

'User experiences of health and social care services'

Full Report

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Background to the Project

This report was commissioned by the Department of Health who required information on service users' experiences of interaction with health and social care services. The service users covered in this report have long-term conditions and are of working age only (18-65). The study was directed towards exploration of following: epilepsy, Multiple Sclerosis (MS), Motor Neurone Disease (MND), Parkinson's disease, brain injury, spinal cord injury, polio and cerebral palsy (the 'target groups'). The study aimed to identify literature that contained evidence on 'user experience of health and /or social care services' within the target groups.

Aims and Objectives

The study aimed to provide an overview of the types of evidence that exist on 'user experience' of health and social care services. 'Users' in this case are people with long-term conditions. Given the short timetable (10 weeks in total), the main focus of the overview study is upon the experiences of service users in the target groups although it is hoped that the evidence may be sufficiently generalisable to be considered applicable to other people with other long-term conditions. Where possible, literature that has 'key messages' on user experiences of health and social care services outside the target groups was also reviewed. The primary purpose of the study is to gather evidence on user experiences of services to underpin other review work being undertaken concerning the experiences of people with long-term conditions. The main objective of the study is to identify and review the key studies on user experience of health and social care service use for each of the target groups.

Research Question

What is known from the existing literature about user* experiences of health and social care services?

*'Users' in this study are in the following target groups only: people with Parkinson's disease, multiple sclerosis (MS) motor neurone disease (MND), brain injury, spinal cord injury, epilepsy, polio and cerebral palsy.

Concept Definition

1. Users' experience

This term is used to denote experiences that users' undergo at the interface with services. The services in question are the Health Service, (primary, secondary and tertiary care) and Social Services.

2. Users' views

This term is used to denote service user's views of the services provided by Health and Social Services (see 1 above).

3. Target groups

Motor Neurone Disease, Multiple Sclerosis, Parkinson's Disease, Brain Injury, Epilepsy, Cerebral Palsy, Polio and Spinal cord Injury. The term 'user experiences' and 'user views' relate only to these target groups.

4. Exclusions

<i>Population Groups</i>	All patients/clients outside the target groups
<i>Interventions</i>	All intervention studies
<i>Experience Areas</i>	All areas not directly related to Health and Social Service patient/client interface
<i>Publication Date</i>	All studies published before 1993
<i>Language</i>	All studies published in languages other than English
<i>Study Focus</i>	Medical, pharmacological or biological research. Disease prevention research. Medical/ pharmacological intervention studies
<i>Study Type</i>	Reference works, book reviews, commentaries and PhD theses

5. Inclusions

<i>Setting</i>	All Health and Social Service patient/client interface settings, both in hospital, out-patient services and community services.
<i>Publication location</i>	Primary focus: UK studies. Secondary focus: studies published in English from other locations.
<i>Methodology</i>	Qualitative, ethnographic studies, patient/client view surveys, grey literature, studies published through target groups' organisations, relevant quantitative studies.
<i>Age Group</i>	Patients/service users between the ages of 18 and 65 years
<i>Study Focus:</i>	Experiences of health and/or social care service use.
<i>Study Types:</i>	Empirical and non-empirical studies, quantitative and qualitative. Grey literature, mainly web based literature.
<i>Language</i>	Only studies published in English.

Methods

The study used a 'hub and spoke' method of reviewing and compilation of evidence. Key studies covering target group service user's experience of health and social services were identified and re-routed to the panel of expert readers for assessment. The latter used a standard proforma containing the criteria below to record their assessments. The evidence from the proformas that appear in Appendix 4 was utilised as the basis for this report. The external experts were invited to a workshop at the end of the project and were there invited to discuss the findings they had made from their reading of the literature. These discussions were tape-recorded and utilised in the compilation of the research evidence.

The main task in the study comprises searching electronic databases, primarily using the internet. Databases searched were as follows:

Database	Host	Hits ¹	Selected ²
AMED	Ovid	64	12
Caredata	Electronic Library for Social Care	20	7
Cinahl	Ovid	102	30
Embase	Ovid	347	63
Medline	Ovid	282	53
SIGLE	Arc	44	4
Sociological Abstracts	Arc	24	6
SSCI	Web of Science	507	40
The Disability Archive UK	Centre for Disability Studies, Leeds ³	*	5

* The Disability Archive UK was hand searched. The archive contained in excess of 250 documents. All searches took place in March 2003. Further details are contained in Appendix 3.

Organisations Contacted

The following organisations were requested to send information concerning target group user's views and experiences and in particular, to identify literature sources/ references and booklists. The vast majority of these organisations responded positively, many offered the use of their librarians and search capacities. The organisations contacted were:

Motor Neurone Disease Association
Multiple Sclerosis Society
Parkinson's Disease Society
Headway
SCOPE
ASPIRE
INSPIRE
Spinal Cord Injury UK
Spinal Injuries Association
The British Polio Fellowship
Long Term Medical Conditions Alliance

Ordering of Evidence

Expert Panel members categorised the studies using the following typology:

- T1 *'User Experience'* – studies/literature written by users or published through their organisations that cover patient/client use of Health & Social Services of any of the target groups

¹ All hits from each search run within the database. This includes duplicates within and between databases

² References loaded into reference manager. Duplicates were removed later.

³ (<http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>)

- T2 *Academic/Professional* – studies/literature produced by academics/professions for publication in the mainstream academic/professional press in any of the target groups
- T3 *General Issues/User produced* -studies produced by users/patients or their organisations that explore general issues of user experience of Health and Social care services with patients/clients *outside* the target groups.
- T4 *General Issues/Academic/professional produced* – studies produced by academics/professionals that explore issues of user experience of Health and Social care services with patients/clients *outside* the target groups

Confidence Rating

Expert Panel members expressed their ‘confidence’ in the findings of each study using the following rating scale:

- High High confidence in ‘robustness’ of the research/study. Ease of replication, generalisable findings that are perceived as valid and reliable.
- Medium Moderate confidence in ‘robustness’ of the research/study. Some concern over ease of replication, generalisability of findings/ validity/reliability.
- Low Low confidence in ‘robustness’ of the research/study. Strong concerns over ease of replication, generalisability of findings/ validity/reliability

Findings Typology

The findings from the study are presented in impairment group order below within a basic typology. The typology used is as follows;

- A) ‘Sudden onset long term conditions’: incorporating Brain Injury, Spinal Cord Injury and Polio;
- B) ‘Intermittent/unpredictable long term conditions’; incorporating Epilepsy; and
- C) ‘Progressive long term conditions’; incorporating Cerebral Palsy, Motor Neurone Disease, Multiple Sclerosis and Parkinson’s Disease.

It has not proved possible to distinguish between the two forms of MS within the literature within the deadline and it is recognised that some of the literature that appears in this heading in group C has implications for group B also.

There is an additional category ‘General’ which incorporates literature that has key messages on user experiences *outside* the target impairment groups.

Group A: Sudden onset long term conditions: Brain Injury, Polio and Spinal Cord Injury

Brain Injury

UK studies

The search yielded only professional/ academic studies (T2) as categorised by the expert panel, although some contain more direct user views/experiences than others.

Wilson *et al.* (2002; NO.58, medium rated) reports on a study carried out in Northern Ireland, which was a regional survey of consultant level neurology, neurosurgical and rehabilitation staff to identify (retrospectively) patients in vegetative or minimally responsive states from their own clinical caseloads (October 1995-97). Thirty-five patients were identified. The majority were not placed in specialist brain injury facilities following acute hospital interventions. The findings are of interest as the extent to which patients in Persistent Vegetative State can be said to have 'user experience' is problematic and there are very few studies that contain their views. It was found that of 12 patients referred as being vegetative or in minimally responsive state, four were considered as having been misdiagnosed (emerged) at follow up, two had been presumed to be vegetative for at least one year. All patients remained 'severely physically disabled' (that is, totally dependent for care) but four were nevertheless able to communicate their preference in quality of life issues and care decisions either by verbal or non-verbal means. These patients need skilled and frequently prolonged assessment and appropriate management from inter-disciplinary as opposed to multi-disciplinary teams as the wider skill repertoire of the former equips them to recognise often subtle improvements in cognitive function and act to maximise individual patient's quality of life. There is a current paucity of service provision for this group of patients. The authors call for the establishment of a regionally situated dedicated service to this patient group.

One medium rated T2 study that devotes a small part to detailing the views of users and carers (but does not distinguish between them) is Williams *et al.* (1996, NO.100). This study is a report of six fieldwork visits to units and services. For patients and their families the most important prevailing concern is the quality of their life at home and in the wider community. The authors report the experience of medium and longer term progressive increase in social isolation for both user and family members providing care. Users and their families require help in coping with major changes in roles within the family, and behaviour and personality changes in the person who has experienced brain injury. In relation to diagnosis, there is sometimes a misunderstanding of acquired brain injury and inaccurate diagnosis of behaviour problems. The authors report a lack of appropriate facilities for users and carers after the initial acute treatment phase and limited access to rehabilitation. Respite and long-term accommodation are rare, and facilities currently on offer appear inappropriate for this group. There is poor communication between services, so it is hard to find out what is available. GPs do not have enough information about services. There are specifically identified needs for: early counselling; information; recognition of needs and knowledge of carers. Service recommendations include (immediately after injury); full and accurate assessment of the needs of the user and

any carers; provision of information, support and counselling for the user, carers and family members; post-acute rehabilitation services and multi-disciplinary teams with knowledge of head injury to link management of the acute stage with longer term needs. For those users who live with their families also identified as important was a comprehensive range of support services in the community and a range of residential service options for people with brain injury. The aim of therapeutic facilities should be to encourage independence and avoid institutionalisation. Users and carers should be involved in the design and planning of services.

Other locations

Buchanan *et al.* (2000, NO.30; highly rated) reports on research with patients and family members concerning neurobehavioural changes (including changes in personality, behaviour, employment, social roles, social contact, sexuality), psychological distress and 'family burden' (semi-structured interviews and use of scales) following surgery for Subarachnoid Haemorrhage (SAH) (12 to 32 months after surgery). Patients and family members were interviewed separately, to compare the patients' assessments with those of family members. It was found that neurosurgeons had over-stated the degree of recovery and normal functioning in patients when comparisons were made with patient and family members' own evaluations.

Peters (1994, NO.97, highly rated) reported that users find information about their condition helps them to cope with medical procedures and to manage their health generally. Users have difficulty accepting information from hospital staff at times of crisis. Users' families benefit from information as much as users themselves; users find that new information on their condition can lead to networking opportunities, that these are mutually beneficial and that they have changed their behaviour based on information received.

In Harker *et al.* (2002, NO.211, highly rated) a comparison was made between TBI and SCI patient independent living outcomes. TBI patients reported substantially higher levels of independent living in terms of participation and productivity than those with SCI and the authors hypothesised that this may be because supported employment is offered routinely to the TBI population whereas those with SCI tend not to benefit from this. They also hypothesise that those with SCI may be more segregated due to mobility problems.

A clinician's observations of the experiences of patients are presented in Prigatano (2000, NO.31, medium rating). The paper is based on a conference speech given by a leading clinical neuropsychologist, to others in his profession, in which the case is made for finding out about the patient's experience of neuropsychological assessments and treatments. The key observation is that patients can be non-cooperative and unhappy if they feel that the clinician has no interest in the patient's own account of their condition/life experiences. This is presented as something that the profession has previously had little interest in. This is seen as detrimental, not least because dissatisfied patients may not pay for treatments (USA study). Another USA study conducted in Colorado (Sample *et al.*, 1998, NO.96, medium rated) used an 'opportunistic' sample of 21 women from support groups run by the local Brain Injury Association. The study raised issues around lack of immediate diagnosis and barriers to accessing care. Physicians and clinicians are often not trained to

recognise mild brain injury and people with brain injury may not be in a fit mental state emotionally and/or cognitively to negotiate barriers to access services and so may need assistance. The study thus points up the value of advocacy for some users.

In Darragh *et al.* (2001, NO.95, low rated) contact was made with 13 support groups in Colorado, 51 people with acquired brain injury were interviewed and thematic analysis yielded three main themes; the role of provider, the helpfulness of the services provided and personal characteristics of the provider. Interpersonal relationships between user and service provider were emphasised and participants wished to be included as part of a team so they felt in control of their treatment. Good service providers were also advocates for their clients, providing information, case management and assistance with referrals. Occupational therapists were seen as helpful as they offered relevant, meaningful and practical strategies. The personal characteristics of the provider that were valued were clear, honest and straightforward communication; professionals who would discuss treatment options and solicit patient opinions. Professionals who did not receive satisfactory ratings were unwilling to listen, poor communicators, overly optimistic or pessimistic or who tended to minimise the patients' symptoms.

Banja *et al.* (1994, NO.65; low rated) argue for a new paradigm in treatment of traumatic brain injury (a person-centred approach to rehabilitation) that ensures a place for the user at the core of the care planning process. Rosenthal (1995; NO.62, low rated) contains methodological insights but no user experience.

Summary of user's experiences with brain injury (highly rated studies marked *)

- *Neurosurgeons sometimes over-state the degree of recovery and normal functioning in patients when comparison is made with patient and family members' own evaluations.
- *Users find information about their condition helps them to cope with medical procedures and to manage their health generally.
- *Users have difficulty accepting information from hospital staff at times of crisis. Users' families benefit from information as much as users themselves; users find that new information on their condition can lead to networking opportunities, that these are mutually beneficial and that they have changed their behaviour based on information received.
- *TBI patients report substantially higher levels of independent living in terms of participation and productivity than those with SCI. This may be because supported employment is offered routinely to the TBI population whereas those with SCI tend not to benefit.
- People with brain injury need skilled and frequently prolonged assessment, appropriate management from inter-disciplinary as opposed to multi-disciplinary team working style – as skill repertoire equips them to recognise often subtle improvements in cognitive function and act to maximise individual patient's quality of life.
- There is a current paucity of service provision for this group of patients.
- Full and accurate assessment of needs of person and any carers.
- Provision of information, support and counselling for user, carers and family members soon after injury
- Post-acute rehabilitation services are required
- A comprehensive range of support services in the community and a range of residential service options are required.
- The aim of therapeutic facilities should be to encourage independence and avoid institutionalisation.
- Users and carers should be involved in the design and planning of services.

Polio

Very few studies were identified that dealt solely with user's experience of service. Identification of references proved difficult, probably due to the demise of polio as a condition (until very recent outbreaks) and insufficient time for children exposed in the late 1990s to reach maturity and therefore fall within the project remit. It seems highly likely that there is very little literature concerning adults with Polio's experiences available.

UK studies

A highly rated (T2) qualitative study that is particularly rich in user experiences is Zarb (1992, NO.6) which deals with the effects of ageing with polio, gathered from 65 individuals. Twenty-nine of this original sample were followed up with in-depth interviews. Themes were identified across a spectrum of issues relating to the disease process. The general message is that ageing with polio brings two sets of experiences, some of which appear to compound the other. 'While the physical consequences of their impairment were difficult to cope with, the additional effects of ageing had made the situation much worse' (*ibid.*, p.5). Health and social services need to respond better to these issues and in particular need to be aware that because polio has been almost completely eradicated, people affected by the disease feel they have been forgotten (*ibid.*), especially from service planning and provision. Users suggest that there is a lack of professional understanding of polio in general, particularly from the medical profession. There is also a lack of co-ordinated response to polio-related issues, particularly ageing. Several users talked of emotional changes as they grew older (particularly anxiety, frustration, loneliness and depression). Anxiety is often related to lack of appropriate and acceptable support. Some users felt they age faster than non-disabled contemporaries (*Ibid.*p6) and that they had to make an unacceptable degree of compromise with how they wished to live their lives (*ibid.*). Maintaining independence appears to become harder with age (*ibid.*, p.7). Physical problems this group experienced include respiratory problems, contractures or muscle wastage, decreased mobility, arthritis, rheumatic pain, reduced energy levels, problems with shoulders, arms or fractures (*ibid.*, p.15). Respondents claim that post-polio syndrome (PPS) was not well understood by the medical profession and sometimes they feel like a 'time wasting hypochondriac' (*ibid.*, p.21). As PPS is difficult to establish, respondents felt the medical profession generally dismissed the idea (*ibid.*). The difficulty here is in separating the effects of polio sustained many years ago, from those of the ageing process. There appears to be a general lack of appreciation of the problems faced by users amongst the medical profession (*ibid.*, p.24) with a lack of specialist clinics. Travelling to large hospital clinics is particularly problematic. There appears to be a lack of routine check ups for people with polio. Some users feel there is very little treatment offered to people with long-term Polio, little understanding of its effects from the medical profession and a lack of research. Users express a desire for more support from medical professionals in general (*ibid.*).

Other locations

A non-UK study that was medium confidence rated (Wenneberg *et al.*, 2000, NO.145) involved qualitative interviews with 15 individuals (interviewed twice) experiencing the late effects of polio. Narratives were gathered on the lifetime experience of polio and its aftermath. With regard to service experiences, the focus is on these users' memories of health services encountered when they contracted polio

in childhood. The narratives presented indicate that these respondents had extremely unhappy and psychologically disturbing experiences of health and social care services some 50 years ago (isolation hospitals and residential institutions for disabled children with brutally strict regimes and harsh treatments). The paper highlights the ways in which these individuals 'overcame' their disabilities to live 'normal lives', but reports that disturbing memories sometimes returned. Respondents were now living with the late effects of polio. The paper gives little attention to these users' current service experiences. The few points made indicate general satisfaction with current services.

A Swedish study (Willen *et al.*, 2002, NO.99; medium rated) was concerned with late effects of polio (muscle weakness, fatigue, muscle and joint pain). In the past users have been led to believe they should exercise in the acute phase to alleviate these effects. However, professionals are now not certain this is a good idea in dealing with late symptoms. Users found hot water therapy beneficial and found the process of group interaction pleasurable.

Summary of User's with Polio experience (highly rated studies marked *)

- *Most users with polio are now older people (many post retirement). Many experienced very poor treatment from health and social care services as children, some appear to be psychologically damaged by these experiences, memories of which sometimes return.
- *Ageing with polio comprises two sets of experience – impairment effects may compound each other. Users found the physical consequences of impairment difficult to cope with – ageing made these worse.
- *As polio has been almost completely eradicated, users feel forgotten by services – especially from service planning and provision.
- *There is a general lack of professional understanding about polio – particularly from the medical profession. Post polio syndrome (PPS) was not well understood by doctors – some users are made to feel that they are hypochondriacs.
- *There is a general lack of specialist clinics and problems with travelling to large hospital sites and lack of routine check ups for users.

Spinal Cord Injury

There are no T1 studies (user experience) identified in this impairment group.

UK studies

Lucke (1999, NO.126, highly rated) was conducted in a rehabilitation unit, and reported that nurses assist patients with SCI to 'get back together' as a person – to reacquaint the self (mind) with the body and to enable the patients to feel in control of themselves and their bodily functions and achieve more independence.

Viadyanthan *et al.* (2001, NO.201, medium rated) used a questionnaire design that was administered to 128 adults with SCI in which they report that 83 per cent wished to receive written information about any changes in their medical condition after an outpatient visit, 81 per cent wished to receive a copy of the report of intravenous urography after they had attended the spinal unit for a routine follow up and 90 per cent preferred to receive a copy of the MRI scan with interpretation of the findings. Also 90 per cent of respondents felt that written information about their medical condition would be useful to show to their GP who may not be acquainted with their medical status.

In the Northern and Yorkshire Regional Council of Community Health Councils study (2001, NO.51, low rated) which was conducted at Pinderfields Spinal Injuries Unit, two thirds of the patients reported they had been given enough information whilst in the Unit but one half (n=78) reported their partners had not been given any support whilst they were patients in the Unit. The majority were satisfied with their nursing care, GP, district nurse, home carer or paid care attendant but a significant number were dissatisfied with Unit food, level of noise, amount of individual space, call buttons, being woken early and very restricted visiting times. In terms of social issues, the vast majority with children said Unit staff did not give them advice on how to look after their children or how to help their children come to terms with the injury. Over two thirds reported that they had not been given any general health information such as on smoking, alcohol and diet.

Other locations

A study from abroad, Osust (1999, NO.228, T1, low rated) is a 'position paper' written by a person with SCI to his case manager, dealing with issues of accessing treatment and insurance.

Findings generalisable to other groups (stroke and brain injury cited) are contained in Nosek (1993, NO.129, high rating) in which a positive relationship was found between the adequacy of personal assistance (PA) and the ability of users to maintain good physical and mental health. Where personal assistance failed, users experienced skin breakdown, urinary tract infection, pulmonary infections and contractures. Inadequate personal assistance also led to extended hospital stays, threats to safety, poor nutrition and poor personal hygiene. Individuals who relied on family alone found they suffer from burnout, family role change and economic strain. People with the best health combined assistance by relatives and unrelated persons. However, there are problems obtaining sufficient personal assistance, which was mentioned by 37 per cent of the sample. Lack of PA also creates difficulties in using and maintaining adaptive equipment.

A study from the Netherlands cites patient problems in accessing sexual rehabilitation services (McAlonan, 1996, NO.128, high rating), patients experiencing discomfort during group presentations, insufficiency of information, direct, open style preference for giving information and fertility and inadequate information coverage on parenthood. The 381 SCI patients surveyed all had access to adaptations and wheelchairs regardless of income (78.3 per cent had adapted housing) but complaints were voiced about wheelchairs – 35.9 per cent about their manual wheelchairs and 47.5 per cent about their electric wheelchairs. Satisfaction with services was acceptable but satisfaction with service delivery was very low. Satisfaction with available services had a significant relationship with functional health status when the type of injury was taken into account and with life satisfaction after the influence of functional health status was taken into account.

In a study from the USA (Murphy *et al.*, 2001, NO.125, high rating) the focus was pain treatment satisfaction. Seventy per cent reported shoulder pain while 74 per cent had dyesthetic pain. Treatment for shoulder pain was perceived as more effective than treatment for dyesthetic pain. Patients reported that pain impacted negatively on their lives. Forty-nine per cent were dissatisfied with medical treatments and only 19 per cent satisfied. The authors believe that not all pain management avenues were adequately tried with this group.

A study from Sydney reported on 20 patients' views of cognitive behaviour therapy (CBT) (Craig *et al.*, 1994, NO.70, high rating). Although patients were initially reluctant to participate they consented when the objectives of CBT were explained. Post CBT, 90 per cent agreed or strongly agreed that the programme had been useful. Seventy-five per cent agreed that CBT had helped them acquire new skills in controlling anxiety, controlling depressed mood, living their lives as a person with sexual needs, coping with future problems and improving communication and assertion skills. Ninety per cent of participants recommended the programme should be a standard component of rehabilitation for people with SCI.

A study from the USA (Steins *et al.*, 1997, NO.67, highly rated) contained a synthesis of user experience and covers in particular; disablement issues; theories of adjustment; patient autonomy; quality of life; community experience; adaptations; enhancing sexuality and minimization of pain after SCI. The patient's experience of disablement; interdisciplinary, person-centred rehabilitation and success of the individual in chosen life roles are emphasized. Another USA study (Frieden *et al.*, 1998, NO.205, unrated) discussed the impact of 'managed care' on people with SCI. It is a literature review (both research and lay literature) informed by the personal experience of the authors (three have personal experience of managed health care plans). The authors claim that service organisation and delivery is unlikely to improve unless service users (particularly those with atypical needs) are more actively engaged in shaping services and anecdotal data suggests that attempts to lower costs by restricting access to services may have a disproportionate impact on people who are higher than average users of health care.

Kittel *et al.* (2002, NO.226, highly rated) is an evaluation of wheelchair prescription practices for people with SCI in South Australia that involved follow up of 128 people from time of prescription to one year post issue. The results were generally favourable but there was evidence that a small group of people experienced an

unfavourable outcome: At 12 months post wheelchair issue eight per cent of the sample were found to have abandoned the wheelchair – half the cases due to death of user. A small percentage had returned their wheelchair as they experienced significant functional recovery and no longer required it. Of the remaining group high levels of dissatisfaction were reported which ultimately led to the abandonment of the wheelchair before the 12 months had elapsed.

Summary of users with SCI experiences (highly rated studies marked *)

- *Users report nurses post injury assist in getting 'back together as a person'
- *Adequate personal assistance is related to the ability to maintain good physical and mental health
- *Inadequate personal assistance leads to extended hospital stays, threats to safety, poor nutrition and poor personal hygiene. Individuals who rely on family alone found they suffer from burnout, family role change and economic strain.
- *Users experience problems obtaining sufficient personal assistance(PA). Lack of PA also creates difficulties in using and maintaining adaptive equipment.
- *Patients experience discomfort during group presentations on sensitive topics. There is generally insufficient information, and a direct, open style is preferred for giving information.
- *Patients would find written information about their medical condition useful to show to their GP who may not be acquainted with their medical status
- *Users need more information on fertility and parenthood
- *Users with the best health combine assistance by relatives with that given by unrelated persons
- *Pain management avenues are not always thoroughly explored
- *Cognitive Behaviour Therapy helps patients acquire new skills in controlling anxiety, controlling depressed mood, living as a person with sexual needs, coping with future problems, improving communication and assertion skills. It is recommended that CBT should be a standard component of rehabilitation for patients.
- *Service organisation and delivery is unlikely to improve unless service users (particularly those with atypical needs) are more actively engaged in shaping services

Group B: 'Intermittent/unpredictable long term conditions': Epilepsy

Epilepsy

All the studies were categorised as T2, professional/academic, with the exception of two (NO.53 and NO.56; T3, general issues, user produced).

UK studies

The most consistent key finding from the studies is that users complain of a 'lack of information' (Jain *et al.*, 1993, NO.120; highly rated; Ridsdale *et al.*, 1996, NO.115, medium rated; Chappell *et al.*, 1998, NO.108, unrated and from other locations; Fisher *et al.*, 2000; NO.162, medium rated).

There were varied reports on the issue of specialist nurses for epilepsy care, with some studies highlighting the fact that provision of such nurses improves communication between patients and healthcare providers (Mills *et al.*, 2002, NO.101, high rating) and claiming that users favour information from a specialist nurse over that provided by a GP, particularly for lifestyle issues (Ridsdale *et al.*, NO.107, unrated). Findings in another study (Mills *et al.*, 1999, NO.105, low rating) suggest that provision of an epilepsy specialist nurse for one year improved communication between patients and health professionals and levels of patient satisfaction, but did not affect health status and use of other health services. It is reported that patients who saw an epilepsy specialist nurse, in comparison with those who did not were less likely to want all or most of their follow-up care to be provided by the GP, but more likely to report their GP care as excellent and less likely to have reported never missing antiepileptic drugs (*ibid.*). In Jain *et al.* (1993, NO.120) users identified a specialist nurse clinic as their preferred option for treatment.

In a study of the long-term outcomes of surgery for intractable epilepsy, approximately half the users reported being free of seizures three years after the operation and 36 per cent were weaned off all anti-epileptic drugs (Wass *et al.*, 1996, NO.171; highly rated). The authors claim surgery is an effective option that meets with patient satisfaction. In a study in which patient's aims for epilepsy surgery were studied prospectively, (Taylor *et al.*, 2001, NO.160, highly rated) the most frequently cited aims constituted 50 per cent of the total and these were: desire for work; driving of a motor vehicle; independence; socializing and freedom from drugs. Patients rarely identified a desire for improvement in cognitive functioning as an aim for epilepsy surgery. The authors conclude that the social and personal aims to accompany relief of epilepsy identified by patients are consistent with the literature on psychosocial adjustment to epilepsy.

In terms of general satisfaction with care, the majority of users rate health services highly (Poole *et al.*, 2000, NO.103, highly rated; Goldstein *et al.*, 1997, NO.111, highly rated; Upton *et al.*, 1996, NO. 113, medium rated), but some studies note that the doctor's interpersonal style is influential in affecting patient satisfaction overall and these include being approachable and accessible (Buck *et al.*, 1996, NO.53, highly rated, T3). There is a general call for patient education to be seen as central to health professionals involved in epilepsy care (Cochrane, 1995, NO.54, highly rated).

A suggestion is made that hospital care should be reorganised into epilepsy centres which would improve the primary/secondary care interface, provide information at any time to patients and be a place of contact (Poole *et al.*, 2000, NO.103; highly rated).

In terms of social effects of epilepsy, there is some evidence of the negative impact of epilepsy on other family members (Ellis *et al.*, 2000, NO.48, highly rated) and this area needs more research. There is also a general plea for patients to be acknowledged as lay experts on their own condition (Wallace *et al.*, 1999, NO.106, medium rated).

Bradley *et al.* (1999, NO.223, medium rated) is an audit of patient perceptions and comparison to standards of care. The authors report that ten per cent of patients do not take medication as prescribed; 33 per cent report a need for more counselling; 41 per cent report a feeling of stigma attached to the condition and 84 per cent report general satisfaction with their GP.

Some users desire more counselling (Coultridge *et al.*, 2001, NO.102; medium rated), particularly at time of diagnosis, (Jain *et al.*, 1993, NO.120, highly rated), and advice on the use of anti-epileptic drugs during pregnancy (Wallace *et al.*, 1999, NO.106, medium rated). Mills *et al.* (2002, NO.101, highly rated) claim that 'effective communication is as much, if not more, of a priority for patients with epilepsy than is controlling the clinical manifestations of their illness' (Mills *et al.*, 2002, p.182, NO.101).

Scambler *et al.* (1996, NO.112, medium rated) report on the effectiveness of specialist nurses in primary care, however the findings are provisional. The costs in terms of finances and quality of life are highlighted. They report that; 90 per cent of respondents want more information on their condition; 75 per cent specifically want information on the side effects of medication and 60 per cent want to discuss their condition with someone other than a consultant. While epilepsy specialist nurses rate highly in terms of patient satisfaction the authors see their contribution as complementary to that of consultants and unjustified in economic terms.

Other locations

Andrewes *et al.* (1999, NO.49, high rating) sounds a note of caution in the 'lack of information' debate as they point out that receptiveness to information is key to understanding. This study categorised respondents into 'monitors and blunters' in terms of receptiveness to information, claiming these styles are key to understanding patient satisfaction.

Users require more information on side effects of medication (ibid; Fisher *et al.*, 2000, NO.162, medium rating). Some concern was expressed about lack of time given to imparting information (Fisher *et al.*, 2000, NO.162) and that patients preferred educators are doctors (Dilorio *et al.*, 1995, NO.118, low rating). Overall satisfaction with 'intractable' epilepsy surgery appears high at around 65 per cent of patients satisfied in one study (Guldvog, 1994, NO.119, medium rating).

Summary of users experiences with epilepsy (highly rated studies marked *)

- *Users want more information to be given on their condition and its management. Receptiveness to information is key to understanding.
- *Specialist nurses improve communication between patients and healthcare providers.
- *Epilepsy surgery is frequently effective in weaning patients off anti-epileptic drugs
- *Users want to work, drive, have independence, socialise and have freedom from drugs
- *The social and personal aims to accompany relief of epilepsy identified by patients are consistent with the literature on psychosocial adjustment to epilepsy
- *The majority of users rate services highly
- *Some studies note that the doctor's interpersonal style is influential in affecting patient satisfaction overall. This includes being approachable and accessible
- *Patient education should be seen as central to health professionals involved in epilepsy care
- *The negative impact on other family members is an area highlighted as needing more research
- Users want to see more effective communication from health care service providers
- Users want more information on side effects of medication and antiepileptic drug use in pregnancy
- There is a particular call for medical and health care staff to spend more time explaining diagnoses to patients
- Users voice support for specialist nurse run provision of services. These services appear to improve communication deficits experienced elsewhere in the system

Group C: ‘Progressive long term conditions’: Cerebral Palsy, Motor Neurone Disease, Multiple Sclerosis and Parkinson’s Disease

Cerebral Palsy (CP)

UK studies

A user experience (T1) study conducted in the UK (Willner *et al.*, 1993; NO.16) with a high confidence rating used depth interviews (analytic quota sampling) with 65 adults with CP. Users expressed a wish to have access to emotional support, counselling and/or psychotherapy. The few who had experienced psychotherapy had found this helpful. The emotional needs of their parents and siblings were often not recognised. Experiences of the education training and employment systems varied. There were some reports of dissatisfaction with schools and discrimination in employment. Fewer than 30 per cent of the users were in employment (94 per cent under retirement age). Professionals were insufficiently familiar with their particular condition. Most users were quite satisfied with their regular GP. Most cases of insensitive or unsatisfactory medical treatment related to experiences in hospital, although two thirds had not seen a consultant in the last five years. In relation to hospital admissions, the majority of doctors and nurses were perceived as sympathetic but dissatisfaction was voiced in a (significant) minority of cases. Although aging brought an increase in physical problems (and this seemed to be at an earlier point than in the general population), few users visit their GP for regular checks and the majority had not seen a consultant or physiotherapist for at least five years. For many this was because they had given up on the idea that they could get treatment that would help. Half of those who experienced spasms reported that these had intensified; more than half described increasing difficulties with mobility (most of these were under 60); one-third described increases in pain. Some users expressed anxiety about the future, particularly in relation to further physical deterioration. Time taken to obtain home equipment and adaptations was often too long. About half the users had social work contact and these divided about equally into those who commented favourably on their assistance and those who commented unfavourably.

Another study categorised as T1, Lamb *et al.* (1994, NO.140; low rated) reports problems in getting aids and adaptations installed in the user’s own home; inadequate support in the community; services paying scant regard to people’s needs, but relying more upon the assumptions of those providing the services; little control over how services are delivered and difficulty getting information about services needed. Respondents had the impression that professionals do not really listen to them, but base decisions on pre-conceived assumptions; feel that their views are not taken into account; doctors do not listen to what respondents say or talk to the carer rather than to them; assessments are humiliating as are designed to explore incapacity rather than ability and whether or not services are provided depends on resources available and not their needs. Users may not be able to get small items through statutory services and cannot afford to buy them; they are unable to obtain larger items such as appropriate wheelchairs or housing adaptations and they experience delays getting funding for adaptations from social services to make housing accessible.

Turning now to T2 studies, a study by Bamford *et al.* (1997, NO.147, highly rated) concerns the 'endemic tensions and creativity of multi-disciplinary working' noting these can have positive or negative effects on service users; that there is a danger that the 'culture of professionalism' negates user views and that 'listening to users' involves moving from reactive crises management to proactive crises prevention services. Also reported is that if a concept of 'total care (social, emotional and psychological needs) is adopted there are 'glaring deficiencies' such as skilled counsellors, lack of support at crisis points and lack of coherence between professionals especially when creating a bridge between core medical needs and wider social needs.

Another text by Bamford *et al.* (1997, NO.148, medium rating) is a report of a pilot study conducted in Northern Ireland, based on eight questionnaires from families with a child affected by CP. The families expressed a need for more help and support especially during the first four months after diagnosis. There was found to be little information available and no indication given of where to go for help (*ibid.*, pp.666/7). Professionals were scored in terms of the quality of help given. Doctors and teachers scored well, GPs got better scores than surgeons and other hospital doctors. Hospital nurses scored highly in contrast to community based nurses and social workers who scored poorly. Some findings relate to 'relative accessibility of different types of help and results indicate that apart from support at crisis point, professional counselling and respite care, access to the remainder of services is possible although persistence and determination are frequently required.

In another T2 study (Darrah *et al.*, 2002, NO.122, medium rated) families and people with CP rated their satisfaction with services over six areas using a seven-point Likert type scale. Later semi-structured interviews with users highlighted that certain individuals within the services had positively influenced their feelings about service provision by investing time and interest; family members complained of having to 'work the system'; adolescent users complained of professionals talking over their heads and using jargon and wanted to have more input on decision-making and that this was always deferred to parents. The adolescents also complained of bullying by peers in educational settings.

Many studies were discounted as outside the remit of the project as they were focused on children with CP. However, some (Parkes *et al.*, 2001;NO.17;unrated) included some general points concerning service delivery that are applicable to the adult age group. For example, users experience similar life expectancy to the rest of the population and this has 'implications for service planning, medico-legal settlements as well as the needs of people with cerebral palsy and their families' (*ibid.*, p.29). In terms of prevalence of CP, the majority of UK estimates range from 1.6–2.5 per 1,000 live births (*ibid.*, p.33). This is comparable with the rest of Europe, with exceptions for Denmark and Slovenia both at 3.0 (*ibid.*, p.35) The major findings on needs for services (again in relation to children in this case) focused on 'timely and accurate diagnosis, professional follow up at home, more respite care and access for extended periods, emergency back up services, access to aids and appliances, financial advice and information on benefits and transport services (*ibid.*, p.39).

Other locations

In terms of T2 studies conducted with adults with CP, one (Buzio *et al.*, 2002, NO.121) highly rated Australian study, (The Spastic Centre, NSW) reported on the experiences of 31 self-selected adults with CP during periods of hospitalisation (questionnaire study) The aim was to find out how people with CP are treated by nursing staff. Many patients felt hospital staff have limited knowledge and skills in caring for people with CP. This results in basic care needs not being adequately addressed during periods of hospitalisation. Changes in nursing assessment, continuing education and discharge planning are recommended. Many respondents reported multiple admissions to hospital within the previous two years. Only 23 per cent of respondents reported being asked by hospital staff for information about their impairment-specific needs as part of the admission process. The majority of respondents (>60 per cent in all disability categories except in relation to medication) felt these needs were never, almost never or only sometimes met by hospital staff. Staff were mostly perceived as ignorant of how to care for people with CP.

In a different T2 study Engel *et al.* (2002, NO.123, highly rated) reported on the treatment of pain for people with CP. It is a retrospective descriptive study of 64 adults with cerebral palsy-related chronic pain. Patients were 18-76 years, 35 women and 29 men – using a protocol-based interview. The authors tried to identify interventions currently being used for adults with CP and to examine the perceived helpfulness of them, and determine the extent to which these individuals were accessing healthcare for the explicit purpose of addressing pain. It was found that the patients sought and used a variety of pain treatments and healthcare providers and rated many of the interventions as being at least moderately helpful. Despite the reported helpfulness of the pain interventions, however, most are only being used by a small subset of the sample. The majority of the sample with chronic pain did not access health care providers for help in managing their pain. Cerebral palsy related pain is undertreated in the adult population with CP.

In a different study O'Day *et al.* (2002, NO.98, highly rated) found that people with CP are generally worried about the aging process and communication difficulties that they experience with health care professionals.

Summary of users with Cerebral Palsy experience (highly rated studies marked *)

- *Users expressed a wish to have access to emotional support, counselling and/or psychotherapy. The few who had experienced psychotherapy had found this helpful. The emotional needs of their parents and siblings were often not recognised.
- *Experiences of the education training and employment systems varied. There were some reports of dissatisfaction with schools and discrimination in employment.
- *Professionals were insufficiently familiar with their particular condition. Most users were quite satisfied with their regular GP. Most cases of insensitive or unsatisfactory medical treatment relate to experiences in hospital.
- *Aging brings an increase in physical problems but few users visit their GP for regular checks and the majority had not seen a consultant or physiotherapist for at least five years. Users express anxiety about the future, particularly in relation to further physical deterioration.
- *Time taken to obtain home equipment and adaptations is often too long. Social work support is viewed favourably in around 50% of cases. Occupational Therapy (OT) received was satisfactory in around 60% of cases.
- *There are endemic tensions and creativity in multi-disciplinary working - these can have positive or negative effects on service users. There is a danger that the 'culture of professionalism' negates user views and 'listening to users' involves moving from reactive crises management to proactive crises prevention services.
- *If a concept of 'total care (social, emotional and psychological needs) is adopted there are 'glaring deficiencies' such as skilled counsellors, lack of support at crisis points and lack of coherence between professionals especially when creating a bridge between core medical needs and wider social needs.
- *Hospital staff have limited knowledge and skills in caring for people with CP. Basic care needs are not being adequately addressed during hospitalisation. Changes in nursing assessment, continuing education and discharge planning are recommended.
- *Cerebral palsy related pain is under-treated in the adult population with CP. Despite the reported helpfulness of the pain interventions, however, most are only being used by a small amount of patients.

Motor Neurone Disease

Few studies identified deal primarily with user's experience in health and social services. Most of the information has been gleaned from publications dealing with a range of other issues. However, in general, most of the evidence included in this review attracted high or medium confidence ratings.

UK studies

In terms of user experience, (T1 studies), a number of 'personal perspective' papers were identified that detail individual service user's experiences. Of these, the highly rated Carus (1980, NO.74) contains many key messages that are echoed in other texts such as, the lack of knowledge and understanding of MND displayed by many medical professionals and by the general public, a lack of information about the diagnosis and a general view that within Motor Neurone Disease Association (MNDA) groups, many other patients hold similar views. These views are in fact very similar to those in Baylis (1995;NO.68, highly rated), with the addition of the suggestion that health professionals require advice and information from people with expertise such as MNDA advisers.

In another T1 study MNDA (2002, NO.78; high rating), the MNDA report on their Tracking survey of views and experiences of people with MND. This paper contains information drawn from 229 completed questionnaires that were sent to MND patients. Seventy-nine percent of these people had received their diagnosis for less than two years after experiencing the first symptoms of MND but 23 per cent still felt that diagnosis had taken too long (*ibid.*, p.20). Many (53 per cent) had been referred to non-neurological specialists, which the patients felt delayed the diagnosis of MND. There does not appear to be a coherent system in place for sensitively communicating a diagnosis of terminal illness to the patient. In this study 32 per cent were given the diagnosis on their own and 'left in a state of shock with no offer of emotional/psychological support at this difficult time' (*ibid.*). Patients complain generally of a 'lack of sensitivity by neurologists and other hospital staff (*ibid.*). There is a note of frustration evident that the tracking surveys of the previous three years made the same finding – that 'people who have been recently diagnosed with MND need information about the disease, sources of help and support and details of the MND Association' (*ibid.*, p.21). The majority of respondents (71%) were not offered an appointment with a neurologist within two weeks of diagnosis which left them feeling isolated. This implies that shorter waiting times or a fast track system would alleviate patient suffering. MNDA have been campaigning for a considerable time for a 'single point of contact' for recently diagnosed MND patients, yet in this survey, 45% were not put in touch with a specialist MND nurse or team and 26 per cent did not have a point of contact and were excluded from any discussions concerning their welfare which added to their feeling of isolation (*ibid.*, p.22). There are a number of recommendations, for example that the MNDA should continue influencing the education of GPs and other health and social care professionals about the early symptoms of MND and encourage early referral to neurologists, encouraging the latter to ensure that patients are not told the diagnosis alone, that professional counselling is available and influencing service providers to urgently supply grants for adaptations and equipment (especially the supply of wheelchairs) (*ibid.*, pp.22/3). These findings are similar to those contained in the previous tracking surveys (MNDA, 2001, NO.77; low rating).

A common theme that is found in Pegg (1992, NO.52; low rating) is that the speed of progression of MND means that equipment often arrives too late to be of use, the patient has deteriorated faster than the ordering time for the particular item. This text also points to the importance of establishing an effective means of communication (in this case via computer) to enable the patient to continue to communicate once speech becomes impossible. Another important point made is that in times of resource limitation and rationing, there is a case to be made for positive discrimination in favour of people with rapidly deteriorating terminal illnesses such as MND.

Several other T1 short articles report on aspects of user's experiences of services such as hospice care, (Oliver 2000; NO.59; low rating), Occupational Therapy services, (MNDA, 2002, NO.76; low rating), palliative care and clinical management, (Howard *et al.*, 2002, NO.63; high rating) Physiotherapy (MNDA 2002; NO.60; medium rating) and speech therapy, (MNDA, 2001, NO.57, low rating). MNDA (2002, NO.60, medium rated) reported on physiotherapy for relief of symptoms of MND and claims that people with MND want to preserve maximum level of mobility for as long as possible. Exercises can improve muscle function and physiotherapy can help people achieve a full a range of movement as possible. Exercises that relieve spasticity, pain and stiffness as well as help prevent muscle cramps and joint deformity can make a considerable difference to patients' quality of life. The majority of these texts contain similar messages concerning MND patients' experiences which are included in the summary.

In terms of professional/academic (T2) studies, one that was highly rated (van Teijlingen *et al.*, 2001, NO.80) reported on use of, need for, and satisfaction with services among people with MND and their carers. A questionnaire was used in 153 interviews with people with MND in Scotland. Sixty per cent of the sample were severely disabled. Only 28 per cent of the sample reported that the health services met their needs completely, with 25 per cent reporting the same for social services. However, only a very small proportion (3-6%) said that these needs were not met at all. This study noted that a key problem is that people with MND can deteriorate quickly, so their needs change quickly, while services are only able to react slowly. People with an identifiable carer were more likely to have their health [service] needs met than those without. Thirty-one per cent of carers would have liked more help. Disturbed sleep was a key problem. There were regional variations within Scotland on use of and satisfaction with services. Since nearly one-quarter of all respondents were not currently followed up in hospital, and two out of five were not currently attending a hospital clinic, the implication is that provision of or planning for care for at least part of this group needs to be organised by community-based services.

Another T2 paper was by Brown *et al.* (2003, NO.47, highly rated) which unfortunately conflated 'user/carer needs'. Twenty interviews; with 11 users and nine carers were conducted. This paper noted the following as important; continuity of care personnel; fast track referrals to paramedical personnel; equipment availability and timely delivery; having named key workers and palliative symptom management. The report also highlights the paucity of information on MND at national level (for example there are no MND databases in England); the low numbers of people with MND (incidence and prevalence). This means dedicated MND service provision is often difficult to procure and the authors suggest that organising services with other

long term conditions such as Multiple Sclerosis and Parkinson's Disease may assist); the MND diagnosis should drive concepts such as speed, specialised equipment and early referrals to paramedical professionals and palliative care providers. Too often this is not the case. There is limited co-ordination of services (health and social care); the system does not accommodate speedy progression of disease to action personnel and equipment and there is limited knowledge of MND amongst the professions. Knowledgeable key workers are required.

Another T2 study, Johnston *et al.* (1996, NO.154, highly rated) found that 'having a label' was generally perceived favourably; an audio tape of the diagnostic interview was favoured by individuals with relatively better prognosis, but not by those who were given a poor prognosis; almost half the participants did not understand the diagnosis; the most common complaint was of being told the diagnosis in vague terms; some participants were alone when they received the news and would have felt better with a family member present; some participants were given the diagnosis in a situation that lacked privacy and some wanted more information at the time, particularly in relation to finding out more about the disease.

Goldstein *et al.* (1998,NO.152, unrated) examined the psychological impact on patients in relation to length of time since onset and changes in functioning.

Other locations

In terms of outside the UK, two papers deal with the setting of standards of care in Ireland, (Irish Neurological Alliance 2000;NO.1 and Neurological Alliance of Ireland 2001;NO.2) but do not report users' experience of services.

Summary of user's experiences with MND (highly rated studies marked *)

- *Users are concerned about the lack of knowledge and understanding of MND displayed by many medical professionals and by the general public. They also experience a lack of information about the diagnosis. This view is held by many patients within Motor Neurone Disease Association (MNDA) groups
- *Health professionals require advice and information from people with expertise such as MNDA advisers
- *Many patients are referred to non-neurological specialists, which they feel delays the diagnosis of MND.
- *Speedy diagnosis is essential for MND patients. Education of medical and health professionals to identify early symptoms of MND would enable patients to make the most of remaining time.
- *At diagnosis, there is a great need for sensitive handling (by the neurologist and other health professionals). Patients should have a relative or friend present when diagnosis is given
- *MNDA should continue influencing the education of GPs and other health and social care professionals about the early symptoms of MND and encourage early referral to neurologists, encouraging the latter to ensure that patients are not told the diagnosis alone, that professional counselling is available and influencing service providers to urgently supply grants for adaptations and equipment (especially the supply of wheelchairs)
- *Since MND is progressive, degenerative and rapid, patients require fast tracking for a number of aids and adaptations. Generally speaking, the ordering systems for equipment appear to fail people as the disease progresses faster than the items can be delivered.
- *Patients can deteriorate quickly, so their needs change quickly, while services are only able to react slowly
- * Continuity of care personnel; fast track referrals to paramedical personnel; equipment availability and timely delivery; having named key workers and palliative symptom management are important to users

Multiple Sclerosis

UK studies

Only one UK study was categorised as T1, this being Scrimgeour *et al.* (2001, NO.215, highly rated) which is a quantitative survey by Lanarkshire Health Board of members of the MS Society to obtain their opinions of the overall quality of health care provided during two previous years in hospital, clinics and at home by doctors, nurses and other health professionals. One hundred and nineteen patients completed the questionnaire, 90 female and 29 male aged 29-60 years. GPs were the most frequently consulted health professionals (75%), followed by hospital specialists (50%) and district nurses (41%); Speech therapy was the least utilised service (7%). 84.5 per cent of patients were generally satisfied with the quality of hospital care. Most patients (70%) were satisfied with GPs whereas only 57 per cent approved of hospital specialists. Many GPs and hospital specialists were deficient in explanations to patients; only 59 and 52 per cent respectively performed satisfactorily. District and night nurses were well regarded. Most other health professional rated well but health visitors and social workers received less approval. Patients frequently complained that they saw a different doctor on every hospital visit and explaining matters to them was deficient in 48.4 per cent of cases and bad in 21 per cent of cases. Health professionals should allot more time to ensuring adequate explanations are provided. More graphic explanations of medical information was requested.

Of the T2 papers, a quantitative study (Howarth, 2000, NO.87, high rating) found that MS patients are more susceptible to experiencing pain the longer they have the disease. An educational programme was set up following this study for patients newly diagnosed with MS which includes pain management and the authors are planning to study to efficacy of aromatherapy massage. Another highly rated UK study was Perks *et al.* (1994, NO.46, high rating) which was a survey of 'marginal wheelchair users in Tayside, Scotland and in which the modal diagnosis was MS, although many other target conditions were covered such as cerebral palsy and polio. The results indicate that 75 per cent of the sample was using standard Ministry model 8 wheelchairs and 67 per cent claimed these are inadequate. Of the 25 per cent who were using alternative wheelchairs, 35 per cent considered these inadequate. These problems were mainly technical in nature and 'general discomfort'. 65% of the sample did not live in purpose built wheelchair accommodation and therefore faced propulsion difficulties. Frailty due to ageing also compounded propulsion problems. Another highly rated quantitative study, (Critchley *et al.*, 1998, NO.185) reviewed outcomes of patients who had undergone thalamotomy for the intention tremor of MS. 24 patients underwent 29 procedures between 1988 and 1995. It reports mixed results of procedures. Twenty-three per cent reported improvement in arm function. Out of 23 patients, four were enthusiastic, and ten satisfied with outcome.

Another highly rated study, (Campion *et al.*, 1997, NO.219), covers the role of the specialist nurse (a much debated theme) which apparently 'improved patients' lives' but it 'had not necessarily reduced the cost to the public purse of caring for MS patients'. The authors claim that 'several' surveys of MS patients (unspecified) reveal 'high levels of dissatisfaction with the psychological care given by the healthcare workers and with the provision of services in their own homes, particularly therapy'

The authors report on a study conducted at Manchester Royal Infirmary that highlighted the absence of information about the disease, the difficulty of getting access to services, poor bladder management and a lack of physiotherapy. It is also reported that the MS Society believe much money could be saved if there was concerted action to ensure spending was focused to best effect, for example, the cost of in-patient admissions to treat MS attacks could be reduced significantly through continuity of care rather than crisis intervention. The argument is that as MS services are 'fragmented', the role of co-ordinating health worker with specialist knowledge of the disease becomes 'critical'. The authors also report that one specialist nurse service was set up in the Lothian region in 1990, and patients, carers and GPs all felt it was helpful and had improved patient' and families' psychological well-being, reduced GP workload and increase patient and doctor knowledge of the management of MS. However, the study concluded that although the service seemed to have improved patients lives it had not necessarily reduced cost of providing services to MS patients.

In a different UK study, ranked medium confidence, (Makepeace *et al.*, 2001, NO.214) patients were asked to rank aspects of importance to them in a community MS team. These were (in order of importance) accessibility (ability to contact team as necessary); home visits; continuity of contact with individual team members; emotional support; information service; equipment, evaluation and prescription and financial advice. Another medium confidence study (Zarb, 1992, NO.7) found that ageing with a disability produces a feeling of being overlooked and that sometimes this group fail to ask for help. These issues are compounded by long periods of isolation and sometimes having insufficient confidence to articulate requirements (particularly the case for older disabled women). People from black and minority ethnic groups faced isolation and several respondents felt concerned about losing independence, physical, personal and wider control over their lives in terms of how they wished to live.

In Barnes *et al.* (1996, NO.45, medium rating) users expressed a preference for a 'drop in system' at the neurological clinic; being able to see just one or two professionals with relevant expertise and to have a doctor based clinic with referral to appropriate therapists.

Three UK studies were ranked 'low' confidence by the expert panel. Anonymous 2000, (NO.237) was a personal account by a woman with relapsing-remitting MS which described her experience of using acupuncture alongside conventional medicine (such as steroids). Acupuncture is claimed to have a positive impact on some symptoms but no effect on others. Another 'low' study is from a Nursing Times reporter (2000, NO.217) on patient dissatisfaction with continence services in relation to MS. In particular users identified that continence problems are seen as the biggest barrier to social life, and that they leads to, relationship problems, difficulties on holiday and problems 'going down the pub'. Users were generally unhappy with the advice received from GPs and in hospital and preferred specialist advice from 'care-pathways'. MS Society (2001, NO.132), also rated 'low' seeks to brief members of the workings and responsibilities of social service departments in order that they might access the full range of benefits and services on offer.

Other locations

The studies from other countries rated highly include Mohr *et al.* (1999, NO.42) which examined the psychosocial impact of MS 'from the patient's point of view' and in which qualitative research was used to generate statements about the impact on life and well-being of living with MS. The resultant 67 statements were presented to a telephone sample of patients for Likert rating and psychosocial effects were divided into three categories; demoralization, deterioration in relationships and benefit-finding (beneficial psychosocial outcomes). Patients indicated that there were some benefits to having MS.

A quantitative study (Cusick *et al.*, 2001, NO.39, high rating) set out to examine levels of agreement between disabled people and 'proxies' about measures of community integration by using measurement scales and claims (controversially) that proxies provide data comparable to users (disabled people) that is highly reliable. The study covered a range of conditions of interest as well as MS such as brain injury and spinal cord injury. Other highly rated studies reported that surgery reduces tremor in some MS patients but this does not always translate into improved quality of life (Berk *et al.*, 2002, NO.82), that patients place 'tremendous reliance' upon family caregivers and respite care is under-utilised, but prolonging home care and postponing early institutionalisation is a high priority (Aronson *et al.*, 1996, NO.188) and that accessing disability benefits in Canada is problematic due to eligibility criteria assessments by physicians (Jongbloed, 1998, NO.186).

A similarly highly rated USA study (Vickery *et al.*, 1999, NO.183) compared general neurologist care with specialist MS neurologist care and found the latter had more experience in advising patients about new treatments and the management of side effects; were perceived as better at communication and were more involved in research and access to MS care in some areas. Their patients were also more likely to be currently taking Interferon, whereas their counterparts under the care of the general neurologist had desisted due to side effects. Another highly rated study (Mohr *et al.*, NO.40) concentrating on Interferon use studied 101 patients with relapsing form of MS and concentrated on self-injection practices and adherence to drug regimes. Pre-treatment injection self-efficacy expectations were significantly related to six month adherence but this relation was mediated by the patient's ability to self-inject and patients' experienced level of injection anxiety was related to adherence but not to method of injection.

A highly rated quantitative study from the USA (Rumrill *et al.*, 1999, NO.184) concentrated on the employment concerns reported by a random sample (n=227) people with MS. Members of MS Society identified 34 employment concerns as most reflective of the career development implications of MS. Survey respondents considered each item along two dimensions, the importance of the item to career development and their satisfaction with the adequacy of services that address that concern. Respondents were most satisfied with issues such as health insurance coverage, potential to work and take control of their lives, wages and benefits and workplace accommodations and were most dissatisfied with issues including fair treatment by employers and the hiring process, access to service providers who understand their needs, access to adequate information about social security programs, optimism regarding their future and issues related to re-entering the

workplace. Implications for vocational rehabilitation practice and future research are discussed.

A further T2 study from abroad is Gulick *et al.* (1993, NO.190, highly rated) which compared change scores obtained on patient self-reported symptoms with the neurological examination of the Kurtzke Functional Systems and change scores obtained on patient self-reported activities of daily living with the neurologist-determined Expanded Disability Status Scale in 100 patients with MS.

The authors' main argument is that using patient self report scales (patient perspective) can be useful in guiding the physical examination, in making comparisons from visit to visit and in assessing patient's quality of life and increasing patient satisfaction with medical care.

McLaughlin *et al.* (1993, NO.14, highly rated) is a qualitative appraisal of the role of self-care in multiple sclerosis and is an international comparison study (Denmark and USA). The authors compared and contrasted self-care practices of 51 Danish and 35 American people with 'various levels of impairment'. Respondents were asked about ways they managed their symptoms and problems during periods of non-medical contact – including methods of following the medical regimen, alternative treatments, use of lay-referral systems and sources of information regarding physical, psychological, social and environmental dimensions of coping with the illness. The two groups varied regarding adaptation strategies and primary sources of information used. Their ultimate aims were similar – to gain control over uncertainty, dependency and physical and emotional decline. The study suggests that the empowering role of self-initiated self-care strategies in chronic illness may transcend differences in health care systems. In a different study, O'Day *et al.* (2002, NO.98, highly rated) reported that some MS patients find that doctors are not well informed of the condition.

In terms of medium rated studies from other locations, Gottberg *et al.* (2000, NO.81) in Sweden calculated utilization of health care resources within Stockholm County and piloted methods for interviewing people with MS and carers. The study was based on the views of 26 people and items they found important to add into the main study include advice and information on social security and psychosocial issues, delivering information at an early stage of the disease and perception of the situation when the diagnosis is given.

Of the three remaining studies reviewed here, Gordon *et al.* (1996, NO.13) was rated 'low' and aimed to provide professionals who employ group techniques with information about the experience of MS so they can run them in an informed way; Sparber *et al.* (2002) (unrated) sought to establish the relationship between patient depression and the willingness to use complementary and alternative medicine, but did not seek user's views, and Miller *et al.* (2001, NO.83, unrated) reported that 'some sufferers report very positive experiences with representatives of the drug manufacturers through telephone support'.

Summary of users with MS experience (highly rated studies marked *)

- *Many GPs and hospital specialists were deficient in explanations to patients. District and night nurses were well regarded. Health visitors and social workers receive less approval.
- *Patients complain that they see a different doctor on every hospital visit and explaining matters to them was deficient in half of cases. Health professionals should allot more time to ensuring adequate explanations are provided. More graphic explanations of medical information is requested.
- *The MS Society believe much money could be saved if there was concerted action to ensure spending was focused to best effect, for example, the cost of in-patient admissions to treat MS attacks could be reduced significantly through continuity of care rather than crisis intervention. As MS services are 'fragmented', the role of co-ordinating health worker with specialist knowledge of the disease is 'critical'.
- *Patients who under thalamotomy for the intention tremor report mixed views on its success. Surgery reduces tremor in some patients but does not always translate into quality of life improvements.
- *Specialist nurses improve patients' lives but do not necessarily reduce the 'cost to the public purse of caring for MS patients'.
- *Users are more likely to experience pain, the longer they have the disease.
- *A considerable proportion of users have problems with standard issue wheelchairs, including technical, propulsion and general discomfort issues.
- * Prolonging home care and postponing early institutionalisation is a high priority
- *Using patient self-report scales (patient perspective) can be useful in guiding the physical examination, in making comparisons from visit to visit and in assessing patient's quality of life and increasing patient satisfaction with medical care.
- *Users wish to gain control over uncertainty, dependency and physical and emotional decline.
- In community MS teams, accessibility to the team is key and users rate highly home visits, continuity of contact with individual team members, emotional support, information services and equipment and financial advice.
- Patients benefit from having access to an MS specialist neurologist
- In terms of injection anxiety, self-efficacy expectations were significantly related to adherence to drug regimes.

Parkinson's Disease (PD)

UK studies

Only four studies were categorised as T1, user experiences. Yarrow (1999, NO.143; medium rated) raised the importance of information about medical subjects and issues such as accessing public transport, environmental barriers and low income. A different study (PDS, 2002, NO.89, unrated) aimed to highlight key aspects of PD for health professionals. These included listening to patients and their families and respecting/valuing their experiences and involving them in the management of their condition. Professionals have to be aware that the nature of the disease is different for every patient in terms of symptoms and progression, that drugs can control symptoms but the on-off syndrome means drugs sometimes work and sometimes do not and some contraindicated drugs used in hospitals to treat complications may worsen the symptoms of PD. Also acknowledged is that PD can affect communication and difficulties can give out misleading signals to health professionals. The latter need to 'look beneath the mask' and give the patient time to respond. Patients need physiotherapy, good nutrition (time to eat slowly and staff patience required) and to discuss administration of drugs with PD specialist. Anaesthetists should know what drugs being routinely taken by patients before surgery.

Bennion (2002, NO.192, low rated) is another 'position paper' by a user with PD whose drugs 'suffered at the hands of the regulators'. The drug (tolcapone) relieves the on/off state of PD and subsequently improves mobility and function and was launched in Britain in 1997. The drug was withdrawn in Europe in 1998 after a few reports of severe hepatotoxicity (toxic effects on liver). Bennion's functioning level dropped dramatically. The main point made is that many people make informed choices over taking certain drugs (e.g. contraceptive pill) that have some inherent risk to health. Bennion felt denied the opportunity to exercise this choice by the actions of the regulator. He now obtains the drug privately but at a high cost (£450 every 3 months).

An unrated T1 study, Birleson (2001, NO.133), reported that consultants do not refer users appropriately to other professionals and users feel they need more advice on medical and lifestyle issues. Users in this study view respite care negatively and feel unhappy that intervention only occurs at times of crisis (many problems being more difficult to deal with at that stage). Users also reported feeling abandoned between consultant appointments (6-12 months apart), feeling they have a lower quality of life due to lack of services and that as a group, they are well able to say what a 'service should look like' (*ibid.*).

Of the T2, professional/academic studies, Jones *et al.* (1999, NO.136) was highly rated and reported that the diagnosis-giving process was not handled well by GPs or specialists, that on-going communication with professionals is similarly poor, that most of the sample did not know about other available services such as respite care and that under-reporting of symptoms (especially depression) is common.

Barber *et al.* (2001, NO.196; highly rated) found users reporting high dissatisfaction with peri-operative management with 94 per cent complaining of confusion or

worsening of their condition post-operatively and that medical administration problems are common.

A T2 study Jenkinson *et al.* (1999, NO.73; highly rated) highlighted the importance of mobility issues; falls; work-related problems; problems in household management, social isolation and limited leisure; difficulty taking holidays, financial problems, premature retirement from work leading to reduced income; more health-related costs, depression, loss of control, speech difficulties and cognitive impairment.

A different T2 study (Reynolds *et al.*, 2000, NO.90, highly rated) is a report on a one year follow up study of 108 randomised patients with PD at three centres to investigate the differences between care provided by the hospital based PD nurse specialist (PDNS) compared with the consultant neurologist (control). Only two out of 22 differences were found where physical functioning and general health improved more in the control group. Provision of PDNS for patients with PD cannot therefore be recommended solely on cost-effectiveness grounds because of similar outcomes but increased costs with PDNS providing additional care. However, medical and nursing specialists valued their complementary expertise and patient and carers responses to consultations also reflect that PDNS make particular contributions to their care.

In terms of UK medium rated studies, Zarb (1992, NO.8) highlighted issues faced by users ageing with PD including transport, housing and financial issues and the role of the PD Society. Trend *et al.* (2002, NO.193, medium rating) investigated 'non-pharmacological approaches to the management of PD' concentrating on the impact of multidisciplinary rehabilitation and a supportive programme of group education (however, cognitively impaired patients were not recruited). It was found that intensive multi-disciplinary rehabilitation for people with PD and their carers results in immediate improvements in patients' mobility, speech, depression and health-related quality of life, but no change in carer well-being. There was some unmet need for social services identified.

Parkinson's Disease Society (2002, NO.114, medium rated) is a survey (256 respondents) on the standards of care received in hospital where patients are admitted for Parkinson's related treatment or for other treatments. It was found that only 52 per cent received their Parkinson's medication at the correct time (yet this is critical). Only 27 per cent of staff understood the on/off syndrome nature of Parkinson's. Patients appeared unable to access the PD Nurse Specialist whilst in hospital and communication, mobility and special dietary needs were unmet. The recommendation is that patients should be permitted to play a more active role in the management of their condition whilst in hospital (for example, being able to self-administer medication).

Other locations

Five (T2) studies came from 'other locations'. The only highly rated T2 study reviewed was by Chrischelles *et al.* (1998, NO.75) and was a quality of life survey attempting to show associations between stage of disease and health related quality of life but did not report user experiences. A different study (USA) Rubenstein *et al.* (1999, NO.197; medium rated) surveyed a group of patients from a range of hospitals across Iowa. The study is a trial of the instrument HRQL (health Related Quality of

Life) and although it appears to show that the measure can be self-administered, there are no user experiences reported.

Mercer (1996, NO.130; medium rated) found that patients enrolled on a health management programme (PROPATH) experienced perceived improvement in general health and psychological well being compared to patients treated in the usual way. Particularly noted was reduction in days of fatigue and decrease in psychological distress. However, PROPATH enrolment had no significant effect on patient satisfaction with medical care but did result in significant reduction in patient visits to their physician or hospital. However, the majority of physicians did not find PROPATH helpful in developing the treatment plan, management of the illness, prior identification of problems or identification of drug side effects. It appears to have a useful role in assisting patients to perceive their *whole* psychological well-being and general health.

Another study rated 'medium' (Siderowf *et al.*, 2002, NO.224) aimed to assess quality of life using preference-based scales and compare scores with measures of clinical severity. The study involved 97 patients with PD (patients with cognitive impairment excluded). The findings were that the preference-based measures (PBM) tested correlated highly with standard measure of disease severity and health-related quality of life. However, there were substantial differences between the scores derived from the PBM. This has important implications for the interpretation of cost effectiveness analysis (CEA). PBM also have a role to play as generic measures of health-related quality of life: they are simple to interpret for professionals and may be particularly appropriate for guiding the use of symptomatic therapies. However, there were notable limitations of the study. The sample was non-random and not necessarily representative. Patients with very mild and the most severe symptoms were underrepresented and there was no discussion of patient views on the use of PBMs.

The final study, (Lacroix *et al.*, 1995, NO.92, medium rating) reported on 'patient statements' from Switzerland (Swiss Parkinson's Association). It was found that there are 'psychological costs' of PD (additional burden of fluctuating symptoms and public perceptions of symptoms, for example appearing to be intoxicated); professional costs, as many patients withdraw from social life to avoid attention, the condition can also affect communication. This can end careers, result in loss of position or retirement. There are also social costs. PD places a heavy strain on relationships with relatives (especially when the role overlaps with 'carer') and financial costs, as not all additional costs are met by health insurance or other forms of social support. Other patients want better information from the start about their condition, better understanding about their medication, and stress the importance of paramedical help (physical/occupational therapy).

Summary of users with PD experiences (highly rated studies marked *)

- *The diagnosis-giving process is often not handled well by GPs or specialists. On-going communication with professionals is similarly poor. Many users do not know about other available services such as respite care and that under-reporting of symptoms (especially depression) is common.
- *Users report high dissatisfaction with peri-operative management with 94 per cent complaining of confusion or worsening of their condition post-operatively and that medical administration problems are common.
- * Mobility issues; falls; work-related problems; problems in household management, social isolation and limited leisure; difficulty taking holidays, financial problems, premature retirement from work leading to reduced income; more health-related costs, depression, loss of control, speech difficulties and cognitive impairment are all important to users
- * Provision of PD nurse specialist (PDNS) compared with the consultant cannot be recommended solely on cost-effectiveness grounds because of similar outcomes but increased costs with PDNS providing additional care. However, patient and carers feel PDNS make particular contributions to their care.
- Patients need to become empowered to take control of their illness and so ensure that it does not impair their quality of life.
- Patients have knowledge and experience and a desire to manage their own condition and these three factors should be harnessed to ensure that resources are used wisely and appropriate services provided
- Patients should have the right to make informed choices on issues such as whether to take part in drug trials and on the pros and cons of a particular treatment and its adverse effects.
- Healthcare professionals and policy makers need to understand that their own perceptions of health may differ from those of their patients.
- Users want to be listened to by professionals and want their experience to be valued and respected.
- Users should have the right to make informed choices over whether to take certain drugs for PD.
- Users need more advice on medical and lifestyle issues. They feel they have a lower quality of life due to lack of key services.
- As a group, users are well able to say what a good service should look like.

General Articles

This section draws together findings from papers that relate to service users outside the target group. The scope and scale of the papers varies enormously as did the confidence with which the expert panel rated the papers.

There were a number of highly regarded projects whose central function was to ascertain the views and experiences of disabled people, notably Begum (1996 NO.4), Clarke (2002, NO.5), Johnson (1995, NO.28, highly rated), Lamb & Lazell (1995, NO.141), Essex Coalition of Disabled People (2002, NO.138) and Shah (2001, NO.3). Other studies, such as Forester-Jones *et al.* (2002, NO.19, highly rated), Preston-Shoot (2001, NO.20), Rea & Rea (2000, NO.15, highly rated), Solas (1995, NO.23, highly rated) and Williams (2001 NO.195, highly rated) were also rated with confidence although their messages were more general.

A number of the general articles solely detailed service users' experience of particular types of treatment rather than user experiences of receiving services - Trail (2001, NO.151, rated medium) on the benefits of various wheelchairs, Ryan & Johnson (2002, NO.194, rated low) on the use of complementary and alternative medicines by patients attending neurology clinics, Mukai *et al.* (2001, NO.159, rated low) on hypnotics, Neimeier and Burnett (2001, NO.38, rated high) reviews the literature on the extent and nature of patients' bereavement associated with the loss of limbs or function, O'Callaghan (1996, NO.44, rated low) on song writing by palliative care patients – and therefore are not considered further here.

Begum's highly rated report (1996, NO.4) explored disabled women's experience of General Practitioners (GPs). GPs are often the passport to whole range of services and support and therefore can have a massive impact on the lives of disabled women. However, disabled women's relationship with their GPs are often problematic, it was felt they were often viewed as disabled first and women second resulting in GPs being reluctant to acknowledge disabled women's need for women's health services. GPs prejudices and low expectations of disabled women influences the sort of support they receive and can lead to women not being adequately supported in making informed decisions and choices particularly around contraception and pregnancy.

NO.138 (Essex Coalition of Disabled People, 2002, rated high) is a guide written for support workers and personal assistants by a group of disabled people. The particular focus is on people who have language but do not use speech. Communication difficulties are linked to impairment/condition but greater difficulty is caused by 'speaking' people not having the experience, time or commitment to try to understand and be inclusive. The guide provides examples of good and bad practice when seeking to include disabled people with communication difficulties.

Shah (2001, NO.3) was a highly rated and recommended study that focused on the experience of health services of disabled people from minority ethnic communities (south Asian and afro-Caribbean). Group and individual interviews highlighted a range of issues including cultural insensitivity across a range of services and the physical barriers that prevents many people accessing health and social care facilities. The report further details their collective response via self-help groups. The

report was particularly recommended for its clear layout, use of illustrations and availability online making it accessible to users and professionals. Similarly Clark (2002, NO.5) was highly rated as an exemplar of research collecting service user views. It contains important recommendations for the provision of accessible information within the NHS. The importance of disseminating and acting on user views is highlighted.

Solas' highly rated paper (1995, NO.23) discusses the importance for social workers, although his findings equally relate to other health and social care professionals, of listening to clients' stories/narratives. This method is seen as much more user-centred and provides space for service users to explore the ways their conditions impact of their lives and to explore what their priorities are.

Williams (2001, NO.195, rated high) is an editorial reviewing the literature and development of involving consumers in research. Key messages from this piece are that health professionals remain uncertain about which consumers to involve, which methods of participation to select and how to adequately support user involvement. It was noted that to move from merely consulting users to working in partnership with them and their organisations requires ensuring service users are fully involved from the beginning of the research process and that decision-making is shared. Furthermore it was recognised that genuine consumerism means hearing voices that speak 'for the perspectives, ideas, interests and values of patients, users and carers *as they define them*'.

Pooley *et al.* (2001, NO.21, rated medium) relates to people living with diabetes but includes important generalisable findings. Issues around time and specifically lack of time were highlighted. Lack of time fragments care, leads to inadequate consultations, and prevents professionals from adequately listening to patients and addressing their needs. The papers also recognised that patients' ability to self-manage their condition and treatment can be seriously damaged by structures and professional practice that disempower them.

Preston-Shoot (2001, NO.20, rated medium) reviews four studies of complaint procedures as a way of assessing user views/redress. Considerable barriers still limit the numbers of users going down the 'complaints path' and staff making the decision to 'whistle blow'. The paper's overall conclusion is that complaint procedures have had little impact in effecting the service changes desired by service users. Rea and Rea (2000, NO.15, rated high) discuss different ways of assessing and integrating user views within the context of mental health services. It was deemed particularly important to ensure service users are involved in service planning and delivery and not just in the retrospective evaluation of services.

Key points from General literature (highly rated studies marked *)

- *Disabled women's relationships with their GPs are often problematic with the result that they are viewed as disabled first and women second. GP prejudice and low expectations of disabled women can lead to women not being adequately supported in making informed decisions and choices particularly around contraception and pregnancy.
- *Communication difficulties are sometimes linked to impairment/condition but greater difficulty is caused by 'speaking' people not having the experience, time or commitment to try to understand and be inclusive.
- *Disabled people from minority ethnic communities (south Asian and afro-Caribbean) experience cultural insensitivity across a range of services and physical barriers that prevent many people accessing health and social care facilities.
- * The provision of accessible information within the NHS is important, as is acting on user views
- *It is important for social workers, to listen to clients' stories/narratives. This method is seen as much more user-centred and provides space for service users to explore the ways their conditions impact of their lives and to explore their priorities
- *Health professionals remain uncertain about which consumers to involve, which methods of participation to select and how to adequately support user involvement. Genuine consumerism means hearing voices that speak 'for the perspectives, ideas, interests and values of patients, users and carers *as they define them*'.
- Disabled people can and want to take control of the management of their impairment/conditions. However, disempowering professional attitudes and practice can limit this
- Inclusive practice is vital to ensure equitable access to services, most notably in relation to physical and communicative access and cultural and gender sensitivity.
- Service user consultation and involvement in research must have tangible results and particular attention should be paid to ensuring findings are suitably disseminated.

Conclusion

Within the confines of a brief review of the available literature it has been possible only to identify the main themes and issues that are important to service users concerning their experiences in using health and social care services.

In terms of main themes (highly rated studies only) from the 'sudden onset' group (A) the following are identified:

- *Neurosurgeons sometimes over-state the degree of recovery and normal functioning in patients when comparison is made with patient and family members' own evaluations.
- *Users find information about their condition helps them to cope with medical procedures and to manage their health generally.
- *Users have difficulty accepting information from hospital staff at times of crisis. Users' families benefit from information as much as users themselves; users find that new information on their condition can lead to networking opportunities, that these are mutually beneficial and that they have changed their behaviour based on information received.
- *TBI patients report substantially higher levels of independent living in terms of participation and productivity than those with SCI. This may be because supported employment is offered routinely to the TBI population whereas those with SCI tend not to benefit.
- *Most users with polio are now older people (many post retirement). Many experienced very poor treatment from health and social care services as children, some appear to be psychologically damaged by these experiences, memories of which sometimes return.
- *Ageing with polio comprises two sets of experience – impairment effects may compound each other. Users found the physical consequences of impairment difficult to cope with – ageing made these worse.
- *As polio has been almost completely eradicated, users feel forgotten by services – especially from service planning and provision.
- *There is a general lack of professional understanding about polio – particularly from the medical profession. Post polio syndrome (PPS) was not well understood by doctors – some users are made to feel that they are hypochondriacs.
- *There is a general lack of specialist clinics for people with polio and problems with travelling to large hospital sites and lack of routine check ups for users.
- *Users report nurses post injury assist in getting 'back together as a person'
- *Adequate personal assistance is related to the ability to maintain good physical and mental health

- *Inadequate personal assistance leads to extended hospital stays, threats to safety, poor nutrition and poor personal hygiene. Individuals who rely on family alone found they suffer from burnout, family role change and economic strain.
- *Users experience problems obtaining sufficient personal assistance(PA). Lack of PA also creates difficulties in using and maintaining adaptive equipment.
- *Patients experience discomfort during group presentations on sensitive topics. There is generally insufficient information, and a direct, open style is preferred for giving information.
- *Patients would find written information about their medical condition useful to show to their GP who may not be acquainted with their medical status
- *Users need more information on fertility and parenthood
- *Users with the best health combine assistance by relatives with that given by unrelated persons
- *Pain management avenues are not always thoroughly explored
- *Cognitive Behaviour Therapy helps patients acquire new skills in controlling anxiety, controlling depressed mood, living as a person with sexual needs, coping with future problems, improving communication and assertion skills. It is recommended that CBT should be a standard component of rehabilitation for patients.
- *Service organisation and delivery is unlikely to improve unless service users (particularly those with atypical needs) are more actively engaged in shaping services

In respect of Group B, 'intermittent/unpredictable' conditions the main findings (highly rated studies only) are as follows:

- *Users want more information to be given on their condition and its management. Receptiveness to information is key to understanding.
- *Specialist nurses improve communication between patients and healthcare providers.
- *Epilepsy surgery is frequently effective in weaning patients off anti-epileptic drugs
- *Users want to work, drive, have independence, socialise and have freedom from drugs

- *The social and personal aims to accompany relief of epilepsy identified by patients are consistent with the literature on psychosocial adjustment to epilepsy
- *The majority of users rate services highly
- *Some studies note that the doctor's interpersonal style is influential in affecting patient satisfaction overall. This includes being approachable and accessible
- *Patient education should be seen as central to health professionals involved in epilepsy care
- *The negative impact on other family members is an area highlighted as needing more research
- Users want to see more effective communication from health care service providers
- Users want more information on side effects of medication and antiepileptic drug use in pregnancy
- There is a particular call for medical and health care staff to spend more time explaining diagnoses to patients
- Users voice support for specialist nurse run provision of services. These services appear to improve communication deficits experienced elsewhere in the system

In relation to Group C, 'progressive' conditions the main themes (highly rated studies only) are:

- *Users expressed a wish to have access to emotional support, counselling and/or psychotherapy. The few who had experienced psychotherapy had found this helpful. The emotional needs of their parents and siblings were often not recognised.
- *Experiences of the education training and employment systems varied. There were some reports of dissatisfaction with schools and discrimination in employment.
- *Professionals were insufficiently familiar with their particular condition. Most users were quite satisfied with their regular GP. Most cases of insensitive or unsatisfactory medical treatment relate to experiences in hospital.
- *Aging brings an increase in physical problems but few users visit their GP for regular checks and the majority had not seen a consultant or physiotherapist for at least five years. Users express anxiety about the future, particularly in relation to further physical deterioration.

- *Time taken to obtain home equipment and adaptations is often too long. Social work support is viewed favourably in around 50% of cases. Occupational Therapy (OT) received was satisfactory in around 60% of cases.
- *There are endemic tensions and creativity in multi-disciplinary working - these can have positive or negative effects on service users. There is a danger that the 'culture of professionalism' negates user views and 'listening to users' involves moving from reactive crises management to proactive crises prevention services.
- *If a concept of 'total care (social, emotional and psychological needs) is adopted there are 'glaring deficiencies' such as skilled counsellors, lack of support at crisis points and lack of coherence between professionals especially when creating a bridge between core medical needs and wider social needs.
- *Hospital staff have limited knowledge and skills in caring for people with CP. Basic care needs are not being adequately addressed during hospitalisation. Changes in nursing assessment, continuing education and discharge planning are recommended
- *Cerebral palsy related pain is under-treated in the adult population with CP. Despite the reported helpfulness of the pain interventions, however, most are only being used by a small amount of patients.
- *Users are concerned about the lack of knowledge and understanding of MND displayed by many medical professionals and by the general public. They also experience a lack of information about the diagnosis. This view is held by many patients within Motor Neurone Disease Association (MNDA) groups
- *Health professionals require advice and information from people with expertise such as MNDA advisers
- *Many patients are referred to non-neurological specialists, which they feel delays the diagnosis of MND.
- *Speedy diagnosis is essential for MND patients. Education of medical and health professionals to identify early symptoms of MND would enable patients to make the most of remaining time.
- *At diagnosis, there is a great need for sensitive handling (by the neurologist and other health professionals). Patients should have a relative or friend present when diagnosis is given
- *MNDA should continue influencing the education of GPs and other health and social care professionals about the early symptoms of MND and encourage early referral to neurologists, encouraging the latter to ensure that patients are not told the diagnosis alone, that professional counselling is available and influencing service providers to urgently supply grants for adaptations and equipment (especially the supply of wheelchairs)

- *Since MND is progressive, degenerative and rapid, patients require fast tracking for a number of aids and adaptations. Generally speaking, the ordering systems for equipment appear to fail people as the disease progresses faster than the items can be delivered.
- *Patients can deteriorate quickly, so their needs change quickly, while services are only able to react slowly
- * Continuity of care personnel; fast track referrals to paramedical personnel; equipment availability and timely delivery; having named key workers and palliative symptom management are important to users
- *Many GPs and hospital specialists were deficient in explanations to patients. District and night nurses were well regarded. Health visitors and social workers receive less approval.
- *Patients complain that they see a different doctor on every hospital visit and explaining matters to them was deficient in half of cases. Health professionals should allot more time to ensuring adequate explanations are provided. More graphic explanations of medical information is requested.
- *The MS Society believe much money could be saved if there was concerted action to ensure spending was focused to best effect, for example, the cost of in-patient admissions to treat MS attacks could be reduced significantly through continuity of care rather than crisis intervention. As MS services are 'fragmented', the role of co-ordinating health worker with specialist knowledge of the disease is 'critical'.
- *Patients who under thalamotomy for the intention tremor report mixed views on its success. Surgery reduces tremor in some patients but does not always translate into quality of life improvements.
- *Specialist nurses improve patients' lives but do not necessarily reduce the 'cost to the public purse of caring for MS patients'.
- *Users with MS are more likely to experience pain, the longer they have the disease.
- *A considerable proportion of users have problems with standard issue wheelchairs, including technical, propulsion and general discomfort issues.
- * Prolonging home care and postponing early institutionalisation is a high priority
- *Using patient self-report scales (patient perspective) can be useful in guiding the physical examination, in making comparisons from visit to visit and in assessing patient's quality of life and increasing patient satisfaction with medical care.
- *Users with MS wish to gain control over uncertainty, dependency and physical and emotional decline.

- *The diagnosis-giving process is often not handled well by GPs or specialists. Ongoing communication with professionals is similarly poor. Many users do not know about other available services such as respite care and that under-reporting of symptoms (especially depression) is common.
- *Users report high dissatisfaction with peri-operative management with 94 per cent complaining of confusion or worsening of their condition post-operatively and that medical administration problems are common.
- * Mobility issues; falls; work-related problems; problems in household management, social isolation and limited leisure; difficulty taking holidays, financial problems, premature retirement from work leading to reduced income; more health-related costs, depression, loss of control, speech difficulties and cognitive impairment are all important to users
- * Provision of PD nurse specialist (PDNS) compared with the consultant cannot be recommended solely on cost-effectiveness grounds because of similar outcomes but increased costs with PDNS providing additional care. However, patient and carers feel PDNS make particular contributions to their care.

References

- Andrewes, D., Camp, K., Kilpatrick, C., & Cook, M. 1999, "The assessment and treatment of concerns and anxiety in patients undergoing presurgical monitoring for epilepsy", *Epilepsia*, vol. 40, no. 11, pp. 1535-1542.
Ref ID: 49
- Aronson, K. J., Cleghorn, G., & Goldenberg, E. 1996, "Assistance arrangements and use of services among persons with multiple sclerosis and their caregivers", *Disability & Rehabilitation*, vol. 18, no. 7, pp. 354-361.
Ref ID: 188
- Averis, A. K. 1996, "Patients' opinions: having a say in epilepsy service provision down under", *Seizure*, vol. 5, no. 1, pp. 57-61.
Ref ID: 117
- Bamford, D., Griffiths, H., Long, S., & Kernohan, G. 1997, "Analysis of consumer satisfaction in cerebral palsy care", *Journal of Interprofessional Care*, vol. 11, no. 2, pp. 187-193.
Ref ID: 147
- Bamford, D., Griffiths, H., & Kernohan, G. 1997, "On Patient Satisfaction in Cerebral Palsy Care", *British Journal of Social Work*, vol. 27, no. 4, pp. 605-614.
Ref ID: 148
- Banja, J. & Johnston, M. V. 1994, "Outcomes Evaluation in TBI Rehabilitation part 3. Ethical Perspectives and Social Policy", *Archives of Physical Medicine and Rehabilitation*, vol. 75, no. 12, p. SC19-SC26.
Ref ID: 65
- Barber, M., Stewart, D., Grosset, D., & MacPhee, G. 2001, "Patient and carer perception of the management of Parkinson's disease after surgery [2]", *Age & Ageing*, vol. 30, no. 2, pp. 171-172.
Ref ID: 196
- Barnes, M. P. & Skeil, D. A. 1996, "Outpatients in neurological rehabilitation", *International Journal of Rehabilitation Research*, vol. 19, no. 1, pp. 39-45.
Ref ID: 45
- Baylis, T. 1995, *Motor Neurone Disease: A Patients Perspective* MNDA, London.
Ref ID: 68
- Begum, N. 1996, "General Practitioners' role in shaping Disabled Women's Lives," in *Exploring the Divide*, C. Barnes & G. Mercer, eds., The Disability Press, Leeds.
Ref ID: 4
- Bennion, E. 2002, "Commentary: The freedom of informed choice", *British Medical Journal*, vol. 325, p. 1169.
Ref ID: 192
- Berk, C., Carr, J., Sinden, M., Martzke, J., & Honey, C. R. 2002, "Thalamic deep brain stimulation for the treatment of tremor due to multiple sclerosis: a prospective study of tremor and quality of life", *Journal of Neurosurgery*, vol. 97, no. 4, pp. 815-820.
Ref ID: 82
- Bewley, C. & Glendinning, C. 1994, "Representing the views of disabled people in community care planning", *Disability & Society*, vol. 9, no. 3, pp. 301-314.
Ref ID: 34
- Birleson, A. 2001, *An Evaluation of Service Need and Availability for the Younger Person with Parkinson's Disease* Institute of Rehabilitation, Newcastle upon Tyne.
Ref ID: 133

- Bloch, S. 2001, "Communication and MND: A few professional reflections", *Thumb Print*, Autumn 2001.
Ref ID: 57
- Bradley, P., Burns, C., Johnson, L., Williams, A., Ray, D., & Burston, L. 1999, "A general practice-based audit of epilepsy care: do primary and secondary care deliver appropriate services for patients?", *Journal of Clinical Governance*, vol. 7, no. 3, pp. 130-135.
Ref ID: 223
- Brown, J., Lattimer, V., & and Tudbal, T. 2003, *Provision of care in Motor Neurone Disease: An Investigation in Hampshire, Dorset and Wiltshire*. University of Southampton, Southampton.
Ref ID: 47
- Buchanan, K. M., Elias, L. J., & Goplen, G. B. 2000, "Differing perspectives on outcome after subarachnoid hemorrhage: The patient, the relative, the neurosurgeon", *Neurosurgery*, vol. 46, no. 4, pp. 831-838.
Ref ID: 30
- Buck, D., Jacoby, A., Baker, G. A., Graham-Jones, S., & Chadwick, D. W. 1996, "Patients' experiences of and satisfaction with care for their epilepsy", *Epilepsia*, vol. 37, no. 9, pp. 841-849.
Ref ID: 53
- Buzio, A., Morgan, J., & Blount, D. 2002, "The experiences of adults with cerebral palsy during periods of hospitalisation", *Australian Journal of Advanced Nursing*, vol. 19, no. 4, pp. 8-14.
Ref ID: 121
- Campion, K. & Cole, A. 1997, "Multiple sclerosis: professional issues", *Nursing Times*, vol. 93, no. 12, pp. 57-62.
Ref ID: 219
- Carrillo, E. H., Gonzalez, J. K., Chacon, P. M., Kirton, O. C., & Byers, P. M. 1998, "Spinal cord injuries in adolescents after gunshot wounds: an increasing phenomenon in urban North America", *Injury - International Journal of the Care of the Injured*, vol. 29, no. 7, pp. 503-507.
Ref ID: 66
- Carus, R. 1980, "Motor neurone disease: a demeaning illness", *British Medical Journal*, vol. 280, no. 6212, pp. 455-456.
Ref ID: 74
- Chaplin, J. E., Wester, A., & Tomson, T. 1998, "The perceived rehabilitation needs of a hospital-based outpatient sample of people with epilepsy", *Seizure*, vol. 7, no. 4, pp. 329-335.
Ref ID: 109
- Chappell, B. & Smithson, W. H. 1998, "Patient views on primary care services for epilepsy and areas where additional professional knowledge would be welcome", *Seizure*, vol. 7, no. 6, pp. 447-457.
Ref ID: 108
- Chesson, R., Cockhead, D., & Romney-Alexander, D. 1999, "Quality of life with Parkinson's disease: views of Scottish consumers and providers," in *Parkinson's Disease: Studies in Psychological and Social Care*, R. Percival & P. Hobson, eds., British Psychological Society, Leicester.
Ref ID: 134

- Clark, L. 2002, *Liverpool Central Primary Care Trust Accessible Health Information: Project Report* Liverpool Central Primary Care Trust, Liverpool.
Ref ID: 5
- Cochrane, J. 1995, "Patient education-lessons from epilepsy", *Patient Education and Counseling*, vol. 26, no. 1-3, pp. 25-31.
Ref ID: 54
- Connections 2000, "Acupuncture and MS - The Patient's view", *Connections*, vol. 36, no. Spring-Summer, pp. 37-38.
Ref ID: 237
- Couldridge, L., Kendall, S., & March, A. 2001, "A systematic overview--a decade of research. The information and counseling needs of people with epilepsy.", *Seizure*, vol. 10, no. 8, pp. 605-614.
Ref ID: 102
- Craig, A. & Hancock, K. 1994, "Difficulties in Implementing Group Cognitive-Behavior Therapy for spinal cord injured persons - a clinical discussion", *Australian Psychologist*, vol. 29, no. 2, pp. 98-102.
Ref ID: 70
- Crischilles, E. A., Rubenstein, L. M., Voelker, M. D., Wallace, R. B., & Rodnitzky, R. L. 1998, "The health burdens of Parkinson's disease", *Movement Disorders*, vol. 13, no. 3, pp. 406-413.
Ref ID: 75
- Critchley, G. R. & Richardson, P. L. 1998, "Vim thalamotomy for the relief of the intention tremor of multiple sclerosis", *British Journal of Neurosurgery*, vol. 12, no. 6, pp. 559-562.
Ref ID: 185
- Cusick, C. P., Brooks, C. A., & Whiteneck, G. G. 2001, "The use of proxies in community integration research", *Archives of Physical Medicine and Rehabilitation*, vol. 82, no. 8, pp. 1018-1024.
Ref ID: 39
- Darragh, A. R., Sample, P. L., & Krieger, S. R. 2001, "'Tears in my eyes 'cause somebody finally understood': client perceptions of practitioners following brain injury", *American Journal of Occupational Therapy*, vol. 55, no. 2, pp. 191-199.
Ref ID: 95
- Darrah, J., Magil-Evans, J., & Adkins, R. 2002, "How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery", *Disability & Rehabilitation*, vol. 24, no. 10, pp. 542-549.
Ref ID: 122
- Dilorio, C. & Manteuffel, B. 1995, "Preferences concerning epilepsy education: opinions of nurses, physicians, and persons with epilepsy", *Journal of Neuroscience Nursing*, vol. 27, no. 1, pp. 29-34.
Ref ID: 118
- Dunk, J. & Swales, T. 2000, "Multiple sclerosis: a fast-track service", *Nursing Times*, vol. 96, no. 25, pp. 35-36.
Ref ID: 85
- Ellis, N., Upton, D., & Thompson, P. 2000, "Epilepsy and the family: a review of current literature", *Seizure*, vol. 9, no. 1, pp. 22-30.
Ref ID: 48

- Engel, J. M., Kartin, D., & Jensen, M. P. 2002, "Pain treatment in persons with cerebral palsy: frequency and helpfulness", *American Journal of Physical Medicine & Rehabilitation*, vol. 81, no. 4, pp. 291-296.
Ref ID: 123
- Essex Coalition of Disabled people & SCOPE 2003, *The Good Practice Guide for support workers and personal assistants working with disabled people with communications impairments*.
Ref ID: 138
- Fisher, R. S., Vickrey, B. G., Hermann, B., Penovich, P., Scherer, A., & Walker, S. 2000, "The impact of epilepsy from the patient's perspective II: Views about therapy and health care", *Epilepsy Research*, vol. 41, no. 1, pp. 53-61.
Ref ID: 162
- Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., & Beecham, J. 2002, "The Quality of Life of People 12 Years after Resettlement from Long Stay Hospitals: user's views on their living environment, daily activities and future aspirations", *Disability & Society*, vol. 17, no. 7, pp. 741-758.
Ref ID: 19
- Frieden, L., Smith, L., Wilkinson, W., Redd, L., & Smith, Q. 1998, "Spinal cord injury and managed care: A consumer viewpoint", *Topics in Spinal Cord Injury Rehabilitation*, vol. 3, no. 4, pp. 80-88.
Ref ID: 205
- Goldstein, L. H., Pender, N., Parshall, A. M., & Fenwick, P. B. 1997, "Patients' and referring doctors' perceptions of treatment on an in-patient neuropsychiatry/epilepsy unit: a study of three cohorts", *Seizure*, vol. 6, no. 1, pp. 13-20.
Ref ID: 111
- Goldstein, L. H., Minchin, L., Stubbs, P., & Fenwick, P. B. 1997, "Are what people know about their epilepsy and what they want from an epilepsy service related?", *Seizure*, vol. 6, no. 6, pp. 435-442.
Ref ID: 110
- Goldstein, L. H., Adamson, M., Jeffrey, L., Down, K., Barby, T., Wilson, C., & Leigh, P. N. 1998, "The psychological impact of MND on patients and carers", *Journal of the Neurological Sciences*, vol. 160, no. Supplement 1, pp. 114-121.
Ref ID: 152
- Gordon, P. A., Winter, R., Feldman, D., & Dimick, K. 1996, "Group Work for Persons with Multiple Sclerosis", *Journal for Specialists in Group Work*, vol. 21, no. 4, pp. 243-251.
Ref ID: 13
- Gottberg, K., Einarsson, U., Fredrikson, S., von Koch, L., & Holmqvist, L. W. 2002, "Multiple sclerosis in Stockholm County. A pilot study of utilization of health-care resources, patient satisfaction with care and impact on family caregivers", *Acta Neurologica Scandinavica*, vol. 106, no. 5, pp. 241-247.
Ref ID: 81
- Guldvog, B. 1994, "Patient satisfaction and epilepsy surgery", *Epilepsia*, vol. 35, no. 3, pp. 579-584.
Ref ID: 119
- Gulick, E. E., Cook, S. D., & Troiano, R. 1993, "Comparison of patient and staff assessment of MS patients' health status", *Acta Neurologica Scandinavica*, vol. 88, no. 2, pp. 87-93.
Ref ID: 190

- Harker, W. F., Dawson, D. R., Boschen, K. A., & Stuss, D. T. 2002, "A comparison of independent living outcomes following traumatic brain injury and spinal cord injury", *International Journal of Rehabilitation Research*, vol. 25: no. 2, pp. 93-102.
Ref ID: 211
- Hogan, B. A. 1999, "Narrative therapy in rehabilitation after brain injury: a case study", *Neurorehabilitation*, vol. 13, no. 1, pp. 21-25.
Ref ID: 61
- Howard, R. S. & Orrell, R. W. 2002, "Management of motor neurone disease", *Postgraduate Medicine Journal*, vol. 78, no. 926, pp. 736-741.
Ref ID: 63
- Howarth, A. L. 2000, "Pain management for multiple sclerosis patients", *Professional Nurse*, vol. 16, no. 1, pp. 824-826.
Ref ID: 87
- Hubert, J. 1995, *Life After Head Injury* Ashgate, Aldershot.
Ref ID: 32
- Irish Neurological Alliance 2000, *Standards of Care for People with Disabling (Progressive and Static) Neurological Conditions in the Hospital and Community*.
Ref ID: 1
- Jain, P., Patterson, V. H., & Morrow, J. I. 1993, "What people with epilepsy want from a hospital clinic", *Seizure*, vol. 2, no. 1, pp. 75-78.
Ref ID: 120
- Jenkinson, C., Fitzpatrick, R., & Peto, V. 1999, "Health-related quality of life measurement in patients with Parkinson's disease", *Pharmacoeconomics*, vol. 15, no. 2, pp. 157-165.
Ref ID: 73
- Johnson, L. 1995, *Getting the message: users' and carers' experiences of community care in Leeds* Leeds Community Health Council, Leeds.
Ref ID: 28
- Johnston, M., Earll, L., Mitchell, E., Morrison, V., & Wright, S. 1996, "Communicating the diagnosis of motor neurone disease", *Palliative Medicine*, vol. 10, no. 1, pp. 23-34.
Ref ID: 154
- Jones, R., D'eath, C., Harnsford, J., Hutchinson, H., Hyde, L., Thurlow, L., & Spanton, L. 1999, "The needs of people with Parkinson's disease and their families: The Parkinson's Disease study, Devon and Cornwall, 1989-92," in *Parkinson's Disease: Studies in Psychological and Social Care*, R. Percival & P. Hobson, eds., pp. 60-78.
Ref ID: 136
- Jongbloed, L. 1998, "Disability income: The experiences of women with multiple sclerosis", *Canadian Journal of Occupational Therapy*, vol. 65, no. 4, pp. 193-201.
Ref ID: 186
- Kilgore, K. L., Scherer, M., Bobblitt, R., Dettloff, J., Dombrowski, D. M., Godbold, N., Jatich, J. W., Morris, R., Penko, J. S., Schremp, E. S., & Cash, L. A. 2001, "Neuroprosthesis consumers' forum: consumer priorities for research directions", *Journal of Rehabilitation Research & Development*, vol. 38, no. 6, pp. 655-660.
Ref ID: 124
- Kittel, A., Di Marco, A., & Stewart, H. 2002, "Factors influencing the decision to abandon manual wheelchairs for three individuals with a spinal cord injury", *Disability & Rehabilitation*, vol. 24: no. 1/3, pp. 106-114.
Ref ID: 226

- Kolakowsky-Hayner, S. A., Kreutzer, J. S., & Miner, K. D. 2000, "Validation of the service obstacles scale for the traumatic brain injury population", *Neurorehabilitation*, vol. 14: no. 3, pp. 151-158.
Ref ID: 149
- Lacroix, A., Jacquemet, S., & Assal, J. P. 1995, "Patients' experiences with their disease: learning from the differences and sharing the common problems", *Patient Education & Counseling*, vol. 26, no. 1-3, pp. 301-312.
Ref ID: 92
- Lamb, B. & Layzell, S. 1994, *Disabled in Britain: A World Apart* SCOPE, London.
Ref ID: 140
- Lamb, B. & Layzell, S. 1995, *Disabled in Britain: Counting on Community Care* SCOPE, London.
Ref ID: 141
- Lunaigh, P. O. 2002, "Views held by service users and colleagues of health visitor provision", *Community Practitioner*, vol. 75, no. 4, pp. 139-141.
Ref ID: 24
- Lucke, K. T. 1999, "Outcomes of nurse caring as perceived by individuals with spinal cord injury during rehabilitation", *Rehabilitation Nursing*, vol. 24, no. 6, pp. 247-253.
Ref ID: 126
- Makepeace, R. W., Barnes, M. P., Semlyen, J. K., & Stevenson, J. 2001, "The establishment of a community multiple sclerosis team", *International Journal of Rehabilitation Research*, vol. 24: no. 2, pp. 137-141.
Ref ID: 214
- McAlonan, S. 1996, "Improving sexual rehabilitation services: the patient's perspective", *American Journal of Occupational Therapy*, vol. 50, no. 10, pp. 826-834.
Ref ID: 128
- McLaughlin, J. & Zeeberg, I. 1993, "Self-Care and Multiple Sclerosis: A View from Two Cultures", *Social Science and Medicine*, vol. 37, no. 3, pp. 315-329.
Ref ID: 14
- Mercer, B. S. 1996, "A Randomized Study of the Efficacy of the PROPATH Program for Patients with Parkinson Disease", *Archives of Neurology*, vol. 53, no. 9, pp. 881-884.
Ref ID: 130
- Miller, C. & Jezewski, M. A. 2001, "A phenomenologic assessment of relapsing MS patients' experiences during treatment with interferon beta-1a", *Journal of Neuroscience Nursing*, vol. 33, no. 5, pp. 240-244.
Ref ID: 83
- Mills, N., Bachmann, M. O., Campbell, R., Hine, I., & McGowan, M. 1999, "Effect of a primary care based epilepsy specialist nurse service on quality of care from the patients' perspective: results at two-years follow-up", *Seizure*, vol. 8, no. 5, pp. 291-296.
Ref ID: 105
- Mills, N., Campbell, R., & Bachmann, M. O. 2002, "What do patients want and get from a primary care epilepsy specialist nurse service?", *Seizure*, vol. 11, no. 3, pp. 176-183.
Ref ID: 101
- MNDA 2001, *Tracking Survey 2001* MNDA, London.
Ref ID: 77

- MNDA 2002, *The Motor Neurone Disease Association's Survey of Occupational Therapists* MNDA, London.
Ref ID: 76
- MNDA 2002, *Report on the survey of views and experiences of people with motor neurone disease* MNDA, London.
Ref ID: 78
- Mohr, D. C., Dick, L. P., Russo, D., Likosky, W., Pinn, J., Boudewyn, A. C., & Goodkin, D. E. 1999, "The psychosocial impact of multiple sclerosis: Exploring the patient's perspective", *Health Psychology*, vol. 18, no. 4, pp. 376-382.
Ref ID: 42
- Mohr, D. C., Boudewyn, A. C., Likosky, W., Levine, E., & Goodkin, D. E. 2001, "Injectable medication for the treatment of multiple sclerosis: The influence of self-efficacy expectations and injection anxiety on adherence and ability to self-inject", *Annals of Behavioral Medicine*, vol. 23, no. 2, pp. 125-132.
Ref ID: 40
- Mukai, M., Uchimura, N., Takeuchi, N., Kuwahara, H., Hashizume, Y., Nose, I., Satomura, T., Tanaka, J., & Maeda, H. 2001, "Study on withdrawal of hypnotics: Questionnaire on hypnotic use and its withdrawal", *Psychiatry & Clinical Neurosciences*, vol. 55, no. 3, pp. 209-210.
Ref ID: 159
- Multiple Sclerosis Society 2001, *Understanding Social Services: Getting the best for people with multiple sclerosis: A briefing for MS Society Regions and Branches in England and Wales* Multiple Sclerosis Society, London.
Ref ID: 132
- Multiple Sclerosis Society undated, *'Square pegs round holes': Does the system deliver for people with changing or hidden disability?* Multiple Sclerosis Society, London.
Ref ID: 131
- Murphy, D. & Reid, D. B. 2001, "Pain treatment satisfaction in spinal cord injury", *Spinal Cord*, vol. 39, no. 1, pp. 44-46.
Ref ID: 125
- Neurological Alliance of Ireland 2001, *Standards of Care for People with Non-Physically Disabling Neurological (and Associated Psychiatric) Conditions*.
Ref ID: 2
- Niemeier, J. P. & Burnett, D. M. 2001, "No such thing as 'uncomplicated bereavement' for patients in rehabilitation", *Disability and Rehabilitation*, vol. 23, no. 15, pp. 645-653.
Ref ID: 38
- Northern and Yorkshire Regional Council of Community Health Councils 1995, *Survey of spinal cord injured patients treated at Pinderfields Hospital and discharged into their local community: Summary Report and Recommendations of the Regional Council*.
Ref ID: 51
- Nosek, M. A. 1993, "Personal assistance: its effect on the long-term health of a rehabilitation hospital population", *Archives of Physical Medicine & Rehabilitation*, vol. 74, no. 2, pp. 127-132.
Ref ID: 129
- Nursing Times 2000, "Patients dissatisfied with continence services... multiple sclerosis", *Nursing Times*, vol. 96, no. 25, pp. 12-13.
Ref ID: 217

- O'Day, B., Palsbo, S. E., Dhont, K., & Scheer, J. 2002, "Health plan selection criteria by people with impaired mobility.[comment]", *Medical Care*, vol. 40, no. 9, pp. 732-742.
Ref ID: 98
- O'Callaghan, C. C. 1996, "Lyrical themes in songs written by palliative care patients", *Journal of Music Therapy*, vol. 33, no. 2, pp. 74-92.
Ref ID: 44
- Oliver, D. 2000, "Hospices - a lifeline to normality", *Thumb Print*, Summer 2000, p. 6.
Ref ID: 59
- Osust, T. T. 1999, "Case management: dealing with spinal cord injury", *Topics in Spinal Cord Injury Rehabilitation*, vol. 4, no. 4, pp. 6-9.
Ref ID: 228
- Parkinson's Disease Society 2002, *Parkinson's disease and Hospital Stays*
Parkinson's Disease Society, London.
Ref ID: 89
- Parkinson's Disease Society 2002, *Secondary Care and Medication: Involving the User*
Parkinson's Disease Society, London.
Ref ID: 114
- Pegg, R. 1992, "I am a being, not an illness", *Therapy Weekly*, August 13, p. 4.
Ref ID: 52
- Perks, B. A., Mackintosh, R., Stewart C.P.U., & BARDSLEY, G. I. 1994, "A survey of marginal wheelchair users", *Journal of Rehabilitation Research and Development*, vol. 31, no. 4, pp. 297-302.
Ref ID: 46
- Peters, A. V. 1994, "Traumatic brain injury information database: a user survey", *Bulletin of the Medical Library Association*, vol. 82, no. 2, pp. 153-159.
Ref ID: 97
- Poole, K., Moran, N., Bell, G., Solomon, J., Kendall, S., McCarthy, M., McCormick, D., Nashef, L., Johnson, A., Sander, J., & Shorvon, S. 2000, "Patients' perspectives on services for epilepsy: a survey of patient satisfaction, preferences and information provision in 2394 people with epilepsy", *Seizure*, vol. 9, no. 8, pp. 551-558.
Ref ID: 103
- Pooley, C. G., Gerrard, C., Hollis, S., Morton, S., & Astbury, J. 2001, "'Oh it's a wonderful practice...you can talk to them': a qualitative study of patients' and health professionals' views on the management of type 2 diabetes", *Health & Social Care in the Community*, vol. 9, no. 5, pp. 318-326.
Ref ID: 21
- Post, M. W., van Asbeck, F. W., van Dijk, A. J., & Schrijvers, A. J. 1997, "Services for spinal cord injured: availability and satisfaction", *Spinal Cord*, vol. 35, no. 2, pp. 109-115.
Ref ID: 127
- Preston-Shoot, M. 2001, "A Triumph of Hope over Experience? Modernizing Accountability: The Case of Complaints Procedures in Community Care", *Social Policy & Administration*, vol. 35, no. 6, pp. 701-715.
Ref ID: 20
- Prigatano, G. P. 2000, "Neuropsychology, the patient's experience, and the political forces within our field", *Archives of Clinical Neuropsychology*, vol. 15, no. 1, pp. 71-82.
Ref ID: 31

- Raty, L., Hamrin, E., & Soderfeldt, B. 1999, "Quality of life in newly-debuted epilepsy. An empirical study", *Acta Neurologica Scandinavica*, vol. 100, no. 4, pp. 221-226.
Ref ID: 50
- Rea, C. A. & Rea, D. M. 2000, "Responding to user views of service performance", *Journal of Mental Health*, vol. 9, no. 4, pp. 351-363.
Ref ID: 15
- Reynolds, H., Wilson-Barnett, J., & Richardson, G. 2000, "Evaluation of the role of the Parkinson's disease nurse specialist", *International Journal of Nursing Studies*, vol. 37, no. 4, pp. 337-349.
Ref ID: 90
- Richman, J. A., Jason, L. A., Taylor, R. R., & Jahn, S. C. 2000, "Feminist Perspectives on the Social Construction of Chronic Fatigue Syndrome", *Health Care for Women International*, vol. 21, no. 3, pp. 173-185.
Ref ID: 9
- Ridsdale, L., Robins, D., Fitzgerald, A., Jeffery, S., & McGee, L. 1996, "Epilepsy monitoring and advice recorded: general practitioners' views, current practice and patients' preferences", *British Journal of General Practice*, vol. 46, no. 402, pp. 11-14.
Ref ID: 115
- Ridsdale, L., Morgan, M., & O'Connor, C. 1999, "Promoting self-care in epilepsy: the views of patients on the advice they had received from specialists, family doctors and an epilepsy nurse", *Patient Education & Counseling*, vol. 37, no. 1, pp. 43-47.
Ref ID: 107
- Ridsdale, L. 2000, "The effect of specially trained epilepsy nurses in primary care: a review.", *Seizure*, vol. 9, no. 1, pp. 43-46.
Ref ID: 104
- Rosenthal, M. 1996, "1995 Sheldon Berrol, MD senior lectureship: The ethics and efficacy of traumatic brain injury rehabilitation-myths, measurements, and meaning", *Journal of Head Trauma Rehabilitation*, vol. 11, no. 4, pp. 88-95.
Ref ID: 62
- Rubenstein, L. M., Voelker, M. D., Chrischilles, E. A., Glenn, D. C., Wallace, R. B., & Rodnitzky, R. L. 1999, "The usefulness of the functional status questionnaire (FSQ) and the medical outcomes study short form (SF-36) in Parkinson's disease research", *Mature Medicine Canada*, vol. 2, no. 1, pp. 44-48.
Ref ID: 197
- Rumrill, P. D., Jr., Roessler, R. T., & Koch, L. C. 1999, "Surveying the employment concerns of people with multiple sclerosis: A participatory action research approach", *Journal of Vocational Rehabilitation*, vol. 12, no. 2, pp. 75-82.
Ref ID: 184
- Ryan, M., Johnson, M. S., Dalmady-Israel, C., & Kaiser, J. M. 2002, "Use of alternative medications in patients with neurologic disorders", *Annals of Pharmacotherapy*, vol. 36, no. 10, pp. 1540-1545.
Ref ID: 194
- Sample, P. L. & Darragh, A. R. 1998, "Perceptions of care access: the experience of rural and urban women following brain injury", *Brain Injury*, vol. 12, no. 10, pp. 855-874.
Ref ID: 96

- Scambler, A., Scambler, G., Ridsdale, L., & Robins, D. 1996, "Towards an evaluation of the effectiveness of an epilepsy nurse in primary care", *Seizure*, vol. 5, no. 4, pp. 255-258.
Ref ID: 112
- Scrimgeour, E. M. & Barnes, J. A. 2001, "How do multiple sclerosis patients in Lanarkshire rate health professionals and hospitals?", *Health Bulletin*, vol. 59: no. 3, pp. 155-157.
Ref ID: 215
- Segar, J. & Abati, F. G. 1994, "Negotiating illness-disability grants and the treatment of epilepsy", *Medical Anthropology Quarterly*, vol. 8, no. 3, pp. 282-298.
Ref ID: 56
- Shah, S. & Priestley, M. 2001, *Better Services, Better Health: The healthcare experiences of Black and minority ethnic disabled people* Leeds Involvement Project, Leeds.
Ref ID: 3
- Siderowf, A., Ravina, B., & Glick, H. A. 2002, "Preference-based quality-of-life in patients with Parkinson's disease", *Neurology*, vol. 59: no. 1, pp. 103-108.
Ref ID: 224
- Solas, J. 1995, "Recovering and reconstructing the client's story in social work", *Australian Social Work*, vol. 48, no. 3, pp. 33-36.
Ref ID: 23
- Somerset, M., Campbell, R., Sharp, D. J., & Peters, T. J. 2001, "What do people with MS want and expect from health-care services?", *Health Expectations*, vol. 4, no. 1, pp. 29-37.
Ref ID: 84
- Sparber, A. & Wootton, J. C. 2002, "Surveys of complementary and alternative medicine: Part V. Use of alternative and complementary therapies for psychiatric and neurologic diseases", *Journal of Alternative & Complementary Medicine*, vol. 8, no. 1, pp. 93-96.
Ref ID: 182
- Stiens, S. A., Bergman, B. S., & Formal, C. S. 1997, "Spinal cord injury rehabilitation. 4. Individual experience, personal adaptation and social perspective", *Archives of Physical Medicine & Rehabilitation*, vol. 78, no. 3, p. s65-s72.
Ref ID: 67
- Taylor, D. C., McMackin, D., Staunton, H., Delanty, N., & Phillips, J. 2001, "Patients' aims for epilepsy surgery: Desires beyond seizure freedom", *Epilepsia*, vol. 42, no. 5, pp. 629-633.
Ref ID: 160
- Thumb Print 2002, "Physiotherapy", *Thumb Print*, vol. Winter 2002-2003, pp. 6-7.
Ref ID: 60
- Trail, M., Nelson, N., Van, J. N., Appel, S. H., & Lai, E. C. 2001, "Wheelchair use by patients with amyotrophic lateral sclerosis: A survey of user characteristics and selection preferences", *Archives of Physical Medicine & Rehabilitation*, vol. 82, no. 1, pp. 98-102.
Ref ID: 151
- Trend, P., Kaye, J., Gage, H., Owen, C., & Wade, D. 2002, "Short-term effectiveness of intensive multidisciplinary rehabilitation for people with Parkinson's disease and their carers", *Clinical Rehabilitation*, vol. 16, no. 7, pp. 717-725.
Ref ID: 193

- Upton, D., Thompson, P. J., & Duncan, J. S. 1996, "Patient satisfaction with specialized epilepsy assessment and treatment", *Seizure*, vol. 5, no. 3, pp. 195-198.
Ref ID: 113
- Vaidyanathan, S., Glass, C. A., Soni, B. M., Bingley, J., Singh, G., Watt, J. W. H., & Sett, P. 2001, "Doctor - Patient Communication: Do people with spinal cord injury wish to receive written information about their medical condition from the physicians after an outpatient visit or after a readmission in the spinal unit?", *Spinal Cord*, vol. 39, no. 12, pp. 650-653.
Ref ID: 201
- van Teijlingen, E. R., Friend, E., & Kamal, A. D. 2001, "Service use and needs of people with motor neurone disease and their carers in Scotland", *Health & Social Care in the Community*, vol. 9, no. 6, pp. 397-403.
Ref ID: 80
- Vickrey, B. G., Edmonds, Z. V., Shatin, D., Shapiro, M. F., Delrahim, S., Belin, T. R., Ellison, G. W., & Myers, L. W. 1999, "General neurologist and sub specialist care for multiple sclerosis: Patients' perceptions", *Neurology*, vol. 53, no. 6, pp. 1190-1197.
Ref ID: 183
- Wallace, H. K. & Solomon, J. K. 1999, "Quality of epilepsy treatment and services: the views of women with epilepsy", *Seizure*, vol. 8, no. 2, pp. 81-87.
Ref ID: 106
- Wass, C. T., Rajala, M. M., Hughes, J. M., Sharbrough, F. W., Offord, K. P., Rademacher, D. M., & Lanier, W. L. 1996, "Long-term follow-up of patients treated surgically for medically intractable epilepsy: Results in 291 patients treated at Mayo Clinic Rochester between July 1972 and March 1985", *Mayo Clinic Proceedings*, vol. 71, no. 11, pp. 1105-1113.
Ref ID: 171
- Wenneberg, S. & Ahlstrom, G. 2000, "Illness narratives of persons with post-polio syndrome", *Journal of Advanced Nursing*, vol. 31, no. 2, pp. 354-361.
Ref ID: 145
- Willen, C. & Scherman, M. H. 2002, "Group training in a pool causes ripples on the water: experiences by persons with late effects of polio", *Journal of Rehabilitation Medicine*, vol. 34, no. 4, pp. 191-197.
Ref ID: 99
- Williams, R., Barrett, K., & Muth, Z. 1996, "Service Users' and Carers' Views," in *Mental Health Services. An NHS Health Advisory Service Thematic Review*, R. Williams, K. Barrett, & Z. Muth, eds..
Ref ID: 100
- Williamson, C. 2001, "What does involving consumers in research mean?", *Qjm: Monthly Journal of the Association of Physicians*, vol. 94, no. 12, pp. 661-664.
Ref ID: 195
- Williamson, V. K. & Henfrey, D. 1996, "Patient participation in medical audit in primary care", *Social Sciences in Health: International Journal of Research & Practice*, vol. 2, no. 2, pp. 67-79.
Ref ID: 222
- Willner, L. & Dunning, D. 1993, *Ageing with Cerebral Palsy* SCOPE, London.
Ref ID: 16

Wilson, F. C., Harpur, J., Watson, T., & Morrow, J. I. 2002, "Vegetative state and minimally responsive patients - Regional survey, long-term case outcomes and service recommendations", *Neurorehabilitation*, vol. 17, no. 3, pp. 231-236.

Ref ID: 58

Yarrow, S. 1999, *Survey of Members of the Parkinson's Disease Society* Parkinsons Disease Society/Policy Studies Institute, London.

Ref ID: 143

Zarb, G. 1992, *Ageing with Parkinson's Disease* University of Greenwich, London.

Ref ID: 8

Zarb, G. 1992, *Ageing with Multiple Sclerosis* University of Greenwich, London.

Ref ID: 7

Zarb, G. 1992, *Ageing with Polio* University of Greenwich, London.

Ref ID: 6