

# Towards a More Cohesive MS Network of Care in the Northern Rivers Region of NSW

## Pathways Project Discussion Paper

### Evaluating Multiple Sclerosis Service Delivery

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Date: 17 July 2008

The Pathways Project is a three part process. The first part of which involved mapping regional approaches to service delivery against a knowledge base, road testing benchmarks suggested by MS Australia and identifying and prioritising regional shortfalls in service accessibility.

Part 2 involved dialogue with and between key agencies and service providers regarding addressing the Part 1 issues and outcomes.

Part 3 identifies significant ongoing unresolved issues. At first glance this may appear to be a protracted process - however the progressive and cumulative outcomes of the overall process have given rise to many benefits to pwMS.

This document relates to the background research associated with Part 1

<http://www.msnetwork.org/horizon/pathways.htm>

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#### The Pathways Project

An Advocacy Project of the Northern Rivers Multiple Sclerosis Network of Care

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## ACRONYMS

CRS	Commonwealth Rehabilitation Service
DADHC	Department of Ageing, Disability and Home Care
MRI	Magnetic Resonance Imaging
MS	Multiple Sclerosis
NCAHS	North Coast Area Health Service
pwMS	Person With Multiple Sclerosis
QoL	Quality of Life

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# 1 EXECUTIVE SUMMARY

## Context and purpose

The Pathways Project is an initiative of the Northern Rivers Multiple Sclerosis [Network of Care](#), a consumer support organisation which aims to increase the access of people with multiple sclerosis (MS) in the Northern Rivers region to services which improve their perceptions of Quality of Life (QoL). The Northern Rivers region is that section of the North Coast Area Health Services between Grafton and Tweed Heads. Formerly the Northern Rivers Area Health service, it now forms part of the larger North Coast Area Health Service.

In the Northern Rivers region, especially since 2002, a number of important MS referral pathways have been discontinued without the provision of reasonably accessible alternatives. This is happening at a time when the MS population in the region is increasing significantly.

*The purpose of this discussion paper is to provide an evidence based framework for discussion with health and community service decision makers about the most pressing service needs of people with MS and options for addressing those needs. In light of recent changes to service provision and resultant gaps, this is now urgent.*

Access Economics, in a study (2005) titled 'Acting Positively - The Strategic Implications of MS in Australia', found that people with MS (pwMS) are over-represented in rural and regional areas, where access to services (particularly respite) and workforce adequacy (notably medical) is poorest.

The Northern Rivers is the fastest growing region in Australia with population increases around double the national average. Anecdotal evidence is that this significant population movement is contributing to an increasing prevalence of MS. A further contributing factor is the increasing rate of MS diagnosis - Australia wide, it is being diagnosed at a rate that exceeds the annual population growth rate with in excess of 1000 people Australia wide newly diagnosed each year. The 2008 population nationally was 18,000. 74% of all cases are women.

## The target population

The majority of people with MS do not become severely disabled. Longitudinal studies have shown that around 50% of people with MS are independently mobile after 15 years and can live normal and productive lives. The focus of the Pathways Project is primarily about the 50% of people who, because of MS, are *not able to live* normal and productive lives. It is estimated that approximately 150 moderately and severely disabled individuals fall into this group in the Northern Rivers region.

## What this paper does

This paper draws on Australian and international research to:

- determine the prevalence of MS in the Northern Rivers, and ascertain specific numbers in the target population
- describe best practice in terms of the services pwMS need
- outline current service arrangements and recent changes
- identify gaps using an evidence-based framework developed in the UK, and rating service benchmarks in light of local feedback and knowledge
- propose priorities for service development to benefit pwMS in the Northern Rivers region.

## The challenge of MS

MS is one of the most common chronic diseases of the central nervous system among young adults in Australia, primarily affecting people between the ages of 20 and 40. Its course is unpredictable. While there is no known cure, nor any way of repairing the progressive outcomes of nervous system damage, there is a range of treatments that may delay its progression

Symptoms and their severity are completely unpredictable and differ enormously. They may include loss of balance and co-ordination, diminished vision, weakness of limbs, extreme fatigue (especially during hot weather), impaired speech and loss of bladder control. A person with MS might experience one, several or all of these symptoms, depending on the location and extent of damage to nerve tissue.

It is estimated that between 45% and 65% of all people with MS experience problems with memory, attention, word-finding, problem-solving, or other cognitive functions as a symptom of the disease. These cognitive changes can vary considerably from one person to another, both in type and severity.

MS Australia, in a submission (2008) to the Australian Government, observed that *'people with MS pose a significant challenge due to the changing nature of their condition which does not respect waiting lists'*. The often progressive and cumulative nature of MS related issues, frequently with little or no forewarning, is at the heart of this challenge.

The submission went on to describe the challenge in terms of the need for *'dedicated lifetime continuous care.'* It highlighted the need for improved coordination in the delivery of dedicated lifetime continuous care programs and services (including respite) for people with MS. It confirmed that Australians living with MS and their families need viable alternative care models to those currently available. Many support programs are designed for static disability groups or ageing, and do not cope with increasing and

changing needs. A further priority in dealing with the unmet demand is overhauling the interfaces of the various care and support programs with and across government jurisdictions.

### **What services do people with MS need?**

A good starting point in matching expectations with outcomes is for services to be delivered in ways that are consistent with the *Guiding Principles for the Provision of Services to people with MS*. Originally developed by the Multiple Sclerosis Society of Great Britain and Northern Ireland, these four principles have broad application in all areas of service delivery to people affected by MS and are reflected in a number of subsequent studies. They are:

- ✓ Maximizing personal potential
- ✓ Involvement and influence of people affected by MS
- ✓ A holistic approach to service provision
- ✓ Meeting agreed standards.

It is not necessary for Australia to “reinvent the wheel” in order to determine the referral pathways that best meet the needs of pwMS. In 2002 The MS Society of the UK, together with clinicians and the MS Community collaborated to develop internationally researched standards to serve as a guide for the development and provision of services to meet the varying needs of people with MS across the continuum of the disease. These standards are included in the publication *‘Developing MS Healthcare Standards - Evidence based recommendations for Service Providers’*. They are built around 43 service delivery benchmarks which serve as a guide for the development and provision of services to meet the varying needs of people with MS across the continuum of the disease. A full set of the benchmarks are reproduced at Section 5.3, where they are used as a framework for identifying gaps in service delivery in the Northern Rivers region.

The benchmarks are distributed across the four 'phases' of MS care needs, which are regularly identified in research. While each phase reflects a number of key issues and approaches to service provision, they do not reflect an individual's disease progression. Rather, they provide a pragmatic framework for discussion and a structure that enables the systematic identification of a wide-ranging list of service needs. Each phase has different implications for service delivery. The four phases are:

1. Diagnostic phase
2. Minimal impairment phase
3. Moderate disability phase
4. Severe disability phase.

The focus of this paper is on the moderate and severe disability phases, where support is needed. One key referral pathway especially relevant to these last two phases is rehabilitation. This paper explains the research that supports the view that achievement and maintenance of optimal function are essential in a progressive disease such as MS.

Timely access to rehabilitation services is essential when there is an abrupt or gradual worsening of function or increase in impairment that has a significant impact on the individual's mobility, safety, independence, and/or quality of life.

#### **Current service arrangements and recent changes**

Current service arrangements are outlined in this paper, and include:

- The MS Society of NSW/Victoria
- General practitioner services
- Specialist services
- Hospital services – inpatient and outpatient
- Education, information and support services
- Private practitioner services – allied health and complementary therapies.

While there is considerable variability in the quality, availability of and access by pwMS to these services, a major concern of the Network of Care is the discontinuation of two key services –

- An MS specific multi disciplinary assessment team and subsequent transport of people to Sydney to access the Society's specialised MS services, provided by the MS Society with the support of the Royal Flying Doctor Service (RFDS). This was discontinued around 2002.
- Multi disciplinary rehabilitation services provided by St Vincent's Hospital on behalf of the Northern Rivers Area Health Service between 2003 -2006, and discontinued as a public health service in 2006.

The process of identifying gaps in service provision, using an evidence-based framework developed in the UK, shows how critical these services were, and are, for pwMS, their families and carers.

#### **Identifying gaps and priorities**

The Northern Rivers Multiple Sclerosis Network of Care receives regular feedback from the regional MS Community about ways to enhance the relevance and delivery of MS support services in a regional context. A recurring theme relates to imbalances between matching the needs, issues and expectations of people with MS with relevant and accessible levels of service delivery. Frustrations flowing from these imbalances have a negative impact for both service providers and those in need of care.

The Planning Group of the Northern Rivers MS Network of Care has used the benchmarks described earlier as a framework within which to identify gaps in services in the Northern Rivers region. Using a simple rating methodology, a set of gaps have emerged that are consistent with views of local consumers and professionals alike. These are shown in Section 5.3.

From these gaps, the Planning Group has reached agreement on a **consolidated set of five priorities underpinned by five guidelines**, for advocacy purposes. Responsibility for providing these services ranges from NSW Health, DADHC and the MS Society, individually or in collaboration.

The priorities are as follows:

1. A core multi disciplinary professional team, with expertise in MS management, accessible locally for *assessment and treatment* of MS. Associated services to include:
  - Accurate information and skilled advice about lifestyle issues and symptoms to help people make informed decisions.
  - Counselling for individuals and families by trained counsellors familiar with MC/chronic illness, covering psychosocial and coping issues.
2. Inpatient and outpatient *rehabilitation* services.
3. *Respite* facilities in an appropriate setting.
4. *Education and training programs* for staff and carers. Staff to be trained in the physical, psychological and psychosocial problems that occur in the later stages of MS.
5. Efficient community *transport* for severely disabled pwMS.

These priorities are to be underpinned by **five key guidelines**:

1. Self management to be encouraged at all times.
2. Use of coordinated and individual care management plans to occur at all stages of the care process that include options for self referral and scheduled recall to assessment and rehabilitation services.
3. PwMS participate fully and make decisions about their support and care, with information and advice to help them make such decisions.
4. Service users and carers are involved in planning and provision of services.
5. There are clear standards for measuring success, to facilitate service improvement.

#### **The special needs of carers**

While the 43 benchmarks appear to cover all aspects of service delivery to people with MS, the Planning Group has noted that they do not deal adequately with the needs of carers. The Group will consider these needs through a supplementary paper as its next advocacy priority.

#### **The way forward**

This paper has been prepared for use in discussion with relevant health and community services agencies about how to better meet the needs of pwMS in the Northern Rivers. As a result of those discussions, it is expected that greater clarity will emerge about

existing services and their capacity to enhance access for pwMS. In addition, it is clear that some new services will be needed, at a minimum to replace those that have existed previously. The Network of Care is interested in participating in discussions about models of care that are evidence based, feasible in terms of resources and optimise accessibility for pwMS across the Northern Rivers region.

## 2 INTRODUCTION AND BACKGROUND

### 2.1 The Pathways Project

The Pathways Project is an initiative of the Northern Rivers Multiple Sclerosis Network of Care, a consumer support organisation which aims to increase the access of people with multiple sclerosis (MS) in the Northern Rivers region to services which improve their perceptions of Quality of Life (QoL). The Northern Rivers region is that section of the North Coast Area Health Services between Grafton and Tweed Heads. Formerly the Northern Rivers Area Health service; it now forms part of the larger North Coast Area health Service.

In the Northern Rivers region, especially since 2002, a number of important MS referral pathways have been discontinued without the provision of reasonably accessible alternatives. This is happening at a time when the MS population in the region is increasing significantly.

The Pathways Project aims to achieve its objectives by:

- creating awareness of the nature and extent of service delivery shortfalls in the Area, and the resulting impact on people with MS., their families, community and workplace; and
- advocating for the provision of appropriate infrastructure to address these shortfalls , for targeted training for service providers, and for more proactive support for carers of people with MS.

Improved access by people with MS to appropriate services will help to optimise their functionality and well-being, thus minimising long-term costs to families and the community.

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Access Economics, in a study (2005) titled 'Acting Positively - The Strategic Implications of MS in Australia', found that people with MS are over-represented in rural and regional areas, where access to services (particularly respite) and workforce adequacy (notably medical) is poorest.

The Northern Rivers is the fastest growing region in Australia with population increases around double the national average. Anecdotal evidence is that this significant population movement is contributing to an increasing prevalence of MS. A further contributing factor is the increasing rate of MS diagnosis - Australia wide it is being diagnosed at a rate that exceeds the annual population growth rate with in excess of

1000 people Australia wide newly diagnosed each year. The 2008 population nationally was 18,000. 74% of all cases are women.

The majority of people with MS do not become severely disabled. Longitudinal studies have shown that around 50% of people with MS are independently mobile after 15 years and can live normal and productive lives. The focus of the Pathways Project is primarily about the 50% of people who, because of MS, are *not able to live* normal and productive lives. It is estimated that approximately 150 individuals fall into this group in the Northern Rivers region.

## **2.2 What is MS?**

MS is one of the most common chronic diseases of the central nervous system among young adults in Australia, primarily affecting people between the ages of 20 and 40. Its course is unpredictable. MS occurs more commonly in geographical areas further away from the equator. While there is no known cure, there is a range of treatments that may delay its progression.

MS causes damage and deterioration of the myelin covering which surrounds nerve fibres in the central nervous system. Myelin acts as an insulator and helps conduct nerve pulses or messages from nerve endings to the brain and visa versa. Scarring of the myelin causes a slowing down, distortion or, in severe cases, complete blockage of the flow of messages from the nerves to the brain and back again.

### **How is MS diagnosed?**

MS is not easy to diagnose. There is no specific test that shows a person has MS, and it shows up differently in each person. MS is typically diagnosed by observing the occurrence of symptoms over a period of time, combined with the results of medical tests. That is why there is always a delay between the appearance of symptoms and the diagnosis of MS. In addition to neurological examination and a comprehensive medical history, common medical tests include magnetic resonance imaging (MRI), lumbar puncture and evoked potentials.

### **What are the symptoms?**

Symptoms and their severity are completely unpredictable and differ enormously. They may include loss of balance and co-ordination, diminished vision, weakness of limbs, extreme fatigue (especially during hot weather), impaired speech and loss of bladder control. A person with MS might experience one, several or all of these symptoms, depending on the location and extent of damage to nerve tissue.

It is estimated that between 45% and 65% of all people with MS (pwMS) experience problems with memory, attention, word-finding, problem-solving, or other cognitive functions as a symptom of the disease. These cognitive changes can vary considerably from one person to another, both in type and severity.

## Quality of Life when living with MS

In keeping with most Multiple Sclerosis Societies worldwide, MS Australia has, as a primary aim, 'enhancing the quality of life of people with MS and reducing the impact of MS on the families and carers of those with multiple sclerosis'. Similar aspirations are reflected in the aims of MS Societies throughout Australia as well as in major worldwide studies relating to the delivery of rehabilitation services to MS communities.

Paradoxically, while a nexus between QoL and physical health is often promoted, studies show that quality of life and health status are quite distinct concepts. In reality, a "health-related" approach to QoL underestimates the challenges faced by pwMS with activities of daily living and basic social routines. More recent [research](#) into QoL suggests that it has stronger associations with psychological factors.

Given that there is no known cure for MS, nor any way of repairing the progressive outcomes of nervous system damage, much of the rehabilitation effort is directed towards managing daily living while at the same time fostering healthy QoL perceptions. Emphasis is placed on 'self managing'. Establishing and maintaining ongoing interdependencies with service providers is an important part of this process. Difficulties in establishing and maintaining these interdependencies negatively impacts on QoL perceptions and in a less than optimum ability to manage the progressive and cumulative nature of MS related issues.

The Pathways Project, as an important 'first step' clarifies and prioritises problems that pw MS (and their carers) have in establishing and maintaining ongoing interdependencies with service providers.

### 2.3 Who is the Target Population?

It is reliably estimated that there are approximately 300 pwMS in the Northern Rivers, as seen in the overview of prevalence data in Table 1.

**Table 1: MS Prevalence – Northern Rivers (Clarence to the Tweed)**

<b>Disability Level</b>	<b>% Female</b>	<b>% Male</b>	<b>Total</b>
Newly diagnosed	74	26	100
Mild	71	25	96
Moderate – Self Managing	37	14	54
Moderate – Support Needed	65	22	84
Severe	49	17	66
<b>Total</b>	<b>222</b>	<b>78</b>	<b>300</b>

Of these 300, some 150 individuals (50%) are moderately to severely disabled, and require support. Table 2 highlights this.

**Table 2: The Target Group: 50% of MS population in need of support**

<b>Disability Level</b>	<b>% Female</b>	<b>% Male</b>	<b>Total</b>
Moderate – Support Needed	65	22	84
Severe	49	17	66
Total	111	39	150

These estimates are based on the Access Economics 2005 study '*Acting Positively - The Strategic Implications of MS in Australia*' and applied to population trends in the Northern Rivers region.

While the Pathways Project is primarily about the 50% of people who, because of MS, are not able to live *normal and productive lives*, there will be flow on benefits to the whole of the Northern Rivers MS community, including carers and families. It is also anticipated that benefits will flow to service providers as a result of better targeted professional development and, in consequence, enhanced job satisfaction in the delivery of services.

## 3 WHAT SERVICES DO PEOPLE WITH MS NEED?

### 3.1 Overarching challenges

MS Australia, in a submission (2008) to the Australian Government, observed that *'people with MS pose a significant challenge due to the changing nature of their condition which does not respect waiting lists'*. The often progressive and cumulative nature of MS related issues, frequently with little or no forewarning, is at the heart of this challenge.

The submission went on to describe the challenge in terms of the need for *'dedicated lifetime continuous care.'* It highlighted the need for improved coordination in the delivery of dedicated lifetime continuous care programs and services (including respite) for people with MS. It confirmed that Australians living with MS and their families need viable alternative care models to those currently available. Many support programs are designed for static disability groups or ageing, and do not cope with increasing and changing needs. A further priority in dealing with the unmet demand is overhauling the interfaces of the various care and support programs with and across government jurisdictions.

### 3.2 Guidelines for addressing the challenges

*The Medical Advisory Board of the National Multiple Sclerosis Society USA* describes these challenges as a process that helps a person achieve and maintain maximal physical, psychological, social, and vocational potential, as well as quality of life consistent with physiological impairment, environment, and life goals. A consistent body of research provides guidelines for addressing these challenges. It does this by:

- Identifying MS care needs according to disability level.
- Highlighting issues frequently encountered by pwMS.
- Clarifying the service delivery expectations of pwMS.
- Highlighting referral pathways that best address the needs of pwMS.

The following sections explain these evidence based guidelines.

#### 3.2.1 IDENTIFYING MS CARE NEEDS ACCORDING TO DISABILITY LEVEL

Four 'phases' of MS care needs are regularly identified in research with each phase reflecting a number of key issues and approaches to service provision. These phases do not reflect an individual's disease progression. Rather, they provide a pragmatic

framework for discussion and a structure that enables the systematic identification of a wide-ranging list of service needs. The four phases are:

1. Diagnostic phase
2. Minimal impairment phase
3. Moderate disability phase
4. Severe disability phase.

Each phase has different implications for service delivery, and these are discussed next. The timing of support provided is therefore of major importance in delivering appropriate care. The individual needs of each person with MS must be considered, as each person's experience is unique.

### 3.2.2 ISSUES FREQUENTLY ENCOUNTERED BY PWMS

An MS Society [study](#) titled '*Living With Multiple Sclerosis in New South Wales at the Beginning of the 21st Century*' identified 20 issues frequently impacting on daily living with MS. The Society surveyed some 2618 people registered with the Society in 2001 (estimated at 70% of the NSW MS population). The results of this study became more widely accessible when published in the International Journal of MS Care in 2006. The study ranks issues according to frequency of reporting. The results, shown in Table 4, correspond to similar experiences elsewhere.

**Table 4: Issues Impacting on Daily Living with MS**

Rank	MS Issue	%	Rank	MS Issue	%
1	Fatigue	87	11	Pins & needles	40
2	Abnormal sensory symptoms	72	12	Concentration	40
3	Weak legs	71	13	Balance problems	35
4	Temperature intolerance	68	14	Speech problems	27
5	Cognitive problems	58	15	Depression	26
6	Memory problems	51	16	Incontinence or bladder problems	25
7	Visual problems	49	17	Pain, including headache	24
8	Mood problems	46	18	Frustration	21
9	Weak arms	44	19	Lack of coordination	18
10	Numbness	41	20	Muscle stiffness	14

The University of California-San Francisco Multiple Sclerosis Center for People with MS (USCF) identified a similar range of issues facing MS patients, families, and caregivers . These include a wide variety of physical and cognitive symptoms, changes in functioning, and psychological reactions including loss of control, self-image, stigma,

anger, isolation, dependence, abandonment, uncertainty, avoidance, stress, needle phobia and impact on children.

### **3.2.3 CLARIFYING THE SERVICE DELIVERY EXPECTATIONS OF PWMS**

A good starting point in matching expectations with outcomes is for services to be delivered in ways that are consistent with the [Guiding Principles](#) for the Provision of Services to people with MS. These principles are the primary focus of the publication 'A Charter for MS Services - the voice of people affected by MS'. Originally developed by the Multiple Sclerosis Society of Great Britain and Northern Ireland, these four principles are reflected in a number of subsequent studies. They are:

- ✓ Maximizing personal potential
- ✓ Involvement and influence of people affected by MS
- ✓ A holistic approach to service provision
- ✓ Meeting agreed standards.

These principles have broad application in all areas of service delivery to people affected by MS and are described in detail below.

#### **GUIDING PRINCIPLES: PROVISION OF SERVICES TO PEOPLE WITH MS**

##### **Maximising personal potential**

In many instances it is not the MS itself that is restricting a person's life, but the expectations and actions of others. Services should encourage people affected by MS to think about and define what they need to continue to achieve their goals and aspirations. Services need to be flexible enough to adjust to their changing circumstances and expectations. People affected by MS must be in a position to participate fully and make decisions about their support and care, with information and advice to help them make such decisions.

##### **Involvement and influence of people affected by MS**

The involvement of service users and carers in the planning and provision of services is a priority within the health and social care fields. Their involvement contributes to the ability of providers to deliver services that are effective and appropriate. It can foster a sense of involvement and clearer expectations of the rights and responsibilities of all concerned.

A challenge for services wishing to involve people affected by MS is to ensure that they include those who might find it particularly difficult to participate. A decision not to participate is an informed choice and should be respected as such, but for some this choice may be due to them not being given appropriate opportunities, or the process is in some way inhibiting their contribution.

Services need to consider new ways of reaching those whose voices are not being heard. They must also work to avoid such involvement opportunities turning into perceived obligations, particularly if they come to be seen as a condition of receipt of services.

### **Holistic approach to service provision**

Good quality service provision requires a full appreciation of each individual's nursing, personal, social and spiritual care needs and expectations. The aim should be to maintain independence as far as possible and ensure that the best quality of life is achieved. It should take advantage of the expertise and specialist knowledge of professionals from a range of disciplines. Multi-disciplinary teams consistently prove the most effective model of working.

### **Meeting agreed standards**

There needs to be clear standards for measuring success. Programs need to be developed to provide advice and support for providers wishing to improve their services. Specific standards can only be developed at the local level, taking into account local structures, resources, professional and service links and of course the needs and expectations of people affected by MS. Working closely with people affected by MS will ensure that agreed standards take account of the complex nature of MS-related care needs.

## **3.2.4 REFERRAL PATHWAYS THAT BEST ADDRESS THE NEEDS OF PWMS**

The fourth and final guideline for addressing the unique challenges of providing services for pwMS is the establishment of referral pathways that best address their needs. The achievement and maintenance of optimal function are essential in a progressive disease such as MS. There are three modalities (or combinations thereof) associated with this endeavour. These relate to:

- self-management
- residential support comprising 'at home', case managed, assisted living and nursing home accommodation) , and
- timely access to other relevant rehabilitation and health care services.

Implicit in this process is the need for both service providers and the MS community to access timely and relevant education, information and service delivery via clearly defined pathways.

It is not necessary for Australia to “reinvent the wheel” in order to determine the referral pathways that best meet the needs of pwMS. The following benchmarks were originally developed (2002) by The MS Society of the UK, together with clinicians and the MS Community who collaborated to develop internationally researched standards. These serve as a guide for the development and provision of services to meet the varying needs of people with MS across the continuum of the disease and are included in the publication “*Developing MS Healthcare Standards- Evidence based recommendations for Service Providers*”. The standards were a precursor to extensive work by the National Collaborating Centre for Chronic Conditions at the Royal College of Physicians in the development of National clinical guidelines for diagnosis and management in Multiple Sclerosis.

In 2004, the NSW MS Society recommended that the benchmarks be used as guidelines for the development of a more cohesive MS network of care in the Northern Rivers region of NSW. In Chapter 5 of this report, the benchmarks are used to identify gaps in current service provision and a complete list of the 43 benchmarks for referral pathways

is provided. For the purposes of illustration here, an **example** of these pathways for people with Moderate Disability (a component of the Target Population) follows.

## **BENCHMARK REFERRAL PATHWAYS FOR pwMS IN MODERATE DISABILITY PHASE**

**MODERATE DISABILITY PHASE:** The issues raised in the minimum phase continue and may be an even greater challenge with increasingly complex disability. Symptoms may be many, varied and interrelated. Management of these symptoms can therefore be challenging and require an integrated multi-disciplinary approach to provide focused neuro-rehabilitation services

**KEY ISSUES:** Responsiveness of services, Access and location, Expertise, Communication and co-ordination, Self Management

### **SERVICE PROVISION RECOMMENDATIONS**

- ✓ *A Specialist diagnostic clinic for MS, with well defined links to MS Society, should be established.*
- ✓ *Should be clear links between local health and social services and neurology services to ensure responsive, timely, seamless service delivery.*
- ✓ *Services and equipment provision should be community based.*
- ✓ *Inpatient and outpatient rehabilitation facilities are critical and should be widely available.*
- ✓ *A core multidisciplinary professional team, with expertise in MS management, should be accessible locally for assessment and treatment of MS.*
- ✓ *Education and training programs should be developed for qualified and unqualified staff and carers.*
- ✓ *Service provision should be coordinated over time, and a comprehensive care plan should be available and updated frequently.*
- ✓ *Self management should be encouraged at all times.*
- ✓ *Clear guidance about legal entitlements should be available.*

### 3.3 The key role of rehabilitation

Guidelines developed (2003) by the National Collaborating Centre for Chronic Conditions at the Royal College of Physicians - UK cover the full range of care that should be available to adults of all ages with MS. The guidelines include the observation that inpatient and outpatient rehabilitation facilities are critical and should be widely available. Recommendations include that self referral to rehabilitation services should be available to every person with MS when they need them, usually when they develop any new symptom, sign, limitation on activities or other problem, or when their circumstances change. As shown above, rehabilitation is a key referral pathway for pwMS in the Moderate Disability Phase.

The comment is also made that health service professionals in regular contact with people with MS should consider in a systematic way whether the person with MS has a 'hidden' problem contributing to their clinical situation, such as fatigue, depression, cognitive impairment and related issues (Section 3.2.2 refers also). The importance of developing a 'seamless' service from a client perspective is emphasized.

In June 2007, the Medical Advisory Board, National Multiple Sclerosis Society USA published *'Rehabilitation Recommendations for Persons with Multiple Sclerosis'* by way of guidelines for physicians, nurses, therapists, insurers, and policy makers regarding the appropriate use of rehabilitative therapies in MS. These guidelines define rehabilitation in MS as a process that helps a person achieve and maintain maximal physical, psychological, social, and vocational potential, as well as quality of life consistent with physiological impairment, environment, and life goals. Achievement and maintenance of optimal function are essential in a progressive disease such as MS.

These Recommendations observe that rehabilitation is a necessary component of comprehensive, quality healthcare for people with MS, at all stages of the disease, occurring in many scenarios. Health care professionals should consider referral of individuals with MS for assessment by rehabilitation professionals—including rehabilitation physician and occupational, physical, and speech and language therapists—when there is an abrupt or gradual worsening of function or increase in impairment that has a significant impact on the individual's mobility, safety, independence, and/or quality of life.

## **4 CURRENT SERVICE ARRANGEMENTS AND RECENT CHANGES**

### **4.1 CURRENT SERVICE ARRANGEMENTS**

Current service arrangements include:

- The MS Society of NSW/Victoria
- General practitioner services
- Specialist services
- Hospital services – inpatient and outpatient
- Education, information and support services
- Private practitioner services – allied health and complementary therapies.

These are briefly described below.

#### **4.1.1 THE MS SOCIETY OF NSW/VICTORIA**

The MS Society provides a 1800 Help Line along with a range of printed material largely directed to the newly diagnosed. It also provides an immunotherapy support program as well as a Community Support Worker based at Coffs Harbour (covering the area from Taree to the Tweed). During the second half of 2008, an additional Community Support worker, based in the Lismore/Ballina area, is to be provided.

The MS Society also offers a range of educational programs (primarily in metropolitan areas) as well as tailored training for service providers. Plans are in train to provide regionally based 'in-service' training for health care professionals providing services to the MS community. However, no dates have been set.

#### **4.1.2 GENERAL PRACTITIONER SERVICES**

Longitudinal studies show that around 50% of people with MS are independently mobile after 15 years and can live normal and productive lives. The MS related health care needs for this population grouping are broadly addressed via GPs with occasional visits to a neurologist. As described above, the MS Society also has a key role for the newly diagnosed. GPs are under pressure to varying degrees across the Northern Rivers area; many have closed their books and many new patients find they have little choice in finding a GP to meet their needs. This is exacerbated even more if they are looking for a GP with more than a basic knowledge of MS. For many, the progressive and ever widening nature of MS related issues provides special problems. Often people are referred from one practitioner to another causing frustration that further exacerbates MS symptoms.

#### **4.1.3 SPECIALIST SERVICES**

Access to an expert and trusted neurologist is fundamental for a pwMS, whatever their level of disability, to monitor progress of the condition, review treatments and provide a baseline of knowledge from which make medical and lifestyle decisions. It is a critical, continuing relationship for the pwMS. In the Northern Rivers, there is only one neurologist, located at Lismore. This can give rise to issues of access, cost and importantly, personal preference. Alternatives involve travel to the Gold Coast, Brisbane, or Sydney.

#### **4.1.4 HOSPITAL SERVICES – INPATIENT AND OUTPATIENT**

NSW Health provides a range of public hospital and community health services in the Northern Rivers region, as part of the North Coast Area Health Service. Rehabilitation services are of most relevance to pwMS, but these are limited. The new inpatient rehabilitation unit at Ballina Hospital is theoretically available to pwMS, although oriented primarily to people being discharged from acute care. Access is an issue, both in terms of eligibility for the service, and geographically for those living a significant distance from Ballina.

Private rehabilitation services are available from St Vincent's Hospital in Lismore – the evolution of this service (including its cessation as a public health service) is discussed in Section 4.8. However, the relatively low levels of private health insurance in this region precludes many from accessing this service – the pwMS who are most in need are the most severely affected, and are less likely to have the protection of health insurance.

#### **4.1.5 EDUCATION, INFORMATION AND SUPPORT SERVICES**

For those with internet access, there is a wealth of information readily available, including interactive forums. As always with the internet, however, the reliability of information provided can be a risk. Staying with national MS organisations is one safeguard against misinformation. PwMS in the Northern Rivers who live in isolated areas, are more severely disabled and/or have spent many years on income support programs, are particularly disadvantaged when it comes to internet access.

The web based [Road Map](#) to MS Support Services on the Northern Rivers (Google – Multiple Sclerosis Northern Rivers) originated in 2003 following the identification of an inability to readily access reliable MS related information as a significant MS rehabilitation issue. Maintained and researched by the Network of Care, it has a strong regional focus cross-referenced to reliable national and international research on the wide range of issues confronting PwMS. It is an ongoing reference point for the Pathways Project.

Priority is given to addressing issues raised by the regional MS community and by service providers addressing the needs of this community. It includes details of many Commonwealth, State and regional support services, as well as private practitioners and regional contacts identified by members of the MS Community. In 2004 the North Coast

Area Health Service supported the project by hosting the Road Map in the Support Groups area of its web site.

The MS Support Group holds monthly meetings, with the aim of providing positive and supportive opportunities for pwMS and their carers, to participate in activities that contribute to their well being. This includes fostering forums for the exchange of ideas and experiences, which is particularly valued by those who can attend. Meetings are held in Ballina, and while some participants travel considerable distances, meetings cannot be accessible to everyone. Satellite groups meet at Murwillumbah and Grafton. The membership of such support groups is of course comprised of pwMS. Coordination and leadership must come from within, and can be a demanding role. The continued operation and effectiveness is dependent on key individuals maintaining their health and well being. The negative nature of problems encountered by the MS community in accessing regional MS related services frequently impact on the ability of the group to achieve its aims. The use of community advocacy groups can be a valuable support for sustainability and Ability Incorporated (Alstonville) is proving a valuable asset to the MS Support Group in this respect.

#### **4.1.6 PRIVATE PRACTITIONERS – ALLIED HEALTH & COMPLEMENTARY THERAPIES**

While this region is generally well served by private allied health and complementary practitioners, they may not be equipped to effectively address the often-complex needs of people with MS – especially those with significant mobility problems. Remedial massage and physiotherapy (including hydrotherapy) are particularly sought after and are well recognised in MS rehabilitation worldwide. Muscle stiffness, coordination and sensory problems are commonly experienced by pwMS. It is extremely important to develop stretching and exercise routines specific to individual needs.

For those with significant mobility problems, combinations of these therapies can significantly assist in activating the immune system, assisting blood flow and encouraging lymphatic flow. They can also stimulate the sensory receptors in the skin and stimulate endorphin production, reducing pain.

A very small number of practitioners make a deliberate decision to “specialise” in MS and as a result, become well known and heavily subscribed. Because of the need to frequently devote considerable time to individual clients with complex conditions, many practitioners are reluctant to undertake work of this nature. This can be compounded by a need for regular home visits. There is currently no ‘rewards system’ that addresses these imbalances. Again, once away from the heavily populated towns, access is also a barrier.

#### **4.1.7 COMMUNITY SERVICES**

The Department of Disability, Aged and Home Care provides a range of community services that can benefit pwMS, such as personal care, home care, transport, home modifications, and some respite care. Richmond Community Options has a case management service which coordinates care and problem solves issues for clients, including a number of pwMS.

## 4.2 Changes in service provision

For the 50% (including many newly diagnosed) who are not able to live normal and productive lives a number of important MS referral pathways have been discontinued , (especially since 2002) without the provision of reasonably accessible alternatives. This is happening at a time when the MS population in the region is increasing significantly.

### 4.2.1 MS SOCIETY

Periodically, over some years, the MS Society based an MS specific multi disciplinary assessment team in the region to identify MS care needs and the referral pathways appropriate to those needs. This was provided courtesy of the Royal Flying Doctor Service (RFDS). The RFDS was also involved in the subsequent transport of people to Sydney to access the Society's specialised MS services. Unfortunately, from around 2002, the RFDS ceased to be available. This subsequently resulted in the Society being unable to continue with this important *Assessment, Referral and Service Delivery* program. No alternate regional options were put in place

### 4.2.2 ST VINCENT'S HOSPITAL AT LISMORE

During the period from 2003 to 2006, St Vincent's conducted residential and non-residential rehabilitation programs on behalf of the Area Health Service. The programs were delivered by multi disciplinary teams, with many of the team members having MS related experience over extended periods of time. Services included general medical assessments and allied health rehabilitation combined with seamless linkages to a host of ancillary services including MS specific 'group therapy'. Flexible and ongoing referral pathways were an important feature of the service. In many respects the approach addressed many of the needs, issues and expectations of pwMS as discussed in Section 3.2. 3 and 3.2.4.

The greater the level of participation the more the program evolved – as did the level of service provider MS expertise and experience. The MS Society offered to enhance this level of expertise by providing health professional staff with MS specific education and support via face-to-face education sessions, teleconferences and videoconferences. As an example, the Society's Neuro psychologist attended and provided a very well received in-service presentation to staff on cognition as it relates to MS and in particular the considerations for rehabilitation programs. The benefits of the St Vincent's approach are discussed in more detail in the handbook *Needs, Challenges, Rewards of Multiple Sclerosis Support Group Leaders* (January 2008). This handbook was developed by Peter Sullivan, Coordinator of the Northern Rivers MS Network of Care, as a regional response to a research project of the same name initiated by the Medical Psychology Research Unit, School of Psychology at the University of Sydney

It is a matter of record that, in 2006 (at relatively short notice), St Vincent's advised of its withdrawal from the provision of public rehabilitation services in the region. In November 2006 the MS Society wrote to the Area Health Service seeking clarification about the future availability of regional MS rehabilitation services. A reply dated 12 December (ref RB: 174) provided a broad overview of the contingency arrangements being put in place.

Some 2 years later no comparable regionally accessible alternative MS rehabilitation option has emerged. This is significantly impacting on the well being of people with MS and their carers. While private rehabilitation services continue to be available from St Vincent's, accessible for pwMS with private health insurance and/or the capacity to pay, they may not necessarily address all of the rehabilitation needs of pwMS.

## 5 GAPS AND PRIORITIES

### 5.1 An evidence based framework for identifying gaps

The Northern Rivers Multiple Sclerosis Network of Care receives regular feedback from the regional MS Community about ways to enhance the relevance and delivery of MS support services in a regional context. A recurring theme relates to imbalances between matching the needs, issues and expectations of people with MS with relevant and accessible levels of service delivery. Frustrations flowing from these imbalances have a negative impact for both service providers and those in need of care.

For those in need of care these frustrations manifest themselves at both the psychological level (QoL perceptions) and in a less than optimum ability to manage the progressive and cumulative nature of MS related issues. Major reasons for this 'imbalance' are frequently related to deficiencies in service provider MS education combined with a desire to 'fit' MS rehabilitation into inappropriate models of care. Factors influencing QoL perceptions as related to MS service delivery include self image (including self management), level of independence and ability to access to quality health care. The service delivery benchmarks set out below illustrate these aspects in a regional context.

As described in Section 3.2.4, these benchmarks were originally developed by the MS Society of the UK, together with clinicians and the MS Community who collaborated to develop standards to serve as a guide for the development and provision of services to meet the varying needs of people with MS across the continuum of the disease. In 2004, the NSW MS Society recommended that the benchmarks be used as guidelines for the development of a more cohesive MS network of care in the Northern Rivers region of NSW. They have since proven to be very useful in a variety of contexts.

### 5.2 Methodology for identifying gaps in service provision

The following framework depicts those needs expressed by way of 36 MS Referral Pathways (Column 1). It also incorporates a further 7 Service Provision recommendations relating factors influencing QoL perceptions, making 43 benchmarks in all.

A Planning Group for the Northern Rivers MS Network of Care assessed each of these benchmarks in the light of feedback from the MS community received over several years, experience gained by the Coordinator in developing the Road Map for the web site, and personal knowledge of group members. These ratings are being used as a first line guide to identify gaps and determine priorities for service development recommendations by the Northern Rivers Network of Care.

The notation **OK** in Column 2 signifies the presence of an appropriate pathway in the Northern Rivers. Column 2 also identifies **gaps** in these pathways graded as **Fair, Poor,**

**Minimal or None.** Eight Pathways are rated **None**, viz, 8, 17, 21, 22, 23, 27, 31 and 33 representing a perceived total absence of a recommended referral pathway. Recognizing the importance of focusing on the most significant gaps, the Planning Group set aside those benchmarks rated **OK** or **FAIR**. Benchmarks rated **None**, **Minimal or Poor** were highlighted for further discussion and priority setting.

An overview of all benchmarks across the four phases of disability is set out below, with ratings provided. A consolidated summary of gaps and priorities follows the overview.

## OVERVIEW OF KEY PHASES OF MS CARE AND SERVICE RECOMMENDATIONS

Column 1 – Recommended Referral Pathway	Col 2
<p><b>DIAGNOSTIC PHASE:</b> This is a very important time for newly diagnosed people with MS which, if not managed properly, may have negative long term effects for the individual and their family.</p> <p><b>KEY ISSUES.</b> Certain, clear diagnosis: Appropriate support at the time of diagnosis: Access to information: Continuing education</p> <p><b>SERVICE PROVISION RECOMMENDATIONS</b></p>	
1. Diagnosis should be made by a consultant neurologist, with interest in MS	OK
2. Referral time to see a neurologist should be within 4 weeks	OK
3. Information about MS should be presented by health professionals	OK
4. Written information packs and MS Society contact details should be provided at time of diagnosis	OK
5. Staff with specialist knowledge of MS and counselling experience should be available in the weeks following diagnosis for support.	OK
6. Individuals and family should have ready access to a specialist nurse or support worker when further information is required	OK
7. Regular information sessions should be established for individuals/ families/ carers	Fair

<p><b>MINIMAL IMPAIRMENT PHASE:</b> Many people may experience long periods of minimal impairment throughout the course of their disease, but still need statutory and health service provision. It is important for health professionals to empower people to take ownership of their own care with the support of services'</p> <p><b>KEY ISSUES:</b> Continuity in service provision, Access to support and informed advice, Access to appropriate treatment and self management, Access to treatment for conditions unrelated to MS</p> <p><b>SERVICE PROVISION RECOMMENDATIONS:</b></p>	
8. Following diagnosis, people should be put in contact with a specialist multi-disciplinary team in their area. At minimum the team should include a neurologist, support worker and specialist nurse. Referral to Neuro physiotherapist, occupational therapist, speech therapist, clinical psychologist,	None

and dietician should also be available.	
9. Accurate information and skilled advice about lifestyle issues and symptoms ( including diet, exercise, family planning, sexual function, tone management, fatigue management, posture, cognitive strategies, continence) should be available to help people make informed decisions -	Minimal
10. Individuals and employers should have up to date access to advice on work related issues & access to specialist employment assessments	Poor
11. Counselling for individuals and families should be available and provided by trained counsellors familiar with MS / chronic illness	Minimal
12. Support groups should be set up and facilitated by MS organisations	Minimal
13. Adequate and appropriate home care support should be available as needed - relevant support should be given to children caring for their parent with MS, or just coping with MS generally	Minimal
14. Drug treatments should be discussed with individuals with MS	OK
15. Clearly written information about MS symptoms and their management should be widely available	Fair
16. GP's should know the facts about MS and have ready access to MS information	Fair
<b>MODERATE DISABILITY PHASE:</b> The issues raised in the minimum phase continue and may be an even greater challenge with increasingly complex disability. Symptoms may be many, varied and interrelated. Management of these symptoms can therefore be challenging and require an integrated multi-disciplinary approach to provide focused neuro-rehabilitation services	
<b>KEY ISSUES:</b> Responsiveness of services, Access and location, Expertise, Communication and co-ordination, Self Management	
<b>SERVICE PROVISION RECOMMENDATIONS</b>	
17. A Specialist diagnostic clinic for MS, with well defined links to MS Society, should be established.	None
18. Should be clear links between local health and social services and neurology services to ensure responsive, timely, seamless service delivery.	Minimal
19. Services and equipment provision should be community based	Fair
20. Inpatient and outpatient rehabilitation facilities are critical and should be widely available	Minimal
21. A core multidisciplinary professional team, with expertise in MS management, should be accessible locally for assessment and treatment of MS	None
22. Education and training programs should be developed for qualified and unqualified staff and carers	None
23. Service provision should be coordinated over time, and a comprehensive care plan should be available and updated frequently.	None
24. Self management should be encouraged at all times.	Poor
25. Clear guidance about legal entitlements should be available.	Fair

<p><b>SEVERE DISABILITY PHASE:</b> At this stage there are often a wide range of complex and interacting physical, psychosocial and cognitive problems. There may be heavy reliance on others to maintain quality of life'</p> <p><b>KEY ISSUES:</b> Access to information, Expertise, Communication and coordination, Adequate community care services, Community mobility, Provision of respite care, Appropriate long term facilities, including palliative care.</p> <p><b>SERVICE PROVISION RECOMMENDATIONS</b></p>	
26. Easily accessible, timely, accurate, up to date and understandable resource information should be available to all stakeholders involved in care, via multiple mediums.	Fair
27. Staff should be trained in the physical, psychological and psychosocial problems that occur in the later stage	None
28. Specialist equipment and environmental aids should be available especially for pressure care and posture	OK
29. Individuals should have a coordinated and individual management plan at all stages of the care process. – see also 41	Poor
30. Follow up services in the community should be available to carry out care recommendations in a timely manner, and they should be flexible enough to meet changing needs	Poor
31. Professional assessment and support services should be available for carers and families and cover psychosocial and coping issues	None
32. Provision of efficient community transport should be available for severely disabled people	Poor
33. Regular respite facilities in an appropriate setting should be available	None
34. Appropriate facilities should be available for long term care	Fair
35. Fulltime care within a person's home should be available as an option for long term care	Fair
36. Palliative care facilities should be available	Fair

<p><b>ENHANCING QUALITY OF LIFE PERCEPTIONS:</b> The World Health Organisation (WHO) defines QoL as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.</p> <p>Frustrations flowing from imbalances in matching the needs, issues and expectations of people with MS with relevant and accessible levels of service delivery negatively impacts on QoL perceptions and in a less than optimum ability to 'self manage' the progressive and cumulative nature of MS related issues. There can also be a negative impact for service providers in terms of job satisfaction in the delivery of services.</p>	

<p><b>KEY ISSUES :</b> Access to information, Access to services, Involvement and influence in decision making, Holistic approach to service provision, Recognition of personal dignity, Maximising personal potential, Meeting agreed standards</p> <p><b>SERVICE PROVISION RECOMMENDATIONS</b></p>	
<p>37. The involvement of service users and carers in the planning and provision of services is a priority within the health and social care fields. Their involvement contributes to the ability of providers to deliver services that are effective and appropriate. It can foster a sense of involvement and clearer expectations of the rights and responsibilities of all concerned – see also 8</p>	Minimal
<p>38. Good quality service provision requires a full appreciation of each individual's nursing, personal, social and spiritual care needs and expectations. The aim should be to maintain independence as far as possible and ensure that the best quality of life is achieved – see also 23</p>	Poor
<p>39. Services need to consider ways of reaching those whose voices are not being heard. They must also work to avoid such involvement opportunities turning into perceived obligations, particularly if they come to be seen as a condition of receipt of services – see also 20</p>	Minimal
<p>40. People affected by MS must be in a position to participate fully and make decisions about their support and care, with information and advice to help them make such decisions. Options for self referral to MS related rehabilitation supported by scheduled recalls for those with Moderate Disabilities and beyond are essential. – see also 9, 20,24,</p>	Minimal
<p>41. Services should encourage people affected by MS to think about and define what they need to continue to achieve their goals and aspirations. Services need to be flexible enough to adjust to their changing needs over time – see also 29</p>	Poor
<p>42. Services should be sensitive and responsive to unique and individual needs and opinions of people with MS encompassing the principles of privacy and dignity</p>	OK
<p>43. There needs to be clear standards for measuring success. Programs need to be developed to provide advice and support for providers wishing to improve their services. Specific standards can only be developed at the local level, taking into account local structures, resources, professional and service links and of course the needs and expectations of people affected by M – see also 21.</p>	None

## 5.3 Summary of gaps

Unless otherwise specified, all gaps and priorities relate to the target population.

### 5.3.1 LEVEL 1 GAPS

These are based on service benchmarks rated “**None**”

- A core multi disciplinary professional team, with expertise in MS management, accessible locally for assessment and treatment of MS.<sup>1</sup>
- Education and training programs for qualified and unqualified staff and carers. Staff trained in the physical, psychological and psychosocial problems that occur in the later stages of MS.
- Professional assessment and support services for carers and families, covering psychosocial and coping issues.
- Regular respite facilities in an appropriate setting
- Service provision coordinated over time, and a comprehensive care plan available and updated frequently that includes options for self referral and scheduled recall to assessment and rehabilitation services

### 5.3.2 LEVEL 2 GAPS

These are based on service benchmarks rated “**Minimal**”.

- Inpatient and outpatient rehabilitation services.
- Accurate information and skilled advice about lifestyle issues and symptoms to help people make informed decisions.
- Counselling for individuals and families, provided by trained counsellors familiar with MC/chronic illness.<sup>2</sup>
- Support groups set up and facilitated by MS organisations.<sup>3</sup>
- Adequate and appropriate home care support, including for children caring for a parent with MS. (DADHC role).

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<sup>1</sup> This benchmark appears in all disability phases, including those of the target population (moderate and severe).

<sup>2</sup> Recommended in the Minimal Impairment Phase, but availability of counselling at this stage can positively affect outcomes in later phases.

<sup>3</sup> While there are support groups in the Northern Rivers, they are run by pwMS not by the MS Society, and may therefore be vulnerable to health fluctuations of key organizers. A partnership approach between pwMS and the MS Society would be more sustainable.

- Clear links between local health and social services and neurology services.

### 5.3.3 LEVEL 3 GAPS

These are based on service benchmarks rated “**Poor**”. The first three gaps refer to the way services are provided and can be encompassed in the Level 1 and 2 gaps and priorities. The last three are non-health roles.

- Self management encouraged at all times.
- Coordinated and individual management plan at all stages of the care process.
- Flexible and timely follow up services in the community.
- Efficient community transport for severely disabled people. (DADHC service)
- Individuals and employers to have up to date access to advice on work related issues and access to specialist employment assessments (CRS role).<sup>4</sup>

### 5.3.4 ENHANCING QOL PERCEPTIONS

Finally, here is a summary of service benchmarks relating to QoL perceptions, to be incorporated in the way services are provided, once those services are in place.

#### **Rating “None”**

- Clear standards for measuring success, to facilitate service improvement.

#### **Rating “Minimal”**

- Involvement of service users and carers in planning and provision of services.
- Services find ways of reaching out to those whose voices are not being heard.
- PwMS participate fully and make decisions about their support and care, with information and advice to help them make such decisions.

#### **Rating “Poor”**

- Appreciation of each individual’s needs and expectations, with the aim of maintaining independence as far as possible and ensuring the best QoL is achieved.
- Services encourage pwMS to think about and define what they need to continue to achieve their goals and aspirations.

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<sup>4</sup> This benchmark appears only in the Minimal Impairment Phase, and therefore is not immediately relevant to the target population.

### 5.3.5 THE SPECIAL NEEDS OF CARERS

While the 43 benchmarks appear to cover all aspects of service delivery to people with MS, the Planning Group has noted that they do not deal adequately with the needs of carers. Benchmarks 11, 22 and 31 reference the role of carers, but only in the context of providing services to pwMS. The Pathways Project will consider the needs of carers through a supplementary paper as its next advocacy priority.

## 5.4 Recommended priorities

From these gaps, the Planning Group has reached agreement on a **consolidated set of five priorities underpinned by five guidelines**, for advocacy purposes. Responsibility for providing these services ranges from NSW Health, DADHC and the MS Society, individually or in collaboration. The priorities are as follows:

1. A core multi disciplinary professional team, with expertise in MS management, accessible locally for *assessment and treatment* of MS. Associated services to include:
  - Accurate information and skilled advice about lifestyle issues and symptoms to help people make informed decisions.
  - Counselling for individuals and families by trained counsellors familiar with MC/chronic illness, covering psychosocial and coping issues.
2. Inpatient and outpatient *rehabilitation* services.
3. *Respite* facilities in an appropriate setting.
4. *Education and training programs* for staff and carers. Staff to be trained in the physical, psychological and psychosocial problems that occur in the later stages of MS.
5. Efficient community *transport* for severely disabled pwMS.

These priorities are to be underpinned by **five key guidelines**:

1. Self management to be encouraged at all times.
2. Use of coordinated and individual care management plans to occur at all stages of the care process.
3. PwMS participate fully and make decisions about their support and care, with information and advice to help them make such decisions.
4. Service users and carers are involved in planning and provision of services.
5. There are clear standards for measuring success, to facilitate service improvement.

## 5.5 The way forward

This paper has been prepared for use in discussion with relevant health and community services agencies about how to better meet the needs of pwMS in the Northern Rivers. As a result of those discussions, it is expected that greater clarity will emerge about existing services and their capacity to enhance access for pwMS. In addition, it is clear that some new services will be needed, at a minimum to replace those that have existed previously. The Network of Care is interested in participating in discussions about models of care that are evidence based, feasible in terms of resources and optimise accessibility for pwMS across the Northern Rivers region.

## ▪ ATTACHMENT 1: MS REGIONAL DISABILITY AND PREVALENCE LEVELS

Source - Access Economics Study (2005) titled 'Acting Positively - The Strategic Implications of MS in Australia'

### Disability Levels

The Kurtzke Disability Status Scale uses a score of 1 to 10 to rate degrees of disability and is often used by physicians and researchers to assess and predict future disability. Using research based upon this scale Access Economics categorised (Table 1.7) levels of MS disability under the classifications of Mild, Moderate and Severe with the following percentages of the Australian MS population falling into each category.

Mild	32%
Moderate	46%
Severe	22%

The only reservation about over relying on these percentages is that the Kurtzke Scale focuses heavily on aspects of physical disability whereas research in recent years also places considerable weight on the 'non physical' aspects of MS, i.e cognitive problems . Elsewhere, Access Economics identify around 50% of a given MS population grouping as in need of support . The categorization at Table 1.7 does, however, provide a useful starting point, for planning purposes, in terms of *minimum* numbers according to disability levels.

### Relationship to MS Standards of Care

The descriptions of *moderate* and *severe* were also adopted in research (by the MS Society of the UK), leading to the development of Standards of Care that serve as a guide for the development and provision of services to meet the varying needs of people with MS across the continuum of the disease. Rather than the expression *mild* the standards refer to the *Diagnostic* stage and the *Minimal Impairment* stage. All in all there is close relationship between the disability levels referred to by Access Economics and those referred to in the Standards of Care.

### Relationship between the Standards and MS Referral Pathways

In July 2004 the NSW MS Society recommended that the Network of Care use the standards to guide its development. The standards were found to provide sound benchmarks for identifying the referral pathways appropriate to each of disability level.

## Prevalence

Access Economics explored the increasing prevalence in Australia from a range of perspectives. Given that the cause of MS is not known (apart from its propensity to manifest itself in cooler climates), the issues canvassed included improved diagnostic tools, immunotherapy and related medical advances, increased lifespan and population movements.

Nationally, Access Economics adopted prevalence rates (per 100,000) of 42.76 for men, 120.17 for women, with an overall average rate of 81.72. Given that their brief was to present a national overview they did not attempt to 'disaggregate' these national statistics.

Statistics were, however, provided (table 1-5) relating to prevalence rates according to age groupings. Details are:

Age Group	Male per 100,000	Female per 100,000
10-19	0.0	5.6
20-29	25.5	33.9
30-39	68.1	149.1
40-49	69.1	229.6
50-59	71.7	273.0
60-69	76.7	153.2
70-79	20.5	69.7

## Population trends

There is a significant (and ongoing) population movement to the Northern Rivers Area allied with an older population mix. Of significance also is the prevalence of MS in the regions from which this population movement is taking place. In an Australian context, regions south of Newcastle are regarded as having a higher prevalence rate of MS than more northerly areas. There is a significant population movement from *South to North* combined with movements from higher MS prevalence areas elsewhere in the world (New Zealand and Europe are two examples)

## Regional prevalence according to disability levels

The following model is based upon an estimated future Northern Rivers population of around 280,000 based upon data supplied by the NSW Local Government and Shires Association. It does not reflect the population age factor or distortions between male and female as statistics on this are not readily available. To compensate for these factors as well as population shifts from 'higher prone' areas an average prevalence rate of 104 per 100,000 has been adopted.

<b>Disability Level</b>	<b>% Female</b>	<b>% Male</b>	<b>Total</b>
Newly diagnosed	74	26	100
Mild	71	25	96
Moderate – Self Managing	37	14	54
Moderate – Support Needed	65	22	84
Severe	49	17	66
<b>Total</b>	<b>222</b>	<b>78</b>	<b>300</b>

The total of 300 exceeds the number of people registered with the NSW MS Society as at March 2008. This is to be expected, as many do not perceive any tangible benefit in registering with the Society. Generally speaking it is believed that a maximum of around 70% of people with MS register with Society. In this context the aforementioned projections, are considered to provide a reasonable base for forward planning.

