

**Neurodegenerative Disorders Project - Report Number 4**

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

**DATA LINKAGE 2006**

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Neurological Council of WA  
Parkinson's Western Australia Inc  
Perth Home Care Services  
Silver Chain  
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## GLOSSARY

Acronym	Definition
ACAT	Aged Care Assessment Team
AHDA	Australian Huntington's Disease Association
ANRI	Australian Neuromuscular Research Institute
CACP	Community Aged Care Package
CAEP	Community Aids and Equipment
CAP	Combined Application Process
CPAP	Continuous positive airways pressure
DSC	Disability Services Commission
EACH	Extended Aged Care at Home
EMG	Electromyography
FTE	Full time equivalent
GP	General practitioner
HACC	Home and community care
HACC MDS	Home and community care minimum dataset
HD	Huntington's disease
ILC	Independent Living Centre
MDS	Minimum dataset
MND	Motor neurone disease
MNDA NSW	Motor Neurone Disease Association NSW
MNDWA	Motor Neurone Disease Association WA
MOU	Memorandum of understanding
MS	Multiple sclerosis
MSA	Multiple system atrophy
MSS WA	Multiple Sclerosis Society of WA
NDD	Neurodegenerative disorders
NDP	Neurodegenerative Disorders Project
NRCP	National Respite for Carers Program
NSU	Neurosciences Unit
OSH	Occupational health and safety
PD	Parkinson's disease
PWA	Parkinson's WA
RBD	Rapid eye movement sleep behaviour disorder
REM	Rapid eye movement
RSD	Respiratory sleep disorders
VPAP	Variable positive airways pressure
WASDRI	West Australian Sleep Disorders Research Institute
WACHS	WA Country Health Service

## PROJECT REPORTS

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

Report 1: Client and Carer Survey Results

Report 2: Client and Carer Interviews

Report 3: Case Studies

Report 4: Data Linkage 2006

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

Report 6: Projections of Unmet Needs

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## 1 INTRODUCTION

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

This report summarises the results of the linkage and data summary components of the project. The summary statistics are provided by organisation or by both organisation and disorder. This allows for some comparison of the characteristics of people receiving services from different providers and agencies.

Studies which used postal surveys to collect information on the characteristics and home support needs of people with NDD have been discussed in Neurodegenerative Disorders (NDP) Report No 1 – Client and carer survey results. Some comparative references are made in Sections 4 and 5 of this report to those studies.

In the following section, the organisations providing data for this component of the project are described. There is also some discussion about other providers within the home and community care sector. The data provided to the project and the methodology used to standardise and link the data are summarised in Section 3. Socio-demographic characteristics by organisation in 2006 are presented in Section 4 and service provision by disorder is discussed in Section 5. The difficulties of data linkage with respect to the organisations participating in this project and suggestions for improvements in organisation data collections are summarised in the Conclusions in Section 6.

## 2 PARTICIPATING ORGANISATIONS AND OTHER SERVICES

In this section, organisations and other services that participated in this project are described in terms of their provision of support for people with neurodegenerative disorders. Ten of these groups provided data and these are summarised in Sections 2.1 to 2.10. In Section 2.11, other groups that participated in the project are also mentioned to round out the discussion of support and services for people with neurodegenerative disorders in Western Australia.

Organisations that offer services to people with MS, MND, PD and HD include the four disorder-specific support agencies – Multiple Sclerosis Society of WA (MSS WA), Motor Neurone Disease Association of WA (MNDAWA), Parkinson's WA (PWA) and Australian Huntington's Disease Association of WA (AHDA), respectively – who provide services such as information, advocacy and counselling together with de facto case management and other specific assistance.

MSS WA is also a provider of home care support services, such as personal care, domestic assistance, social support and in-home respite, in metropolitan and regional areas. Other organisations that provide home care support services in the metropolitan area include Brightwater, Mercy Aged Care (MAC), Perth Home Care Services (PHCS) and Silver Chain. Silver Chain also provides home care support services in regional areas and palliative care services in the metropolitan area.

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

The Neurological Council provides services to people in the country and brokers services to people in the metropolitan area. The Neurosciences Unit of the WA Department of Health provides gene testing for people with a family history of HD and, for people who are symptomatic with HD or are gene-positive, provides information, advocacy and counselling together with de facto case management throughout Western Australia.

Clinical support for people with neurodegenerative disorders is provided, in the main, by neurologists, other medical specialists (for example, respiratory specialists and geriatricians) and general practitioners. A subset of these practitioners was interviewed during another component of this project (see NDP Report No 5 – Key issues and unmet needs – Health, allied health and service provider perspectives) and it appeared to be appropriate to mention these services in Section 2.11. Note that other health professionals and allied health professionals who are not associated with any of the aforementioned organisations may also be providing support to people with neurodegenerative disorders. Some of this support may be hospital-based. However, no interviews were conducted with these professionals or with hospital or hospital-based staff.

## **2.1 Motor Neurone Disease Association WA (MNDAWA)**

MNDAWA is a support agency for people with MND and their families. There are three care advisors at MNDAWA (representing full-time equivalent hours (FTE) of 1.3) who provide a variety of services and case-management type of assistance for people with MND and their families who may or may not be members of MNDAWA. The service is offered from diagnosis until death (or after death for families), starting with a home visit to assess needs and provide information. Towards the end of life, this role is passed to Silver Chain's Hospice Care Service (see Section 2.5.1) which, using a palliative care team, can provide 24 hour care, symptom management and support.

MNDAWA has about three or four inquiries each month from newly diagnosed people with MND and between 110 and 130 people on their client list at any one time. Generally, the people with MND and/or their families make contact with MNDAWA within a week of being diagnosed, having been provided with agency contact details by their neurologist. Initially, a care advisor will meet with the member (and their family). Sometimes, people with MND want no contact beyond this initial conversation. Sometimes there is denial of the diagnosis or attempts to manage the disorder without advice and support. In the main, contact tends to increase if dependency increases and cuts back if and when a person's condition stabilises.

In general, people with MND and their families seek information about the disorder and its treatment and about the help that might be available from various sources. They are usually able to articulate their needs well.

MNDAWA provides a range of services, as follows:

- Equipment library. Despite a one-off increase in Disability Services Commission (DSC) funding to MNDAWA in mid 2007, there are still waiting lists for equipment and assistive devices, particularly wheelchairs and beds. The longest wait is for electric wheelchairs. Whilst MNDAWA may supply equipment, the care advisors refer the members to their own occupational therapists (privately arranged or from public hospitals) for instruction on how to use the equipment, except for very straightforward items.

- Support volunteer service. Under the guidance of care advisors and a volunteer co-ordinator, this service trains volunteers then matches them to members and their families. Volunteers provide emotional and social support to individuals and families. MNDAWA care advisors report that this service works well.
- Carer support program. This includes monthly meetings, 48 hour carer retreats (twice a year), get togethers every second month, training sessions (for example on the correct procedure for manual handling) and couples' breaks.
- Advocacy. Care advisors are able to advocate, on a member's behalf, with home care support, health and allied health providers and funding bodies with regard to the quantity and timing of services, the availability of equipment, etc. They can and do assist families in applying for financial support such as advising who to apply to and how to apply. Not all people are eligible for Community Aids and Equipment Program (CAEP) or are successful with Combined Application Process (CAP) funding.
- Education. Care advisors provide hard copy information and give talks to health professionals, agency care workers, nursing home staff, neurosciences students and volunteers (eg at Murdoch Community Hospice). MNDAWA volunteers might also be invited to talk to service clubs.
- Information. Providing information in response to requests is a key role of the care advisors. In addition, they provide appropriate advice, monitor people's symptoms and level of home care support (asking the right questions, interpreting the answers in the context of experience with like cases, being aware of the next stage of the disorder before the client is aware), and refer people to other services (such as therapy, home care or the Independent Living Centre) as appropriate.

MNDAWA receives about \$100,000 pa in funding from the WA Department of Health and supplements this with about \$150,000 pa in donations and fundraising, membership fees, equipment hire, and other grants (such as Lotterywest, Carers Association of WA and the Red Cross). In 2007/2008, one-off additional funding for equipment was provided by the WA Disability Services Commission under a roll-out of funds for people with rapidly degenerating conditions.

## **2.2 Multiple Sclerosis Society WA (MSS WA)**

MSS WA is a support agency for people with MS and their families as well as being a provider of home care services. Currently MSS WA provides services to over 1,400 people with MS, and to their families and carers. Services apply from diagnosis to end of life and, because of the individual nature of the disorder, the type of services provided can be quite complicated. For many people with MS, their physical difficulties are compounded by their cognitive problems and their social circumstances (for example, they may be in abusive or violent relationships).

About eight to 15 new referrals, mostly from people who are newly diagnosed, are received each month. Types of services provided to people with MS include physiotherapy and massage, occupational therapy, social work, advocacy, counselling, home nursing, community access co-ordination, information, advocacy, hospital liaison and transport. Some people with MS have been diagnosed up to ten years prior to their contact with MSS WA which is precipitated by their need for help with drug therapy. MSS WA also provides personal care, social support and meal preparation to people with MS who are living at home and eligible for DSC funding. Care workers might first try and find other services for people that might be suitable.

MSS WA conducts seminars for people who are newly diagnosed, and their families. There is also a peer support service in which trained volunteers, who are paired with people who are newly diagnosed, provide support over the phone. Outreach groups exist in Beechboro, Rockingham, Albany and Bunbury and the MSS WA care team regularly visits members in regional areas. MSS WA has a respite care house with 5 beds (plus one emergency or partner bed) and a permanent care facility comprising 6 units and housing 10 residents. Both facilities are located in the metropolitan area.

The MSS WA multi-disciplinary care team, located in Perth, provides care and support to people with MS throughout WA. The team includes:

- Registered and enrolled nurses who provide education and support for those clients/members on immunotherapy/injections and other MS-related problems such as incontinence. These nurses, taking a holistic approach, do the initial in-home assessments.
- Occupational therapists who assess in-home needs related to equipment, transport and housing and assisting in applications for funding, such as vehicle modifications via the Independent Living Centre (ILC), air-conditioning through Lotterywest and home security by application to various charities. They also undertake an Occupational Safety and Health (OSH) assessment in the home in anticipation of care workers and others working in the home.
- Social workers who follow-up on care and advocacy issues.
- Care co-ordinators who locate funding and other resources for individuals and co-ordinate in-home care support, etc.

The MSS WA care team often meets with other providers, including health professionals at hospitals, to case manage particular clients. Note that people with MS may present at hospitals with symptoms related to poor nutrition or urinary tract infections, both of which may signal that their carer may not be coping or that care in the home is compromised by violence or abuse.

Self referrals of people with MS are generally dealt with, in the first instance, by nurses who can visit the home and provide information and counselling and also refer clients to other members of the care team. Follow-up contact is usually made with the social worker unless the social worker is the first point of contact. People are usually visited at home at least once by a member of the care team. The care team provides support for both the person with MS and their families. The care team assesses the family regarding the type and amount of support there will be for the individual as their disorder progresses.

MSS WA provides services and support mainly to people with MS but also to people with other neurological conditions. MSS WA is managing the distribution of DSC funds, announced in mid 2007 and commencing in 2008, to younger people with neurodegenerative disorders whose needs for home care support fall outside criteria of other funding models.

The services from MSS WA are available from diagnosis to end of life and are necessarily flexible to accommodate the complexity and uniqueness of each individual's experience. MSS WA is now having to wait-list people for services (personal care, physiotherapy, respite, etc) due to funding not keeping up with demand. This has not previously been necessary.

In addition to the support and services provided to people with MS and their families, MSS WA funds research into the cause and a cure for Multiple Sclerosis and plays a part in the education of health professionals and the community about MS and its effects (The Multiple Sclerosis Society of Western Australia (Inc), 2007).

### **2.3 Neurological Council**

The Neurological Council of WA was formed in 1992 to support the neurological sector and its member organisations. The organisation has developed to have a number of different roles, including as the peak advocacy body for the neurological sector, as a service provider to provide support for people suffering from neurological conditions and their families and carers, and as a provider of community neurological nurse specialists in regional areas.

The Neurological Council has two metropolitan care co-ordinators who service south and north of the river, respectively. There are also four regional nurses who are allocated to the three Home and Community Care (HACC) regions – South West (two nurses), Midwest (one nurse), and Great Southern (one nurse). (See Attachment D for a map of Western Australia showing these regions.)

In the metropolitan area, clients have regular visits. The Neurological Council brokers services, such as personal care and in-home respite, for these clients. The care co-ordinators develop care plans that include 6 weeks follow-up phone calls and 12 week follow-up visits.

In the country, clients are visited by regional nurses on an as needs basis. The regional nurses educate their clients about their choices but do not undertake any clinical nursing. They may instead suggest that a client visits a doctor. The regional nurses are *de facto* case managers, organising in-home services, respite, social support, equipment, etc, and *de facto* social workers, for example, encouraging clients to consider writing a will or appointing a guardian. Most of their country clients live at home.

### **2.4 Neurosciences Unit**

The Neurosciences Unit (NSU) of the WA Department of Health runs two programs which provide support to people with HD and their families. First, NSU provides predictive testing, based on international protocols, to determine if a client (or foetus, in the case of prenatal tests) has the HD gene<sup>2</sup>. Clients can only be tested if they are at least 18 years of age. Some people participate in the testing but withdraw before receiving their results. One FTE social worker is allocated to this program which also has access to psychiatry and neurology services.

The second program provided by NSU is clinical management for people with HD or who are gene-positive. This program is offered by social workers (3.5 FTE), a speech pathologist (1 FTE), a neurologist (sessional) and a psychiatrist (sessional). NSU also has access to a neuropsychiatrist as required. Case management is commonly a significant component of the services provided by this team at NSU, a service made necessary by the degenerative nature of HD. This involves assessment, co-ordination and referral/advocacy for services and resources for clients and carers across a range of government and non government sectors through the progression of the disease from early diagnosis to advanced stage care either in the home or in a residential care facility.

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<sup>2</sup> The HD gene was discovered in 1993.

Generally, NSU promotes independence in the home for as long as possible, if appropriate and sufficient home care support services are available.

NSU case management involves referral for a number of services and programs. These include HACC services, ACAT assessment for respite, care packages and permanent care, DSC CAP applications (for programs such as Accommodation Support, Intensive Family Support and Alternatives to Employment), Neurological Council and AHDA support, hospitals (for occupational therapy or physiotherapy assessments and equipment), the Independent Living Centre for equipment and adaptive devices, Homeswest (the State's public housing authority) regarding public housing and Centrelink (the national agency providing support to those in need) for income support. NSU can also request Silver Chain's Hospice Care Service for people with end stage HD or whose symptom management is compromised. As the disorder progresses, NSU support has to be constantly reviewed and revised resulting in increases or supplementation as necessary.

NSU provides services to individuals with HD wherever they are living. Of NSU's 125 current clients, about 40 per cent are in residential accommodation and 60 per cent are living in the community. The amount of contact between the NSU care team and clients will often depend on the level of support the individual has available. Thus if the individual with HD lives alone, particularly if they lack insight or have a carer who isn't coping they will have more contact, whereas someone with a competent carer will tend to have less contact.

Reviews are offered as part of NSU's case management service, often at the time of medical reviews at the NSU or following home visits. Follow-up support can also be initiated by the client or carer at any time when care needs change or if a crisis situation arises. The functioning of clients with HD deteriorates in a step-wise fashion and timely reassessment is important. Because of the hereditary nature of HD, social workers become familiar with whole families over a long period of time.

NSU also undertakes research including collaboration in international research programs, for example, the PREDICT study has found that the HD gene is switched on from birth so that symptoms (such as eye gaze (see Cooper, 2006)) may be present from a much earlier age.

NSU can provide symptomatic management which can reduce the chorea associated with HD as well as help with issues such as night-time sleep disturbance, anger management and depression. Counselling by NSU care workers includes family planning but is not prescriptive.

NSU provides support to both country and metropolitan individuals and families that are affected by HD. NSU collaborates closely with AHDA whose support services are described in Section 2.6. For example, every four months, AHDA and NSU operate a clinic at Bunbury (3 days, 2 evenings) which is attended by up to 16 HD families resident in the South West region. NSU and AHDA also provide professional development for care workers at nursing homes and for providers of home care support.

AHDA holds a quarterly forum in Bunbury for HD families with a guest speaker which has encouraged social support with a number of support groups being set up – carers, gene-positive, and early symptomatic. NSU participates in these support groups. These groups reduce the need for more formal individual and/or family counselling from NSU. The AHDA gene-positive group includes people with HD and their partners only; it doesn't include the whole family.

## **2.5 Silver Chain**

Two interviews were conducted with representatives of two sections of Silver Chain's Community Care services. The first of these was with the General Manager, Health and a clinical nurse consultant from Silver Chain's Hospice Care Service. The second interview was with the Managers of regional services for the three regions – Midwest/Wheatbelt, South West and Great Southern/Goldfields. Note that Silver Chain also provides community care services in both the metropolitan and country areas including personal care, domestic assistance, social support, nursing, allied health and in-home respite.

### **2.5.1 Hospice Care Service**

Silver Chain's Hospice Care Service offer specialised palliative care to clients and their families in their own homes in the metropolitan area. Palliative care is specialised health care for dying people to maximise quality of life as well as support carers and families before and after death. The majority of clients of the palliative care team have cancer but the team also, from time to time, provides services to people with neurodegenerative disorders, mainly MND. There have been rare instances of clients with HD and no clients with MS. If the team sees clients with PD, the primary diagnosis tends not to be PD. At any one time, the team provides services to 20 to 30 people with MND who have palliative care needs.

The palliative care team is interdisciplinary and comprises a nurse (who is the case co-ordinator), doctor, care aide, social worker, counsellor, chaplain and volunteer(s). The team supports both the client and their family. During normal working hours (Monday to Friday, 9 am to 5 pm), the client and their family will be seen by specific care workers assigned to them from within the team. After hours and weekend support is provided by other care workers in the team to ensure 24 hour availability. Relief care workers may be used if assigned care workers are sick or on leave.

The palliative care team provides a brochure of disorder specific information for the client and their family and puts together a plan of care that details specific actions should deterioration in symptoms arise. The role of the team is primarily symptom management that allows clients to die at the place of their choice.

Referrals to the palliative care team can occur, and be processed, in a number of ways. First, clients and/or their carers may be referred to the service by their neurologist or general practitioner. Alternatively, a support agency such as MND AWA may make the referral. Some clients have many and complex needs, for example, they may be experiencing difficulties with bowels and secretions and problems with pain management, as well as emotional and psychological issues. These people can be helped by the team. Sometimes the issues are beyond the scope of the team. For example, some individuals have housing design issues that restrict their movements inside the home. Some carers may not be coping, physically or otherwise. For example, their changed circumstances may mean that they have financial problems.

Some clients who are referred to Hospice Care Service are not struggling with symptom management. In these cases, the team will speak with the neurologist about the client's life expectancy, etc, and perhaps trial one month of support. If the client's condition remains stable or the care issues are beyond the purview of the palliative care team, the client will be referred back to the support agency or health professional.

Another means of referral is when clients receive services for non-invasive respiration at the Respiratory Sleep Disorders Clinic at QEII Medical Centre. In such cases, there is automatic referral to the Silver Chain Hospice Care Service which then offers a 'meet and greet' appointment to inform (potential) clients about palliative care support. Individuals and their carers can then choose to pursue this – be assessed and receive services – or not.

### **2.5.2 Country Services**

As mentioned earlier, Silver Chain offers home care support in both metropolitan and country areas. Services to country clients are organised within the three regions of Midwest/Wheatbelt (Geraldton, Avon and Carnarvon Service Centres), Great Southern/Goldfields (Albany, Narrogin and Kalgoorlie/Boulder Service Centres) and South West (Bunbury, Busselton, Harvey, Collie, Bridgetown, Manjimup and Margaret River Service Centres). These regions are roughly equivalent to HACC or WA Country Health Service (WACHS) regions with the same names. See Attachment D for a map of Western Australia showing these regions. Community services are also organised from a few of the remote sites such as Lancelin in the Wheatbelt, Leeman in the Midwest and Walpole in the South West.

Silver Chain services in the country are similar to those in the metropolitan area – a few of which are: domestic assistance, personal care and social support – and provided under similar funding arrangements – Home and Community Care (HACC) or Community Aged Care Package (CACP)/Extended Aged Care at Home (EACH) packages depending on eligibility. Some younger people with NDD are ineligible for either an EACH or a CACP package. Silver Chain country services deliver what they can and also refer individuals to other providers such as DSC. In partnerships with other providers, Silver Chain may be the lead organisation for particular clients. For clients with MS, MSS WA, which has access to other funds, generally takes the lead in provision of home care support and contracts Silver Chain to 'top up' services. Silver Chain might also broker services to ensure support for country clients at home.

## **2.6 Australian Huntington's Disease Association**

Due to the overlap of services with NSU, some discussion of the role of AHDA in the support of people with HD and their families and carers has been included in Section 2.4.

AHDA provides advocacy, support, information, education and referrals to members of the Huntington's community – individuals with HD and their families. To these ends, AHDA runs support groups for carers as well as for gene-positive and early symptomatic people with HD; undertakes home visits and counseling with support provided for both individuals and their families; and provides emergency financial assistance, advocacy and referrals. AHDA holds various retreats for HD-symptomatic people and, separately, for carers. Retreats for gene-positive people and their partners are also held.

As mentioned in Section 2.4, AHDA holds a quarterly forum with a guest speaker in Bunbury for HD families. Other community activities and information and education forums are conducted by AHDA in metropolitan and regional areas. The Association has a resource library with National and International Huntington's Association newsletters, books, videos and articles.

## **2.7 Mercy Aged Care**

Mercy Aged Care provides services in the home which, for people with NDD, include in-home respite under the National Respite for Carers Program (NRCP), social support and domestic assistance.

## **2.8 Perth Home Care Services**

Perth Home Care Services (PHCS) provides a range of home support services that are relevant to people with neurodegenerative diseases. These services are provided from within particular funding programs, including HACC, DSC, National Respite for Carers Program and, on some occasions, CACP. PHCS also provides a nurse consultancy service that is available for all these programs to assist with clinical, manual handling and equipment matters. The nurse consultants also train care workers to carry out a range of specialised care tasks such as bowel care and suctioning that are often required by people in this target group.

This capacity to support people to continue to live at home, even though their needs are quite complex, has been an intentional direction for PHCS. The organisation's vision of "People Living at Home with Dignity " is achieved by a person-centred approach that means that people with neurodegenerative disorders are able to receive a service that is individualised, flexible and responsive to their changing needs. The care from PHCS may be supplemented by other organisations and in these situations ongoing liaison and communication is another important feature of the service.

## **2.9 Brightwater**

Brightwater provides services in the home which, for people with NDD, include in-home respite, social support, personal care, domestic assistance, nursing (in relation to wounds or catheter maintenance) and allied health (for example, a speech pathologist to assist with communication and swallowing difficulties). Brightwater also manages the DSC funded Ellison House which houses 12 adults with HD.

## **2.10 Disability Services Commission**

Specialist disability services for people with disabilities, their families and carers are directly provided by the Disability Services Commission (DSC) or organisations that are funded by the Commission. The programs have specific eligibility and access criteria and may be accessed by eligible people with neurodegenerative disorders who acquire their disability prior the age of 65 years. These programs include:

- support for people to continue to live in the community;
- services such as physiotherapy, psychology, occupational therapy, social work or speech pathology;
- funding for people with disabilities who require an alternative activity to paid employment so that they can develop skills and participate within their community;
- funding for equipment and home modifications to assist people with disabilities to stay in their own home. Funding is provided to promote independence, for safety and to assist unpaid carers;

- product subsidies and a professional management and advisory service for adults with chronic continence needs (this program is jointly funded by the DSC and the WA Department of Health);
- Local Area Co-ordination support is provided throughout the State in local communities. Local Area Co-ordination is focused on supporting people with disabilities by providing information, planning for the future, advocacy and working to build inclusive communities;
- funding for families and carers to take a break from the caring role. This funding can assist a person with a disability to be involved in community activities or have a short stay away from the home; and
- advocacy services are provided by several community organisations for people with disabilities to assist them to resolve issues and create change.

## **2.11 Other Organisations and Services**

### **2.11.1 Parkinson's WA**

Three PWA nurse specialists – two are funded by WA Department of Health, one is funded by PWA - work in the metropolitan area. One nurse specialist provides support to people in the northern metropolitan area, as far north as Moora. Another provides services in the southern metropolitan area, as far south as Pinjarra, in addition to developing a follow-up clinic in Mandurah. This was trialled in an effort to reduce the travel time associated with home visiting in the Mandurah area and allows more follow-up sessions to be conducted. The initial assessments, however, are always conducted in the person's home. The third nurse specialist provides support to people in the eastern metropolitan area, as far east as Chittering.

Limited services are provided by PWA to people with PD in country areas. The Neurological Council nurse specialists assist by providing home visits and assessment to PD clients in some country areas. PD clients from the country, who have previously visited the PWA office for assessment, can have follow-up phone consultations. General PD enquiries are also taken by the nurses from people in the rural community with resources being posted out as required.

On occasions, a particular regional area or country town may arrange for the PWA nurse specialist to visit the area (eg Geraldton, Broome or Moora). During these visits, the PWA nurse will generally conduct education sessions followed by several home and hospital visits.

The process by which the PWA nurses support their clients is as follows. Following referral from family or doctor or self-referral, the PWA nurse makes a home visit. The client has to have received a diagnosis of PD or PD plus (for example, multiple system atrophy (MSA) which has a quicker progression). In those cases where the diagnosis is later questioned, the PWA nurse specialists will continue to provide support until a differential diagnosis is made. This may happen if the client is subsequently diagnosed with Lewy body dementia or Alzheimers disease. In these cases, the PWA nurses will refer the member or client to the Alzheimer's Association which has access to other funding, for example for respite.

PWA nurse specialists encourage people to have their diagnosis confirmed by a neurologist. However, in Mandurah there is currently no neurologist, although a geriatrician visits Peel Health Campus twice a week.

If the client is newly diagnosed, then they may only need information from PWA. Sometimes a client may suffer from depression triggered by the diagnosis (see Veasey, 2005 for discussion of depression as a psychiatric symptom of PD or as a negative emotional and debilitating consequence of PD). The clinical manifestation of depression sometimes includes “suicidal ideation without suicidal behaviour ... (that is) although PD patients may experience more suicidal ideation, suicide is not common in the Parkinson’s disease patient population” (Stenager, et al. (1994) and Cummings (1992) cited in Slaughter, Slaughter, Nichols, Holmes, & Martens, 2001).

An initial assessment in the home is needed to see the circumstances under which these people with PD are living, as well as for the PWA nurse specialist to get a clinical summary of where her client is in the progression of their disorder. PD individuals can be quite different in terms of manifestations of their disorder. For example, it may be difficult for the person with PD to know whether or not they are experiencing tremor (a symptom of PD) or dyskinesia (a side effect of the popularly prescribed PD medication, levodopa).

Following the initial visit to the home, the PWA nurse specialists report their assessment to their client’s general practitioner (GP) or specialist, and might also suggest referral to allied health professionals (for example, a speech pathologist or occupational therapist). The PWA nurse specialists may refer clients in middle or difficult stages on to providers of HACC services. PWA does not itself receive any HACC funding. Follow-up reports to GPs/specialists are on an as needs basis or if anything changes. Sometimes GPs/specialists report (minimally) back to PWA.

Subsequent contacts with clients are generally via phone calls, but can also be home visits. Contact is generally on an as needs basis. However, clients are sometimes reluctant to bother the PWA nurse specialists because they know they are busy (previously there were two Parkinson’s nurse specialists for the whole of the metro area). Individualistic planned care is needed. To that end, PWA nurse specialists fulfil a case management role.

Advocacy on the PD client’s behalf can be time consuming and can involve the PWA nurse specialist making approaches to employers and work colleagues, to Disability Services Commission, to public or private housing providers and to education authorities. This has to be done on an individual basis. Support organisations like PWA have more opportunity to provide such advocacy. They can tailor care solutions to an individual’s specific needs. This differs from the constraints under which home care support providers are funded.

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. In addition, information is left in the home for care workers so that they understand the fluctuating nature of PD and the importance of medication (particularly the timing of the medication). For people with PD-plus conditions and special needs, this information is particularly critical. However, the high turnover of care workers and the widespread use of relief care workers frustrate the provision of informed care to people with PD.

Clients can continue to be supported by the PWA nurse specialists if they go into residential care or hospital.

### **2.11.2 Neurologists**

GPs who suspect their patient may have a neurodegenerative disorder refer their patient to a neurologist for confirmation of the diagnosis. In addition, medical staff in public hospitals might request a neurological consultation for a patient with chronic or acute symptoms whose medical history suggests a neurodegenerative disorder.

Some neurologists specialise in the diagnosis and treatment of MND and they have caseloads within the public health system. Similarly, some GPs are known for having relative high caseloads of clients with MND or PD. In addition, geriatricians are alternative specialists for people living in areas that are not serviced by neurologists. Continuity of care is thought to be an important component of the successful clinical management of people with NDD, and this can be provided by a GP, neurologist, geriatrician or other specialist.

For all of these health professionals, there is some turnover of patients – new patients are accepted, some existing patients stay current and are reviewed (three monthly), some previous patients do not return for scheduled reviews by choice (for example, if they seek alternative curative treatments), and others die.

Neurologists most commonly receive referrals from GPs when people present with symptoms such as weakness in limbs or hands/feet, difficulties with speech and swallowing, muscle wasting or twitching. The GP may make a diagnosis of, or suggest that the patient has, MND before referring the patient to the neurologist. GPs with prior experience of patients with MND or any neurological disorder may recognise a pattern of difficulties, such as muscle wasting and twitching. These GPs may have arranged testing, for example an electromyography (EMG) scan which detects abnormal function of the spine and muscles.

MND patients of other neurologists or specialists (such as geriatricians) may be referred to either of the MND clinics for a second opinion or for access to the allied health professionals on the multidisciplinary team. There are two MND clinics. The Shenton Park Campus of Royal Perth Hospital (north of the river) provides a multidisciplinary team approach to the care of patients with neurological disorders. This clinic runs every 6 – 8 weeks with a multidisciplinary team that includes neurologist(s) and allied health professionals such as a physiotherapist, speech pathologist, dietitian, occupational therapist, clinical psychologist and dental therapist together with palliative care workers and a support agency care advisor. This co-ordinated care or team approach enables professionals with the expertise and interest to deliver timely care to people with MND, thereby increasing their longevity and life satisfaction. A similar clinic operates in Fremantle (south of the river). Attendance at either of the Perth MND clinics is not mandatory but patients need a referral.

Patients may come to the clinic initially for the development of a care plan as well as connection to a GP, Silver Chain's Hospice Care Service and the Respiratory Sleep Disorders (RSD) Clinic, together with information on respite, procedures such as gastrostomy, non-invasive ventilation and energy supplements. Once the care plan is working properly in the early and middle stages of the disorder, people do not necessarily need to keep attending the clinic. However, the clinics can play a major role in updating care plans on a regular basis and guiding suitable care in other centres as the physical condition declines and social situation changes. Declining mobility and the difficulty of getting transport usually prohibit visits to the clinic in the later stage of the disorder. At this time, there is often limited benefit from the multi-disciplinary team available at the clinic and more benefit from Silver Chain's Hospice Care Service which has a vital role. However, the transfer of care from the clinic team to the palliative care team is most effective if palliative care is instituted early in the course of the disorder and it is not delayed until the end stage.

The RSD clinic is the clinical arm of the West Australian Sleep Disorders Research Institute (WASDRI) located at the QEII Medical Centre in Nedlands. It arranges, on referral, investigation and management of breathing disorders of sleep. Hence, patients include people with MND.

A protocol has been set up so that any patients with MND who present at the RSD clinic are automatically referred to the Silver Chain's Hospice Care Service. This is important because the clinic advises on the use of non-invasive positive ventilation (continuous positive airway pressure (CPAP) or variable positive airway pressure (VPAP)). Patients need to know that, if having become ventilator-dependent they then decide to discontinue, the equipment needs to be withdrawn with sedation under the direction of the palliative care team and that this is a life-limiting decision.

MND clinics with a multi-disciplinary approach, representing world-wide best practice and enabling professionals with a commitment to, and interest and expertise in, the co-ordinated care of people with MND to combine their skills, have operated in Sydney for a number of years, most notably at the Royal North Shore Hospital which currently is involved in managing between 60 to 80 MND patients. In addition, the MND support agency Motor Neurone Disease Association of NSW (MNDA NSW) provides nurse co-ordinators for these Sydney clinics who play a vital role co-ordinating the clinic as well providing patient care.

### **2.11.3 General Practitioners**

As discussed in Section 2.11.2, a patient may be referred by his GP to a neurologist, after which the neurologist and/or the GP provide symptom management and periodic review. GPs associated with the Silver Chain's Hospice Care Service (see Section 2.5.1) are more likely to have experience with NDD, in particular, MND. Given the geographical spread of individuals with MND and the low prevalence rate, most GPs have not treated patients with MND. Some GPs may have had patients with PD and/or MS.

People with MND require fast access to care and support. The usual family GP, who has a long-standing relationship with their patient, is best placed to provide ongoing medical care to individuals with MND. This GP can, if necessary, brush up on the current treatment and care of people with MND. Importantly, this GP has already established a rapport with the individual and their family and will know their medical history as well as other details, such as occupations and interests, about their lives. This family GP can collaborate with the neurologist about suitable treatment and support for their patient.

In addition, end of life matters need to be discussed early on so that individuals and their families can make decisions and be informed. GPs are in a good position to provide holistic care for the individual with MND and their family. The stress and strain on the carer from caring for someone who is terminally ill can be easily gauged by the GP who can address resultant health issues and advise on obtaining home care support such as respite. In the case of a high needs patient living alone or not having family support, the only possibility as their condition deteriorates is supported accommodation of some form such as a hostel.

For most people newly diagnosed with MND, they enter a new world of hospitals and medical/health and community care. GPs can be instrumental in helping them navigate through these systems successfully. If a hospital stay is required, then it is important that the hospital liaise with the GP about post-acute care.

Because of the small number of people with MND as well as the large number of morbidities associated with MND, hospital staff may not have the experience to appropriately manage patients' symptoms. This could be improved with professional development for these staff together with liaison with the patient's GP and specialist/neurologist.

There are a number of difficulties for GPs in providing timely and appropriate services to patients with NDD. First, some patients are in denial about their condition and do not maintain contact with their GP thereby jeopardising their symptom management. Some patients might seek services from a number of other GPs or alternative therapists which can result in poor continuity of care which, at the end stage of the disorder, may compromise quality of life in the lead up to death.

Another difficulty related to GP services is that many GPs are now working part-time which means that they may not be available when patients need to see them. In GP practices, these patients may be seen by a doctor other than their regular or preferred doctor. Most GPs do not make house calls any more. Having the family GP involved in their care allows a humanistic approach to offset the regimentation that dominates the life of the patient with a NDD. The role of the GP can include helping people to remain themselves, to keep as normal a life as possible and to sort out what is important. The GP can thus provide balance.

### **3 DATA AND METHODOLOGY**

#### **3.1 Data**

Data were collected from ten organisations participating in this project. Whilst the goal was for these organisations to provide data for the period 1996 to 2006, only one organisation was able to do this – Motor Neurone Disease Association of Western Australia (MNDAWA). Disability Services Commission (DSC) and Silver Chain were able to provide data for 2002 to 2006 and 1999 to 2006, respectively. The other seven organisations provided data for 2006 only. In the main part of this report, analyses of the 2006 data only are reported. Longitudinal data summaries for MNDAWA, DSC and Silver Chain are provided in the appendices.

There are a number of reasons for the paucity of longitudinal data. First, most organisations have moved to different or upgraded software, resulting in either a loss of historical data, or the inability to access past data or to combine past years data with that for 2006. Second, each database reflects the purposes for maintaining it.

In the case of member support agencies, the database is, primarily, the members' mailing list. In the case of service providers, the database contains a service log. It is not unexpected, therefore, that the data are not easily retrievable or in a format for comparative analysis.

As mentioned, the support agency datasets were derived from membership databases. These databases provide current mailing lists for agency newsletter distribution and fundraising endeavours, enable agencies to complete reports to funding bodies and allow agency business, for example the hiring of equipment, to be managed. In only one support agency, MNDAWA, did the updated mailing list preserve information on past members. That is, non-current members remain on the list and both current and non-current members could be easily identified as such.

Providers also maintain databases related to the conduct of their business, their accounting practices and their need for reporting to funding bodies. Some organisations have to conform to minimum dataset (MDS) requirements. For these organisations, the datasets are more easily comparable.

The data were to include people who had one of the four neurodegenerative disorders of interest, and who were living at home in 2006. The original datasets, however, sometimes contained people who did not fit these criteria. For example, one Brightwater client had one of the disorders of interest but could not be more precisely classified. This client was excluded from the linked dataset. Some of the datasets contained records for people who were in residential facilities of some kind, such as a number of people with Huntington's Disease living in the Brightwater facility, Ellison House. A number of clients or members had died prior to 2006; these were also excluded.

There are two other anomalies affecting the comprehensiveness of the linked dataset. First, Silver Chain's dataset did not include all clients with Huntington's Disease as this disorder does not have a unique classification code in the client database. Nonetheless, two people in the Silver Chain client database were identified as having Huntington's Disease. Second, some people with Huntington's Disease use a number of different names. This is not uncommon for people who are concerned about genetic discrimination (Bonn, 2000; Harris, Winship, & Spriggs, 2005). This would apply, in particular, to people who have been confirmed as gene-positive for Huntington's Disease, but who are not experiencing any symptoms. However, using different names, and therefore having difference Linkage keys, will result in their client record at one organisation not linking to their client or membership records at other organisations.

The differences in the ten contributed datasets are shown in two ways. Table 1 gives an indication of the number of members or clients with neurodegenerative diseases who are living at home in 2006. The figures are not strictly comparable as some organisations have provided point-in-time data and others, data over a period of time. An example of the former is Perth Home Care who provided data for clients who were receiving services in December 2006. For support agencies, the dataset represents the membership for the whole of the year. Here, whether the person joined at 1 January 2006 or 1 December 2006, they would be counted as part of the 2006 membership. Often only the year of joining is recorded, if at all. Data storage and reporting idiosyncrasies of various organisations prevented either approach to enumeration being used across all organisations.

Also shown in Table 1 are totals. Total observations are the sum of the ten contributed datasets. Here we see that men represent 28 per cent of the observations overall, although they are represented more or less in individual datasets. For example, 60 per cent of MNDAWA members are men and 76 per cent of MSS WA members are women. The overall gender imbalance is not unexpected as 60 per cent of total observations come from the MSS dataset.

The final row in Table 1 gives the total number of unique individuals in the linked dataset. This number is 69.0 per cent of the total number of observations. This means that some people are members and/or clients of between two and five of the ten organisations represented in the linked data.

Table 1: Agency And Provider Datasets, 2006

Agency or Provider <sup>a</sup>	Number of Members or Clients <sup>b</sup> in 2006		
	Male	Female	All
Australian Huntington's Disease Association of WA (AHDA)	25	26	51
Brightwater Care Group	1	3	4
Disability Services Commission (DSC)	255	664	919
Mercy Aged Care	0	2	2
Motor Neurone Disease Association of WA (MNDWA)	68	46	114
Multiple Sclerosis Society of WA (MSS WA)	540	1,677	2,217
Neurological Council of WA <sup>c</sup>	4	6	10
Perth Home Care Services	8	22	30
Silver Chain	80	205	285
WA Department of Health (Neurosciences Unit (NSU))	31	32	63
<b>Total observations<sup>d</sup></b>	1,012	2,683	3,695
<b>Total unique individuals<sup>e</sup></b>	715	1,835	2,550

Notes: <sup>a</sup> Parkinson's Western Australia did not participate in this component of the project. Hence, any clients with Parkinson's Disease are excluded from the linked dataset and subsequent analyses. Alzheimer's Association of WA, whilst part of the cross-provider group that established the project, did not subsequently participate in the project. <sup>b</sup> Members or clients with one of the diseases of interest – Multiple Sclerosis or Motor Neurone, or Huntington's Disease. <sup>c</sup> These data are for metropolitan clients of Neurological Council only. <sup>d</sup> These are the summation of the ten datasets prior to linkage. <sup>e</sup> This is the size of the linked dataset, that is, after linking multiple occasions of service for applicable individuals. Tables 2 and 3 compare the content of the datasets provided by each of the ten organisations to the project. In all cases, this content reflects what and how service details and individual characteristics are recorded electronically, respectively.

Service information, if recorded, was different for each of the ten organisations and this is summarised in Table 2. MSS WA categorised its membership in terms of five client types – member, associate member, hospital liaison nurse client, immunotherapy client, respite client. The member category accounted for 98.6 per cent of the 2006 membership of 2,217 people.

Perth Home Care has two categories of clients including clients at home and clients who were accessing occasional respite. Total hours of service given to PHC clients in December 2006 are also included. Neurological Council provides assessment, case management and counselling services to all its clients as well as offering social support and/or respite.

As summarised in Section 2.10, DSC services are flagged as either DSC funded or DSC provided. DSC provided services include local area co-ordination, therapy support and accommodation support. Apart from local area co-ordination, DSC provided service eligibility is based on having an intellectual disability. DSC funded services include therapy, adult alternatives to employment, advocacy, centre-based and flexible respite, group homes, in-home accommodation support, large and small residential, other community access, post school options, recreation or holiday program, equipment and respite brokerage. All of these services may be accessed by people with NDD.

Silver Chain records the start and end dates for particular services across a number of service types as well as the total hours of service supplied to the client for each service type. In addition to this service information, Silver Chain also collects data on ethnicity, language and country of birth for each client. Missing values on these socio-demographic variables are under 1 per cent.

Silver Chain's service types include nursing, home help or cleaning, personal care (showering, dressing and meal preparation) and equipment. Other types of services provided by Silver Chain have been grouped together (as Other services) in the linked dataset.

Table 2: Service Characteristics In Agency Or Provider Datasets

Agency or Provider	Client Type	Service Hours	Service Type
Australian Huntington's Disease Association			
Brightwater Care Group			
Mercy Aged Care			
Disability Services Commission			√
Motor Neurone Disease Association of WA			
Multiple Sclerosis Society of WA	√		
Neurological Council of WA			√
Perth Home Care Services	√	√ <sup>a</sup>	
Silver Chain		√ <sup>b</sup>	√
WA Department of Health (Neurosciences Unit)			

Notes: <sup>a</sup> Total hours for December 2006. <sup>b</sup> Total hours since start of service.

Individual characteristics are collected by most organisations as shown in Table 3. In column 1 it can be seen that some organisations did not have the Linkage key. However, they did have sufficient information (surname, given name, date of birth, gender<sup>3</sup>) for it to be generated for the research team. One support agency's Linkage key required modification to ensure comparable conventions were met<sup>4</sup>. Several organisations capitalised the name prefix in their Linkage key; others used lower case. These had to be changed to upper case in order for the duplicate observations to be discerned and the linkage to succeed.

All organisations had date of birth and gender, and most had postcode or location information as shown in columns 2 and 3. Some organisations had a date of diagnosis in their datasets as shown in column 4, but there were varying degrees of missing values. For example, MNDAWA had a date of diagnosis for 56 per cent of members whilst MSS WA had these data for 72 per cent of members. Silver Chain had a date of diagnosis for less than 10 per cent of clients and, in many cases, this was incorrectly recorded<sup>5</sup>.

<sup>3</sup> In some cases gender was not specified in the dataset but title was given. Either gender or title was used to compute the gender variable.

<sup>4</sup> See Attachment A for details of the construction of the Linkage key.

<sup>5</sup> Often the first of the month was given as the date of diagnosis when month was known but date was unknown. The first of January was given when the year was known but the exact date was unknown. Some people were given 31 December 1999 as their date of diagnosis but this was the date of the move from one database system to the new system.

Column 5 in Table 3 shows that three organisations provided date of death<sup>6</sup> – MNDAWA, AHDA and NSU. In the case of MNDAWA, their unique longitudinal dataset and small membership has allowed, in most cases, past members to be identified as having died when their membership lapses<sup>7</sup>.

Similarly, the Neurosciences Unit of the WA Department of Health maintains longitudinal data which includes people who participate in predictive testing for Huntington's Disease and other familial neurological conditions. Australian Huntington's Disease Association (WA) has year of death for some past members. Disability Services Commission does keep client data over a number of years but does not record either reasons for separation, including death, or date of death.

Year joined is known for most MNDAWA members and year services commenced is known for all Silver Chain clients (column 6 of Table 2). The Silver Chain dataset also had a variable for the date of service ending. To get some idea of client retention, it is useful to look at how many are still receiving services after a year. One quarter of Silver Chain clients with neurodegenerative disorders who started receiving services in 2006 were still clients in the first half of 2007. Eighty per cent of these NDD clients have MND. AHDA also records the date of first contact.

Member or client status (column 7) refers to whether or not the person with the neurodegenerative disorder is a 2006 client or member or a past client or member (including whether or not they are deceased). This characteristic could be derived from the data provided by all organisations.

Whether clients or members live alone or not (column 8) or have a carer or not (column 10) are collected by most organisations as an MDS requirement. In some cases, more detail, such as who the member or client lives with (column 9) and whether or not the carer and care recipient are co-resident (column 11), is also collected. Type of residence (column 12) is known by most organisations. If type of residence was private residence or independent living unit, then it was assumed that this meant clients or members were living at home.

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<sup>6</sup> The Silver Chain client database has a field for date of death but this was not included in the data request for the linkage.

<sup>7</sup> See Attachment B for the MNDAWA membership numbers for 1996 to 2006.

Table 3: Member Or Client Characteristics In Agency Or Provider Datasets – Common Variables

Agency Or Provider	Linkage Key (1)	Date Of Birth And Gender (2)	Postcode Or Location (3)	Date Of Diagnosis (4)	Date Of Death (5)	Year Joined Or Services Commenced (6)	Member Or Client Status (7)	Living Arrangements		Carer Arrangements		Type Of Residence (12)
								Alone Or Not (8)	Who With (9)	Carer Or Not (10)	Carer Resides Or Not (11)	
Australian Huntington's Disease Association <sup>a</sup>		√	√		√	√				√	√	
Brightwater Care Group		√	√				√	√		√		√
Disability Services Commission <sup>b</sup>	√	√	√					√	√	√	√	√
Mercy Aged Care		√	√				√					
Motor Neurone Disease Association of WA		√	√	√	√	√	√					
Multiple Sclerosis Society of WA	√	√	√	√			√	√	√	√	√	√
Neurological Council of WA	√	√	√				√	√		√	√	
Perth Home Care Services	√	√	√				√	√	√	√	√	√
Silver Chain <sup>c</sup>	√	√	√	√		√	√	√	√	√	√	√
WA Department of Health (NSU)	√	√	√		√		√			√	√	√

Notes: <sup>a</sup> Some of these data were missing for some members. <sup>b</sup> DSC provided two datasets, one for the computations of summary statistics and one to be used for the linkage exercise. There is a slight difference in the variables in each. In Tables 3 and 4, DSC variables may be found in either dataset. <sup>c</sup> Silver Chain also has data on ethnicity, language and country of origin.

### 3.2 Methodology

As stated in Section 3.1, organisations involved in the project were initially asked to supply summary statistics across a range of characteristics of interest for the period 1996 to 2006 and to provide a dataset that could be used in the linkage process<sup>8</sup>. However, it subsequently seemed more efficient for organisations to supply the longitudinal data, if they were able, so that the research team could produce the summary statistics. Ten organisations were able to partially or fully meet these requests for data.

The first step in the process of building the linked dataset was to examine the characteristics of members and clients that were being made available from the agency and provider datasets. As summarised in Section 3.1, there were a number of common characteristics and some characteristics that were organisation-specific. A master list of characteristics and their valid values (see Attachment E) was then developed to include all available information<sup>9</sup> from the ten participating organisations.

The processes of analysing the datasets to produce summary statistics for 2006 and of compiling the datasets for the linkage stage of the project were undertaken simultaneously. That is, the datasets were firstly modified to reflect the Linkage data master variables, labels and codes. Importantly, the Linkage key was constructed or amended, as per the guidelines in Attachment A, if not already provided.

It should be noted that the terms ‘link’ and ‘merge’ are often used interchangeably. However there is a subtle difference as follows. For this project, the ten modified datasets were firstly merged or stacked together. The size of this merged dataset,  $M$ , is therefore the sum of the sizes of the ten contributing datasets ( $\sum_{i=1}^{10} m_i$ ) where the size of dataset  $i$  is  $m_i$ . As shown in

Table 1 and discussed in Section 3.1,  $M = 3,695$  and the  $m_i$  range from 2 for Mercy Aged Care to 2,217 for MSS WA. The dataset  $M$  can be visualised as a large spreadsheet with the rows representing members or clients, and the columns representing the characteristics of these people, the services they receive and the organisations that provide these services. One of the columns contains the Linkage key for each member or client. This key, which contains elements of name, date of birth and gender, is unique for each individual.

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<sup>8</sup> Parkinson’s Western Australia (PWA) was not involved in this part of the project.

<sup>9</sup> There were a few occasions where an organisation’s dataset included a particular variable but values for the variable were missing in most cases. If this variable was organisation-specific, it was excluded from the linked dataset. If values for this variable were available in other datasets then this variable was retained.

The 3,695 rows in this spreadsheet do not correspond to 3,695 people. Sorting the spreadsheet on the basis of Linkage key enables a visual appreciation that some rows have the same Linkage key and therefore provide information for the same person from one or more sources. For example, a Silver Chain client (observation or row number 100) may also be a member of Multiple Sclerosis Society WA (observation 101) and a client of Perth Home Care (observation 102). Thus, the merged dataset contains three observations, or rows of data, for this person. These observations should contain similar information, such as date of birth, gender, postcode and disorder<sup>10</sup>.

The observations will also show disparate information. The number and type of Silver Chain services will have non-missing values in row 100 and missing values in rows 101 and 102. Service hours received from Perth Home Care in December 2006 will be non-zero in row 102 and zero in the other two rows. Finally, client type will be non-missing in row 101 and missing in row 100.

If there are multiple observations for a single Linkage key, then the linkage process can produce a single observation (all the information pertaining to that person) that combines the information from the multiple observations. In the linkage process, the information that is similar provides core information for the person, and the different information is appended to this. The number of variables in the dataset (columns in the spreadsheet) increases to accommodate this extra information. Thus, three observations become one and the size of the linked dataset (number of rows in the spreadsheet) reduces to  $N < M$  (or  $N < \sum_{i=1}^{10} m_i$ ).

The difference in size between the merged and linked datasets is shown in Table 4. The first column gives the number of unique individuals disaggregated by the number of organisations that have provided data for them. The column total is the size of the linked dataset,  $N$ . The second column gives the number of rows of data in the merged dataset, also disaggregated by number of organisations. The column total here is the size of the merged dataset,  $M$ . These totals were introduced earlier in Table 1.

*Table 4: Numbers Of Individuals And Records By Number Of Organisations*

<b>Number of Organisations</b>	<b>Number of Individuals (size of the linked dataset, <math>N</math>)</b>	<b>Number of Service and/or Membership Records (size of the merged dataset, <math>M</math>)</b>
1	1,627	1,627
2	724	1,448
3	178	534
4	19	76
5	2	10
<b>All</b>	<b>2,550</b>	<b>3,695</b>

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<sup>10</sup> For some individuals, their demographic characteristics were recorded differently by different organisations.

An important outcome of the linkage process is that the response rate for the postal survey (see NDP Report No 1) can be re-estimated. The response rate calculated as the percentage of surveys mailed out that were returned was around 38 per cent. Knowing the extent of the overlap between mailing lists, the revised response rate is 54.0 per cent<sup>11</sup>.

The development of the ten datasets to the point at which they could be merged and then linked was time-consuming for two reasons. First, at the same time that the datasets were being collected, the research department changed its statistical software to Stata (StataCorp LP, 1996–2008). The research team, along with others in the research department, attended formal training sessions in the use of the software and needed to build up some expertise in the type of analyses needed for the summary statistics.

The second reason for the slower progress is that the Stata software is clear about the requirements for merging datasets, namely that the datasets must be identical in structure. That is, the variables must be listed in the same order, have the same variable names and valid values or codes, and the codes must be labelled identically. In addition, the variables need to be of the same type and format. If any of these requirements are not met, a merged dataset will not have the complete data from each of the component datasets. That is, any variables that do not match exactly are dropped from the resulting merged dataset.

Two datasets required an internal linkage as both had multiple observations for many clients. The DSC dataset contained multiple observations for the same clients depending on how many services they were receiving in 2006 from DSC. Hence this dataset required internal linkage. The Silver Chain dataset had two files. One of these had client information and the other had service information. The service data file had multiple observations for many of its clients with each observation detailing a specific service and service period. Thus the service data had to be internally linked before linking with the client information.

The attention to detail required for preparing each of the datasets for the linkage procedure minimised loss of information. However, it did not resolve conflicts of information from various providers. For example, someone with MS may be recorded in their MSS WA record as having a carer and as having no carer in their Silver Chain record. In this case, the linked dataset has flagged the carer variable as unknown for this person. Other variables that are prone to conflicting information are living situation and residence type. Some people had different postcodes recorded at each organisation. In these cases, the postcode recorded for their service provider took precedence over the postcode of their support agency on the assumption that the address needs to be accurate for the delivery of services to clients. On the other hand, members may have moved and not informed their support agency because the only repercussion is not receiving regular mail.

The resulting linked dataset (N = 2,550) provides, for each person in the dataset, a comprehensive account of their home care support services<sup>12</sup>.

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<sup>11</sup> 2,939 surveys were posted. Adjusting for duplicates gives 2,028  $[(2,550/3,695) * 2,939]$  unique postings. Given that the completed and returned surveys numbered 1,097, the revised response rate is 54.0 per cent  $((1,097/2,028)*100)$ .

<sup>12</sup> Insofar as the organisations contributing data to this linkage process are the key service providers. The survey of clients and members found that services were also provided by diverse organisations such as the Red Cross, local government authorities and small, local not-for-profit organisations. It is not possible to determine from the survey or linkage data, the extent to which these organisations supplement services from the main support agencies and service providers in this project.

There are a number of shortcomings in the linked dataset. First, linked information for people with Parkinson's Disease is not included as the PWA dataset was not supplied for this project. The two Parkinson's nurses<sup>13</sup> provide considerable and varied specialist services to over 800 people in WA with PD and may be the only service for those who are recently diagnosed or having few difficulties.

The Neurological Council dataset included clients from the metropolitan area only. This should be noted in the analysis of geographic distribution of members and clients and the services they receive.

Finally, whilst every effort was made to ensure the Linkage key was constructed according to the same rules (see Attachment A), some anomalies still arose. For example, some organisations capitalised the name letters (first five characters or the Linkage key) and others used lower case. One organisation placed the two letters of the given name before the three letters of the family name. The rule for construction of the Linkage key is the reverse of this. Missing names, nicknames and aliases also confounded the linkage of individuals across organisations. However, every effort was made to ensure that anomalies in the Linkage keys, in particular, were resolved.

Some organisations included the same individual twice in their dataset with each entry having slightly different information, even spelling of names, for the client or member. The lack of concordance of some information meant that duplicates within an organisation's dataset were not necessarily being picked up by the internal linking process.

The following Sections provide results using the linked dataset (N = 2,550), firstly with summary statistics on age, gender and living arrangements by organisation (Section 4) and then a breakdown of service information by disorder (Section 5).

#### **4 SOCIO-DEMOGRAPHIC CHARACTERISTICS BY ORGANISATION, 2006**

The following tables summarise socio-demographic characteristics and service information by support agency and service provider for 2006 using the linked dataset described in Section 3.2. Only people with MS, MND or HD who are living at home are included. Table 5 shows characteristics by organisation and Tables 6 to 9 show age, gender and living arrangements by organisation as well as by disorder.

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<sup>13</sup> A third nurse for PWA has subsequently been appointed (see NDP Report No 5).

Table 5: Comparison Of Members Or Clients: Average Age, Proportion Of Males And Living Arrangements, 2006

Agency or Provider <sup>a</sup>	Average Age in Years (n)	Percentage of Males (n)	Percentage Living Alone (n)	Percentage With Carer (n)
Australian Huntington's Disease Association WA	53.0 (38)	49.0 (51)	14.3 (7)	83.0 (47)
Brightwater Care Group	66.5 (4)	25.0 (4)	66.7 (3)	50.0 (2)
Disability Services Commission	51.8 (918)	27.8 (919)	19.5 (727)	71.3 (589)
Mercy Aged Care	62.5 (2)	0.0 (2)	50.0 (2)	50.0 (2)
Motor Neurone Disease Association of WA	64.5 (96)	59.6 (114)	9.5 (21)	95.2 (21)
Multiple Sclerosis Society of WA	52.3 (2,170)	24.4 (2,217)	19.8 (1,191)	66.7 (881)
Neurological Council of WA	56.2 (10)	40.0 (10)	0.0 (8)	100.0 (8)
Perth Home Care Services	55.0 (30)	26.7 (30)	27.3 (11)	73.9 (23)
Silver Chain	59.6 (285)	28.1 (285)	24.8 (258)	77.3 (247)
WA Department of Health (Neurosciences Unit)	52.0 (63)	49.2 (63)	14.3 (7)	77.4 (62)
<b>All</b>	52.9 (2,471)	28.0 (2,550)	19.7 (1,300)	68.0 (1,078)

Notes: <sup>a</sup> Includes only those agencies and providers that have members and clients with MND, MS or HD.

In Table 5, the average age is shown to range from 51.8 years for DSC clients to 66.5 for clients of Brightwater. The proportion of males is highest for MNDAWA at 59.6 per cent and lowest for members of MSS WA, 24.4 per cent. These results reflect the gender distribution of these disorders in the general population.

The data on living arrangements is sparse. Columns 3 and 4 in Table 5 show the proportion of people living alone and the proportion of people with carers, respectively. It should be noted that the incidence of missing information for these variables is large - 49 per cent in the case of information on whether people live alone or not and 32 per cent in the case of information on whether people had a carer or not.

For DSC, MSS WA and Silver Chain the proportions of people living alone are 19.5 per cent, 19.8 per cent and 24.8 per cent, respectively. Across the linked dataset, this proportion is 19.7 per cent. The proportions of people with a carer range from 50.0 per cent for Brightwater and Mercy Aged Care clients to 95.2 per cent for MNDAWA members. Overall, the proportion of people recorded as having a carer is 68.0 per cent.

In the following sections, client and member attributes are discussed in relation to both organisation and neurodegenerative disorder.

#### 4.1 Average Age

Table 6 presents average age by organisation and disorder in 2006.

Table 6: Comparison Of Members Or Clients: Average Age By Disorder, 2006

Agency or Provider	MND	MS	HD
	Average Age in Years (s.d. <sup>a</sup> )		
Australian Huntington's Disease Association WA	n.a.	n.a.	53.0 (11.18)
Brightwater Care Group	81.0 (-)	62.0 (-)	61.5 (3.54)
Disability Services Commission	61.2 (14.38)	51.1 (13.20)	40.5 (3.54)
Mercy Aged Care	n.a.	62.5 (10.61)	n.a.
Motor Neurone Disease Association of WA	64.5 (13.72)	n.a.	n.a.
Multiple Sclerosis Society of WA <sup>b</sup>	54.5 (7.78)	52.3 (14.05)	n.a.
Neurological Council of WA	53.5 (9.19)	54.5 (4.23)	64.0 (0.00)
Perth Home Care	60.0 (-)	55.3 (10.96)	51.8 (13.6)
Silver Chain	63.7 (12.69)	58.5 (12.64)	63.0 (5.66)
WA Department of Health (Neurosciences Unit)	n.a.	n.a.	52.0 (12.03)
<b>All</b>	63.6 (14.36)	52.1 (14.32)	52.2 (11.99)

Note: <sup>a</sup> For samples with n = 1, standard deviation is shown as (-). <sup>b</sup> MSS WA has two clients with MND. This could be because they were initially diagnosed as having MS and had joined MSS WA. Subsequently they were re-diagnosed as having MND but they retained their membership of MSS WA.

Generally, people with MS are slightly younger than people with HD and people with MND are, on average, ten years older than both these groups. The average age for people with MND in the linked dataset in 2006 is 63.6 years. This ranges from 53.5 years for those people living in the metropolitan area and receiving services from the Neurological Council to 81 years for a client of Brightwater. For MNDAWA members the average age is 64.5 years and the range of ages is from 29 to 104 years.

Other studies report similar mean ages for samples of people with MND. For example, the average age of people with MND across three Australian states and reported in the Kristjanson study (2003) was 65 years. Teijlingen, Friend and Kamal (2001) found that fifty per cent of their Scottish sample was 65 years or older. Hughes *et al.* (2005) reported that 67 per cent of their sample, drawn from people with MND living in three boroughs in London, was at least 70 years.

In addition to examining average age, it is useful to also look at the distribution of ages around the mean. This is shown in Figure 1. Ages are grouped, approximately, 17 (a DSC client) to 24.2 years, 24.2 to 31.5 years and so on until the last category of 96.8 to 104 (a MNDWA member) years. The modal category is 60.5 to 67.8 years which includes the mean age of 63.6 years and the median age of 64 years. That these measures of central tendency are close in value suggests that the skew ( $k = 3.59^{14}$ ) in the distribution towards older members is small. In other words, there are proportionately fewer members at ages below the mean, but the difference in proportion compared to older members is small.

Figure 1: Age Distribution For People With MND, 2006

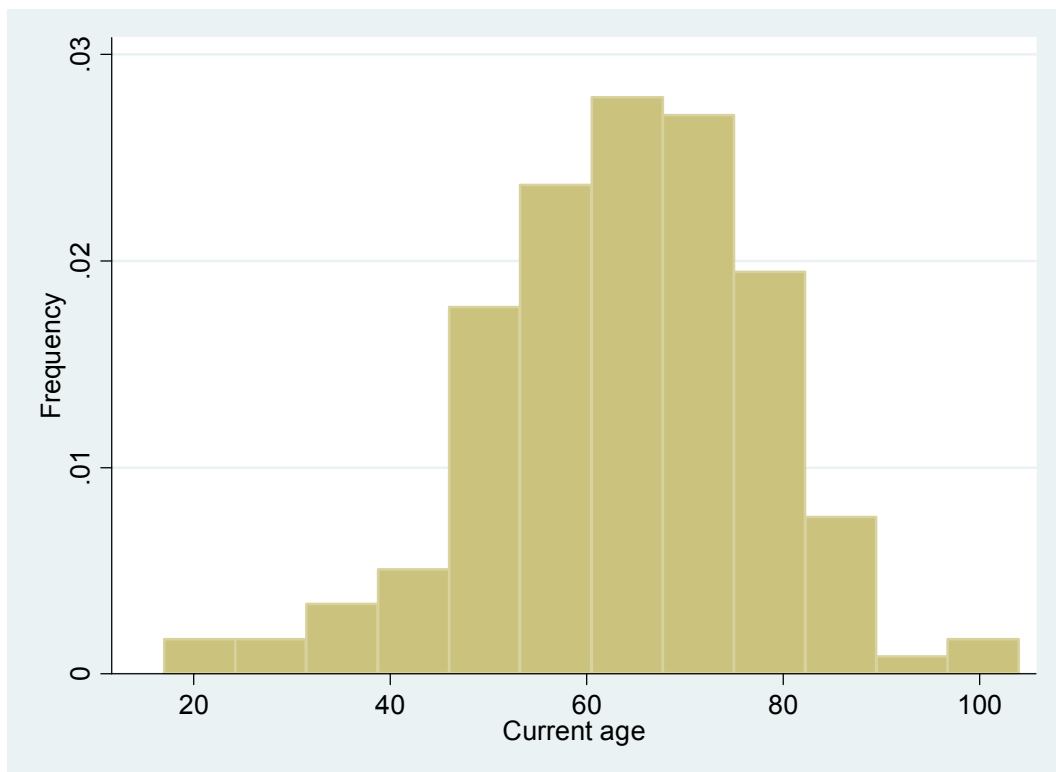
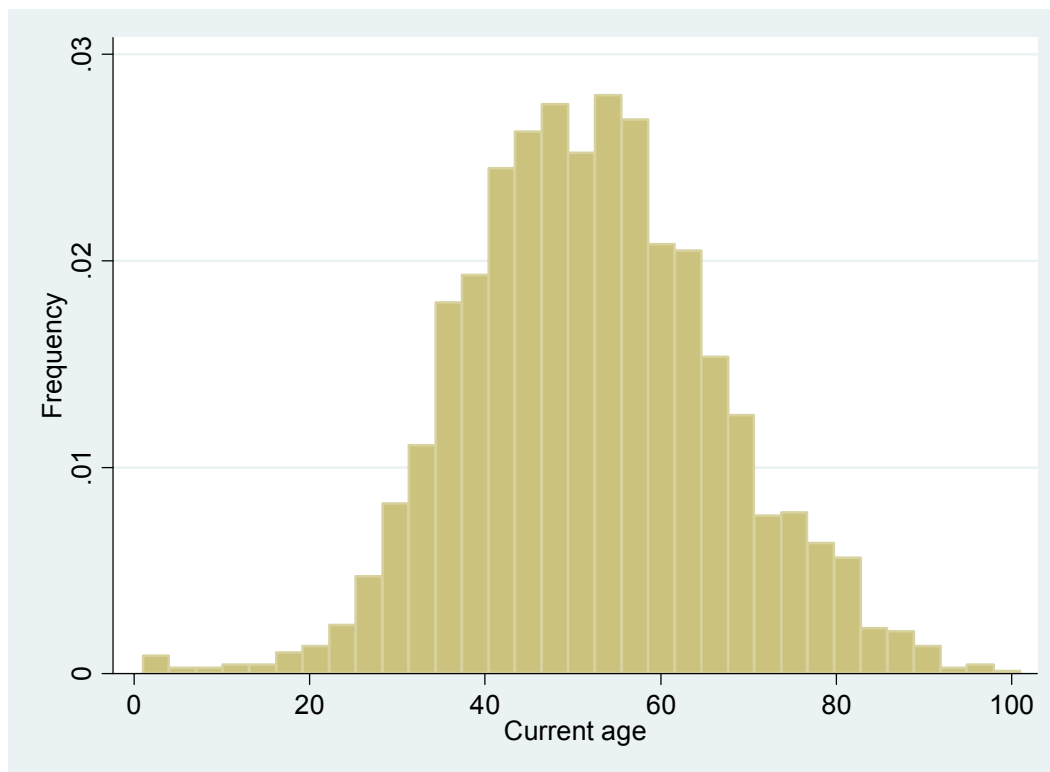


Table 6 shows that members of MSS WA have an average age of around 52 years and, as these make up 97 per cent of the people with MS in the linked dataset, it is not surprising that the mean age for this group is also 52 years. The mean ages of MS clients of the Neurological Council, Perth Home Care and Silver Chain are 54 years, 55 years and 58 years, respectively. MS clients of Mercy Aged Care and Brightwater are older on average, at 62 years.

<sup>14</sup> A kurtosis value of 3 is assigned to the standard normal distribution. The positive but small value for excess kurtosis ( $3.59 - 3 = 0.59$ ) suggests a slightly higher peak (hence is leptokurtic) than one would obtain with the standard normal distribution.

In Figure 2, ages of people with MS in the linked dataset are grouped from the youngest at one to four years to the oldest at 98 to 101 years. This distribution is shown to be bi-modal, and the modal categories are 44 to 47 years ( $n = 229$ ) and 50 to 53 years ( $n = 220$ ). However, the skewness is small ( $k = 3.21$ ) suggesting that the shape of the distribution is approximately normal.

Figure 2: Age Distribution For People With MS, 2006



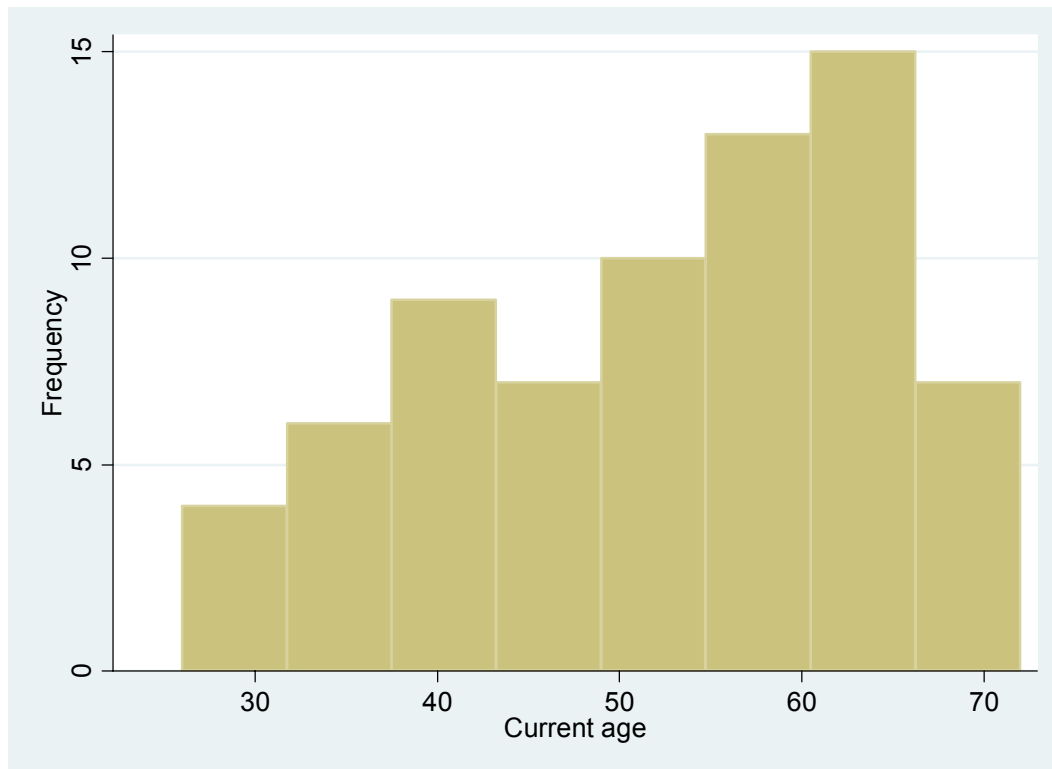
Fourteen people with MS in the linked dataset are fifteen years old or younger. This represents about 0.05 per cent of the MS cohort in the linked dataset. This is a much lower proportion than reported by MSS WA for 2006/2007 - about 0.5 per cent of their members are 15 years or younger (The Multiple Sclerosis Society of Western Australia (Inc), 2007). In the linked dataset, about 6 per cent of people with MS ( $n = 145$ ) are over the age of 75 years. This can be compared with the MSS WA figure of 3.3 per cent for those members aged 76 years and older (The Multiple Sclerosis Society of Western Australia (Inc), 2007).

MS is the most common cause of neurological disability in young and middle-aged adults (Solari, Ferrari, & Radice, 2005). Hence, it is not surprising that the mean age of people with MS in the linked dataset, 52.1 years, is relatively low. Males with MS (52.2 years) are slightly older than females with MS (52.1 years), but this difference is not statistically significant ( $F = 0.01$ ;  $p = 0.9256$ ).

The cohort of people with HD in the linked dataset has an average age of 52 years. DSC clients with HD have an average age of 40.5 years and HD clients of the Neurological Council living in the metropolitan area have an average age of 64 years. Other studies have reported comparable sample ages ranging from 46.9 to 51.3 years (Black, Grant, Lapsley, & Rawson, 1994; Kersten *et al.*, 2000; O'Hara, DeSouza, & Ide, 2004; Solari *et al.*, 2005; Tribe *et al.*, 2006). None of these studies reported gender differences in average age.

Table 6 shows that the average age of clients and members with HD ranges from 40.5 years for clients of DSC (n = 2) to 64 years for clients of the Neurological Council (n = 2). The Neurosciences Unit (NSU) and AHDA have 63 clients and 51 members, respectively, with 30 of these people listed on the databases of both organisations<sup>15</sup>. The age distribution for HD people in the linked dataset is skewed to the right as shown in Figure 3 (k = 2.06). Here, the age categories start at 26 to 31.8 years with the last category being 66.2 to 72 years. The modal age category is 60.5 to 66.2 years.

Figure 3: Age Distribution Of People With HD, 2006



It should be noted that some Neurosciences Unit (NSU) clients and AHDA members may not be symptomatic. For example, NSU offers gene testing for people with a family history of HD. Some family members may be tested and confirmed as gene-positive. They will therefore develop the disorder even if they are currently free of symptoms. NSU makes available to these people counselling and other services. They would be included in the data along with people diagnosed with HD who are symptomatic. Membership of AHDA also includes gene-positive but asymptomatic individuals. Some people who have been diagnosed as gene-positive may join to obtain information and advice and to make contact with others who are in similar circumstances. AHDA runs support groups for gene-positive members as well as early symptomatic and other members and carers.

<sup>15</sup> The linkage of records for people with HD has been confounded by missing information, particularly on date of birth, and the fact that the use of aliases results in the same people having different linkage keys in different datasets. Hence, the overlap between NSU clients also being AHDA members is likely to be higher than the 30 people identified in the linked dataset as belonging to both organisations.

Of the earlier literature on people with HD and their home support needs, only one study reported a mean age for its HD sample. This was Kristjanson, Aoun and Yates (2006) who found that the average age of people with HD is 56.8 years. This is close to the mean age of HD people in the linked dataset, 52.2 years. The study by Skirton and Glendinning (1997) reported that 64 per cent of its sample of people with HD were over 50 years. Dawson *et al.* (2004) found that most of their sample was aged between 51 and 60 years.

#### 4.2 Gender

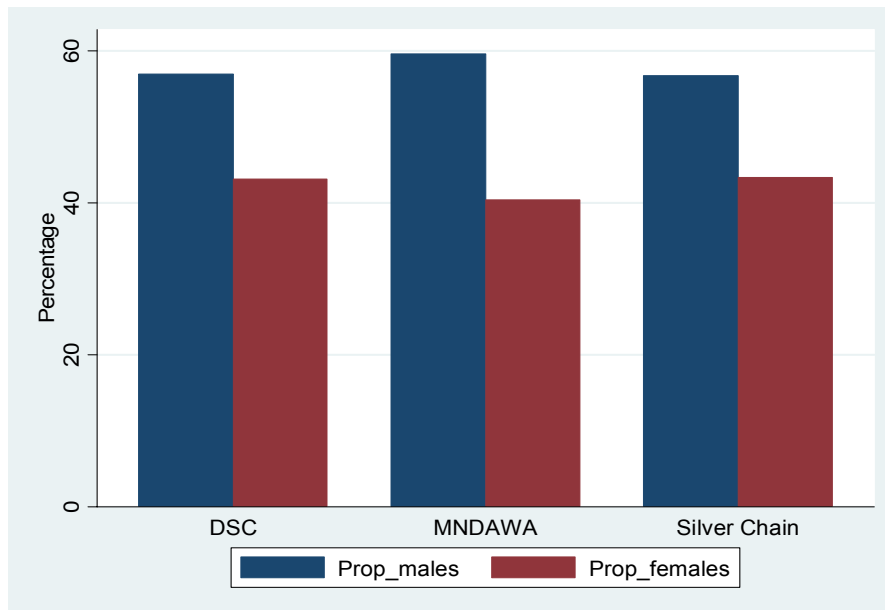
In addition to differences in average ages between organisations and disorders, differences also arise in terms of gender profiles. For example, it is well documented that more females are affected by MS and more males by MND and that there are no appreciable differences in terms of gender for people with HD. Table 7 reports the proportions of males with each of the three disorders by organisation.

Table 7: Comparison Of Members Or Clients: Proportions Of Males By Disorder, 2006

Agency or Provider	Percentage of Males (total number with disorder)		
	MND	MS	HD
Australian Huntington's Disease Association WA	n.a.	n.a.	49.0 (51)
Brightwater Care Group	0.0 (1)	0.0 (1)	50.0 (2)
Disability Services Commission	56.9 (65)	25.6 (852)	0 (2)
Mercy Aged Care	n.a.	0.0 (2)	n.a.
Motor Neurone Disease Association of WA	59.6 (114)	n.a.	n.a.
Multiple Sclerosis Society of WA	0.0 (2)	24.4 (2,215)	n.a.
Neurological Council of WA	100.0 (2)	0.0 (6)	100.0 (2)
Perth Home Care Services	0.0 (1)	28.0 (25)	25.0 (4)
Silver Chain	56.7 (60)	20.2 (223)	50.0 (2)
WA Department of Health (Neurosciences Unit)	n.a.	n.a.	49.2 (63)
<b>All</b>	60.8 (181)	24.6 (2,285)	50.0 (84)

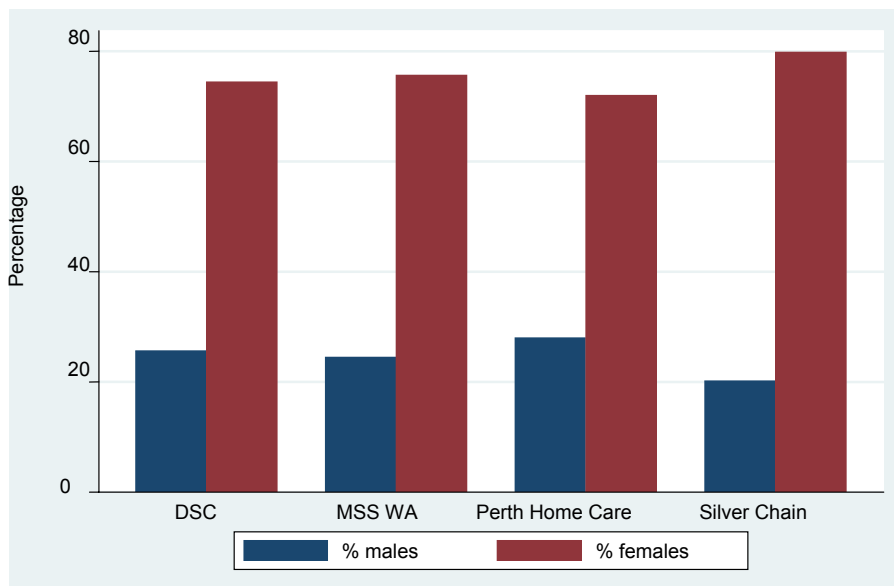
MNDAWA, Silver Chain and DSC have large numbers of members or clients with MND. The percentages of males with MND in 2006 are 59.6 per cent for MNDAWA (n = 114), 56.7 per cent for Silver Chain (n = 60) and 56.9 per cent for DSC (n = 65). Perth Home Care and Brightwater each had one female MND client in 2006, and Neurological Council had two male clients with MND. Most of the studies of people with MND and their home care support needs also report a higher proportion of males in their samples. One such study, by Hughes *et al.* (2005) found a ratio of men to women of 2:1. Other studies reported ratios of 1.6:1 (Krivickas, Shockley, & Mitsumoto, 1997), 1.9:1 (Kristjanson, 2004) and 1.3:1 (van Teijlingen *et al.*, 2001). Figure 4 shows, for three organisations, the proportions of clients with MND who are male and female.

Figure 4: Proportions Of Males And Females With MND, 2006



It is well-known that significantly more females than males are affected by MS (Pozzilli *et al.*, 2002). This phenomenon is supported in Figure 5 which compares the gender profiles of people with MS in the MSS WA, Silver Chain, Perth Home Care and DSC datasets. Figure 5 confirms that there are three times as many women with MS as there are men, irrespective of which organisation is examined.

Figure 5: Proportions Of Males And Females With MS, 2006



The gender split for people with HD is generally thought to be 50:50. Both AHDA and NSU have a large number of HD members and clients, respectively, with about 49 per cent being male. Across the linked dataset, 50 per cent of people with HD are male.

Much of the literature on people with HD has shown that the gender profiles are similar, with males being only slightly less represented than females (Foroud, Gray, Ivashina, & Conneally, 1999; Kirkwood, Su, Conneally, & Foroud, 2001; Kristjanson, Aoun, & Oldham, 2006; Skirton & Glendinning, 1997; US-Venezuela Collaborative Research Project & Wexler, 2004). Analysis of the gender distribution of past NSU clients, however, finds that the proportion of males with HD is slightly higher, at about 55 per cent.

### 4.3 Living Arrangements

One of the influences on the type and quantity of home care support required by people with neurodegenerative disorders is their living arrangements. This incorporates both where they live and with whom. It is expected that people living on their own in a private residence (including public housing) will have greater needs than people living with others, who may or may not be their carer, or who are living in supported accommodation. This is generally true when comparing people with the same level of difficulties, mobility and functionality. The linked dataset, however, has no variables to reflect member or client mobility, difficulties or level or stage of disease. Tables 8 and 9 compare living arrangements in terms of whether or not people have a carer and whether or not they live alone, respectively.

The highlighted cells in Table 8 show proportions calculated using reasonable sample sizes (Lenth, 2001). Samples of size under ten are not useful for extrapolating to larger samples. For example, in the larger datasets in Table 8, it appears that between two thirds and three quarters of people with MS have carers. This contrasts with two people with MS who receive services at home from Mercy Aged Care, only one of whom has a carer. Because of the small sample size ( $n = 2$ ), it would not be useful to use the Mercy Aged Care proportion of fifty per cent to represent the proportion of people with MS who have carers.

Table 8: Comparison Of Members Or Clients: Having A Carer By Disorder, 2006

Agency or Provider	MND % (n)	MS % (n)	HD % (n)
Australian Huntington's Disease Association WA	n.a.	n.a.	83.0 (47)
Brightwater Care Group	0.0 (1)	n.a.	100.0 (1)
Disability Services Commission	82.5 (40)	70.4 (547)	100.0 (2)
Mercy Aged Care	n.a.	50.0 (2)	n.a.
Motor Neurone Disease Association of WA	95.2 (21)	n.a.	n.a.
Multiple Sclerosis Society of WA	0.0 (1)	66.8 (880)	n.a.
Neurological Council of WA	100.0 (2)	100.0 (4)	100.0 (2)
Perth Home Care Services	100.0 (1)	73.7 (19)	66.7 (3)
Silver Chain	79.7 (59)	76.5 (187)	100.1 (1)
WA Department of Health (Neurosciences Unit)	n.a.	n.a.	77.4 (62)

For people with MND, most have carers as seen in the data from DSC (82.5 per cent), MNDAWA (95.2 per cent) and Silver Chain (79.7 per cent). Similarly high proportions of people with HD have carers, 83 per cent of AHDA members and 77.4 per cent of NSU clients.

Table 9: Comparison Of Members Or Clients: Living Alone By Disorder, 2006

Agency or provider	MND % (n)	MS % (n)	HD % (n)
Australian Huntington's Disease Association WA	n.a.	n.a.	14.3 (7)
Brightwater Care Group	100.0 (1)	100.0 (1)	0.0 (1)
Disability Services Commission	11.1 (36)	20.0 (689)	0.0 (2)
Mercy Aged Care	n.a.	50.0 (2)	n.a.
Motor Neurone Disease Association of WA	9.5 (21)	n.a.	n.a.
Multiple Sclerosis Society of WA	100.0 (1)	19.8 (1,190)	n.a.
Neurological Council of WA	0.0 (2)	0.0 (4)	0.0 (2)
Perth Home Care Services	100.0 (1)	14.3 (7)	33.3 (3)
Silver Chain	22.0 (59)	25.8 (198)	0.0 (1)
WA Department of Health (Neurosciences Unit)	n.a.	n.a.	14.3 (7)

Information on whether people lived alone or not was sparse for a number of organisations and this is reflected in the small cell counts for HD and some providers. If we look at the highlighted cells in Table 9, we can see that most people with neurodegenerative disorders who remain at home live with other people. These are usually partners and/or family. There are some differences in the proportions of people who live alone, however, depending on the disorder and the organisation. About ten per cent of people with MND who are clients of DSC and/or members of MNDAWA live alone. Silver Chain data show that 22 per cent of MND clients live alone. About 20 per cent of MSS WA members and DSC clients with MS live alone compared with one quarter of Silver Chain clients.

## 5 SERVICE PROVISION BY DISORDER, 2006

In their study of the home care support needs of high cost clients (reported in Silver Chain, 2003), the cross-agency provider group examined linked data from three major HACC agencies in the metropolitan area servicing 15,462 clients with a total of 508,070 hours of care (excluding respite and centre based day care). Services for these clients averaged 1.26 hours per week. The study reported that less than 2 per cent of these clients used multiple agencies. However, about 18 per cent of high cost clients received services from more than one agency. Of those clients with the highest costs (including respite and centre based day care), one in two accessed multiple agencies for home care support.

In February 2005, after a year of discussion, the cross-agency provider group signed a memorandum of understanding (MOU) that was aimed at, after investigation of the duplication of services, minimising overlapping care for high cost clients that may be neither efficient nor effective. The MOU included the proposal that a single organisation, after consultation with other providers, takes on the case management for an individual high cost client. As the discussion to follow reveals, this approach has been reasonably successful although there are a small number of people who still receive services from a combination of Silver Chain, Perth Home Care, Brightwater and Mercy Aged Care.

The results of the earlier study of high cost clients were instrumental in developing the current collaborative study of the comprehensiveness of the home care support needs of people with neurodegenerative disorders. In this Section, the degree to which people with MND, MS and HD are serviced by different organisations is derived from an analysis of the linked dataset which has been disaggregated by disorder.

Before reporting on the analysis of the linked dataset in terms of services, it is necessary to clarify the terminology being used. The types of organisations are quite different. For example, the support group for people with MND, MNDAWA, provides equipment and advice. It might also provide financial help to members. MNDAWA receives some funding from government but relies heavily on fundraising. A not-for-profit organisation like Silver Chain provides an array of services to clients including domestic assistance, nursing, personal care, social support, equipment and assorted other services. Most of the funding comes from government and there are strict rules about eligibility for services and the amount and type of services that can be provided to clients. For the purposes of the discussion in the Section, both types of organisation will be said to be providing services.

The ten organisations that supplied datasets for the linkage process, and whose provision of services to people with MND, MS and HD are included in the linked dataset, are not the only providers of services to these groups of people. To the extent that other organisations provide similar or diverse services, the contribution of the linked dataset to the understanding of multiple service provision is constrained. Nonetheless, it is thought that the results might be reasonably representative of the help provided to people with these disorders who are living in the community.

Before disaggregating service provision for each disorder, it is useful to look at the frequency of services by disorder. This is shown in Table 10. It should be noted that the last column of Table 10 gives the same information as Column 1 of Table 5. The total of 2,550 is the number of individuals in the linked dataset. About 90 per cent of these have MS whilst the proportions of individuals with MND and HD are 7 per cent and 3.3 per cent, respectively. These proportions are given in brackets in the last row of Table 10. The cells in the centre of the table show the numbers of people in each category, as well as the proportion of the column total that these numbers reflect. The cells in the total column show numbers of people and the proportions of the column total that these numbers represent.

Table 10: Number Of Individuals By Number Of Organisations Providing Services And Disorder, 2006

Number of Organisations	Disorder			Total
	MND	MS	HD	
1	129 (71.3%)	1,446 (63.3%)	52 (61.9%)	1,627 (63.8%)
2	40 (22.1%)	659 (28.8%)	25 (29.8%)	724 (28.4%)
3	12 (6.6%)	161 (7.0%)	5 (5.9%)	178 (7.0%)
4	0	18 (0.8%)	1 (1.2%)	19 (0.7%)
5	0	1 (0.0%)	1 (1.2%)	2 (0.1%)
<b>Total</b>	181 (7.1%)	2,285 (89.6%)	84 (3.3%)	2,550 (100.0%)

There are a number of differences between the distributions of people in each disorder by the number of organisations that provided services to them. These differences are statistically significant at the 5 per cent level ( $\chi^2 = 20.0057, p = 0.010$ ). The proportion of people with HD who have services from more than one organisation (38.1 per cent) is similar to the proportion of people with MS who have multiple services (36.7 per cent) and both are higher than the proportions of people with MND who receive services from at least two organisations (28.7 per cent). Another difference is that there are people in the linked dataset who have either MS or HD and who receive services from more than three organisations. In contrast, people with MND are provided with services from three organisations at most.

## 5.1 Motor Neurone Disease

In this Section, the characteristics of people with MND and the services they receive are explored. Due to missing values on some of the characteristics, some information is not presented. For example, when disaggregated by the number and combinations of organisations providing services, the sample sizes for calculating the proportion of people having a carer or the proportion of people living alone are very small. As mentioned earlier, this is a problem if these characteristics within the profiles are to be used in a broader context.

In terms of socio-demographic characteristics, the linked dataset can produce only two with reasonable reliability – average age and proportion of males – and these are shown in Table 11.

There are a number of interesting results in Table 11. First, the incidence of multiple services decreases as the number of organisations providing services increases. Hence there are 129 people with MND receiving services from only one organisation, 40 receiving services from two organisations and 12 receiving services from three organisations. Of people with MND who are receiving services from one organisation only, 65 per cent ( $n = 84$ ) are members of MNDAWA. These people may be recently diagnosed with few mobility issues, hence they may be only receiving advice in 2006 from the MNDAWA Care Advisors.

Table 11: Age And Gender By Number Of Organisations, MND, 2006

Number of Organisations	Organisation(s)	n	Average Age in Years	Percentage of Males
1	MNDAWA	84	64.7 <sup>a</sup>	65.5
	Silver Chain	18	67.6	72.2
	DSC	27	59.9	63.0
	All receiving one service only	129	64.0 <sup>b</sup>	65.9
2	MNDAWA, Silver Chain	10	65.1	50.0
	Silver Chain, DSC	18	61.6	55.6
	MNDAWA, DSC	7	68.7	42.9
	DSC, Neuro Council	1	60.0	100.0
	MNDAWA, MSS	1	60.0	100.0
	Silver Chain, Brightwater	1	81.0	0.0
	MNDAWA, MSS	1	60.0	0.0
	MSS, Silver Chain	1	49.0	0.0
All receiving two services only	40	63.8	47.5	
3	MNDAWA, Silver Chain, DSC	11	60.7	45.4
	Silver Chain, DSC, Neuro Council	1	47.0	100.0
	All receiving three services only	12	59.6	50.0
	All people with MND in linked dataset	181	63.6 <sup>c</sup>	60.8

Notes: <sup>a</sup> Due to missing dates of birth in the MNDAWA dataset, this average age is calculated with n = 66. <sup>b</sup> Calculated with n = 111. <sup>c</sup> Calculated with n = 163.

For the 18 people with MND who are only receiving services from Silver Chain in 2006, four are receiving only one type of service and the remainder are receiving a combination of nursing, domestic assistance, personal care, equipment and/or other services.

People with MND who are clients of DSC and who receive no services from any other organisation (n = 27) received a variety of DSC services in 2006. Two thirds of these people received DSC funded or supported therapy. Other DSC services provided to this group are case management (n = 6), in home respite (n = 1), other community access services (n = 1), other community support (n = 3) and other services (n = 3). Two people received both case management and therapy services from DSC.

A second result in Table 11 is that, as the number of organisations providing services increases, the average age of the recipients of these services decreases. Thus, the average age of people with MND who are provided with services from one organisation only is 64 years, from two organisations is slightly lower at 63.8 years and from three organisations is 59.6 years. This may reflect the deterioration in functioning and concomitant need for help by younger as opposed to older people with MND. From the interviews and surveys for this project (see NDP Reports No 1 and No 2), a number of older people who have been diagnosed for a longer period need and receive less help than some younger people with more recent diagnoses and more rapid loss of functioning.

A final result in Table 11 is the difference in the gender profile of people with MND who receive services from one or more organisations. That is, about two thirds of people who receive services from only one organisation are men (similar to the profile of people with MND), whereas less than half of people who receive services from two organisations are men. For people with MND who receive services from three organisations, the gender split is 50:50. It is unclear why these differences occur.

## 5.2 Multiple Sclerosis

Two socio-demographic characteristics of people with MS are presented in this Section in terms of the organisations from which they receive services. These are average age and proportion of males. Table 12 summarises this information for the 2,285 people with MS in the linked dataset.

Table 12: Age And Gender By Number Of Organisations, MS, 2006

Number of Organisations	Organisation(s)	n	Average Age in Years	Percentage of Males
1	MSS WA	1,379	52.4 <sup>a</sup>	24.4
	Silver Chain	16	65.6	18.8
	Perth Home Care	48	41.3 <sup>b</sup>	39.6
	DSC	2	40.0	0.0
	Neuro Council	1	51.0	0.0
	All receiving one service only	1,446	52.2 <sup>c</sup>	24.8
2	MSS WA, DSC	622	50.1	26.2
	MSS WA, Perth Home Care	1	55.0	0.0
	MSS WA, Silver Chain	33	61.2	18.2
	Silver Chain, DSC	2	67.5	50.0
	Perth Home Care, Silver Chain	1	57.1	0.0
	All receiving two services only	659	50.6	25.8
3	MSS WA, Silver Chain, DSC	152	57.0	18.4
	MSS WA, DSC, Neuro Council	2	56.5	0.0
	MSS WA, Perth Home Care, DSC	6	54.5	0.0
	MSS WA, Mercy Aged Care, DSC	1	55.0	0.0
	All receiving three services only	161	56.9	17.4
4	MSS WA, Silver Chain, Perth Home Care, DSC	14	58.3	50.0
	MSS WA, Silver Chain, Brightwater, DSC	1	62.0	0.0
	MSS WA, Silver Chain, Mercy Aged Care, DSC	1	70.0	0.0
	MSS WA, Silver Chain, Perth Home Care, Neuro Council	2	57.5	0.0
	All receiving four services only	18	59.1	38.9
5	MSS WA, Silver Chain, Perth Home Care, DSC, Neuro Council	1	48.0	0.0
	All people with MS in linked dataset	2,285	52.1 <sup>d</sup>	24.6

Notes: <sup>a</sup> Due to missing dates of birth in the MSS WA dataset, this average age is calculated with n = 1,332. <sup>b</sup> Date of birth was missing in 1 case. Calculated with n = 47. <sup>c</sup> Calculated with n = 1,398. <sup>d</sup> Calculated with n = 2,237.

Overall, Table 12 shows that there is no apparent correlation between average age and the number of organisations providing services to people with MS. However, when the services represented by the shaded cells (reasonable sample sizes (Lenth, 2001)) are examined, it appears that people with MS requiring only one service tend to be younger (41.3 to 52.4 years) than those who require more than one service (50.1 to 61.2 years).

The gender distribution over all people with MS in the linked dataset is roughly three females to every one male. However, there are a number of shaded cells in Column 3 of Table 12 that show higher or lower proportions of men. The proportion of male MS clients who only receive services from Perth Home Care is higher than the overall proportion, at 39.6 per cent. The proportion of males who receive services from MSS WA and Silver Chain or MSS WA, Silver Chain and DSC is about 18 per cent, lower than the overall proportion. Confounding influences such as availability of a carer or living alone may be influencing these results. However, it is not possible to check these due to missing values.

Also shown in Table 12 are a number of people with MS who receive services from more than one home care service provider. For example, there is one person who receives help from two organisations - Perth Home Care and Silver Chain (nursing). Seventeen others receive help from Perth Home Care and Silver Chain in addition to being members of MSS and clients of Neurological Council and/or Disability Services Commission. One female receives services from five organisations including Silver Chain (nursing, domestic assistance and equipment) and Neurological Council (social support, assessment counselling and care co-ordination).

### 5.3 Huntington's Disease

The smallest group in the linked dataset is people with HD. In 2006, this group numbered 84 individuals. Table 13 shows that average ages ranged from 35 years for a client of NSU and Perth Home Care to 67 years for a client of AHDA, NSU and Silver Chain.

Table 13: Age And Gender By Number Of Organisations, HD, 2006

Number of Organisations	Organisation(s)	n	Average Age in Years	Percentage of Males
1	AHDA	20	56.1 <sup>a</sup>	55.0
	NSU	32	51.8	53.1
	All receiving one service only	52	52.6 <sup>b</sup>	53.8
2	NSU, AHDA	23	51.0	43.5
	NSU, Perth Home Care	1	35.0	0.0
	AHDA, DSC	1	38.0	0.0
	All receiving two services only	25	49.9	40.0
3	AHDA, NSU, DSC	1	43.0	0.0
	AHDA, NSU, Silver Chain	1	67.0	100.0
	AHDA, NSU, Neuro Council	1	64.0	100.0
	AHDA, NSU, Perth Home Care	2	56.5	50.0
	All receiving three services only	5	57.4	60.0
4	AHDA, NSU, Brightwater, Neuro Council	1	64.0	100.0
5	AHDA, NSU, Brightwater, Silver Chain, Perth Home Care	1	59.0	0.0
	All people with HD in linked dataset	84	52.2 <sup>c</sup>	50.0

Notes: <sup>a</sup> Due to missing dates of birth in the AHDA dataset, this average age is calculated with n = 7. <sup>b</sup> Calculated with n = 39. <sup>c</sup> Calculated with n = 71.

The shaded cells in Column 2 show average age for people receiving services from one or two organisations as 51 to 52 years. Small sample sizes for people receiving services from three or more organisations preclude any conclusions being drawn about the correlation of age and amount of servicing.

Half of the HD cohort in the linked dataset is male. There are some differences in proportions of males by number of organisations as can be seen in the shaded cells in Column 3. For example, 55 per cent of members of AHDA who are living at home and receiving only AHDA services are male as are 53 per cent of NSU clients who are living at home and only receiving services from NSU. Interestingly, the proportion of males with HD who are members of AHDA as well as clients of NSU is lower, 43.5 per cent.

Table 13 shows that some people with HD are receiving services from more than one home care service provider. For example, one female is receiving care from Brightwater, Silver Chain (domestic assistance only) and Perth Home Care.

## **6 CONCLUSIONS**

One of the important discoveries in the linkage process and the analyses of the linked dataset described in this report is that missing or inaccurate information dilutes the extent to which the linkage results can be generalised. Unfortunately, due to their organisation-specific purposes, the client and member datasets were not initially comparable. Hence, considerable effort was expended in ensuring that the number of data items common to all datasets was maximised and that the items contained values that adhered to the same coding schema.

It would be useful for organisations, both providers and support agencies, to maintain datasets that comply with a minimum dataset such as the Home and Community Care minimum dataset (HACC MDS) (Department of Health and Ageing, 2006). Not only will this enable more efficient linkage exercises in the future, but it will facilitate comparison of summary statistics that can be reported in, for example, organisation annual reports and funding submissions.

Another outcome of the linkage exercise was being able to estimate the extent of overlap of the mailing lists used for the postal survey. Importantly, it seems that the 3,695 observations in the merged dataset represented 2,550 individuals. That is, three records in every ten are redundant. This result has enabled the response rate for the postal survey to be recalculated from 38 per cent to 54 per cent (see NDP Report No 1 – Client and carer survey results for a discussion of this response rate, and the profile and representativeness of the respondents).

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## ATTACHMENT A: THE LINKAGE KEY

### *About Linkage Keys*

Linkage keys can be constructed for each person's record in a database by combining together specific elements of the data contained in their record.

All support agencies and service providers in the study used the same rules to construct a linkage key for each member or client record. Thus if a member or client is on the database of more than one organisation, they will have the same linkage key in each one. The linkage key will allow data from participating organisations to be matched. Hence we can obtain a more comprehensive picture of how many individuals there are (addresses the problem of double counting) and the services these individuals receive from a variety of providers.

Linkage keys are not a new concept. In fact, they are commonly used within the health and service sectors to collate data from multiple sources so that the total services received can be described. In Western Australia, 'linked' health data has been analysed for over fifteen years with the results influencing policy in several areas.

### *Construction Of The Linkage Key*

The Linkage key used in this study is 14 characters long. It is constructed as follows:

Linkage Key Characters	Source
1 – 3	2 <sup>nd</sup> , 3 <sup>rd</sup> and 5 <sup>th</sup> letters of the family name (surname)
4 – 5	2 <sup>nd</sup> and 3 <sup>rd</sup> letters of the first (given) name
6 – 13	date of birth (DDMMYYYY)
14	gender (M = 1 / F = 2)

The Linkage key variable then becomes another variable in the database.

In the event of missing or incomplete source variables, there are two basic rules – one for missing parts of a variable and one for missing variables. That is, if any letters of either surname or first name are missing, a 2 is substituted. If a surname or first name is missing, then 99 is used. If date of birth is missing, then 99999999 is used.

**ATTACHMENT B: MNDAWA MEMBERSHIP 1996 TO 2006**

*Table B1: MNDAWA Membership Retention, 2002 to 2006*

Year of Joining	New Members	Membership <sup>a</sup> At Year's End											Actual 2006	Unknown 2006
		1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006		
1996	10	10	6	5	2	2	2	2	2	2	2	2	1	1
1997	28		25	16	11	7	7	7	7	6	6	6	3	3
1998	25			20	14	10	7	6	5	4	4	4	2	2
1999	45				34	19	15	10	8	7	6	5	4	1
2000	43					38	25	17	11	7	6	6	3	3
2001	36						29	19	13	5	4	4	2	2
2002	26							20	10	7	5	5	4	1
2003	56								45	30	24	18	16	2
2004	45									32	19	13	13	0
2005	40										33	18	16	2
2006	35											29	28	1
	389	10	31	41	61	76	85	81	101	100	109	110	92	18

Figure B2: Percentage Of Deceased And Current Members By Year Of Joining MNDAWA, As At 2006

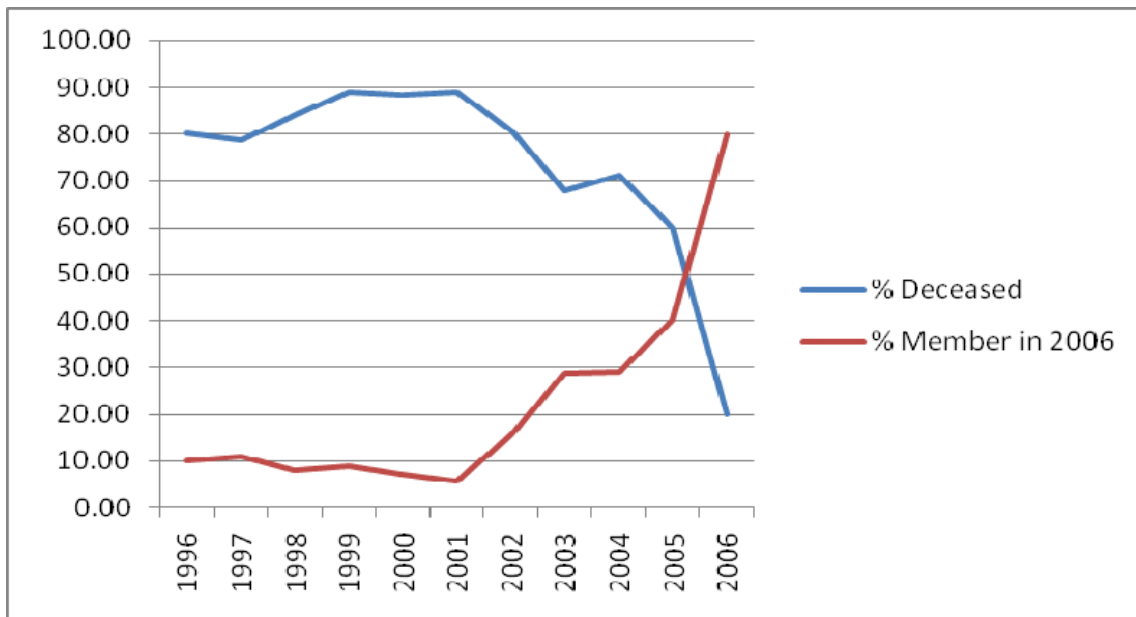


Table B3: Service Length By Year Of Joining MNDAWA 1996 To 2006

Year of Joining	Service Length <i>n</i>	Average Age at Joining <i>n</i>	Average Age at Death <i>n</i>	Current Age <i>n</i>
1996	2.78 9	68.5 8	68.4 7	88.0 1
1997	2.60 25	65.8 27	68.2 21	71.2 6
1998	2.35 23	62.8 20	67.2 16	58.2 4
1999	2.09 44	60.3 24	62.4 20	64.0 4
2000	2.24 41	61.5 30	64.4 26	57.8 4
2001	1.76 34	64.8 27	66.5 24	66.0 3
2002	1.52 25	65.1 21	65.1 18	74.0 3
2003	1.72 54	67.6 41	70.3 27	66.6 14
2004	1.13 45	62.9 34	64.8 24	61.3 10
2005	0.82 40	63.9 33	65.8 20	62.1 13
2006	0 35	64.1 30	72.8 5	62.2 25
1996 - 2006	1.61 375	64.2 295	66.4 208	63.9 87

Table B4: Service Length By Year Of Joining MNDAWA 1996 To 2006

Characteristic	Number of Members	Mean Age	Standard deviation	Maximum Age	Minimum Age
Current age	101	64.81	13.8540	103	28
Male	64	65.41	14.2837	103	32
Female	37	63.78	13.2059	87	28
Age at diagnosis	270	61.74	14.4400	100	18
Male	163	61.19	13.9202	100	25
Female	107	62.58	15.2260	87	18
Age at death	231	66.14	13.3824	103	18
Male	140	65.64	13.3827	103	37
Female	91	66.92	13.4183	91	18
Age at joining	295	64.18	13.6168	100	19
Male	178	63.52	13.6009	100	26
Female	117	65.17	13.6390	88	19
Service length	375	1.61	1.7591	10	0
Male	220	1.69	1.8542	10	0
Female	155	1.49	1.6131	9	0

**ATTACHMENT C: DSC NDD CLIENTS 2002 TO 2006**

*Table C1: Numbers And Percentages Of Clients By Disorder And Gender, 2002 to 2006*

Disorder	2002		2003		2004		2005		2006	
	N	%	N	%	N	%	N	%	N	%
MND										
Male	26	55.3	28	53.8	37	57.8	32	58.2	51	58.6
Female	21	44.7	24	46.2	27	42.2	23	41.8	36	41.4
All	47	4.0	52	4.7	64	4.7	55	4.1	87	6.8
MS										
Male	291	26.2	264	25.8	385	28.3	400	32.1	326	28.0
Female	818	73.8	760	74.2	885	69.7	847	67.9	838	72.0
All	1109	94.0	1024	92.8	1270	93.4	1247	93.7	1164	91.0
HD										
Male	11	52.4	12	52.2	9	52.9	11	52.4	8	40.0
Female	10	47.6	11	47.8	8	47.1	10	47.6	12	60.0
All	21	1.8	23	2.1	17	1.3	21	1.6	20	1.6
PD										
Male	3	100.0	3	60.0	4	44.4	3	37.5	3	37.5
Female	0	0.0	2	40.0	5	55.5	5	62.5	5	62.5
All	3	0.3	5	0.5	9	0.7	8	0.6	8	0.6
Total										
Male	331	-	307	-	435	-	446	-	388	-
Female	849	-	797	-	925	-	885	-	891	-
All	1180	-	1104	-	1360	-	1331	-	1279	-

Row percentages by gender are the proportions of the disorder group with the corresponding gender. For example, 55.3 per cent of DSC clients with MND in 2002 are male. The row percentages for all people in each disorder groups are the proportions of all clients in the corresponding year with each disorder. For example, 4 per cent of DSC clients in 2002 had MND.

Figure C2: Mean Age Of Clients By Disorder And Gender, 2002 To 2006

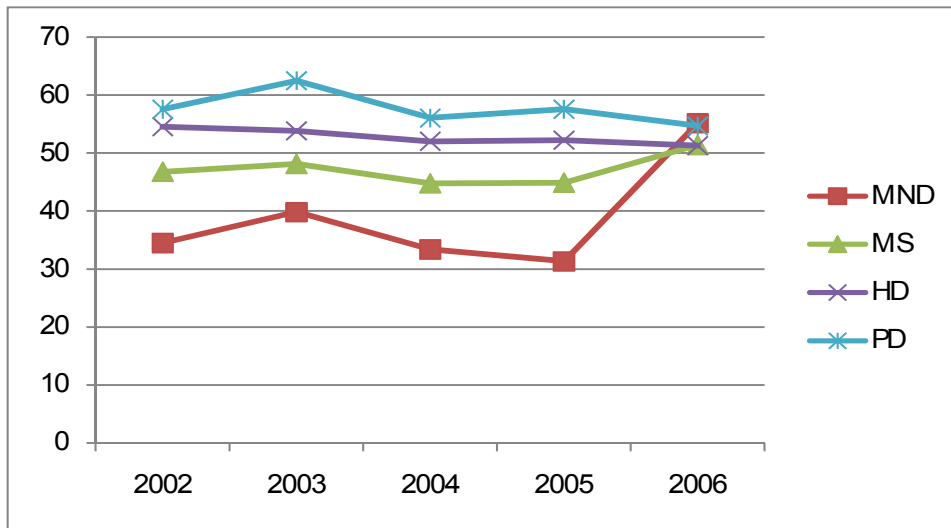


Figure C3: Metropolitan Clients As A Percentage Of All Clients, 2002 To 2006

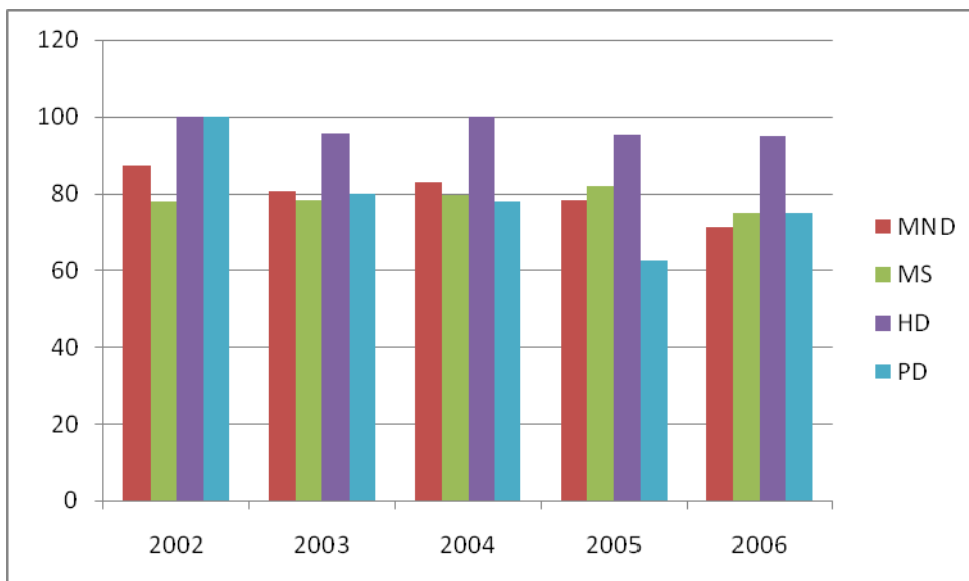


Figure C5: Percentage Of All Clients Who Are Living Alone, 2002 To 2006

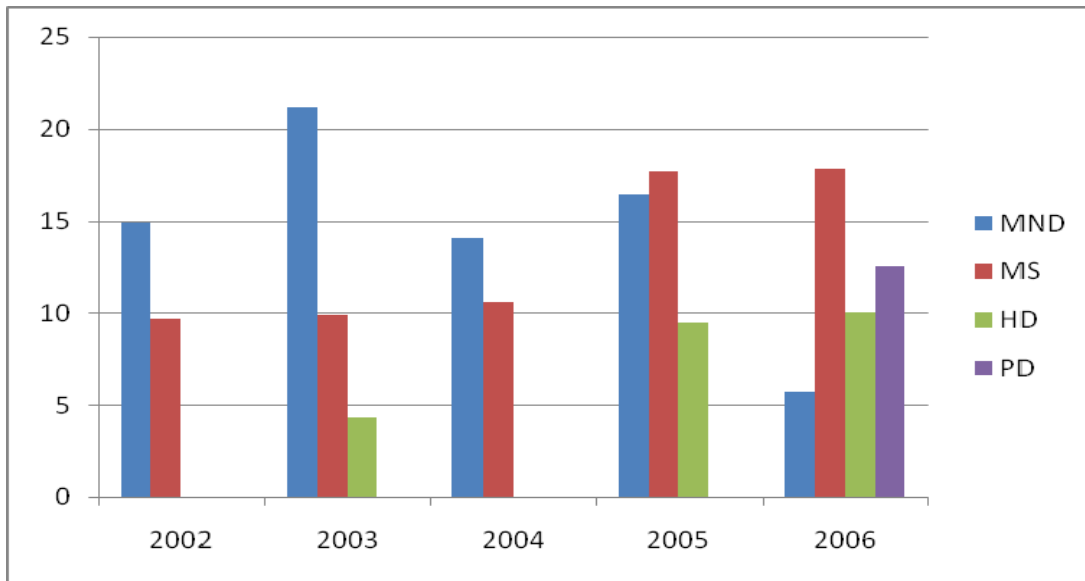


Figure C6: Percentage Of All Clients Who Have Carers, 2002 To 2006

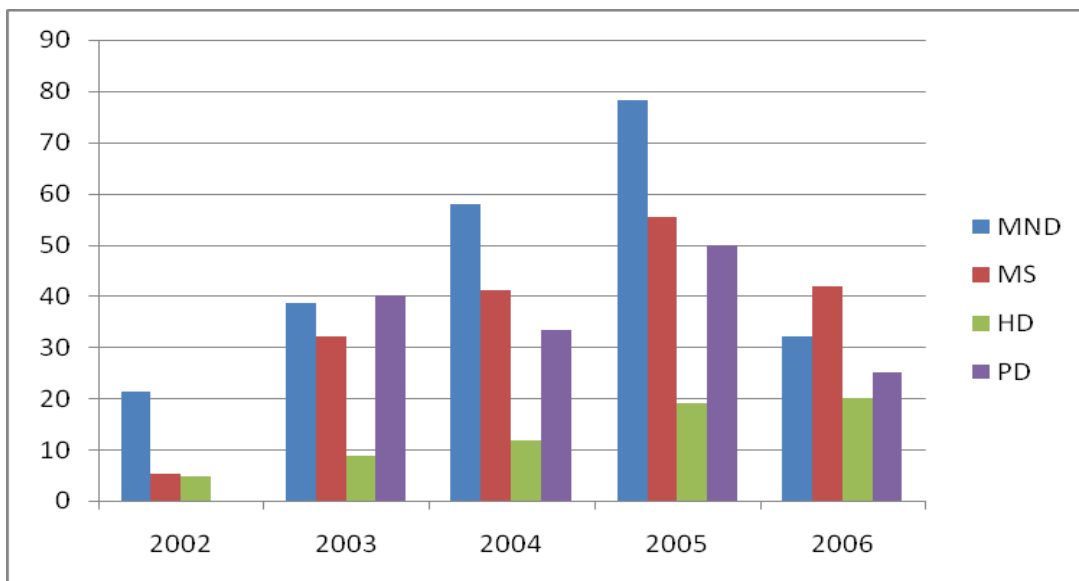


Figure C7: Percentage Of All Clients Who Have Carers That Reside With Them, 2002 To 2006

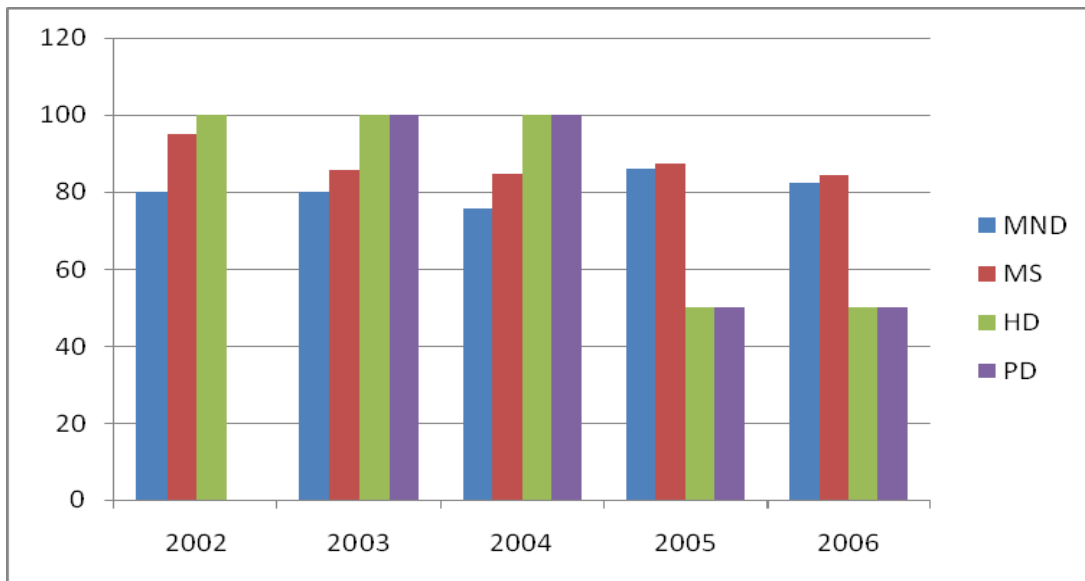
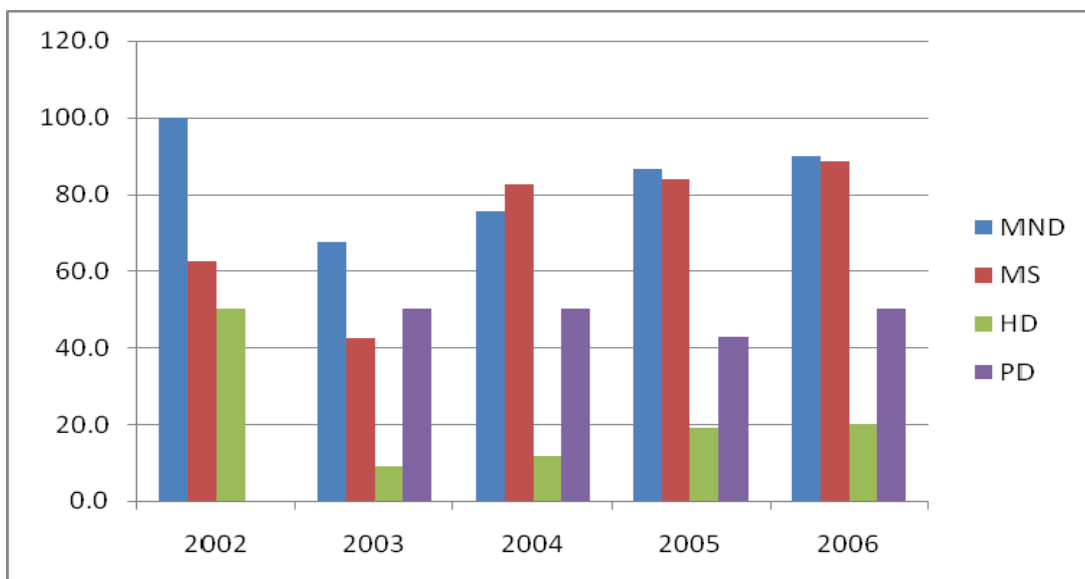
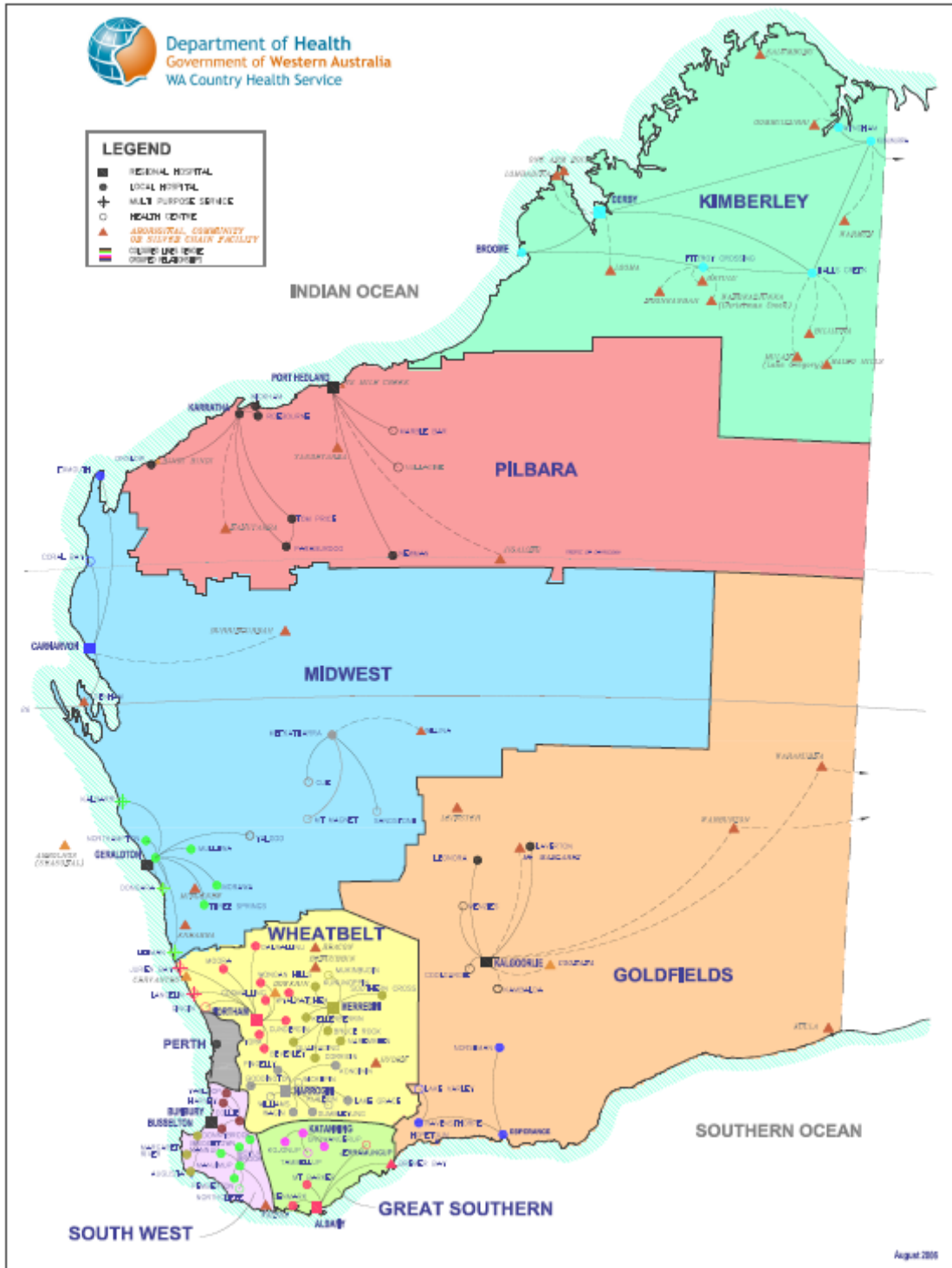


Figure C8: Percentage Of All Clients Who Live In Private Residences Or Independent Living Units, 2002 To 2006



**ATTACHMENT D: WA COUNTRY REGIONS**

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



## ATTACHMENT E: LINKAGE DATA MASTER VARIABLES, LABELS AND CODES

No	Variable Name <sup>a</sup>	Variable Label	Type of Variable <sup>b</sup>	Variable Format <sup>c</sup>	Value Label (for categorical variables) <sup>d</sup>	Variable Values
1	LINKAGEKEY	Linkage key	str14	%14s		
2	Disease	Disease type	byte	%10.0g	Disease	1. MND 2. MS 3. HD 4. PD
3	No_orgs	Number of organisations	byte	%9.0g		
4	MNDAWA	Motor Neurone Disease Association of WA	float	%9.0g	Dummy	1. MNDAWA member 0. Not MNDAWA member
5	MSS	Multiple Sclerosis Society of WA	float	%9.0g	Dummy	1. MSS member 0. Not MSS member
6	AHDA	Australian Huntington's Disease Association of WA	float	%9.0g	Dummy	1. AHDA member 0. Not AHDA member
7	PWA	Parkinson's WA	float	%9.0g	Dummy	1. PWA member 0. Not PWA member
8	Silver Chain	Silver Chain	float	%9.0g	Dummy	1. Silver Chain client 0. Not Silver Chain client
9	Brightwater	Brightwater	float	%9.0g	Dummy	1. Brightwater client 0. Not Brightwater client
10	Mercy_Aged_Care	Mercy Aged Care	float	%9.0g	Dummy	1. Mercy Aged Care client 0. Not Mercy Aged Care client
11	Perth_Home_Care	Perth Home Care	float	%9.0g	Dummy	1. Perth Home Care client 0. Not Perth Home Care client
12	NSU	Neurosciences Unit	float	%9.0g	Dummy	1. NSU client 0. Not NSC client
13	DSC	Disability Services Commission	float	%9.0g	Dummy	1. DSC client 0. Not DSC client
14	Neuro Council	Neurological Council	float	%9.0g	Dummy	1. Neurological Council client 0. Not Neurological Council client
15	Postcode	Postcode	int	%10.0g		
16	Date_of_birth	Date of birth	int	%dD_m_Y		

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No	Variable Name <sup>a</sup>	Variable Label	Type of Variable <sup>b</sup>	Variable Format <sup>c</sup>	Value Label (for categorical variables) <sup>d</sup>	Variable Values
17	Gender	Gender	byte	%10.0g	Gender	1. Male 2. Female
18	Date_of_diagnosis	Date of diagnosis	int	%dD_m_Y		
19	Year_joined	Year joined or services commenced	int	%10.0g		
20	Date_of_death	Date of death	int	%dD_m_Y		
21	Age_at_diagnosis	Age at diagnosis	float	%9.0f		
22	Age_at_death	Age at death	float	%9.0f		
23	Deceased	Whether or not deceased	byte	%9.0g	Deceased	1. Deceased (known) 2. Not deceased or unknown
24	No_dob	No date of birth	byte	%9.0g	No_dob	1. No date of birth 0. Has date of birth
25	Age_at_joining	Age at joining or services started	float	%9.0f		
26	Service_length	Length of service or membership	int	%9.0g		
27	Age_current	Current age	float	%9.0f		
28	Metro	Location of residence	byte	%9.0g	Metro	1. Metro WA 0. Country WA 8. Not WA 9. Not known
29	Lives_alone1	Whether lives alone or not	byte	%9.0g	Lives_alone1	1. Lives alone 0. Does not live alone 9. Unknown
30	Lives_alone2	Who client lives with	byte	%9.0g	Lives_alone2	1. Lives alone 2. Lives with dependent children 3. Lives with partner 4. Lives with partner and children 5. Lives with other relatives or family 6. Lives with parents 7. Lives with others 9. Unknown

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No	Variable Name <sup>a</sup>	Variable Label	Type of Variable <sup>b</sup>	Variable Format <sup>c</sup>	Value Label (for categorical variables) <sup>d</sup>	Variable Values
31	Carer	Whether client has a carer or not	byte	%9.0g	Carer	1. Client has carer 0. No carer 9. Unknown
32	Carer_resides	Whether carer lives with client or not	byte	%9.0g	Carer_resides	1. Carer lives with client 0. Carer does not live with client 8. No carer 9. Unknown
33	Residence_type	Type of home residence	byte	%9.0g	Residence_type	1. Private residence 2. Residential aged care facility 3. Hospital 4. Independent living unit 5. Supported accommodation 6. Group home 7. Other 9. Unknown
34	NCService_type	Service type	byte	%9.0g	NCservice_type	1. Social support 2. Respite 9. Not applicable
35	MSSClient_type	MSS type of client	byte	%9.0g	MSSClient_type	1. Member 2. Associate member 3. Hospital Liaison nurse client 4. Immunotherapy client 5. Respite client 9. Unknown
36	How_long	Years since diagnosis	byte	%9.0g		
37	PHCClient type	PHC type of client	byte	%9.0g	PHCClient type	1. Client 2. Respite client 9. Unknown
38	PHC_Servhrs	PHC service hours at Dec 31 2006	float	%9.2f		
39	DSC_CASEM	Whether DSC client receives case management services	byte	%9.0g	Dummy	0. No 1. Yes 9. Not applicable

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<b>No</b>	<b>Variable Name<sup>a</sup></b>	<b>Variable Label</b>	<b>Type of Variable<sup>b</sup></b>	<b>Variable Format<sup>c</sup></b>	<b>Value Label (for categorical variables)<sup>d</sup></b>	<b>Variable Values</b>
40	CountCASEM	How many case management services received by client	byte	%9.0g		
41	DSC_INHOME	Whether DSC client receives in home support services	byte	%9.0g	Dummy	0. No 1. Yes 9. Not applicable
42	CountINHOME	How many in home support services received by client	byte	%9.0g		
43	DSC_THERAPY	Whether DSC client receives therapy services	byte	%9.0g	Dummy	0. No 1. Yes 9. Not applicable
44	CountTHERAPY	How many therapy services received by client	byte	%9.0g		
45	DSC_CBRESP	Whether DSC client uses centre-based respite	byte	%9.0g	Dummy	0. No 1. Yes 9. Not applicable
46	CountCBRESP	How many occasions of centre-based respite used by client	byte	%9.0g		
47	DSC_OTHERCA	Whether DSC client receives other community access services	byte	%9.0g	Dummy	0. No 1. Yes 9. Not applicable
48	CountOTHERCA	How many other community access services received by client	byte	%9.0g		
49	DSC_OCSUPP	Whether DSC client receives other community support services	byte	%9.0g	Dummy	0. No 1. Yes 9. Not applicable
50	CountOCSUPP	How many other community support services received by client	byte	%9.0g		
51	DSC_Otherserv	Whether DSC client receives any other DSC services	byte	%9.0g	Dummy	0. No 1. Yes 9. Not applicable
52	Non_ATSI	Whether or not ATSI	byte	%9.0g	Non_ATSI	0. ATSI 1. Non-ATSI 9. Unknown

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No	Variable Name <sup>a</sup>	Variable Label	Type of Variable <sup>b</sup>	Variable Format <sup>c</sup>	Value Label (for categorical variables) <sup>d</sup>	Variable Values
53	Language	Language	byte	%9.0g		
54	Country	Country of birth	byte	%9.0g		
55	Pension_status	Pension status	byte	%9.0g		
56	SC_stream	Silver Chain stream	byte	%9.0g		
57	SCtotal_serv	Total number of Silver Chain services received	byte	%9.0g		
58	Year_last	Year of last Silver Chain service	byte	%9.0g		
59	SC_Nursing	Whether SC client received any nursing services	byte	%9.0g		
60	NUhours	How many hours of nursing services in total	byte	%9.0g		
61	SC_Homehelp	Whether SC client received any home help hours	byte	%9.0g		
62	HHhours	How many hours of home help services in total	byte	%9.0g		
63	SC_Personalcare	Whether SC client received any personal care services	byte	%9.0g		
64	PChours	How many hours of personal care services in total	byte	%9.0g		
65	SC_Equip	Whether SC client received any equipment	byte	%9.0g		
66	EQhours	How many hours of equipment-related services in total	byte	%9.0g		
67	SC_Otherserv	Whether SC client received any other type of services	byte	%9.0g		
68	Otherhours	How many hours of other services in total	byte	%9.0g		
69	Living_at_home	Whether or not client is living at home	byte	%9.0g		

No	Variable Name <sup>a</sup>	Variable Label	Type of Variable <sup>b</sup>	Variable Format <sup>c</sup>	Value Label (for categorical variables) <sup>d</sup>	Variable Values
70	MNDserv		byte	%9.0g		<ol style="list-style-type: none"> <li>1. MNDAWA</li> <li>2. Silver Chain</li> <li>3. DSC</li> <li>4. MNDAWA and Silver Chain</li> <li>5. Silver Chain and DSC</li> <li>6. MNDAWA and DSC</li> <li>7. DSC and Neuro Council</li> <li>8. MNDAWA and PHC</li> <li>9. Silver Chain and Brightwater</li> <li>10. MNDAWA and MSS</li> <li>11. MSS and Silver Chain</li> <li>12. MNDAWA, Silver Chain and DSC</li> <li>13. Silver Chain, DSC and Neuro Council</li> </ol>

No	Variable Name <sup>a</sup>	Variable Label	Type of Variable <sup>b</sup>	Variable Format <sup>c</sup>	Value Label (for categorical variables) <sup>d</sup>	Variable Values
71	MSSserv		byte	%9.0g		<ol style="list-style-type: none"> <li>1. MSS</li> <li>2. Silver Chain</li> <li>3. PHC</li> <li>4. DSC</li> <li>5. Neuro Council</li> <li>6. MSS and DSC</li> <li>7. MSS and PHC</li> <li>8. MSS and Silver Chain</li> <li>9. Silver Chain and DSC</li> <li>10. PHC and Silver Chain</li> <li>11. MSS, Silver Chain and DSC</li> <li>12. MSS, DSC and Neuro Council</li> <li>13. MSS, PHC and DSC</li> <li>14. MSS, Mercy Aged Care and DSC</li> <li>15. MSS, Silver Chain, PHC and DSC</li> <li>16. MSS, Silver Chain, Brightwater and DSC</li> <li>17. MSS, Silver Chain, Mercy Aged Care and DSC</li> <li>18. MSS, Silver Chain, PHC and Neuro Council</li> <li>19. MSS, Silver Chain, PHC, DSC, Neuro Council</li> </ol>

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No	Variable Name <sup>a</sup>	Variable Label	Type of Variable <sup>b</sup>	Variable Format <sup>c</sup>	Value Label (for categorical variables) <sup>d</sup>	Variable Values
72	HDserv		byte	%9.0g		<ol style="list-style-type: none"> <li>1. AHDA</li> <li>2. NSU</li> <li>3. Brightwater</li> <li>4. NSU and AHDA</li> <li>5. NSU and PHC</li> <li>6. AHDA and DSC</li> <li>7. AHDA, NSU and DSC</li> <li>8. AHDA, Silver Chain and NSU</li> <li>9. AHDA, NSU and Neuro Council</li> <li>10. AHDA, PHC and NSU</li> <li>11. AHDA, Brightwater, NSU and DSC</li> <li>12. AHDA, Brightwater, NSU and Neuro Council</li> <li>13. AHDA, Silver Chain, Brightwater, PHC and NSU</li> </ol>

Notes: <sup>a</sup> Variable name in the Stata dataset. <sup>b</sup> <sup>c</sup> Stata formatting requirements. <sup>d</sup> Stata requires user-defined labels for coding categorical and dummy variables.