



# **Needs Assessment of People Affected by Multiple Sclerosis Living in Gateshead**

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## **Needs Assessment of People Affected by Multiple Sclerosis Living in Gateshead**

### **Executive Summary**

**Dr. Toby Brandon, Northumbria University, September 2007**

#### **Background**

In 2006 Gateshead Council stated that an examination of the needs of people who are living with Multiple Sclerosis (MS) was critical to the future of local service development. Since the closure of the Gateshead branch of the MS Society there has been no accurate information available on the numbers and needs of people with MS and there is a concern that people have potentially been 'lost' to both the MS Society and Local Authority. The MS Society therefore provided funding for work with the following aims:

- Development of a 'user voice' for people living with MS and their family members in Gateshead.
- An opportunity for people living with MS to inform service design and delivery locally.
- To provide evidence for a business case for future service developments.
- An opportunity to raise awareness of the needs of people living with MS and their family members locally.
- To develop and strengthen partnership working between the MS Society, the Physical Disabilities and Sensory Impairment Partnership Board and Northumbria University.

This work was designed to listen and record some of these people's experiences around need and record their suggestions for future service developments. A comparison was also made to the criteria laid down in the National Service Framework for Long Term Conditions (2005) and The National Institute for Health and Clinical Excellence guidelines (2003).

## **Methods**

The work used a 'participatory' approach, in which people with MS and family members were given a variety of ways to be involved in the research. These included attending focus groups or having face to face/telephone interviews. Service providers from both statutory health and social care and the voluntary sectors were also involved. A small postal questionnaire was also used to gain a contribution from those people who preferred not to attend a focus group or be interviewed.

## **Recommendations**

No grand claims are presented here, but there are specific recommendations relating directly to Gateshead:

1. Existing information systems need to be enhanced and potential new ones explored. This would include an investigation of the role of an 'MS information broker'; this person would not necessarily be from any one particular profession but would have to have specialist knowledge of MS. Their role would be in a sense as a 'one stop shop' connecting service users with a wide variety of ever changing services. This role could also be part of a potential MS specialist team.
2. The waiting lists for equipment services need to be reduced. In addition the service needs to be made to be more flexible and responsive to the changing needs of people with MS.
3. The viability of increasing the number of MS specialist nurses in the locality should be examined. This would ensure that MS service users have a 'core' or 'key' worker to help them navigate both health and social care systems. This could be a different 'professional' role to the potential 'information broker'. This role could also be part of a potential MS specialist team.
4. The number of Occupational Therapists in the locality needs to be increased (problematic due to national shortage in this profession), it is perceived that this would reduce waiting lists for adaptations and improve the overall service.
5. Specialist carer and MS service user advocacy services should be investigated and if viable developed. Peer group advocacy may be an option.
6. A service providing specialist mental health support for people with MS should be examined for viability. Whether this is part of a generic counselling service or a more specialist psychology service needs to be researched.
7. An audit of accessible environments within the councils and other facilities, needs to take place, this would focus on local post offices and swimming pools and ensure there accessibility to MS service users.
8. Bus and taxi support services need to be examined with regards to response times and frequency of service, in particular while people are on outpatient visits.
9. A review of local Respite Care services needs to take place. This would include service user involvement and voice in the review process.

10. Gateshead council needs to support the MS Society to examine the potential to re-launch a local branch of the Society. This would need to be developed with the support and advice of local people affected by MS. This would ensure a responsive, age appropriate service.
11. The isolation of people with MS in Gateshead is evident. Some further work needs to examine the feasibility of creating, perhaps in conjunction with the MS Society, an age appropriate 'somewhere to go' for people with MS. This would have elements of health and exercise, social networking, information and advocacy.
12. A review of the existing Direct Payments scheme to simplify and support people to make greater use of it is advised. The new Individualised Budget (IB) system may answer some of the issues raised.
13. People with MS require more continuity of care so that repetitive full assessments across health and social care are avoided and as near as possible a seamless service is developed.
14. Finally the work presented here should be seen as part of an ongoing process of participation where the voices of people affected by MS are heard and services are continued to be developed around them.

### **Full Report**

This final report will be presented to the MS Society and its recommendations to the Physical Disabilities and Sensory Impairments Partnership Board and Health and Social Care Partnership in the autumn of 2007. It is also intended that the work will be presented, with the support of people with MS and their families, at a dissemination event to be arranged for the beginning of 2008.

**For a copy of the full report please get in contact with the  
MS Society (London) on: 020 8438 0700**

## 1.0 Introduction

Multiple Sclerosis (MS) is one of the most common neurological conditions for adults, according to the National Institute for Health and Clinical Excellence (2003), MS is diagnosed in 1,800 to 3,400 people each year, which means that in total between 52,000 and 62,000 people have MS in England and Wales. On a local level in Gateshead, according to the Primary Care Trust, as of September 2006, 364 people have MS. MS being the biggest single condition referred into the Council's Physical Disabilities and Sensory Impairment Team.

MS is a complex, life long condition that affects different people in different and diverse ways. This means that people affected by MS use both health and social services to varying degrees. Some people have very few symptoms while others have many. The most common being fatigue, bladder and bowel concerns, impaired vision, tremors, impaired speech and swallowing difficulties along with impaired mobility. They also often experience various forms of social stigma.

Since the closure of the MS Society's local branch in Gateshead in 2005, many people with MS have potentially been 'lost' to both voluntary and statutory sector services and their needs have not been recorded or met. Initial discussions with a service development worker within the Council and the Physical Disabilities and Sensory Impairment (PDSI) team indicated that there was a requirement for a needs assessment to take place with the service user and family members subject to Fair Access to Care Criteria. Edmonds et al (2007) in their research into peoples' experience of MS remarked that 'little is known about the needs and experiences of people severely affected by progressive or relapsing-remitting MS' (p.661)

In direct response to this the proposed works main aim is to build an evidence base for targetting resources/service development to identify need and to establish new ways of working with people with MS in Gateshead. In addition it is intended to be used to establish a 'user and carer voice' and generally raise awareness of the needs of people living with MS locally. To achieve this a 'population needs assessment' was conducted which included a focus group with people with MS, one with families and telephone interviews with service providers. Provision was also made for service users and family members wanting to participate but who were unable to attend the focus groups either with through a postal questionnaire, telephone interviews or face to face visits.

The conclusions drawn from this work cannot be concretely generalised to the total population of people affected by MS in Gateshead or beyond. With caution it is possible to suggest that other people with MS will be experiencing similar issues however this is not the purpose of the qualitative approach chosen within the study. With the relatively small number of respondents in this study (disappointing with reference to the postal questionnaire) the findings are intended to provide a detailed understanding of the concerns, experiences and aspirations of all involved. This then acts as indication for where future work and service development should be focused. Within the discussion section of the report the findings (primarily the personal experience of people with MS) will also be used to reinforce or challenge findings from other research and the priorities laid down in relevant policy.

The work was a collaborative partnership between the MS Society, Gateshead Council and Northumbria University. The MS Society provided funding to cover the salaries of the academics involved, in total £9,066. In summary Gateshead Council conducted the sampling procedure and provided access and support to the participants. Northumbria University completed the data collection, analysis and final report. The main aim of the work was to investigate what services people with MS in Gateshead are currently accessing, to explore their experience of using such services and record any perceived gaps in these services. To achieve this a 'participatory' approach was taken in order to hear the key 'voices' of people with MS locally. The existing structure of physical disability services in Gateshead can be found in appendix 7. A Service Resource List of organisations for people with MS is provided in appendix 9. It is intended that this work will provide a whole range of outcomes for all the participants involved:

- Development of a 'user voice' for people living with MS and their family members in Gateshead.
- An opportunity for people living with MS to inform service design and delivery locally.
- To provide evidence for a business case for future service developments.
- An opportunity to raise awareness of the needs of people living with MS and their family members locally.
- To develop and strengthen partnership working between the MS Society, the Physical Disabilities and Sensory Impairment Partnership Board and Northumbria University.

This final report will be presented to the MS Society and its recommendations to the Physical Disabilities and Sensory Impairments Partnership Board and Health and Social Care Partnership in the autumn of 2007. It is also intended that the work will be presented at a dissemination event in the winter of 2007/8.

### **1.1 Terminology**

The terms used to refer to the 'participants' in this study fall into the following three categories.

*Family members:* refers within this study to the partners of someone with MS

*Service User:* refers to the person who is affected by MS.

*Service Providers:* refers to the service providers either from voluntary or statutory sectors.

The use of any terminology can be problematic. 'Carer' within the disabled people's movement has been criticised for implying a negative, passive or potential patronising role, so 'family member' was the preferred term 'Need' can refer to norms defined by experts, wants or expressed demands often based in a comparison to others (Bradshaw, 1972). Needs are the main focus of this work and are considered anything that any of the respondents deem to be important to inform change in the provision of services.

For more detail of the terms used in this report please see the Glossary in Appendix 8.

### **1.2 Content of Report**

This reports structure provides a brief literature review of the main international, national and local policy relevant to MS in terms service quality and development. This work acts in two ways, firstly to set the agenda for the findings and secondly to provide a useful reference for people generally interested in MS and service provision. The methods section provides an overview of how the project was conducted and the findings section presents quotes and figures derived from the respondents. The conclusions draw all these findings into one summary and the recommendations are born of findings combined with the literature section. They are a mixture if reviews, suggested service developments and consolidation of existing resources. Finally it may be useful to note that the appendixes contain a list of organisations working with people affected with MS in the locality. Again this is intended to be a resource for people interested in the area.

## **2.0 Literature Review**

A literature search was conducted around ‘MS’, ‘Needs’, ‘Quality of Life’ and ‘Service Development’. Particular attention was paid to relevant international, national and local policy objectives for service around people with MS. What follows is an overview of all this relevant work.

### **2.1 International Policy**

The Multiple Sclerosis International Federation (MSIF) in 2002 published a document entitled ‘Principles to Promote the Quality of Life of People with Multiple Sclerosis’. In summary it stated that services should ensure that:

1. People with MS are empowered as full participants in their communities and in decision-making about the management and treatment of the diseases. (p.20.)
2. People with MS have access to medical care treatments and therapies appropriate to their needs.....people with MS must have access to information about MS that is specific to newly diagnosed individuals, together with information on local and national support, rehabilitation, and life-planning services. (p.24)
3. People with MS have access to a wide range of age-appropriate care services that enable them to function as independently as possible. (p.27)
4. People with MS have the information and services they need to maintain positive health practices and a healthy lifestyle. (p.28)
5. Family members and caregivers receive information and support to mitigate the effort of MS. (p.30)
6. People with MS have access to their communities through accessible public transportation and assistive technology. (p.32)
7. Support systems and services are available to enable people with MS to continue employment as long as they are productive and desire to work. (p.33)
8. Disability entitlements and services are available to those in need. (p.36)
9. MS does not inhibit education. (p.37)
10. Accessibility, both of public buildings and in the availability of accessible homes and apartments, is essential to independence for people with MS. (p.38)

The MSIF in particular highlights the importance of age appropriate services and quality information systems.

## 2.2 National Policy

The National Institute for Health and Clinical Excellence (NICE) Guidelines for Multiple Sclerosis (MS Society, 2003) includes the following:

1. Identify local services and individuals with skills that can provide support to families and carers.
2. Ready access to specialist neurological services .....: doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers.
3. Identify services capable of delivering a multi-professional range of expertise and specify how each is contacted.
4. Agree guidance on availability of specialist and generic disability services and how patients are linked to them.
5. Develop protocols for involving people with MS in service planning.
6. Agree an integrated approach to rehabilitation, vocational and leisure services.
7. Define responsibility for enabling people with MS to access self-help skills and knowledge.
8. When several healthcare and other professional are involved with a person with MS, they should work together with the person and his or her family, as a team.
9. Services should cater for the varying needs of people with MS over time, by; responding in a timely and flexible way to the intermittent acute needs of people with MS.
10. Ensure that the person with MS knows who to contact and how to contact them, in the event that the person with MS experiences a change in their situation.
11. People receive timely, quality assured, culturally appropriate information in a range of formats on relevant aspects of service provision and their condition and how best to manage it and wider social inclusion issues such as employment and transport.

In summary NICE indicates that the key issues around care of people with MS are the access and responsiveness of services, including leisure, and the improved communication and self-management of their condition. The document itself states that people with MS are 'often hampered by the lack of co-ordination of information source and a general fragmentation of service provision'. (p.12)

It is important to note its final recommendation states that 'support groups, specifically for people with minimal impairment (and their families) should be set up and facilitated either by a specialist nurse or support worker...' (p.14)

In addition service users themselves stated that 'The health services tend to be reactive rather than proactive - they only give services if you know what to ask for.' (p.11)

The importance of specialist workers in the area was also stressed by users 'The MS nurse visits and the contact I have received over the last 3-4years has been the greatest benefit I have received' (p.11)

The proposed research addresses some of the issues above, in that it is setting up a MS focus group to improve communication links and proactively record issues around access and improve information sharing and the shaping of services. The Multiple Sclerosis National Clinical Guideline for Diagnosis and Management in Primary and Secondary Care (2004) importantly stresses service user involvement in work around needs: 'People with MS can experience one or more of a wide variety of symptoms and difficulties. Each person's needs are unique, and a flexible response is required from the NHS. We recommend that all service personnel within the health care sector should recognise and respond to the varying and unique needs and expectations of each person with MS. The person with MS should be involved actively in all decisions and actions.' (p.xii)

This document also stressed the importance to recognise the individuality of the health/care pathway of someone with MS. Thus there is a need for a person centred approach. This is again reinforced by the first quality requirement in the National Service Framework (NSF) for long term conditions. A ten year programme to improve health and social care services for people with long term conditions including MS. There are 11 'quality requirements' in total within the NSF:

1. Person centred service – Integrated assessment and planning of services with information to aid them to make informed decisions about their treatment and care.
2. Early recognition and prompt diagnosis and treatment – as close to home as possible.
3. Emergency and acute management in a timely manner.
4. Early and specialist rehabilitation – of a high quality.
5. Community rehabilitation and support – comprehensive range to increase their independence and autonomy.
6. Vocational rehabilitation – assessment and on going support.
7. Providing equipment and accommodation – maintain health and improve quality of life.
8. Providing personal care and support – maximum choice about living independently at home.
9. Palliative care – comprehensive range.
10. Supporting families and carers – access to appropriate support and services.
11. Caring for people in hospital or other health care settings.

The Neurological Alliance is a collaboration of 50 organisations in the UK working in the field of neurology. Their document Quality Services for People with Neurological Conditions (2002, p.2) sets out key principles to underpin quality service development:

- Independence and quality of life
- Speedy access
- Comprehensive assessment
- High quality information
- Well trained interdisciplinary professionals
- Prevention
- On-going access
- Equity of service provision
- Co-ordinated care across sectors

- Access to voluntary sectors
- User involvement
- Holistic rehabilitation
- Established care pathways
- Good record keeping
- Address the needs of carers.

Quality around supporting the needs of carers is particularly emphasised here.

### **2.3 Local Policy**

The Primary Care Trust (PCT) led Long Term Conditions Partnership Board document (March, 2007) identified a challenge that only a 'small proportion of users of regional specialist services come from Gateshead'. Much of this presented work echoes the national policy presented in the NSF and NICE guidelines. Priorities arising from the work included the following:

- Up to date information
- Improved access to specialists including medicines management.
- Holistic knowledge base across all sectors, staff training – wider.
- Continuity of care across all sectors using collaborative partnerships and networks and patient held records.
- Person centred commissioning from GPs to service users.

Further issues arose around the identified need for appropriate housing, specialist support for carers, and signposting in the community. The need for a single managed process rather than 'starting again' each time a new service or issues was also highlighted. MS is the biggest single condition referred to the Council's Physical Disabilities and Sensory Impairment team. Gateshead Councils service plan for people with disabilities (2006-2009) states that a statutory requirement is to provide information, assessment of need, arrangement of care and the monitoring and review of care packages. The MS Society's Charter for MS Services: the voice of people affected by MS (2002, p.7) states that people affected by MS should have services:

1. that recognises their personal dignity.
2. that seek to maximise their personal potential
3. that enable them to be fully involved in and to influence decisions about service provision
4. and that take account of the full range of physical, cognitive, emotional, economic and social implications of having MS
5. that meet agreed standards
6. that are subject to continual improvement
7. that are accessible to them when and how they need them
8. that are delivered by appropriately skilled and experienced professionals
9. that are provided equitably and efficiently, irrespective of geography or organisational and professionals boundaries.

The fourth aspiration picks up on the social and emotional aspects of need in regard to working with people with MS. Edmonds et al (2007) writes that 'Despite the publication and implementation of these national standards, our study suggests that the needs of people severely affected by MS in the UK in 2003 were still not adequately addressed.' (p.665)

## 2.4 Further literature

The MS Society document 'Developing MS Healthcare standards: evidence-based recommendations for service providers' (2002) presents recommendations around the 'need for certain and clear diagnosis followed by appropriate support' (p.9).

This includes written information in packs to everyone diagnosed with MS, contact numbers for the MS Society and ideally knowledge from a specialist professional. Importantly the document points out the need for an opportunity for counselling and specialist MS nurses or support workers to liaise with people with MS in the community and be able to visit people in their own homes. The following are the key priorities from the report:

- Following diagnosis people with MS should be put in contact with a specialist multi-disciplinary team in the area. Ideally, this team should include a neurologist or rehabilitation specialist, and support worker or specialist nurse. (p.12)
- Counselling for individuals or families in need should be available within a reasonable distance, and should be provided by trained counsellor's familiar with MS and/or the effects of chronic illness. (p.14)
- All services should be flexible and responsive to the needs as defined by the persons with MS. (p.18)
- Professional staff should recognise that the needs of people with MS may vary over time and that services may have to be adapted to meet these needs. (p.21)

In a report around psychological interventions for MS, Thomas et al (2007) state that there is reasonable evidence that cognitive behavioural approaches are beneficial in the treatment of depression, and in helping people adjust to, and cope with, having MS. Beal and Stuijbergen (2007, p.169) wrote about the loneliness of women with MS: 'Findings from this study suggest that loneliness is not an uncommon complaint of the experience of women with MS, occurring most often in those who reported lower levels of social support, greater functional limitation, lower self-rated health status.'

Dawson et al, (2004) examined four flagship services for physiotherapy and concluded the importance of involving service users in the consultation process for service development and an increase of research around fatigue programmes. Kristjanson et al (2006, p.156) asked are supportive services meeting the needs of Australians with Neurodegenerative conditions and their families? Their results 'underscored the need for tailored and flexible models of care for these groups, taking into consideration the unique illness trajectories and long-term and notable demands on carers. Lack of information about services, patient dependency, and carer fatigue may delay access to appropriate supportive and palliative care services.'

Forbes et al's (2007) research into the role of the carer of someone with MS recognised the substantial contribution made by carers. Pointing out that the carer role around MS is transitional, developing as the person with MS may have periods of high need. Results suggested that there is a need to develop further interventions for assessing carers and reducing their activity levels and care burden in both objective and subjective ways. The work of MacLurg, (2005, p.382) into the primary care-based needs assessment of people with MS concluded that 'A patient's sense of well-being is not related to the services they already receive, as might be anticipated, but is

related to them having a perception of unmet needs.....addressing these unmet needs may improve patients sense of well being.’

The research of Baker (1998, p.106) into the information needs of people with MS concludes that ‘health professionals need to be aware of the continuing need for relevant, current, and specific information to help people with MS retain their independence and to empower them to make informed decisions’

Forbes, et al (2007, p.12) state in their own needs analysis of people with MS: ‘It must be recognised that people with MS are not a homogeneous population, and their needs vary according to the individual experiences of the disease and its symptoms.’ Interestingly they go on to write that ‘Previous studies with people with MS report a general dissatisfaction with the care they receive including: poor management of the diagnosis; variations in the availability, accessibility and quality of care, high levels of preventable complications; low levels of psychological support; a lack of information; and poor co-ordination between services’. (p.12)

Finally Edmonds et al (2007) in a study based in London on the experiences of people with MS reported the struggle they go through to get their needs met: ‘These patients often have difficulties attending hospital outpatients clinics, and are frequently lost to outpatients follow up, although they may be admitted to hospital acutely as a result of complications, such as bedsores or urinary tract infections. Many are cared for at home or in nursing homes by family members and staff who do not necessarily have the skills or appropriate support to cope with their specific needs.’ (p.660)

They go on to emphasise that ‘Two interlinked themes – the lack of continuity and co ordination of care and the lack of information about services, aids and adaptations, welfare benefits and end of life issues. Many interviewees felt that they did not systematically receive information about services, and that the information they did obtain (and, consequently, what support they received) was highly dependent on chance.’ (p.664)

From all the literature both policy and research presented in this section a number of common themes are worth noting. Firstly that of the drive for ‘patient centred services’, that is where people affected with MS are in control of their own services. In effect this means they feel empowered enough to make choices over their treatment and other issues. Secondly, to be able to do this they need quality information systems and networks of professionals who communicate effectively with them and between each other. Thirdly, they need to be able to participate meaningfully in their communities with the support of wide variety of specialist services. These services should also cater for the varying needs of people with MS and those people who care for them over time.

### 3.0 Methods

In terms of the methods utilised in this work, primarily a qualitative approach was taken. The key to this is a 'participatory approach' in which the direct experiences and opinions of the respondents in their own words are paramount. These formed the bases of the presented findings, conclusions and recommendations. Data collection took place initially through two focus groups, one for people with MS and one for family members. Provision was also made for service users and family members wanting to participate but who were unable to attend the focus groups either to contribute via telephone interviews, face to face visits or postal questionnaire. This encouraged people to participate in the work on their own terms. What follows is an outline of the methods employed.

### 3.1 Steering Group

The steering group for the research proved vital to the success of the work. The group consisted of Gateshead Council members and service user representatives. The role of the group was to support the project and advise on the:

- Facilitation of access to respondents
- Ethical concerns
- Practical arrangements for focus groups and other data collection methods
- Scrutiny of draft reports
- Co-ordinate a dissemination strategy
- Presentation of the ongoing work to the Physical Disabilities Partnership Board.

### 3.2 Respondents

Contact was initially be made by letter (see appendix 1) to all people on the councils Care First and other data bases indicated to be living with MS. The letter invited people to be involved in the work in a way of their own choosing. Table 1 shows the breakdown of respondents and the means they choose to respond by. As recommended by Gateshead's research governance committee, to counteract any potential for service users to become distressed by the research process the service user will be asked in advance if they would like a person of their choice present at the interview or focus groups. Failing this for all service users involved a named support contact will be within easy reach if required. Numbers were a little low in the focus groups (5 and 3) but the qualities of the ensuing discussions were excellent. Similarly of the 28 postal questionnaires sent out only 10 were returned. What the table below shows is the diversity in which participants became involved in the research.

	<b>Postal Questionnaires</b>	<b>Telephone Interviews</b>	<b>Focus Group Membership</b>	<b>Face to Face Interviews</b>	<b>Totals</b>
<b>Service Providers</b>	N/A	10	N/A	N/A	10
<b>Service Users</b>	10	3	5	3	21
<b>Family Members</b>	N/A	2	3	N/A	5
<b>Totals</b>	10	15	8	3	<b>Total Inputs: 36</b>

### **3.3 Focus Groups**

Focus groups ran as intended with people with MS and their Family Members. The format used at the focus groups was similar to the structure of both a home visit and telephone interview to ensure equity and continuity of data collection (see appendix 4).

The aim of the work as previously stated was to explore people's experiences of MS around needs and the potential for service development. They were brought together to discuss and comment on MS and perceived needs against the National Service Framework for Long Term Conditions (2005) and the National Institute for Health and Clinical Excellence (2003). The focus group approach concerns the explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group (Morgan 1997, p.2 and Powell and Single 1996). The facilitator creates an environment that encourages participants to share perceptions and points of view, without pressurising them (Krueger and Casey 2000, p.4 and Morgan 1997, p.2). The groups were held in a comfortable environment; St Chads Community Project, Bensham, Gateshead. Refreshments and travel expenses were provided. The facilitator from Northumbria University was independent from the service provision so not in a position of direct power over the respondents. Both negative and positive comments were encouraged from the group members. The role of the facilitator was to keep the discussion on track, generally in line with topics of need and MS, while also providing opportunities for group members to raise other issues of importance to them. The facilitator tried to avoid showing any form of agreement or disagreement and approval or disapproval with any points of view expressed. Each focus group lasted around one and half hours.

### **3.4 Face to Face Interviews**

The face to face interviews offered to the respondents followed the topics of the focus groups (see appendix 4). They were conducted in the participants own home, if requested, with the support of one of the Physical Disabilities and Sensory Impairment Team members. Each interview lasted approximately one hour.

### **3.5 Telephone Interviews**

The telephone interviews followed the topics of the focus groups (see appendix 4). One of the Physical Disabilities and Sensory Impairment Team members made the initial phone call to the service user or family member and then the phone was handed to the researcher thus assuring anonymity and confidentiality. Telephone interviews covering current and future service developments around MS were also conducted with service providers (see appendix 6) from the following organisations; Gateshead Carers Association, Crossroads Care, Gateshead Access Panel, Gateshead Advocacy and Information Network (GAIN), Occupational Therapy and Adaptations Team, Physiotherapy Team, Gateshead Care Call, Individualised Budgets, MS Nurse Team and the Physical Disabilities Team.

### **3.6 Postal Questionnaire**

A postal questionnaire was developed (see appendix 5) with the support of the steering group and a university work colleague who has MS. In total 28 questionnaires were sent out to those people canvassed who did not want to be directly interviewed or take part in a focus group. May (1997, p.82) writes on postal questionnaires that they are 'characterized by the collection of data from large, or even very large, numbers of people... Virtually all surveys aim to describe or explain

the characteristics or opinions of a population through the use of a representative sample...The purpose of surveys is likewise varied...from governments wanting social economic data to local needs'

May (1997) goes onto to discuss that questionnaires should be constructed in a rigorous way, stressing the importance of conducting pilots to make them ready for use with the group to be studied. The questionnaire presented was piloted directly with one person with MS outside of Gateshead. This piloting removed ambiguous questions and aided the operationalising of the projects aims. A consideration of socio-demographic factors such as age and gender of the respondents was also made. A combination of open-ended questions and more closed questions allowed both clear set answers (tick in boxes) and slightly deeper exploration.

### **3.7 Ethics**

The Ethics Committee at Northumbria University and Gateshead Council's Research Governance Committee scrutinised and approved the research proposal.

With regards to the research design presented here informed consent was vital and was considered part of a larger ongoing democratic process where by respondents consent is not a one off non-retractable event but a continuous negotiation. A consent form (see appendix 3) along with an information sheet (see appendix 2) were drawn up with the steering group and distributed to the participants.

Confidentiality is concerned with not revealing private and personal information about an individual during or after the project. Anonymity is concerned with making people unidentifiable within the project. This is more than just changing their names in any reports published. Codes and ID numbers were used and all data was held in accordance with the Data Protection Act. In practice this meant that no names or personal details of service users were held by the researcher. All computers were password protected and all relevant paper materials were kept in locked filing cabinets. No one outside the direct research team was privy to information and it will all be destroyed within 6 months of the end of the study. This was all explained to the prospective participants. The transcription was conducted by the researcher himself. It is important to note that in focus groups facilitators can't give a total assurance of confidentiality, as group members may report others' comments outside the group. However the implications and responsibilities around confidentiality were discussed in the groups.

To conclude within the Disability Studies division of Northumbria University the following ethos is practiced: 'Any research undertaken in disability studies in terms of its aims and execution will not only avoid harm and distress but also attempt to promote the 'well being' of all those involved. In addition we recognise that we work within a 'disabling society' and that any research with disabled people is a political act. As such the degree of control and benefit that disabled people can attain within any proposed project needs to be considered and discussed. In disability studies we don't view disabled people as simply vulnerable as this can be patronising. We acknowledge the oppression they may have experienced and often perpetuated by research conducted 'on' not with them.' (Brandon 2004, p.3)

### **3.8 Analysis**

The focus groups, telephone and face to face interviews were all taped recorded and transcribed. The qualitative content of the questionnaires underwent thematic analysis, was coded and put into themes to compare against relevant policy and research. Each individual was given a code and their comments analysed in relationship to the concepts of 'need' and potential 'service development', these comments were grouped together and presented in the next section under different sub themes.

## 4.0 Findings

What follows are quotes illustrating the main sub themes derived from the data collected from Service Providers, Service Users and Family Members. Small tables under selected sub headings represent the data from 10 returned postal questionnaires. These questions refer to what degree the needs of services users/family members have been met.

It was stated in the background to the work that in early 2006 no accurate figures of the numbers of people affected by MS in Gateshead were available. After a separate audit was conducted by the Primary Care Trust (PCT) in September 2006, it is noted that this figure is 364. Across the data collection methods utilised in this work i.e. focus groups, interviews and postal questionnaires 36 service users and family members responded (see table 1). This means that approximately 10% of those affected by MS or those representing them contributed to this study across Gateshead. Overall this is a relatively high percentage for a qualitative study.'

### 4.1 Living in Gateshead

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
Visiting places of interest	1	5	3	1	
Sports and leisure	2	5	2	1	
Shopping		4	4	1	1
Library			6		1

The Library was rated quite highly, but people had difficulty gaining access to their local post offices: *'The local post office where I get my invalidity benefit had a foot high step to get into it so I needed someone to push me into it. The Library locally is ok to get into.'* (Service User 6)

The Metro Centre was reported very positively by a number of participants: *'The Metro Centre is accessible – you can get in the shops, get to the toilet, go for a drink. You can do your own shopping and the car parking is on the level. Most of the local shops have ramps going into them. However pavements are not wide enough where I live (Leighton) and for the scooter there are no dips in the curbs and cars will park in the wrong places, there should be signs up to stop people parking there. Some of the junctions and roads are not good it's all not consistent.'* (Service User Focus Group)

One focus group respondent remarked on the problems associated with going swimming: *'I was in America a few years ago and its chalk and cheese compared to here. It's like the third world here in terms of access. There are no handrails here you need handrails with MS as you need to pull your legs up. The library in Gateshead is not bad for access but the swimming baths are terrible. All of them – they have no access to get in – they need to have a slope with a hand rails or steps, the hoist is too embarrassing. If you do need to have a hoist then why use it. Not a lot of toilets that you can use outside of the Metro Centre.'* (Service User Focus Group)

One service provider remarked that one of the council's priorities is developing accessible communities and the problems around allowing people good access to local facilities: *'One big area we are looking at is countryside parks and urban areas. Motorcycle barriers (these to prevent motorbikes getting into pedestrianised area) are*

*a big problem (as they also obstruct people using wheelchairs and scooters). One of our people with MS had a barrier put right outside her house that stopped her getting to the local facilities. The council had to remove it in the end.'* (Service Provider 3)

#### **4.2 Diagnosis**

The people affected with MS reported their experience of diagnosis as almost universally negative. Long waits of months and in some cases years to find out they had MS. At this point the actual experience of the diagnosis being an unsupported shock with little information provided: *'When I discovered I had MS I was just told I had it and that was it so I went out and got mortal drunk with some friends as I thought I was going to die.'* (Service User 6)

*'I was diagnosed when I was 24, I'm 41 now and went to the General Hospital and the consultant took us in a room and said you have MS and bye and that was it. I walked out and I cried and a nurse asked me if I was alright and she said I would be alright.'* (Service User Focus Group)

It is important to note that the respondents would have been diagnosed twenty or more years ago. However one service provider pointed out a need to improve current practice around diagnosis and accompanying information system: *'I would fast track support and services for diagnoses because what I always find is once they have a diagnosis they can start sorting their life out. They can then think about the next step forward. What will I be entitled too? What about my employment? They need reassurance at this point. Whether its information in a leaflet or a person that is needed. Someone with MS may have poor eyesight so a leaflet may be too difficult to read.'* (Service Provider 3)

#### **4.3 Assessment**

One issue that did arise is the potential need for professionals to re assess people with MS every few months. This was seen as onerous: *'Every time I contact them they come out and do the same community care assessment. 4 times I have it in 7 years – it's very, very frustrating as you go over the same ground time and time again.'* (Service User 11)

#### **4.4 Information**

A major theme arose around 'information'. A shared experience was lack of clear information around available services: *'I was also told nothing, given no support and given no information. Physiotherapy, I was only aware of it as I spoke to someone on the ward. What they need is a human being to tell you exactly what to expect. This is what could happen, be aware of what might happen. Somebody in the know rather than someone with MS.'* (Service User 11)

The potential complexities of obtaining information on and contacting services are highlighted in the following quote from a service user: *'If you make one phone call to Walkergate they sort it all out but in Gateshead you have to ring all over the place. If I want a physiotherapist, Dunston Hill, for Neurology the QE, for OT, Whickham, for Social Work the Civic Centre and for benefits the Job Centre Plus.'* (Service User 11)

The need for a person as a conduit for up to date information was stressed by a number of respondents, it was not important that they should be a nurse, social worker or OT, it was also suggested that someone with MS might also take this role. What was important is that they had specialist knowledge of MS: *'There should be an OT that tells you everything in an area that's available etc. The library is one place – but not everyone can get there. Your social worker should come and tell you. Consistent information is the key an MS nurse in the region who can tell you exactly what is going on. Someone who knows all about it. Someone who has MS with some empathy would be good. Its like if someone comes round to help you stop smoking and they say you can do this or that and they have never smoked. Someone with MS understands what people go through. It does not have to be someone who is qualified but knows what's going on. It would not matter if they had MS or not it would matter what they knew.'* (Service User Focus Group)

It was pointed out by family members that some existing information systems are of worth but further assistance is needed: *'There is an information centre and library at Walkergate Park which is excellent, not just MS but other neurological problems. This place needs to be better known as any one can walk in. A specific information officer in MS should exist in the local area. Someone at the early stages need to come and step in and explain what is out there. It would be helpful to explain how things might happen. No two MS patients are the same, we were told that my wife had a mild sensory form of MS so she would never end up in a wheelchair and 19 months later she was in a wheel chair they said the MS had changed I did not even know it could change. A one stop shop with information and on the end of the phone on practical things like equipment would be helpful. You end up spending money and then their condition changes and the money is wasted. It changes differently in people but more information would help.'* (Family Member Focus Group)

The positive role of the social worker in the dissemination of information was pointed out by one family member: *'A list of everyone I might need and then the social worker arranges meetings – if it was not for our social worker we would not know about half the services we get.'* (Family Member 17)

Service providers highlighted a series of issues around the importance of quality information: *'Clinicians always feel there is a scarcity of information – who to go for what? For example if you need a wheelchair assessment where do you go, if you get headaches who do you go too, if you need support with your house? It's about the patient being able to help themselves. Information needs to be provided in a number of different ways it could be a person or leaflets or web page or a directory of services.'* (Service Provider 9)

*'What needs changing most is sign posting – that is information to people and organisations that can help. Part of this is helping people to understand what they are eligible for. A person with MS might move into the area and need to know how they can get bathroom adaptations and other stuff.'* (Service Provider 1)

*'Information is always one of the big issues, particularly the earlier the information the better. More funding into information would benefit MS in particular. Its always a problem information as not always people use websites, GP surgeries is the best*

*place to have the information systems, if you had a trained worker there it would be a brilliant facility.’ (Service Provider 3)*

The role of the MS Society was also pinpointed as key in information along with the need for varying formats for the distribution of information: *‘The MS Society etc needs to put a directory of all the services together to go out to everyone patients, carers, Doctor Surgeries through different formats. Ideally they could look up the area they are in and see what services are available. This would help say with which rehab service in the broader areas of Northumberland exist. Put it on CD so it could be updated easily.’ (Service Provider 5)*

#### **4.5 Waiting Lists**

Waiting lists are a concern for both service providers and family members: *‘We have recently been trying to reduce these lists. People with debilitating conditions such as MS will be prioritised by our service. The only advantage of the long waiting list is that we can use the time to gather information on the person – phone them up and ask them a whole series of questions about what they need etc. We can then make more informed decisions.’ (Service Provider 2)*

*‘In most areas there is a high waiting list perhaps 6 months. It is really difficult if you know someone needs something but they have to wait.’ (Service Provider 2)*

*‘Also if you recognise a change in your partner not having to wait 6 months for an appointment would help.’ (Family Member Focus Group)*

Another service user commented on the long wait to see a social worker: *‘If you want to see a social worker it takes months. I wanted to see one last September and I am still waiting.’ (Service User 11)*

#### **4.6 Equipment**

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
Equipment at home				5	3
Adaptations			3	3	4

In contrast to the table above service users commented on the concerns around the up keep of equipment: *‘I had a hoist fitted and a closomat toilet from an initial assessment to getting it took one year and 3 months. The OT is dependent on what the company say they can do, they do not tell you what other companies can do. Running costs of equipment are not paid for; my lift is out of warranty and costs me £95 every time the engineer comes out.’ (Service User 11)*

A second service user comments on the need to plan ahead with regards to equipment. *‘The council have an idea of what they want for you – but because MS is progressive you do not want to go to the end point. For example I will need a hoist sometime in the future and I know that the OT will take so long to get it I better order it now. I do not want to start using it now as I will lose any muscle tone I have got.’ (Service User 11)*

Equipment was a major issue for family members who also commented on negative experiences with equipment, around, training in its use, availability and

appropriateness: *'The experiences with equipment is horrendous and in places where you would expect decent equipment. My wife was recently in the QE and she found it so bad that she rang up and asked to come home even though she really needed the treatment. The nurses claimed they did not have the equipment and when it was finally produced they said they did not have the training to use it. It was just stand aids. When I went in and made a bit of noise they managed to produce one.'* (Family Member Focus Group)

Equipment in hospitals was also criticised: *'They did not have the right equipment in the hospital for her to use the toilet, they tried using a bed pan but it just cut her. So the advice they gave was just wet the bed which she did 5 times that night. They then decide to put a catheter in.'* (Family Member Focus Group)

One family member recounts the experiences of poor equipment at a GP surgery *'At her GP its difficult to say go in for a routine smear test as they do not have a trolley low enough for her to get onto. The last two occasions we have had to take her into hospital for a smear test. On each occasion she has got an infection so she has just refused to go for a smear test. Little things that become very important.'* (Family Member Focus Group)

Wheelchair services were singled out as problematic, not the staff involved but the system itself: *'Wheelchair services are really slow – I do not know what the problem is but if you need a modification of some sort by the time it comes through things have moved on. It took them 11 months to get the wheelchair sorted so I could get him out and about. It's not the personal it's under resourcing. Some bits of equipment is rapid it's the big stuff that takes time as it has to go through all sorts of reviews. From deciding we needed a tracking hoist to being in a position to use it was 2 years.'* (Family Member Focus Group)

The implication for the slow delivery of equipment was mentioned by one family member: *'If you need equipment like something for the bath you have to wait 6 to 8 weeks for it. If you need it you need it there and then not in 8 weeks. If you need a hoist and you have to wait 8 weeks then that person is stuck in bed for 8 weeks.'* (Family Member 17)

#### 4.7 Service Professionals

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
MS Nurses		2	3	4	
Social Workers				5	3
OTs				5	2
GPs			6		3
Physiotherapists		3		2	

Comments were recorded on a series of professional groups.

##### MS Nurses

MS nurses knowledge base was praised and a desire to have more locally based was expressed. *'MS nurse specialists do not seem to have time to talk they are alright if you want something specific. The MS nurse would be an ideal person to say this is what might happen be aware of it.'* (Service User 11)

*'The MS nurses are generally very good, caring and nice people with a lot of knowledge. But the only access is when you go to the hospital. It would be good to get them out more to your home.'* (Service User 13)

*'The MS nurse in hospital was really good they know a lot and can find solutions to your problems.'* (Service User 14)

*'I think it would be extremely useful to have one in Gateshead not just Newcastle. Only real contact is around crisis and facilitating contact with other professionals.'* (Family Member Focus Group)

#### Social Work

One service user reported that: *'I have been not assigned a social worker despite numerous requests.'* (Service User 6)

One social worker comments that they did *'not have the resources to constantly case manage people.'* (Service Provider 20)

#### Physiotherapy

One service user in the postal questionnaires requested more Physiotherapists. Two family members report positive experiences with Physiotherapists. *'The Physiotherapist has been smashing. With the Physiotherapist it motivates her.'* (Family Member 17)

*'Physiotherapist comes to see her, tries to be once a month, if she relapses she comes once a week or may come if I need her in a couple of days – she is really good.'* (Family Member 18)

#### General Practitioners

One service user has had a very positive experience of their GP service: *'My GP is very good he will pop in for a while to see how I am doing if he has not seen me for a while – he has my interests at heart.'* (Service User 11)

#### Speech Therapist

One service user pointed out that Speech Therapists had a limited understanding of MS: *'The speech therapist was not so great their knowledge of MS was not great they need to have special training.'* (Service User 14)

#### Occupational Therapist

Also from the postal questionnaire more OTs were requested. One Service Provider reported the need for more OTs with specialist knowledge. *'What we do not have is OT to do specialist OT with MS (long term neurological conditions). A physiotherapist would be able to do some rudimentary assessment but an OT would know of better tools, techniques and assisted technology for the patient.'* (Service Provider 9)

#### Specialist Team

One Service Provider suggested the need for a specialist MS team in the locality. *'In an ideal world I would like to see an MS team set up with OTs, social workers within that team MS nurses. Within our own work we cover a vast amount of cases to*

*have specialist workers who have knowledge you could talk about the clients within the team and build up skills. Sometimes it's really difficult to arrange reviews for clients but trying to get a date for everyone to come together is really difficult, but if you were in a team then everyone would know about the clients. You end up with a bank of information about clients between yourselves.'* (Service Provider 20)

#### **4.8 Isolation**

The isolation of both service users and family members was a strong theme across the data collection. *'There is only one MS physiotherapist in Gateshead. Everything is with the GP now. I use to see a neurologist at the RVI but they said it was not needed. I feel really isolated now. Don't see any other health workers or social workers. People in the hospital seemed to ignore me I was only in the one day they were not that interested in the MS. The only person who comes to see me is my daughter my friends live a good distance away.'* (Service User 12)

*'From a service user perspective it (tele-health) is a lot about reassurance. You have a lot of people who are socially isolated who might not have any friends or family. They might need an eye on them if there is an emergency or just some advice...a lot of families are not what they used to be they are dispersed now'* (Service Provider 1)

*'People are very isolated with MS. MS tends to isolate people more than other conditions because of its progression. It can affect speech and not every where is accessible.'* (Service Provider 20)

One family member stressed the social isolation felt in connection to MS *'At first it is less important but as time goes on you also have the loss of the social life as it gets increasingly difficult to move around and get into other peoples houses as they do not have the facilities like lifts and hoists and it means you are cut off. This means for me that I have to double check everywhere we go, actually visit the place and not take someone's word down the phone. Most facilities are not any good.'* (Family Member Focus Group)

#### **4.9 'Somewhere you could go to'**

Another strong theme particularly from the service user focus groups was that of a place for people with MS and their family members. *'It would be nice if there was somewhere for people with MS to go too like a gym. I have a couple of friends with it. A club would be good so you could get beauty treatments in an accessible place.'* (Service User 12)

*'Need a centralised community place that you can lift the phone up and talk to someone and arrange things and give you information.'* (Service User Focus Group)

*'Something you could go to even if you can't work to give you something to do in the day. Social activities and be able to talk to people. Not just for people with MS other people as well. I get on with people but there are not many ways to meet people.'* (Service User 13)

Service users reported that they did not want to go to what they saw as a 'traditional' MS Society meeting *'I used to be in the MS society in Gateshead and the MS society in Newcastle – its very depressing they want to play bingo and you get treated like an*

*old person. I was not very old when I was first diagnosed and I saw them as more tea and cakes. It's like a dying place and you all have this disease and that. I would rather go somewhere you can go and do exercise. They give the carers the same treatment. You feel so relaxed when you go it's marvellous (MS Research and Relief Fund, Stobhill, Morpeth) What is needed is another centre funded by the council for people with MS.'* (Service User Focus Group)

Factors for this kind of meeting included the full age range of people with MS: *'It fluctuates and affects young people with an onset 20-30s. They have tried to set up a young persons group in Newcastle/ Gateshead to cater for younger people. They do not want to go to the branches where there are older people and people who are more advanced in the disease. They do not want to go and meet a load of people in wheelchairs. It may not happen to them but you just do not know. They do not want to have it like the normal branch meetings. Doing things for children would also be good ideas as a lot of children are affected by MS if their parents have it. Just support for them and help them understand. A fun educational day and the children can talk about how they feel – as they may not wish to talk about things in front of their parents as they do not wish to upset them. I need the time to do this. Looking at pregnancy is another issue my colleague has tried to look at this.'* (Service Provider 5)

#### 4.10 Mental Health

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
Counselling	2	4			1
Self help groups	1	4			

A number of respondents commented on the need for mental health support around MS. Two respondents' requested more emotional and mental health support. Two people affected with MS remarked that *'All my life I have been in control and now I am not and that really gets to us. A counsellor to talk too might be helpful'* (Service User 12)

*'MS can make you very depressed and people start to live off their depression and let it get a hold of them. Stress affects MS. You have to get on with it, I'm not going to bung down loads of tablets and say I've got MS; I'm not going to give into it. Got to have a positive mind.'* (Service User Focus Group)

Two service providers also remarked on the need for more mental health support for people affected by MS: *'For some people MS is enormous, their whole life has been turned up side down. There are a lot of services out there but where do they start? It all comes across as a little fragmented. What they may need is support mechanisms before they need adaptations. We had one guy with MS he lived on his own and gave us one or two problems shall I say. To me it seemed if he needed some sort of bereavement counselling. His old life and the old person had died and been replaced with a new person – he was struggling to come to terms with it all. I am not sure what is out there in terms of counselling.'* (Service Provider 2)

*'The other issues were related to psychological issues – it was felt to be a lack of access to psychological support services. After talking to the clinical psychologist there is no designated service to help this particular group. Access to counselling for*

*themselves and their families in terms of coming to terms with the disease is what they wanted.* (Service Provider 9)

#### 4.11 Direct Payments

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
Direct payments			3	2	1

With regards to direct payments there was a mixed response about its usefulness. One service user was happy with her social care remarking *'Social services asked me to do direct payments but I get on with all the people who come in to care I'm really happy with the setup.'* (Service User Focus Groups)

One family member remarked on the complexities of organising direct payments in particular relating to older people. *'Direct payments are such a pain, all that paper work and timesheets – you had to sort out their time sheets I thought it was all too much. If it was a simpler scheme it would be excellent – it is a good system but for an older person there is a lot of paper work.'* (Family Member 17)

The next comments come from service providers, firstly one respondent remarked on the life changing effects of direct payments *'Direct payments have a direct impact on services for people with MS. Given a lot of independence allowing domiciliary care workers to come into people's houses. Help people get out of bed in the morning. I remember when direct payments came along one of our services users at the time said that direct payments had totally changed their life. From being stuck in the house not doing anything to be being able to get out and attend meetings. This has been the biggest thing. Now individual budgets will add to this - Gateshead is a pilot for the individual budgets so we have not sorted the process out totally yet so we do not know exactly what the influence will be yet. There will hopefully be a major impact for people with MS through IB.'* (Service Provider 3)

A second service provider described some of the practicalities of using direct payments: *'Some clients can manage a direct payment really well but you have other people who are at the very progressive end stage of MS who often have cognitive problems. It's difficult for them to manage direct payments. I have had clients where the disease has progressed she has been less able to manage it and the direct payments team is really small. You see you have got everything to do – latest legalisation, manage employers, manage money, holidays/ sickness, you have to be aware of all of that. Sometimes it seen as an easy option – for example if you were trying to manage a package of care and you could not get hold of a suitable external provider and the relatives were willing to be involved it becomes an easy not best option but it's the only way they would not get stressed out by the nitty gritty of legislation. Someone at the end stages of MS does not want to go to a tribunal. I will always tell people about DP but will be honest and source support for people in having it – direct payments giving ongoing support. IB scheme has not learnt from problems on DP and is therefore heading for problems. The paperwork needs to be right to make sure people do not get into huge debt.'* (Service Provider 20)

#### 4.12 Engaging with services

One family member commented on concerns around engaging with services.

*'Things have been really bad for the last few years but we have struggled on, on our own as we are those kinds of people. We do not want to be involved with agencies unless we can avoid it. Then she had a very, very bad relapse in January of this year. She was in hospital for 10 weeks I had no option but to use services and looking back now I do not know how we have managed without them. In the early days you manage quite successfully but its not 24 hours as the situation deteriorates you put more and more time in and you manage it but there comes a point when you need outside help. But it's difficult to invite a dozen strangers in.'* (Family Members Focus Group)

A service provider reported issues around costings of services. *'The greatest concern for people with MS is those in the private sector who are means tested out. For example if you have someone who has MS and his wife works they are not going to get any grant assistance. We can help them get the quotes but not arrange the adaptations themselves. At the end of the day they would have to pay the money themselves.'* (Service Provider 2)

#### **4.13 Location - Support**

The following section draws together issues around support within various settings.

##### Support at home

Two family members expressed concerns about the quality of support they were receiving at home: *'The nature of these services is that you get 12 ladies, usually ladies that come in 2 at a time for a few hours a day – these jobs are not well paid so the turn over is high. So you see new faces all the time and the house is not your own any more. You are constantly explaining the same things to people and they come with different levels some are brilliant with nursing qualifications others are immigrants and care but have problems with the language and other people are just not good and you have to do something about it.'* (Family Member Focus Group)

*'A big issue for me if people (workers) are moving between other peoples houses is MRSA. With MS your immune system is really low so the staff who come to me don't go anywhere else. A district nurse came in one morning and night and I was appalled how they did not wash there hands when they came in – one got a catheter out of her pocket which was not sterile rubbed her hand down the catheter and her phone went so she got it out her pocket answered it and then continued. They are G grade so senior. You need a constant carer that's what you need.'* (Family Member Focus Group)

A second family member commented on the importance of having professionals come out to the home *'I try to create an environment where if we need a professional they come to see us, this means we do not have the difficult task of trying to get to them – it makes it easier.'* (Family Member Focus Group)

##### Support in nursing home

The one person affected by MS interviewed living in a nursing home had a positive outlook on her care. *'The nursing care here is just as efficient as the hospital, but instead of a quick slam you over here to put the dressing on you and slam you over the other side of the bed to put dressings on you again – there's a gentleness and they take their time.'* (Service User 6)

Support in hospital

Generally the support people received in hospital was viewed negatively, in particular a number of family members commented on the lack of specialist understanding of MS within generic hospital wards. *'The NHS has good aspects but when you go in for a particular need at the Freeman they could not grasp that this was someone with MS and pneumonia not someone with just pneumonia. She has very special needs that overlay everything. I would walk on the wards and you could see the nurses say oh god he is back again as I would say what about this or that. The operation can often trigger a relapse but the orthopaedic surgeons could not get it into their minds that they needed to talk to a neurologist. There seems to be walls between the specialities.'* (Family Member Focus Group)

A service user makes a similar point: *'The QE is a busy hospital usually understaffed and the average nurses do not know much about MS.'* (Service User 6)

Service providers also commented on the need to improve the hospital experience of people affected by MS and the need for continuity of care: *'Modern matrons I know wish to address this and hopefully this will change. For instance: you might like to be washed with a certain type of soap as you may be allergic to any other kind of soap. Every time someone was washed it could be with their soap and this would reduce cross infection as well. There is also a concern that the care package that has been arranged for them will stop when they come into hospital. The carers will not come in to provide care for them.'* (Service Provider 9)

Respite Support

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
Respite			2	3	

Respite was recognised as important by services users: *'My family could do with a bit of respite I had it once. I did not like the Highlands a couple of years back – they hoisted me up over the bath and left me hanging in mid air. I could hardly dare breathe.'* (Service User 7)

Concern was expressed over the existing respite provision. *'Originally they decided that I needed 6 weeks of respite – first occasions she went in were ok but one occasion it was awful and she point blank refused to go. For me the support has been flexible, even going into hospital to care for him. It really depends on the agency you use.'* (Family Member Focus Group)

*'You have to stay overnight with them to ensure the standard of care. I do not trust anyone to do respite.'* (Family Member Focus Group)

*'One issue we have as we have moved from respite to support in the evenings. They say they are not trained to give medication – so I have to come back from respite to give her the medication. The person with MS knows what they are taking but a person with dementia you could give them anything.'* (Family Member Focus Group)

Finally the need for development of further respite care was proposed: *'What we need to be building are houses that are ready for adaptations when ever they are needed.'*

*These are ordinary houses- the council plans to be more proactive in the development of such housing for disabled people and people who become disabled.’ (Service Provider 1)*

#### 4.14 Caring

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
Caring	1	2	2	2	2

One family member commented on their concerns of being too pivotal in the care process: *‘What bothers me is that I have almost become the centre of gravity for it all. To sit down and think what happens if I get wiped out tomorrow and the consequences of that do not bear thinking about in terms of the impact on the rest of my family. It is quite a responsibility for me. I did not realise that I could get carers allowance until recently. In my case things just fell apart at the point of my retirement when I was looking forward to a reasonably pleasant life.’ (Family Member Focus Group)*

One service provider pointed out the need to work with and assess younger carers: *‘Often people who have MS get it in relatively young life and what we do not have is much work with young carers. The tricky one for us is to identify some specialist areas we think that there are 25,000 (overall) carers in Gateshead. We need to look at the mutual support that carers with people with MS can support each other. Perhaps we should look at this area. I do not know if they need anything different. We would not be doing anything different except focus on the group as a whole. We need to survey the carers locally to find out what their needs are. From this we can develop a database. People with MS’s carers should be receiving carer assessments, it is not happening.’ (Service Providers 15)*

A second service provider spoke of their concerns for the hidden carers who do not contact carer organisations *‘We are no where near the 25,000 we have 600 and the other sister organisation has 16,000. There must be many hidden carers out there. Some of them must be carers of people with MS. We have 10 or so on our books relating to MS it should be nearer 100 or more.’ (Service Provider 16)*

One service user commented on the way services appear to wrongly view MS as an older persons condition *‘When I ring for the OT I get put though to the older people’s service. Had a new worker the other day and assumed my wife was my daughter. She thought that the people they seem to have are all elderly no one can rationalise that it can be a younger person. Carers Association is geared to older people.’ (Service User 11)*

#### 4.15 Advocacy

Advocacy was only commented on by service providers: *‘Taking someone who has MS working with someone else with MS, like peer advocacy, giving work support and advice. I would like to see more peer advocacy and mentoring. Advocacy comes under support – they must understand that advocacy is about empowerment.’ (Service Provider 3)*

A second point was made about the need for advocacy for carers and younger people with MS: *‘All the current projects struggle with funding. The major gaps in advocacy services are the need for a service specifically for carers. Also the need for a service*

*co-ordinated push to younger peoples services. With regards people with MS as they are often younger. The chicken and egg thing is how much of a demand for this kind of service would be. If there is not a project offering it then people tend to not know they want it. One of the problems is people do not commonly know what advocacy is.'* (Service Provider 8)

#### 4.16 Transport

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
Blue badge scheme			5		3
Adapting a vehicle			3		2
Mobility scheme			2		3
Local transport systems	2	4	1		

The Taxi link and ambulance service came in for criticism: *'Taxi link service - I would use it a lot more but the service is poor. I am unable to go out when I want to.'* (Service User 5)

*'As they get more disabled they have to use an ambulance they say they are left waiting for hours before and after appointments for transport.'* (Service Provider 9)

One service user commented on the short comings of the local bus services. *'The buses with the platforms that go down are too few and far between. If the bus comes and there is someone in the space already I have to wait and I don't go to the Metro Centre on the bus as I could wait for a long time for a space to be free on a bus. Someone puts a push chair in it (tell them to shift). Is there any service for wheelchair users the care bus and dial a ride? No one tells me this information. More bus stops would also be good.'* (Service User Focus Group)

#### 4.17 MS Society

<i>Postal Questionnaire</i>	Very Poor	Poor	OK	Well	Very Well
MS Society		4	1	1	1

A number of service users stated they did not want to be in a MS Society meeting with older and more impaired people than themselves. They wanted something lighter: *'I did use to go to the MS society for a while but they talked about MS and I did not want to do that. I wanted them to do other things – sitting around with other people talking about how to get this or that benefit did not interest me.'* (Service User 6)

*'I do not want to meet people who are worse than me and learn how bad I can become. I know it will be bad enough with that. People are often very negative so I am better off on my own. The MS Society all they talk about is the negative things. The MS Society needs to focus on what people can do not what they can't.'* (Service User 7)

*'A lot of people with MS do not want to talk about it. I have met people with MS and everyone I met was younger than me and I felt I could not speak to them – that was at the MS Society they were nice but not everyone wants to talk about the ins and outs of what's going on. First time I went to an MS meeting I was walking and everyone else was in a wheelchair and I thought is this the future and I did not want to look at it.'* (Service User 13)

Others saw the information support offered by the MS society as important: *'The MS Society sends me a newsletter which is useful and read about how it's affecting them. It makes you realise that there are other people out there.'* (Service User 12)

*'I used to be in the MS society in Gateshead and the MS society in Newcastle – its very depressing they want to play bingo and you get treated like an old person. I was not very old when I was first diagnosed and I saw them as more tea and cakes. It's like a dying place and you all have this disease and that. I would rather go with someone where you can go and do exercise.'* (Service User Focus Group)

*'Never been to MS society I find it a bit depressing. They are good on the phone and they are very supportive – they helped me force the council get a carer for me at home for a month I was there. They could not find any one to care for me 2 years ago because I live a bit out of the way.'* (Service User 14)

Concerns were also expressed about not having a local branch of the MS society in Gateshead: *'In the amalgamation of the Newcastle and Gateshead branches of the MS society it's not always easy for people in Gateshead to get across to Newcastle. It's a wide area in itself.'* (Service Provider 4)

#### **4.18 Stigma**

The stigmatisation of people with MS was also stressed by both Service Providers and service users. *'People with MS often have quite a stigma attached the changing look and movement of their parents or sibling. They are singled out as odd etc – the community is difficult to accept these conditions.'* (Service Provider 16)

Three service users expressed the same issue that they had wrongly been mistaken for being drunk when they were experiencing the symptoms of MS. *'The big issue is understanding. The problem with MS is the misunderstanding – the first time I was diagnosed people generally assumed I was drunk'*. (Service User 13)

*'For a long time the Dr kept telling me not to drink so much as I was falling over. Then went to RVI for a week and they told me I had MS – you are put into the world with a problem and it's up to you to get past that problem.'* (Service User Focus Group)

*'I was asked if I was drunk at work occasionally but I was staggering and I said no I have MS and in the end it was getting so awkward for me thinking as they did I just gave up work. I got a medical retirement with a good pension. I just thought I do not want to go through it all anymore.'* (Service User 6)

## 5.0 Conclusions

The conclusions drawn from this work cannot be generalised to the total population of people affected by MS in Gateshead or beyond. The mass of qualitative data presented in the previous section is designed to produce questions and areas where local services should be examined and developed. One written comment from the postal questionnaire encapsulates the sentiments of a number of service users, which include the current lack of information, a sense of isolation, mental health and the desire for independence:

*'I receive newsletters from the MS Society in which they refer to MS nurses and day centres etc which as far as I know there are none in Gateshead. I did see a physiotherapist at Dunston Hill when I was first diagnosed for 6 weeks but at home I am unable to remember the exercise shown. I do try to do them but worry about doing them wrong. I am determined to do what I can to stay independent but sometimes when the MS is bad I feel I need to talk to someone who understands.'*  
(Service User - Postal Questionnaire)

The findings in total present a vast and rich series of issues around the perceived 'needs' of people with MS locally. In terms of the specific guidelines laid down in NICE (MS Society, 2003) the findings support concerns around the need for more 'Ready access to specialist neurological services .....: doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers'. In addition concerns were expressed around how to 'Identify services capable of delivering a multi-professional range of expertise and specify how each is contacted'. The sheer effort required by service users to contact the range of services was noted. More specifically specialist occupational therapists and MS nurses were valued and requests made for an increase in this service.

In terms of the support offered the one nursing home involved in the study was seen in a very positive light. Respite was not viewed so favourably, one bad experience tending to put people off for life.

Generally speaking there was very positive feedback from both service users and family members in regard to both the services they received and the professionals involved in delivering these services. Individual physiotherapists, occupational therapists, MS nurses and social workers were all singled out for praise, particularly in the way they brokered both information and services. However this kind of process for passing on information is sporadic at best, appearing to lack a coherent structure. It was interesting to note that the focus group members shared with each other a lot of useful information and many were surprised by what services they were unaware of.

Again in terms of NICE the findings reinforce that 'Services should cater for the varying needs of people with MS over time' and 'People receive timely, quality assured, culturally appropriate information in a range of formats on relevant aspects of service provision and their condition and how best to manage it and wider social inclusion issues (e.g. employment and transport).' The distribution of up to date, high quality information on services and facilities locally for people with MS became a major issue for both service users and their family members. Walkergate Hospital was praised for its library, but concerns were expressed in particular by service users over the need for one place or person to provide this information at the end of a

telephone or in person. This study therefore supports both Edmonds et al (2007) and Bakers' (1998) research findings and conclusions in the need for relevant, current and specific information. NICE also highlighted that services tend to be reactive rather than proactive giving out information and providing services only when requested. This was also expressed in the findings from the presented study. The importance of specialist workers in providing information in this area was also stressed by service users both in NICE and this study.

With regards to the NSF (2004) the findings point to concerns around developing so called 'person centred services' as a number of respondents did not feel empowered by their experience of services. Part of improving services is always going to be the recognition and shift of control to people with MS themselves, so their voice is strengthened. In particular the MSIF (2002) stated that people with MS should have access to a wide range of 'age-appropriate care services' that enable them to function as independently as possible. This linked with the concerns service users expressed about being treated as 'older people', bearing in mind that the average onset of MS is between the ages of 20s or 30s.

It was also significant that in the NSF people with MS wanted better access to their communities through both public transportation and assistive technology. The study highlighted that there are difficulties in the timely provision of adaptations and equipment for people with MS in Gateshead. Concerns were also expressed by family members over the levels of appropriate adaptive equipment at GP surgeries and on general hospital wards. In addition within the hospital setting criticism was levelled at the lack of communication between speciality services (e.g. neurology and orthopaedics) and the understanding of MS by medical staff on general wards was problematic.

In terms of local policy objectives the need for a 'single managed process' rather than 'starting again' assessments each time a new service was requested or issues were highlighted by family members and services users alike. This was strongly felt by some service users in particular as they reported having to every few months go through a total re-assessment in health and social care for slight changes in their situation.

With regards to living in Gateshead the Metro Centre came in for praise in terms of its accessibility and the various facilities on offer. However leisure centres were criticised for having inaccessible swimming pools and local post offices for not being adapted to peoples needs.

The work of the MS Society was perceived in a mixed light. The MS Society meetings were seen as old fashioned and potentially depressing as some service users felt they would be reminded of how the illness may progress. Others saw the information support offered through newsletters and telephone help lines by the MS Society as important. Finally concerns were also expressed about not having a local branch of the MS Society in Gateshead.

Service users and family members sense of isolation was a very strong recorded theme; many of the respondents had few friends and very limited social contact outside of the services they received. Many of them also had few services involved in

their lives. Family members also stated that even within their own extended families there was little appreciation of what their 'caring role' entailed. It was also reported that with the often progressive nature of MS this sense of isolation tended to be reinforced with time. In response to this; service users, family members and service providers stated a strong desire to have 'somewhere to go' and socialise, exercise and relax. This potential place was characterised by a positive age appropriate environment where people did not sit around complaining about their condition.

Mental health issues were highlighted by service users and family members who reported a desire for help and support to cope with isolation, stress and depression. In addition various service providers referred to people with MS having a sense of 'loss' and their lives being 'turned upside down'. Some service users also commented on the stress caused by the stigma attached to having MS, such as being perceived as drunk all the time. The research highlighted the need for increased mental health support for people with MS, this is in line with the work of Thomas et al (2007) and Beal and Stuijbergen (2007).

Finally it needs to be noted that the presented research conclusions and recommendations are limited in application by the small size of the data set. However they carry weight in terms of the validity of people experience. Further research around MS service user perspectives and involvement would carry the work presented on. It is important to also note that the researcher recorded that participants gave very positive feedback on their involvement in the research process.

## 6.0 Recommendations

The following recommendations lead directly from the findings of this research which are the reported experiences and opinions of people with MS, their family members and selected service providers in Gateshead. They are also informed by the current context of national and local policy around the proposed 'needs' of people with MS:

1. Existing information systems need to be enhanced and potential new ones explored. This would include an investigation of the role of an 'MS information broker'; this person would not necessarily be from any one particular profession but would have to have specialist knowledge of MS. Their role would be in a sense as a 'one stop shop' connecting service users with a wide variety of ever changing services. This role could also be part of a potential MS specialist team.
2. The waiting lists for equipment services need to be reduced. In addition the service needs to be made to be more flexible and responsive to the changing needs of people with MS.
3. The viability of increasing the number of MS specialist nurses in the locality should be examined. This would ensure that MS service users have a 'core' or 'key' worker to help them navigate both health and social care systems. This could be a different 'professional' role to the potential 'information broker'. This role could also be part of a potential MS specialist team.
4. The number of Occupational Therapists in the locality needs to be increased (problematic due to national shortage in this profession), it is perceived that this would reduce waiting lists for adaptations and improve the overall service.
5. Specialist carer and MS service user advocacy services should be investigated and if viable developed. Peer group advocacy may be an option.
6. A service providing specialist mental health support for people with MS should be examined for viability. Whether this is part of a generic counselling service or a more specialist psychology service needs to be researched.
7. An audit of accessible environments within the councils and other facilities, needs to take place, this would focus on local post offices and swimming pools and ensure their accessibility to MS service users.
8. Bus and taxi support services need to be examined with regards to response times and frequency of service, in particular while people are on outpatient visits.
9. A review of local Respite Care services needs to take place. This would include service user involvement and voice in the review process.
10. Gateshead council needs to support the MS Society to examine the potential to re-launch a local branch of the Society. This would need to be developed with the support and advice of local people affected by MS. This would ensure a responsive, age appropriate service.
11. The isolation of people with MS in Gateshead is evident. Some further work needs to examine the feasibility of creating, perhaps in conjunction with the MS Society, an age appropriate 'somewhere to go' for people with MS. This would have elements of health and exercise, social networking, information and advocacy.
12. A review of the existing Direct Payments scheme to simplify and support people to make greater use of it is advised. The new Individualised Budget (IB) system may answer some of the issues raised.

13. People with MS require more continuity of care so that repetitive full assessments across health and social care are avoided and as near as possible a seamless service is developed.
14. Finally the work presented here should be seen as part of an ongoing process of participation where the voices of people affected by MS are heard and services are continued to be developed around them.

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Appendix 1: Letter of Invitation



**Local Population Needs Assessment of People Affected  
by MS Living in Gateshead**

Date

Dear Respondents Name

As part of our commitment to the ongoing development and improvement of services for people living with MS in Gateshead we would like to hear your views. Any information you could provide will help adapt the service to the needs of people who have similar experiences to you. Your contribution is extremely valuable, whether you are living with MS yourself, or looking after someone who has. We will be doing the research in a variety of ways, including individual conversations, telephone calls, questionnaires and group discussions. If you would like to be involved please select from the list below, you are welcome to tick more than one box. If you express interested we will then contact you with more information. Independent researchers from Northumbria University Professor John Swain and Dr Toby Brandon will carry out the research and your personal details will be treated as strictly confidential. This means we will not pass on your name or address and your views will be presented anonymously.

Yours sincerely

---

Respondents Name

Please return to Hayley Quinn at Gateshead Civic using the envelope provided.

Speak to someone in person

Telephone conversation

Questionnaire by post

Group discussion

Appendix 2: Information Sheet



**Needs Assessment Of People Affected By MS Living In Gateshead  
Information for Participants:**

**Who am I?**

Dr. Toby Brandon an independent researcher based at Northumbria University carrying out a study, which is funded by the MS Society while working in partnership with Gateshead Council.

**What's the study for?**

It is intended that the information obtained for the work will help service providers to give better future services for people with MS in Gateshead.

**What are we interested in finding out?**

What you think now of services for people with MS in Gateshead and what is needed for the future?

**What does the research involve?**

People, who have agreed to help, will attend a discussion group with other people with MS or be interviewed for about an hour. If you agreed your comments will be tape recorded.

**What do we want you to talk about?**

Your experiences of the existing services you receive and what you would like to see changed and developed in the future.

**What about confidentiality?**

The people who agree to help in this project will be given the utmost respect. The information that you give us will be treated confidentially and you will not be identified in any way. No-one but the researcher will listen to the tapes during the project. The tape will also be destroyed after the project ends. You will have the right to withdraw from the project at anytime without question and with no effect upon any services you receive.

Who to contact if you want to ask more questions about the study:

Tracy O'Reilly on .....

Appendix 3: Consent Form



Needs Assessment Of People Affected By MS Living In Gateshead  
Consent Form:

*Please tick*

**I have read the information sheet and understand the purpose of the study**

**I have had the chance to ask questions about the study and these have been answered to my satisfaction**

**I'm willing to be involved in a discussion group with other people with MS or be interviewed for about an hour**

**I'm happy for my comments to be tape-recorded**

**I understand that I can withdraw at any time if I change my mind and this will not affect any services I receive**

**I know that my name and details will be kept confidential and will not appear in any documents.**

**I agree to take part in this project:**

Your Name: {Print}.....

{Signed}.....

Researchers Signature.....

Date.....

Thank you very much for your help

Who to contact if you want to ask more questions about the study:  
Tracy O'Reilly on .....

Appendix 4: Topics guide – Focus Group



Multiple Sclerosis Society

**Local Population Needs Assessment of People Affected  
by MS Living in Gateshead**

Focus Group Topic Guide

**Background Information**

I'm Dr. Toby Brandon an independent researcher from Northumbria University working in partnership with Gateshead Council. I'm currently carrying out a study, which is funded by the MS Society into what you think of services for people with MS in Gateshead. It is intended that the information you give will help develop better services for people in the future.

Today is entirely voluntary but I would be grateful if you could take the time to complete it and post it back in the envelope provided. The information that you give me will be treated confidentially and you will not be identified in the final report in any way.

I plan to tape record this session.

Many thanks in advance of your support with this work.

**I'm interested in finding out two things today firstly what you think in terms of meeting your needs of the services you currently use. Secondly what service would you like to see developed in the future?**

- 1) Health Support** including; Physiotherapy, MS Specialist Nurse, GP Dietitian, Speech Therapist, Occupational Therapist, Pain Management Complimentary Medicine.
- 2) Employment Services** including; service around looking for work that is work schemes and programmes, support while in work, your employment rights.
- 3) Financial support services** including what you may be entitled to Disability Living Allowance Attendance Allowance.
- 4) Home and housing options** including; equipment at home, supported housing schemes and care homes.
- 5) Education and training** including; Further education, Higher education and Disabled Students' Allowances.
- 6) Motoring and transport** including; Blue Badge parking scheme, Adapting a vehicle, Motability Scheme, local public and community transport.
- 7) Leisure and recreation**, including; visiting places of interest, sports and hobbies, shopping both essential and pleasure and the Library.
- 8) Other services and support** including; counselling and support, self help groups, rehabilitation, MS Society Advocacy and Direct Payments (IB).
- 9) Other support**, including; rehabilitation, support for your carers and for your family
- 10) Please list any services that you use that have not been included in the above and comment on them in terms of needs.**
- 11) What are the main ways that services and support could be developed to be as effective as possible in meeting needs?**

**Thanks again**

Dr. Toby Brandon

Appendix 5: Postal Questionnaire



Multiple Sclerosis Society

**Local Population Needs Assessment of People Affected  
by MS Living in Gateshead**

Dear ....

I'm Dr. Toby Brandon an independent researcher from Northumbria University working in partnership with Gateshead Council. I'm currently carrying out a study, which is funded by the MS Society into what you think of services for people with MS in Gateshead. It is intended that the information you give will help develop better services for people in the future. Filling out the attached questionnaire is entirely voluntary but I would be grateful if you could take the time to complete it and post it back in the envelope provided within the next two weeks. The information that you give me will be treated confidentially and you will not be identified in the final report in any way.

If you have any questions or require a different format (e.g. larger print) for this questionnaire please contact me on .....

Many thanks in advance of your support with this work.

Toby Brandon

**a) Background Information**

Please provide the following information:

- |   |                          |                          |
|---|--------------------------|--------------------------|
|   | Yes                      | No                       |
| 1) Are you someone with MS?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 2) Do you care for someone with MS?   | <input type="checkbox"/> | <input type="checkbox"/> |
| 3) Approximate date of Multiple Sclerosis diagnosis: .....                  |                          |                          |
| 4) Approximate date of first onset of symptoms of Multiple Sclerosis: ..... |                          |                          |
| 5) Main symptoms you experience: .....                                      |                          |                          |
| .....   |                          |                          |
| 6) Would you say the MS is:   | Fluctuating:             | <input type="checkbox"/> |
|   | Progressively worsening: | <input type="checkbox"/> |

**For each of the questions below please tick one box rating how well the service meets YOUR NEEDS:**

**7) Health and Social Support**

**a) Physiotherapy**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**b) MS Specialist Nurse**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**c) GP**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**d) Dietitian**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**e) Speech Therapist**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**f) Occupational Therapist**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**h) Social Worker**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**g) Pain Management**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**h) Complimentary Medicine (for example acupuncture)**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**11) Employment Services (with regards to information and access)**

**a) Support around looking for work**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**b) Work schemes and programmes (for example 'access to work')**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**c) Support given to you and your employer while in work**

Very Poorly  Poorly  OK  Well  Very Well  Not Applicable

**12) Financial support services (both information and access)**

**a) Around what you may be entitled to**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**b) Your use of Disability Living Allowance**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**c) Your use of Attendance Allowance**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**13) Home and housing options**

**a) Equipment at home**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**b) Supported housing schemes**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**c) Care homes (both short and long term)**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**d) Respite**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**e) Adaptations**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**f) Personal assistant in your home**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**14) Education and training****a) Life long learning**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**b) Higher education**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**c) Disabled Students' Allowances**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**15) Motoring and transport****a) Blue Badge parking scheme**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**b) Adapting a vehicle**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**c) Motability Scheme**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**d) Local public and community transport**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**16) Leisure and recreation in Gateshead****a) Visiting places of interest**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**b) Sports and hobbies**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**c) Shopping both essential and pleasure**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**d) Library**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**17) Other services**

**a) Counselling**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**b) Self help groups**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**c) MS Society**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**d) Advocacy**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**e) Direct Payments and Individual Budgets**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**18) Other support**

**a) For your carers**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**b) For your family**

Very Poorly	Poorly	OK	Well	Very Well	Not Applicable
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Appendix 6: Topic guide – telephone interview - service provider



**Service Provider Phone Interview  
Local Population Needs Assessment of People Affected  
by MS Living in Gateshead**

**1) Background:**

*There is concern that since the closure of the MS Society's local branch in Gateshead in 2005, many people with MS are being 'lost' to both voluntary and statutory sector services and their needs have not been recorded or met. In direct response to this the projects main aim is to build an evidence base for targetting resources/service development and to establish new ways of working with people with MS in Gateshead. In addition it is intended to be used to establish a 'user voice' and generally raise awareness of the needs of people living with MS locally. Family Members and other Service Providers views will also be sought as part of the research process. To achieve this a 'population needs assessment' will be conducted which will include a series of focus groups run with people with MS, their carers and service professionals working within the area. An independent report will be written by Northumbria University by the end of September 2007.*

**I will be using the information you provide in the final report but will not be using your name or identifying details in any quotes.**

*Can I tape you?*

**2) Personal Information:**

Date/time

Name:

Job Title:

Profession:

How long have you been working in Gateshead:

**3) What is the role of your service?**

**4) Comment on how people currently use of Statutory and Voluntary services and Support:**

**5) How could service do more for people with MS?**

- Consider Communication
- Multidisciplinary working
- Information
- Accessibility
- Challenges
- Opportunities

**6) Finally**

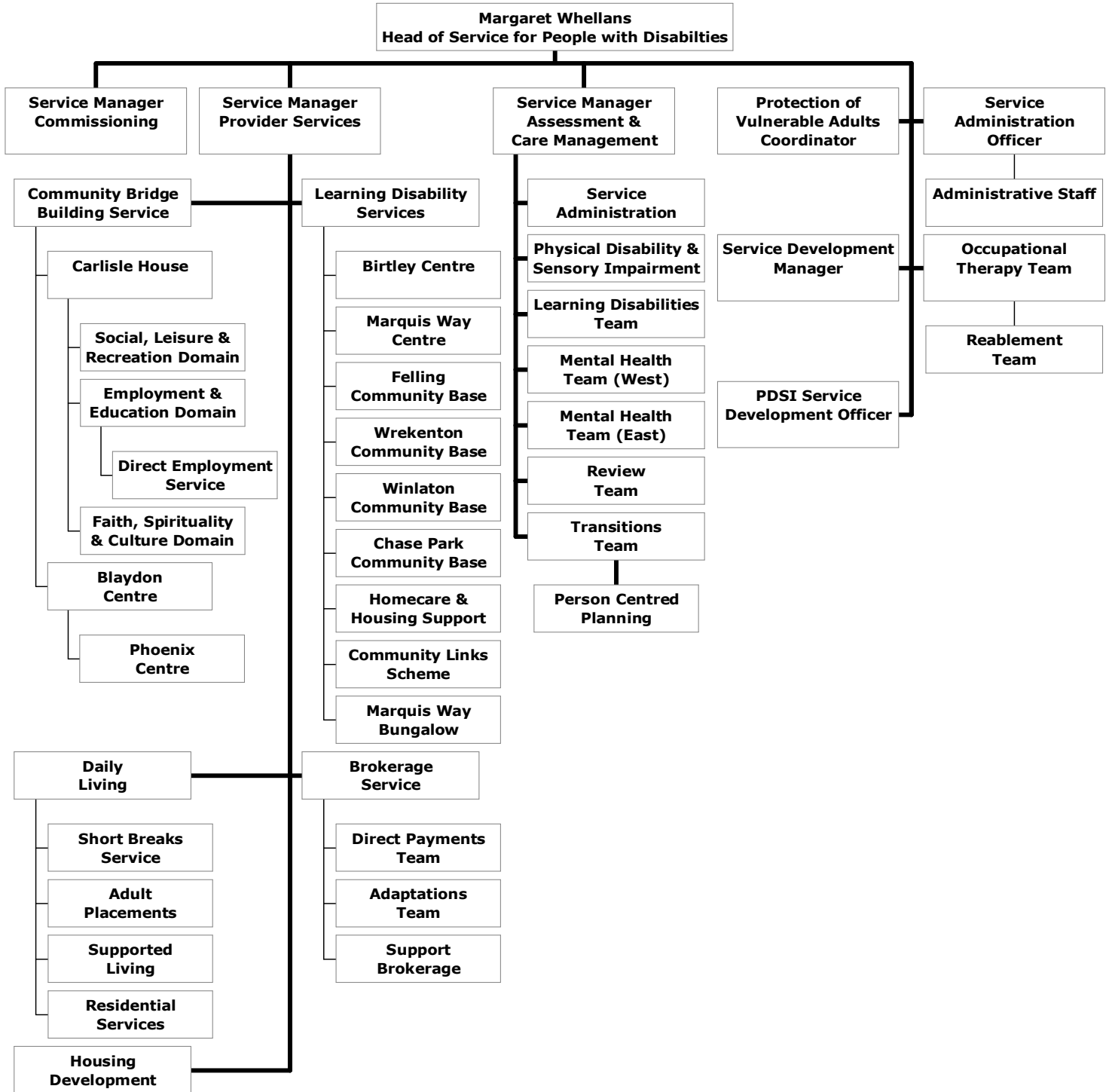
Would you like a copy of the executive summary?

Please send me information on their services?

Can I contact you again after I have interviewed service users and carers?

Appendix 7: Service chart

## Services for People with Impairments



## Appendix 8: Glossary

### Glossary

(Constructed with reference to the MS Society  
<http://www.mssociety.org.uk/applications/glossary/glossary.rm>)

#### **Acute**

Having rapid onset, usually with recovery; not chronic or long-lasting

#### **Advocacy**

Is the representation of someone else's needs, desires and wants as if they are your own.

#### **Catheter**

A catheter is a hollow tube used to drain bodily fluids. In MS, catheters are most often used to empty the bladder via the urethra.

#### **Cognitive Impairment**

Changes in cognitive function caused by trauma or disease process. Some degree of cognitive impairment occurs in approximately 50–60 percent of people with MS, with memory, information processing, and executive functions being the most commonly affected functions.

#### **Coordination**

An organized working together of muscles and groups of muscles aimed at bringing about a purposeful movement such as walking or standing.

#### **Complementary Therapies**

Refers to a whole range of treatments which are not prescribed on the NHS.

#### **Cochrane Report**

Refers to evidence based database.

#### **Dementia**

A generally profound and progressive loss of intellectual function, sometimes associated with personality change, that results from loss of brain substance and is sufficient to interfere with a person's normal functional activities.

#### **Department of Health**

UK government department in charge of health and well being.

#### **Effectiveness**

The extent to which a service under normal conditions gives what it is intended.

#### **Evidence-Based**

The process of systematic work to produce findings.

**Exacerbation**

The appearance of new symptoms or the aggravation of old ones, lasting at least twenty-four hours (synonymous with attack, relapse, flare-up, or worsening); usually associated with inflammation and demyelination in the brain or spinal cord.

**Fatigue**

Is a feeling of overwhelming tiredness. It is a common symptom of MS, affecting 85% of people with the condition.

**Focus Groups**

Methods were a small group of respondents are brought together to discuss a particular topic.

**Guidelines**

A tool to describe the aspects of care to be given.

**Immune system**

A complex network of glands, tissues, circulating cells, and processes that protect the body by identifying abnormal or foreign substances and neutralizing them.

**Impairment**

As defined by the World Health Organization, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function. It represents a deviation from the person's usual biomedical state. An impairment is thus any loss of function directly resulting from injury or disease.

**Literature Review**

A process of collecting, collecting and evaluating a body of published material in a given area.

**Methodology**

The approach to a research project, that is the methods to be used and why.

**Neurologist**

Physician who specializes in the diagnosis and treatment of conditions related to the nervous system.

**Occupational Therapist (OT)**

Occupational therapists assess functioning in activities of everyday living, including dressing, bathing, grooming, meal preparation, writing, and driving, which are essential for independent living. In making treatment recommendations, the OT addresses (1) fatigue management, (2) upper body strength, movement, and coordination, (3) adaptations to the home and work environment, including both structural changes and specialized equipment for particular activities, and (4) compensatory strategies for impairments in thinking, sensation, or vision.

**Primary Care Trust (PCT)**

The NHS organisation responsible for improving the health of local people, through services such as GPs.

**Physiotherapy**

Uses physical methods e.g. heat, massage and exercise, to treat people with a physical disability.

**Qualitative Methods**

Research techniques used to describe the life experiences and meanings of people. For example focus groups and interviews.

**Speech/language Therapist**

Speech/language pathologists specialize in the diagnosis and treatment of speech and swallowing disorders. A person with MS may be referred to a speech/language pathologist for help with either one or both of these problems. Because of their expertise with speech and language difficulties, these specialists also provide cognitive remediation for individuals with cognitive impairment.

**Symptom**

A subjectively perceived problem or complaint reported by the patient. In multiple sclerosis, common symptoms include visual problems, fatigue, sensory changes, weakness or paralysis of limbs, tremor, lack of coordination, poor balance, bladder or bowel changes, and psychological changes.

Appendix 9: Service Resource List

## Service Resource List

Physical Disabilities and Sensory Support Team Gateshead Council 0191-4333000  
Adaptations Team Gateshead Council 0191-4333000  
Direct Payments Team Gateshead Council 0191-4333000  
Sight Service 0191-4785959  
Vulnerable Adults Co-ordinator Gateshead Council 0191-4333000  
Carers Association 0191-4900121  
Gateshead Access Panel 0191-4430058  
Gateshead Crossroads 0191-4782423  
GAIN (Gateshead Advocacy and Information Network) 0191-4783130  
GAP (Gateshead Access Panel) 0191-4430058  
Helping Hands (Voluntary Service for Domestic Help) 01661 843839  
24/7 Drug and Alcohol Team 0191-4333000  
Community Mental Health Team 0191-443 8100  
CAB (Citizens Advice Bureaux) 0191-4771392  
Gateshead Law Centre 0191-4408575  
GES Gateshead Equipment Service 0845 11 11155  
MS Nurse 0191-2825403  
Whickham Villas Chase Park (Specialist Nursing Home Specialising in MS with  
outside SPA facilities) 0191-4887351  
MS Society (London) 020 8438 0700  
MS Research and Relief Fund 01670-505829  
St Chads Community Project 0191-4901032  
Gateshead Call Care 0191-4787665  
Gateshead Individual Budgets Pilot 0191-4332404  
Occupational Therapy and Adaptations Team 0191-4333000  
Physiotherapy Team 0191-4456445