordination of health and community care services led to the development of policies and practices based on person-centred care. Importantly, it was recognised that this approach “can only be effectively delivered through access to person-centred records and systems, which will equally require the introduction of person-centred information governance” (Hill, 2007: 13). Hill argued that the keys to successful implementation were service users' access to information as well as their ability to manage that access. Given the potential for the negative experiences of information gathering and sharing reported by Dickinson (2006), Hill (2007) argues for common language and understanding between practitioner groups, acknowledgement and recognition of expertise, identification of practice differences and alignment of professional codes of practice (pg 14). As summarised in Section 1, Hughes (2005: 71) raised the issue of providers having incomplete information which could be remedied through better coordination and information exchange within and between care teams.

A final point is that information sharing and a service database of the type discussed and put forward in this Section, can only be as good as the primary data from which it is constructed. This should complement Hill's (2007) emphasis on the importance of access and the management of that access.

3.3 The Gaps in Home Care Support

Overall, the availability of services for people with NDD and their families is heavily dependent on current funding models and localised services. There is no single bucket of funds and assistance. Providers have found that flexible and individualised use of funds, other than through limited access care packages, is not possible.

¹⁰ In NSW, photo diaries are kept by some clients and their carers to facilitate the use of respite.

As one provider stated in relation to people with MND, “*home care support criteria are too limiting for, and means testing should not apply to, people with MND. That is, (these) people should be able to access whatever is necessary in a timely fashion.*” Increased needs can include more showering time, more periods of respite, or night-time visits by care workers to re-position or toilet clients that live alone. In the main, providers feel that it is the inflexibility of funding assistance that is most to blame for gaps (unmet needs) in home care support. Yet, there are also other dynamics that impact on whether or not services are matched to needs at any point in time.

When people are first diagnosed, often their symptoms are minimal and they have no need for assistance in the home. In the main, they need information about their disorder and contact details for the support agencies that could provide this. They may also need clinical management that can slow the progress of their disorder or alleviate their current symptoms. The neurologist might set up a review appointment. Providers have found that how people and their families respond to their diagnoses varies considerably. Some people approach the management of their disorder methodically, seeking information and treatments and finding out what home care support they might be able to tap into in the future when the need arises. Others rely on information volunteered by their health professional but do not have the skills of inquiry to obtain more details or to think about what they may need as their conditions deteriorate. Providers acknowledge that some gaps in home care support can be linked to these innate differences between people.

As discussed in Section 3.2, a comprehensive and accessible client database would be useful in the provision of assistance to people with NDD who are living in the community. Similarly a database of available support, services and funding would be of considerable benefit to case managers. Providers’ knowledge of the availability of funding and home care support mechanisms is varied. Many health and allied health professionals are less familiar with the eligibility rules for HACCC, DSC and packaged care funding or what home care support services can be subsidised. Without a single one-stop-shop for services for people with NDD, some care workers admit that they are struggling to support their clients. For example, they may know of some funding possibilities but can’t find providers that will deliver services with this funding for their clients.

In addition, some providers are unable to discover what the access rules are for this funding. In some cases, combinations of care are chosen from familiar or favoured home care support providers in the absence of having complete information about the most appropriate type and level of care. That is, some providers concede that services for particular clients may be based less on what is best for the client and more on who the care workers have links and good past experiences with.

This parochialism appears to be more noticeable in regional areas and is thought to be exacerbated, in both metropolitan and country areas, by frequent changes in staffing and structures within most organisations and within the community care sector as a whole. Matching clients and services is considered by some providers an art form. Mismatches represent gaps in support that may be difficult to articulate, let alone estimate.

Support agency staff and other care workers, who were interviewed for this project and who are used to case managing clients, seem to have a reasonably thorough understanding of the community care system. Those who have been working in this system for a long period also seem to be more cognisant of the interplay between the health (in particular, hospitals), community care and social services (such as support provided through Centrelink) systems. These skills are essential for navigating the myriad of opportunities, and extracting the best possible 'choreography of care' for which people with NDD may be entitled. In the absence of these skills, unmet need for home care support can and does arise.

One of the difficulties of providing appropriate and timely home care support for people with NDD is changes in needs as the disorder progresses. Most providers admit that they are generally more adept than the individuals themselves at identifying the subtleties of deteriorations in health status and functioning. This is especially true of care workers working for disorder-specific support agencies as well as care workers at the Neurological Council and social workers at the Neurosciences Unit. Whilst this enables providers to anticipate needs for additional support, they recognise that they should be discreet when informing the individual and the family of the need to revise home care support plans. If the changes (usually increases in support) can be implemented as necessary, clients can continue to receive the requisite level of care. If there are delays in making the necessary changes (due to providers not being able to find new services or families deferring their agreement to changed levels of assistance), then gaps in home care support may arise. Neurologists, specialists or general practitioners appear to have more success in encouraging their patients to accept higher levels of support.

Gaps in home care support can also arise irrespective of whether individuals and families agree to more support. Providers report that whilst their clients may be eligible for more support, it doesn't always follow that the support is available. For example, one provider reported that a care package had been approved for a client, but there was no service for the provision of that package in the area in which the client lived. Additionally, this provider discovered that although care packages in an adjacent area were under-subscribed, the movement of available packages between areas was not permitted by the funding body. In this case, the client could not access the higher level care package that they required. Most providers agreed that this type of inflexibility in the community care system is not uncommon.

Home care support is not just about showering, cleaning, gardening and socialising, which, together with respite, form the cornerstone of funding support for people who remain at home during their illness. It can also include the provision of information. The Dawson *et al.* (2004) study reported that, although people with HD and their carers appreciated being kept informed about the disease, its progression and the available supports, there was a "delicate balance between the amount, timing and type of information" (pg 126). Too much or too little information could be stressful. Providers in the current project suggest that families could benefit by this information being filtered by care workers. Dawson *et al.* did not comment on how widespread or useful such filtering was from the point of view of professionals.

As mentioned in Section 3.1, contact with social workers, care advisors and nurse specialists is an important part of home care support as these care workers tend to have case management roles. Whilst the initial contact, which may be client initiated, is usually in the home, subsequent contact tends to be on a needs basis and may be in the home or over the phone. Providers report that there is no pre-determined schedule of contact visits or phone calls with the level and type of contact being determined on a case-by-case basis.

All providers reported having clients that were at risk (for example, women with NDD who were living in violent and abusive relationships). Such clients tended to be contacted more frequently and case managed more closely. Other clients are provided with initial disorder and contact information but it remains for them to follow up with service providers and care advisors if they need it.

Providers have reported that sometimes people delay in making these subsequent contacts because they feel that the care workers are too busy and have more important cases to manage. This reticence may result in the home care support for these people falling behind their needs to the detriment of their own and their carer's health and well-being. However, providers feel that it is important for people to keep some control over this type of decision-making (that is, deciding whether or not the time has come to ask for more help) in the face of the lack of control they have over the progression of their disorder. Some care workers suggest that it is difficult to intervene if families, who may not be coping with the demands of home care, are reluctant to maintain contact or accept help or advice. Gaps in home care support can arise in this way.

Providers agree that in the final weeks/months of the disorder, the home care support needs for people who are remaining in their home are going to be the highest (up to 24 hours per day care of various kinds) and the gaps in the need for and provision of care are going to be the widest. For some providers at this stage, their interaction with individuals and families may diminish as other providers increase their assistance. For example, involvement by the palliative care team at this time usually involves a handover of care responsibilities from other care workers and health and allied health professionals. GPs and nurse specialists with the palliative care team usually take over responsibility for symptom management and care workers from within the team take over the personal care responsibilities. When the palliative care team is providing services in the home, including 24 hour nursing availability, most people with NDD and their families are getting sufficient support. Gaps are usually evident in the lead up to acceptance of palliative care or, if the client's condition stabilises or improves, when the services from the team are removed.

Two interesting problems in relation to gaps in home care support for clients in the south west were raised by a number of regional providers. First, they found that some people with NDD, who had moved to the south west for a sea/tree change, had previously received a high level of care in the metropolitan area. They then expected this same level of service would be provided in their new country locale. When this wasn't forthcoming, there was a lot of angst and animosity towards providers. Second, some city-to-country movers were well prior to their move and did not give any thought to the difficulties of coping with a degenerative illness in the country. After they developed symptoms and were subsequently diagnosed they found it difficult to come to terms with further changes to their cherished lifestyle plans, not least of which is the probable need to return to the city. Finally, the south west is an attractive tourist destination and some interstate visitors expect that temporary home care support arrangements can be easily acquired and that these can replicate the services they received in their home state. Again, frustrations with the community care system are voiced to regional providers whose resources are already stretched in terms of finding support for permanent south west residents. Providers were generally unclear about whether these gaps should be prioritised given that they arise from personal choices about where to live and to visit.

3.4 The Availability and Use of Respite

In their report on creating flexible options for respite, De San Miguel and Smith (2004: 4) discuss the meaning of respite thus:

“The term ‘respite’ is sometimes met with confusion by carers and care recipients who are often unsure of what respite is and exactly what it encompasses. More recently the term ‘short-break’ has been emerging as a term to describe respite because it is one that carers understand and can identify with. What constitutes a ‘short-break’ for a carer is a highly individual thing, (a holiday, going to a movie, playing sport, catching up on sleep, visiting a friend) and, as such, respite can take on many differing forms ... at its best respite is ‘shared and flexible care that provides support in whatever form meets the needs expressed by either (or both) the carer or the person requiring the care. It will enhance and sustain the carer in their role as well as the care and well being of the care recipient’ (Aged and Community Services Australia (ACSA), 2004: 7).

Providers argue that different types of respite, catering to different needs, should be available to individuals with NDD and their families. One type of respite that providers find is rarely provided but would be well subscribed is overnight respite in the home. This type of respite would allow the carer to have a good night’s sleep whilst the care recipient remains safe, with toileting and other night-time needs met. For example, symptoms of Parkinson’s Disease (PD) can be particularly acute at night. People with PD can have nightmares, act out dreams or call out in the night. They may have altered rapid eye movement (REM) sleep behaviour disorder (RBD) (Boeve, Silber, & Ferman, 2004; Salah Uddin & Jarmi, 2007). They may have lots of physical movements – “loss of normal voluntary muscle atonia¹¹” (Salah Uddin & Jarmi, 2007). This disruption to sleep continuity can result in broken sleep for both the person with PD and their carer. In addition, often people with PD need toileting during the night (up to 8 or 9 times) which necessitates help from their carer because of their mobility difficulties. Again, carers can have interrupted sleep.

Providers are also cognizant of the benefits of both short and long term residential respite. Short term (less than one week) planned respite in a residential facility would allow the carer the opportunity to spend some time in the home, or away from the home, without caring responsibilities and to refresh. This would also be useful, for example, when small housing modifications are being made so that the disruption to the care recipient, including compromised breathing, is avoided (see Karol & Giles, 2008 for issues related to residing at home during modifications)¹¹. Longer term (more than one week) planned respite in a residential facility is also needed. This might enable the individual to have their care plan refined, their symptoms to be stabilised and their clinical treatment plan to be evaluated and revised. It can also allow the carer the opportunity to have a holiday.

¹¹ Most people with (neurodegenerative disorders) have compromised respiratory systems and consequently may have problems with breathing. These problems can be exacerbated by dust and noise arising from building works. Moreover, there is evidence that volatile organic compounds (VOC), commonly found in typical house paints and varnishes, in laminates and in fabrics and furniture, impact on the immunologic and neurologic functions. Spengler (1990) points out that for those people with compromised immunological and neurological systems, including the frail aged, VOC are particularly damaging. Further, it is this group of vulnerable people who spends the majority of the day at home and may not be inclined to use or have access to good natural ventilation, thus compounding potential breathing problems (Karol & Giles, 2008: 225).

Finally, providers argue for the increased availability of emergency respite in a residential facility. This type of respite is needed if the carer suddenly, through ill health or stress, is not able, temporarily, to provide the level of care required. Most providers felt that, in the absence of this type of respite, people with NDD tend to be admitted, via presentation at Accident and Emergency or outpatient departments, to public hospitals in a crisis situation, especially in the palliative phase of the disorder. One provider noted that the high dependency ward (24 hour care) at Sir Charles Gairdner Hospital is sometimes used for respite but felt that this was not satisfactory for the individual, their family or the hospital. They felt that it was an inappropriate use of the high care ward which “*should be allocating beds to emergency patients*”. As stated by another provider, “*it is usually preferable for patients to try to avoid a public hospital death*”.

Generally, providers are clear about the types of respite available and the need for respite for both the carer and the care recipient. However, some are less clear about eligibility rules. For example, as respite allows carers a break from their caring role, if a care recipient does not have a carer, then they are technically ineligible for respite. Fortunately, the definition of ‘carer’ for the purposes of respite funding is broader than the definition applied for the purposes of eligibility for the Carer Payment (Department of Families Housing Community Services and Indigenous Affairs, 2008). Importantly, a ‘carer’ can be someone who is ineligible for the Carer Payment, for example, someone providing less than full-time care. Department of Health and Ageing defines a carer as “a person who, through family relationship or friendship, looks after a person who is frail, aged, has disability or a chronic illness” (Department of Health and Ageing, 2006). This can apply to a carer who lives in a different home. Some providers commented that knowing this distinction and its implications would benefit their provision of case management services or *de facto* case management support to clients.

Providers raised a number of other difficulties in relation to obtaining respite for their clients. First, some providers felt that there are insufficient respite beds available on either a regular or a needs basis. In particular, overnight and emergency respite in both metropolitan and regional areas appears to be scarce. They were unclear whether this reflected increased demand for or reduced supply of respite beds. All providers noted that there is a scarcity of disorder-specific residential facilities for either permanent placement or respite. Most providers are aware of the only two dedicated facilities in the state – the Multiple Sclerosis Society of Western Australia (MSS WA) metropolitan respite facility which caters to people with MS and some others with neurological conditions and similar care needs, and the Brightwater residential facility for young people with HD, Ellison House. This is also located in the metropolitan area. However, the MSS facility has only 6 respite (including one emergency) beds and Ellison House has 12 permanent beds. Both facilities appear to have long waiting lists.

One provider reported that there are also limited opportunities to pre-book periods of residential respite. Another provider recounted experiences where a respite bed at a residential facility became temporarily available when a permanent resident had died. In this case, filling the bed from the waiting list for permanent placement would have taken a few days, thus leaving the bed vacant during that period. This provider felt that the opportunity to use the bed for temporary or emergency respite would not be wasted due to the unmet need for respite.

A second difficulty highlighted by providers is the suitability of respite in nursing homes. This is especially relevant for people with Parkinson's Disease (PD) because of the fluctuation in their needs during the day. For example, an Aged Care Assessment Team (ACAT) assessment undertaken at a time in the day when the person with PD is functioning well may approve low level care for residential respite.

However, as this person's functioning fluctuates considerably during the day, their care needs will go from low care to high care, including needing help with transferring, throughout the day. The respite facility may not, for staffing and other reasons, be able to accommodate the high level of care. Compounding this issue of fluctuating needs is that the effectiveness of PD medications requires that they be given at precise times throughout the day. This timing has been determined to complement their lifestyle, therefore can impact hugely on their quality of life if not adhered to. At home, the individual or their carer can ensure this. However, one provider felt that, in a residential facility, it may be impractical to manage the daily medications for a large number of residents in a timely way.

Some respite in residential facilities, most of which cater to the frail aged or those with dementia, is only available in shared rooms. Providers pointed out that this is difficult for most people with neurodegenerative disorders who may have a lot of equipment, are younger (such as individuals with MND or MS), and who want their partners and children to be with them.

Compounding the difficulties of finding and accessing respite, is the cost of respite and, concomitantly, who can fund it. Whilst one provider commented that there are many subsidised services, for example the National Respite for Carers Program, where fees can be waived, others referred to the costliness of respite. For example, respite in the home is particularly costly with an overnight stay of 12 hours by a care worker costing the provider up to \$280¹². These providers argued that, in their experience, sustained funding at this level from Home and Community Care (HACC) or care packages is not possible and financially distressed families are unlikely to be able to self-fund or co-contribute. In addition, some providers report having difficulty trying to access enough respite for clients in the presence of dollar funding limits for total weekly respite hours or total hours over the funding period.

Another difficulty with respite that providers have highlighted is the high level of care required for people with middle to late stage symptoms of a neurodegenerative disorder. For example, people with Huntington's Disease (HD) can have physical, psychiatric and cognitive difficulties that require complex, individualised care. In many cases, their challenging and unpredictable behaviours preclude people with HD from being cared for, even temporarily, in traditional nursing homes. Similarly for those people with NDD who have swallowing difficulties that require careful attention at meal-times and for those who need re-positioning throughout the day. Both needs are time-consuming for care workers and therefore at odds with the routines of most nursing homes. Even if in-home respite is available to an individual with an NDD, some providers feel that the advantages are eroded if the care worker is new to the client/home and doesn't know anything about the disorder or how to manage the equipment and care procedures, for example percutaneous endoscopic gastrostomy (PEG) feeds.

¹² As at April 2008, one agency charged overnight respite at \$249 (passive) and \$277 (active) for a block of 12 hours. Generally, in-home respite costs about \$40 per hour.

Some providers report that some individuals or carers are reluctant to access respite. The individual with the disorder may not want to go to residential respite because of the fear of being institutionalised or not receiving the appropriate care, or a misapprehension about the stage they are at in their disorder. One provider stated that “*some clients won’t accept strangers caring for them*”. This provider also reported that some carers were reluctant to relinquish their care responsibilities (“*no-one can care as well as I can*”), even at the risk of their own physical or mental health. However, providers agree that if a client has a good first experience with respite, then they are more likely to want to go again. If there is a bad first respite experience, then it becomes almost impossible to get them to go again even to a different facility.

From the carer point of view, a good respite experience for the care recipient will encourage the carer to include regular respite in their lives whereas a bad experience will compound their guilt in relinquishing care (De San Miguel & Smith, 2004: 10).

One difficulty raised by some providers relates to the quality of care workers. That is, these providers believed that community and residential care workers with knowledge of neurodegenerative disorders, as well as the experience and expertise in the care of people with any of these disorders, are rare. In part this reflects the low incidence of these disorders (see NDP Report No 4 – Data Linkage 2006). That is, it is difficult to gain experience if the caseload is primarily people who do not have a NDD. Whilst efforts are made by various providers¹³ to provide professional development (related to symptoms, medications and care needs) to care workers in a variety of settings, most providers acknowledge that high care worker turnover and absenteeism disrupt the continuity of appropriate care for any one individual.

A final observation from one provider is that families often consider only a narrow set of choices for the care of the person with the NDD. These choices are either managing at home with in-home support and, perhaps, temporary spells of residential care, or being admitted, prematurely, to an aged care residential facility. However, with more support in the home, such as social support and in-home respite, providers envisage that families can manage at home for much longer. That is, the presumption of institutionalisation is redundant. If families can be encouraged to access more home care support, then providers feel the demand (and unmet need) for beds, whether respite or permanent, in residential facilities would reduce.

Importantly, accommodation options for people with NDD should be based on their capabilities and needs and not necessarily or solely on their age and type of disorder.

¹³ For example, MNDAWA care advisors provide hard copy information to, as well as give talks to, health professionals, agency carers, nursing home staff, neurosciences students and volunteers (such as those helping at the Murdoch Community Hospice). MNDAWA volunteers also talk to service clubs. Neurosciences Unit and AHDA provide professional development regarding the care of people with HD for care workers at nursing homes and for providers of home care support in Bunbury. PWA members talk to university medical students about the importance of PD medication, and its timing, to their ability to function effectively (catch public transport, converse, undertake single tasks, etc).

3.5 The Need For and Use of Transport

In many respects the transport issues for people with NDD are similar to issues faced by any disabled person. Providers note that, generally, these people (especially those in wheelchairs) will need specialised transport, such as multi-purpose or maxi taxis (MPTs). For people whose mobility is challenged, accessing a suitable vehicle is only one of a number of hurdles they may encounter. A significant stumbling block to the use of MPTs is their availability. Unlike taxis for able-bodied individuals, MPTs are in limited supply¹⁴, making up only 6.5 percent of the taxi fleet in Perth (WA Department for Planning and Infrastructure, 2008b).

The mileage by MPTs as a proportion of total fleet mileage is less than 6.5 percent primarily because disabled people travel shorter distances and do not do much travelling outside of daytime hours. Whilst the MPT driver can access standard taxi fares and group bookings, their first priority must always be wheelchair work (WA Department for Planning and Infrastructure, 2008a). Even in the taxi industry, there is recognition that services to people with disabilities are inadequate because there is a lack of financial incentives to drivers to provide timely and appropriate services (Market Equity, 2005).

It is not just whether or not a taxi can be booked in advance or requested in real time. Providers also report that pick-up and drop-off times can never be certain, so clients cannot rely on taxis. They therefore cut back on activities such as visiting family, attending support groups, etc. Regional providers noted that it is hard for country people to get transport to go to medical appointments. Metropolitan providers found that this is also an issue for people living in the outer metropolitan area. In both cases, the geographical spread of the population appears to make taxi operation unviable. Even in the inner city, short trips in maxi taxis are the least viable of fares. Current moves to exclude taxi services from the requirements of equal opportunity legislation will, if successful, further disadvantage disabled people.

One provider noted that *“people who live alone and who need to access taxi services are particularly vulnerable”*. Another provider agreed that *“complaints are difficult for people with low energy, and they feel vulnerable and therefore are unwilling to complain”*. Some providers highlighted that, without access to transport, people, especially those living alone, are unable to visit family, attend support groups, go shopping, etc. They can then become socially isolated, thereby reducing their quality of life.

These problems of transport supply are compounded by eligibility criteria for and limits to subsidised transport assistance. For example, providers report that HACC transport will only take the eligible person; hence it won't help with transporting children to school or accompanying their parent to medical appointments, etc. They also report that TUSS vouchers have a limited dollar value and a kilometre maximum. Again, people who live in the outer metropolitan area who are trying to attend medical appointments and have to travel longer distances are disadvantaged, having to pay for their own travel.

¹⁴ Whilst most providers were aware of taxi industry reviews, none were aware of recent State government initiatives to increase the number of multi-purpose taxis in metropolitan and regional areas via new and upgraded subsidy schemes.

Providers report a number of repercussions for the health care system arising from problems that people with NDD might have with transport. Some people, particularly in the advanced stage of their disorder, cannot get transport for medical appointments and do not like to see different locums so they tend to use the hospital rather than their GP and neurologist to help them manage their symptoms.

Another issue raised by providers was the threshold for driving competence. That is, providers find that the point at which functioning has deteriorated so much as to preclude the person with NDD from driving their own vehicle is unclear. Medical professionals confirm that, although they are able to recommend that driving ceases, often the person is unwilling to let go this very important symbol of independence. The support agencies cannot enforce driving restrictions and police are often reluctant to take away driving rights.

3.6 The Transition to Residential Care

Providers are unanimous - living and dying at home is preferred to living and dying in residential care. This is an opinion that providers say is shared with their clients. However, providers, and some clients and carers, acknowledge that if the necessary services and other supports are not in place or the carer and the individual are not coping, then this preference should be set aside.

Providers are supportive of people with NDD remaining in the community throughout the course of their disorder for a number of reasons. First, providers confirm what their clients might fear - that institutionalisation may result in exacerbated dependency.

The routines and trappings of home are familiar and providers feel that this familiarity can help someone to remain competent and self-sufficient for longer than if they are removed to unfamiliar surroundings with new people (other residents and care workers). One provider noted however that someone who has been living alone may have improved functionality when they have been admitted to a residential facility as the responsibility of care has shifted to care workers.

Second, if someone is admitted to a residential facility then it is often in another location, away from their community, family, friends and other supports. As with the familiarity of home, the familiarity of location is thought by providers to be important to the well-being of clients. A concomitant reason is that the carer may be less able to visit if the residential facility is out of area. Some providers cite cases of frail aged carers who don't drive and have difficulty in visiting their life partners whose nursing home is a few suburbs away and not directly reachable by public transport. A regional provider noted that this is particularly hard on farming families where the care recipient is placed in a residential facility in the town. Some families then have long distances to travel to visit.

A final reason that providers support clients staying at home is a concern that residential facilities have levels of care that are insufficient for people in the later stage of an NDD and that are in any case inappropriate for this group of, generally younger, people. Providers argue that nursing homes do well in catering to the frail aged and those with dementia but are generally not suited to younger disabled people who may have children and partners that they want to be with regularly and often. This concern has been raised elsewhere. For example, Howe (2008) states that "the simple aged-based target population used for planning residential aged care is out of line with the dependency-based definition of the HACC target population" (pg 18).

In contrast to arguments in favour of remaining in the community, providers raised two issues that would be sufficient reasons for admitting a client with NDD to residential care. First, some people with declining social cognition may no longer be safe in their own home. This is often the defining reason why people with dementia are admitted to secure facilities. Second, some providers also acknowledge that people living alone with a degenerative condition, which can manifest with falling and other mobility and functioning difficulties, may need to have 24 hour surveillance, especially in the later stage of their disorder. They would not have this even if they received the maximum hours of home care support in their own home.

The preceding discussion summarises the providers' overall positions on supporting people with NDD in the home or moving them into residential care at some point in the progression of their disorder. In interviews, these providers were also asked to comment on what they would envisage to be ideal configurations of residential care for their clients. Their responses are as follows:

- Neurological-specific supported accommodation facilities that are similar to Ellison House (for young HD clients; 12 beds) or Fern River (for MS clients; 10 beds).
- A range of accommodation options (self care, low care, high care, hospice) within new and existing residential facilities.
- Age-appropriate residential places, for example, for young, high needs clients in both metropolitan and country locations.
- Family-friendly residential places, to accommodate, for example, mothers with young families.
- Residential facilities that provide community interface, that is, allowing younger people to get out into the community regularly to engage in activities and support groups, with appropriate transport being available.
- Transition accommodation that allows people who are at the end stage of their disorder and who have had a temporary stay in hospital for symptom management to receive care in their convalescence that is better than what they would get at home but is not taking up a high cost hospital bed.

Providers envisage that most of these options should provide sufficient respite beds that are both pre-booked and emergency.

4 OTHER ISSUES RELATED TO THE CARE OF PEOPLE IN THE HOME

A number of other issues were raised by providers. Whilst peripheral to the need for home care support, these concerns appear to be important to the wellbeing of individuals and their families. Importantly, some providers feel that these issues impact, in some way, on their own roles and their abilities to provide the best possible care to their clients.

4.1 Information and Group Support

As mentioned earlier, the Dawson *et al.* (2004: 126) study reported that although people with HD and their carers appreciated being kept informed about the disease, its progression and the available supports, there was a “delicate balance between the amount, timing and type of information”. Too much or too little information could be stressful. Families could benefit by this information being filtered by care workers. Dawson *et al.* did not comment on how widespread or useful such filtering was from the point of view of professionals.

Similarly, whilst the role of disorder-specific and carer support groups in sustaining individuals and their carers, respectively, is generally thought to be useful, the groups are not always and everywhere effective. Providers have found that some groups allow people to problem solve and learn from each other, and that people who attend these types of groups tend to be those who are reasonably self sufficient and who don't give up when faced with challenges.

As with first experiences with respite, first encounters at support groups can determine whether or not people continue to attend. Providers are aware that for early stage people with NDD, attending support groups in which there are others at later stages “*can be too confronting*”. They suggest that there is some streaming into stage and/or age appropriate support groups as well as support groups for carers. For example, AHDA WA has three support groups – for gene positive people, for early symptomatic clients and for carers. MSS WA has carer support groups and a carer peer support program as well as providing two carer camps each year. Client and carer groups are also thought to work well with some people as does having care workers from the disorder-specific support agency facilitating meetings or starting up groups.

4.2 Family Finances

Some individuals have no employment income, having given up work because of their disorder (that is, the impact of their symptoms on their ability to continue in the same or different work) and rely on a disability pension. Their partner might also have given up work to take on the caring role. Whilst the carer might receive a carer's payment, the combined family income is unlikely to be anywhere near the income before the change in circumstances. Most providers are aware of these decisions and their impacts on clients and their families. The financial stress of this change is worsened if the couple is of pre-retirement age, paying off a mortgage or paying ever-increasing rents, and having dependent children. Providers comment that co-contributions for HACC and other funded support (not DSC) as well as unfunded respite also impact on family budgets.

The providers interviewed for this project reported that the major costs for people with NDD relate to their medications, their care in the home (personal care, cleaning, social support and in-home respite), transport, equipment and incontinence aids. For people with MND, considerable costs are incurred also for equipment and home modifications. The financial impost of HD is highlighted in this quote from a health professional interviewed in the Dawson, *et al.* (2004) study:

“There was a general sense of struggle with the costs of medications, equipment, transport and home modifications. The behavioural component of Huntington's disease and what it does to the family system and relationships is probably more critical, but those that have managed to maintain that sort of closeness and want to care for each other are often limited by the fact that they financially can't afford it” (pg 128).

In some cases, some providers report that couples, who would otherwise end their relationships, stay together for financial reasons.

Another considerable cost is childcare which is often necessary, for example, if the mother with MS cannot care full-time for her dependent children and their father is working full-time, or if the mother is single and without family assistance. However, none of the funding supports include the cost of childcare.

People with cognitive problems can have problems managing their finances, but may not be considered incompetent. However, they may be vulnerable and open to exploitation. Providers comment that there is no legal process to help with this. These people fall outside the purview of the Guardianship and Administration Act 1990 which

“... enables a substitute decision-maker to be legally appointed to make decisions in the best interests of a person who is not capable of making reasoned decisions for themselves due to conditions such as dementia, intellectual disability, mental illness and acquired brain injury. This is referred to as a decision-making disability” (WA Attorney-General, 2006).

A disorder-specific support agency cannot step in to provide this type of assistance, however, it can provide financial advice or support. Some care workers stated that their agency had limited per annum funds that can be used to support a particular need. As mentioned in Section 3.1, some agencies help people with funding applications, Centrelink processes, etc.

4.3 Counselling

Individuals and their families experience grief and loss from the time of diagnosis. Providers report that there is chronic sorrow throughout the course of the disorder (from diagnosis to death) for the clients and their families. There are good days and bad days (see NDP Report No 3 – Case Studies). There is a loss of roles, as well as of function which, in many cases of NDD, includes the ability to communicate verbally. Care advisors and nursing staff provide emotional support (allowing carers to offload their concerns) but do not provide professional counselling. Some disorder-specific support agencies, for example MSS WA, have counselling services that are free to financial members and their carers.

Whilst in-home professional counselling would help, providers have discovered that it isn't available unless the care recipient is immobile or is receiving care from a palliative care service. In the latter case (in the metropolitan area), bereavement counselling on a fee-for-service basis is offered, although this fee is waived for clients and families at high risk and with few financial resources.

Providers suggest that out-of-home counselling is also expensive although limited Medicare subsidies are now available. Regional providers commented that attending a local clinical psychologist is not popular as the closeness of communities precludes the sort of professional distance that clients generally want. Moreover the local practitioner may not be able to assist with disorder-related behavioural problems such as arise with individuals with HD.

Most providers acknowledged that care workers can be an outlet for client and carer frustration at the difficulties with the health care and community care systems such as conflicting advice from medical staff, and inadequate and inflexible home care support. Difficulties with transport, equipment and accommodation are also discussed by clients and carers with their care workers. Most providers feel that listening to their clients is the best they can do. However, if there are specific changes that they can pursue on their client's behalf, or referrals they can make, then they will provide this support.

4.4 Housing and Equipment

If people remain in their own home as their disorder progresses, or even if they move to a different (for example, smaller house) home, they will usually have to make some changes if they want to live safely and comfortably (Karol & Giles, 2008). However, some providers have found that a number of their clients refuse to modify in denial of their deteriorating functioning and increasing needs. Others have commented to some providers that modifying their homes would ruin the aesthetics thereby reducing the home's resale value. Some providers have found that some homes with narrow doorways and inaccessible bathrooms cannot be modified. This results in, for example, individuals being showered by care workers in the laundry.

Many homes are badly designed (see NDP Report No 1 – Client and Carer Survey). That is, building standards that reflect accessible design, which are still not mandatory in Australia, have been ignored. Whilst this is not an issue for able-bodied residents, it can be a serious issue for people who are frail, disabled or infirm, including people with NDD.

Home modifications to improve accessibility will depend on funding¹⁵, practical assistance, and family. For example, some people may rely on members of their family to undertake necessary housing renovations (for example, removing the shower hob) because the cost of contracting is too high. Some providers report that, even if the family members are skilled tradesmen, the work may not always be satisfactory. If homes are rented, then people may not have the option to modify.

Housing adaptations that cannot be paid for or require people to be on long waiting lists to have work done, can result in safety and quality of life repercussions. This can also happen if modifications are not done properly, for example by unskilled family members. Some regional providers reported that, in a few areas, there is the problem of getting trades people to undertake home modifications. Moreover, these providers found that priority was often given to people with short term (post acute¹⁶) rather than long term (chronic, eg neurodegenerative disorders) needs.

In a number of cases, providers have found that a particular housing feature represents an occupational safety issue and have requested that the client make the necessary modifications. If these are not made, then the provider may withdraw the service or find a way of delivering the service that doesn't compromise care worker safety. For example, one provider allows care workers to give clients a bed bath if their bathrooms cannot take a hoist and shower chair. Other providers report similar arrangements.

¹⁵ Such as Disability Services Commission Community Aids and Equipment Program (CAEP) funds.

¹⁶ For example, ramps may be installed following a hospital stay as a result of a fall in the home.

People with NDD can apply for specialist housing (Homeswest Disability Housing) but some providers have found that the waiting list for such housing is as long as five years. This is not helpful for people with rapidly degenerating disorders. Similarly, providers have found that waiting lists for equipment result in some people receiving a style of equipment they can no longer use. For example, someone whose mobility has deteriorated such that they need a wheelchair may find that by the time a manual wheelchair is provided, they have lost upper body strength and functioning and actually need an electric wheelchair. Some support agencies, for example MNDAWA and MSS WA, have equipment loan programs and can better match equipment to needs.

5 CONCLUSIONS

The interviews with providers provided diverse and comprehensive information regarding the needs of people with NDD who wish to stay at home. Nonetheless, some common themes emerged and whilst there was some lack of knowledge and understanding of issues of funding and subsidies, eligibility, and types and availability of services, there was an overwhelming concern that this group of people, whose health is despairingly compromised, need improved home care support at all levels. As stated by one provider:

“people with neurodegenerative disorders need their own package of care that is funded appropriately with eligibility criteria that suits their circumstances (where they live, whether they have a carer who lives with them, what type of housing they live in, etc) but is not means-tested, and is flexible in the quantity and type of services provided at any one time and over time and is individualised”.

Moreover, providers argue that total home care support has to be both quantitatively increased and qualitatively enhanced and these improvements need to happen with haste. Without these improvements, people with NDD and their families have a quality of life that becomes progressively appalling. Importantly, the need for this support is likely to increase in the future as a result of overall population increases as well increased longevity due to improved treatments for NDD and changes to the age profile of the population.

In summary, providers recommend that people with NDD receive individualised and case managed home care support that is sufficiently flexible and timely as well as documented and kept current for all services providers to access, comprehend and use. They suggest that this support includes physical and social support, and sufficient and different types of respite. Importantly, providers are unanimous in their support for people to stay at home rather than be institutionalised or hospitalised. Providers are clear that dying in a public hospital or in an inappropriate aged care residential facility should be avoided. Results of interviews with clients and carers showed agreement with this (see NDP Report No 2 – Client and Carer Interviews).

However, most providers agree that *“the key to successful home management of the needs of patients ... is having a competent and physically and mentally fit carer as well as living within a geographical area that has sufficient access to services including good palliative care support. In this case, their desire to remain at home throughout the course of their disorder can be achieved. There will be no need for them to go into a nursing home”.* In the absence of a committed carer or access to sufficient assistance, an individual requiring high level or palliative care will ultimately require admission to a residential facility or hospice.

In summary, providers support a holistic model of care with multidisciplinary care teams that can enable a better life, and end-of-life, experience for people with NDD.

Providers welcome the decision by Disability Services Commission to increase funding (\$4m for services over 4 years commencing in 2008, and additional equipment funding from 2007) of a four-year pilot program to provide flexible levels of support to enable people with rapidly degenerating conditions to continue to live at home. MSS WA will manage this funding.

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ATTACHMENT A: PROVIDER INTERVIEW INFORMATION SHEET

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

A Lotterywest funded research project involving the Cross Agency Provider Group, support agencies, Edith Cowan University and the Neurosciences Unit of the WA Department of Health

INFORMATION SHEET FOR INTERVIEW PARTICIPANTS

You are being asked to participate in a research study. Please take your time to read this information statement and the attached consent form, which you will be asked to sign at the interview. The interviewer is Dr Margaret Giles who is the co-ordinator of the project.

What is this study about?

Many people living with neurodegenerative diseases need support to remain living in the community. This study will examine the provision of home care services to these individuals. This will help health care planners, policy makers and providers, such as Silver Chain, better understand the needs of individuals and families living with these disorders, and how they may be assisted to live well at home.

Who is invited to participate in an interview?

In 2007, the project team conducted interviews with people with neurodegenerative disorders and their carers. The interview questionnaire included asking who were the health and allied health professionals and service providers from whom they were receiving any care. When this information was collated, it was apparent that most have had regular contact, sometimes over a long period of time, with a variety of professionals:

- Neurosciences Unit social workers for people with HD,
- Parkinson's WA nurses for people with PD,
- Professionals in the Multiple Sclerosis Society care team for people with MS,
- Care advisors at the Motor Neurone Disease Association WA for people with MND,
- Regional nurses and metropolitan co-ordinators of the Neurological Council,
- Palliative care team at Silver Chain,
- Neurologists, and
- General practitioners.

Representatives of each of these professionals or groups of professionals have been chosen for interview.

What will the interview involve?

The interview will take place at a time, day and location suitable to you. It is expected to last about an hour. The questions will be about your experience of providing services to people with neurodegenerative disorders and their carers and families.

How will your privacy be protected?

You will be asked whether the interview can be recorded to allow the interviewer to consult the tape later and ensure that the essence of everything you have said is included in the interview summary. You will not be identified by name on the recording or on the interview summary. Anonymity and confidentiality will be maintained at all times. In accordance with national research guidelines, all study records will be stored for five years by the Silver Chain Research Department in a secure location and then destroyed.

Voluntary Participation

It is important for you to know that you do not have to take part in this project. If, after agreeing to participate, you later change your mind, you may withdraw your consent at any time simply by phoning Dawn Woods, the Research Support Officer at Silver Chain, on 9201 6758. We would then destroy any project records containing your information.

Risks and Discomfort

As a result of hearing or responding to questions in the interview, you may experience some stirring of emotions and feelings that you may wish to discuss further. The interviewer can refer you to a counsellor at no cost to you. Anything you discuss with the counsellor will remain confidential and will not be included in this study.

What if you have any concerns or a complaint about how the study is conducted?

Approval for this study and its procedures have been given by the Silver Chain Human Research Ethics Committee and the ethics and research committees of collaborating agencies and providers. Any concerns or complaints about the conduct of the study should be directed to the Chairperson of the Ethics Committee at Silver Chain on 9242 0242.

Who to contact if you have any questions about the study?

If you have any questions about this study, the interviewer, Dr Margaret Giles, can be contacted before or after the interview on 9242 0185. Alternatively you might want to ask questions during the interview.

Thank you for taking the time to read this statement.

Cross agency provider group, support agencies and collaborative partners:

Alzheimer's Assoc of WA
Australian Huntington's Disease Association WA
Brightwater Care Group
Disability Services Commission
Edith Cowan University
Mercy Aged Care
Motor Neurone Disease Association of WA
Multiple Sclerosis Society of WA
Neurological Council of WA
Parkinson's Western Australia Inc
Perth Home Care Services
Silver Chain
WA Department of Health (Neurosciences Unit)

ATTACHMENT B: PROVIDER INTERVIEW QUESTIONNAIRE

Name(s) of Interview Participants:

Provider: _____

Interview held at: _____

Phone Number: _____

Before we start the interview, have you read the information sheet?

Are you ready to sign the consent form?

About the Project

The Neuro Project is Lotterywest funded. It commenced in mid 2006 and is due for completion by July 2008. Dr Gill Lewin is the Project Manager and Dr Margaret Giles commenced as Project Co-ordinator in October 2006. The project is overseen by a Steering Group with representatives of the support groups and service providers involved in the project. Edith Cowan University is also represented. The project is also supported by a State Advisory Panel.

The main aim of the project is to determine the gaps in home support for people with Multiple Sclerosis, Motor Neurone Disease, Parkinson's Disease and Huntington's Disease. In addition to service provider interviews (to be held in early 2008), the project includes a survey of people with these disorders and their carers (completed in March/May 2007), interviews with a sample of survey respondents (undertaken in July/September 2007), analysis and of support agency and service provider datasets (completed in 2007), linkage of datasets (completed in 2007) and projections of the future home support needs for these groups of people (to be undertaken in March/May2008).

About this Interview

The survey and interview responses from care recipients and carers have highlighted gaps in home care support from their points of view. The provider interviews, including this one, will provide information on gaps in home support from a delivery perspective.

In this interview, we are interested in learning more about the needs of clients with neurodegenerative disorders and their families and the extent to which current home care support responds to these needs during the progression of the disorder. Your experiences as health and allied health professionals and service providers are important in helping to understand this better from the perspective of ongoing supportive care and palliative care.

- 1 To begin, could you please tell me about your own work with clients who have neurodegenerative disorders? (Probes - how long, in what context, in what location, type of service delivered, number of patients with whom you have contact – at any one time? in a year?)
- 2 Can you tell me about the types of supports you believe are needed to help these clients/carers manage the disorder? How do you see these needs changing over time? (Probes: what supports, who can provide the support, who can suggest/offer the support).
- 3 It is also important to understand needs patients might have to help them cope with the changes and challenges of this type of illness. Could you please talk a little about the needs patients have in this area? (Probes: emotional needs, counselling needs, moral support, encouragement, help with loss, grief, worries and concerns, etc?).
- 4 How well do you believe families are supported? Are there resources that should be offered to family members to help them cope with their relative's illness? (Probes: family worries, children's needs, care needs, support for family, practical family help?)
- 5 Do you see that it is helpful for patients and families to meet with individuals who have similar illnesses and their families? (Probe: might support groups for individuals and their carers be helpful?)
- 6 What do you see are the practical issues that these patients and their families face that you think could be better addressed or managed? (eg, accommodation including home modifications or moves, respite, ongoing support, transportation, provision of aids and equipment, financial issues).
- 7 How well do you believe that these patients and their families are supported to remain in their own home by the health care system? (Probe: emotionally, physically, practically? Where are there gaps, overlaps, special needs, eg rural?)
- 8 How well do you believe that these patients and their families are supported to remain in their own home by the community care system? (Probe: availability, timeliness, responsiveness, barriers to access, policies, program guidelines, access to services?)
- 9 If you were to recommend the best possible supportive care for these patients and their families, what would you suggest? (Probe: home, supported accommodation, residential facility or hospital?)
- 10 Are there other things we haven't covered that you would like to mention?

Many thanks for taking the time to help with this project and offer your experiences. It is expected that changes to the provision of home care services to people with neurodegenerative disorders will be reviewed within 12 to 15 months from the end of this project mid-2008. These changes are most likely to affect the amount and timing of services.

ATTACHMENT C: PROVIDER INTERVIEW CONSENT FORM

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

**PROVIDER INTERVIEW
CONSENT FORM**

- I have read the information statement about this study and any questions I have asked have been answered to my satisfaction.
- I agree to participate in this interview, realising that I may withdraw at any time.
- I agree for the interview to be audio taped.
- I agree that the research data collected for this study may be published, provided that I am not identifiable.

PARTICIPANTS:

Signed _____ Name _____

Signed _____ Name _____

Signed _____ Name _____

Signed _____ Name _____

Date _____

RESEARCHER:

Signed _____ Name _____

Date _____

ATTACHMENT D: WA COUNTRY REGIONS

(Silver Chain country regions are similar to WA Department of Health, WA Country Health Service regions)

