

Involving users in shaping motor neurone disease services



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Involving users in shaping motor neurone disease services

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Introduction

User involvement in the planning, development and delivery of health and social care services is becoming increasingly common practice, but the meaningful involvement of people affected by motor neurone disease (MND) is likely to pose particular challenges. With the BUILD project, we were interested in finding out whether users would want to be in touch with others in a similar position, share their views and experiences of services, and together bring about service change, or whether this would be experienced as a burdensome demand.

Within the scope of a one-year project we combined two rather different approaches. We started with a series of research interviews using qualitative methods. Capturing the themes and issues emerging from this research, the second part of the project adopted a community development approach to explore the possibility of involving people with MND, their carers and family members through a local user group, a local network and the establishment of a virtual group through a website-based forum.

Throughout the life of the project, our methods altered in response to participants' views, their levels of engagement and the logistical challenges we encountered. We were aware of the limitations which MND was imposing on their time and energy. By seeking their involvement with us we were also aware of their need to balance priorities which could include organising complex packages of care and support.

Many of the users who participated in the project talked about their experiences of living with increasing disability and the emotional impact of a shortened life but, despite these enormous challenges, our meetings with users were defined more by their emotional generosity and laughter than any sense of tragedy. We hope that our report has succeeded in conveying this.

Executive summary

BUILD (Building User Involvement in MND) was a one-year project exploring how people with MND and their families could be involved in planning and monitoring the delivery of the health and social care services they were using.

Background to the project

- The catalyst for BUILD was the study of user involvement and terminal care by Small and Rhodes (2000) which highlighted the challenges for people with a rapidly progressive illness, speech and mobility difficulties and a relatively low incidence.
- People with MND often need to use a range of different services, but may experience a lack of effective multidisciplinary teamwork and flexible, responsive provision.
- Recently introduced policy and legislation require health and social care services to develop user involvement strategies that include people with MND.

Overview of the project

- BUILD used community development strategies to develop user involvement and empower people affected by MND.
- The project was based in an NHS specialist MND Care and Research Centre which had a positive approach to user involvement.
- The main project activities were: qualitative research interviews with people with MND, their informal carers and relevant professionals; the development of a local user group and a local user network; and an internet-based forum (a 'virtual group').
- Participants in the research interviews, local group and network lived in three South London boroughs with high levels of social deprivation and a substantial population drawn from black and minority ethnic communities.
- BUILD used two approaches to capturing the learning from the project: a qualitative approach to the research interviews; and audio recordings and field notes for the community development work with the local group, local network and virtual forum.

Project activities

- People with MND, their carers and health and social care professionals working with local users participated in semi-structured interviews which helped to establish possible agendas for a user group.
- The interviews focused on the impact of living with MND; experiences of using services and suggestions for improving provision; views on user involvement and the possible roles and function of a local group; potential barriers to user involvement; and views on establishing a virtual forum.
- The project worker and volunteer made home visits to two sets of people with MND and their carers, including some who had participated in the research interviews, who described the potential barriers to participating in user involvement activities, their motivations for joining a group or network, their experiences of services and suggestions for service change.
- Most of the first set chose to join the local group which, after potential barriers had been addressed and practical arrangements made, met twice at monthly intervals before the project ended.
- Users who chose not to join the local group became part of a local network who remained in touch with the project, and some of whom contributed to the group's activities.
- Contact was also made with a wider group of MND service users through the launch of the BUILD website with a virtual forum.

Project findings

- The project demonstrated that people with MND and their carers have extensive knowledge and experience through which MND policy and service provision can be improved.
- Participants expressed the wish to be more involved in all aspects of service planning and delivery.
- BUILD identified the need to involve users in the development of an improved model of care.

- People affected by MND are often required to organise their own packages of care but, paradoxically, the time and effort required to do this can prejudice their quality of life and their involvement in social and community activity.
- Contrary to expectations, many of the people with MND who chose to participate in the local group were severely disabled.
- The younger and more recently diagnosed people with MND chose to maintain an arm's-length involvement with the project through a local user network.
- It is possible to involve sections of the UK-wide MND community through developing and sustaining an internet-based virtual forum. One outcome was that users confidently challenged professionals to justify the medical profession's right to bar access to unproven treatments by people who are terminally ill.
- There are indications that younger people with MND find communication via the internet a particularly accessible and appropriate medium for exchanging advice and information, campaigning, and debating issues relating to clinical trials and other research activity.

1 Background

This chapter describes the starting point for the BUILD project, the nature and impact of MND, the role of health and social care services and the relevance of user involvement and community development approaches to the project in the following sections:

- the origins of the project
- an introduction to MND
- the impact of MND
- health and social care services for people with MND
- user involvement and MND: the policy context
- user involvement and community development
- an overview of this report.

The starting point for BUILD

User involvement plays an increasingly important role in healthcare policy and practice and our point of departure for this project was a study of user involvement in palliative care by Neil Small and Penny Rhodes.

Too Ill to Talk? (Small and Rhodes, 2000) explores the policy and professional context for user involvement and analyses the role of self-help groups and new information and communication technologies in the context of palliative care and empowerment. Their final chapters, focusing on the views and experiences of people with life-threatening illnesses, include one on MND (2000, pp. 125–54) which is the subject of our project.

Apart from the work of Small and Rhodes there has been very little research looking at the ‘lived experience’ of MND, although an increasing amount has been written from the perspective of the person with MND (e.g. Anderson, 2002; Eadie, 2002). These accounts often appear in newspapers or as radio programmes and serve to increase public understanding of the impact of MND. National media coverage has also focused on high-profile court cases such as Diane Pretty’s attempts to clarify the law relating to the ‘right to die’ (Dyer, 2002).

An introduction to MND

- MND is an illness causing degeneration of the motor nerves which are responsible for controlling voluntary movement in all the body's muscles. As nerves degenerate, the affected muscles can become effectively paralysed.
- There are two main forms of MND. About 75 per cent of people with MND are diagnosed because their limb muscles are affected (limb onset MND) and about 25 per cent of people with MND are diagnosed because their facial and swallowing muscles are affected (bulbar onset MND). In a few cases, respiratory muscle weakness is the initial symptom of the disease.
- Whether diagnosed with limb or bulbar onset MND, most people will develop both limb and bulbar symptoms over the course of the illness.
- The figures for the number of people who will be diagnosed with MND each year and the total number of people in the UK with MND are not collected centrally and estimates vary widely. The MND Association note on their website that 'the incidence (that is the number of people who develop MND each year) is approximately 2 per 100,000; the prevalence (the number of people who actually have MND at any one time) is thought to be approx 7 per 100,000. The estimated number of people with MND in the UK is up to 5,000' (What is MND?, www.mndassociation.org.uk).
- The cause of MND is unknown in most cases, although in 5–10 per cent of people there is a family history and one gene has been identified to date as causing a familial type of MND.
- MND affects more men than women (a ratio of 3:2).
- There are no appreciable trends between people from different ethnic and cultural backgrounds.
- The average age of onset is 55 years old (Haverkamp *et al.*, 1995), although about 13 per cent of people diagnosed are under the age of 40 (Turner *et al.*, 2002) and some are in their twenties.
- Most people with MND die within five years of the onset of symptoms, although 5–10 per cent of people live more than ten years after diagnosis. People diagnosed when they are younger tend to survive longer.

- Treatment includes one licensed drug which has been shown to have a moderate effect on survival (Lacomblez *et al.*, 1996). Symptomatic treatments, such as assistance with breathing using ventilatory support and feeding using a gastrostomy tube, can prolong life and relieve symptoms, and there is a wide range of aids and equipment to help people maintain their quality of life and independence at home.

Motor neurone disease (MND) is also known by the term amyotrophic lateral sclerosis (ALS) in Europe and the United States and MND and ALS are sometimes used interchangeably, particularly with reference to the international MND/ALS community. This report generally uses the term MND.

The impact of MND

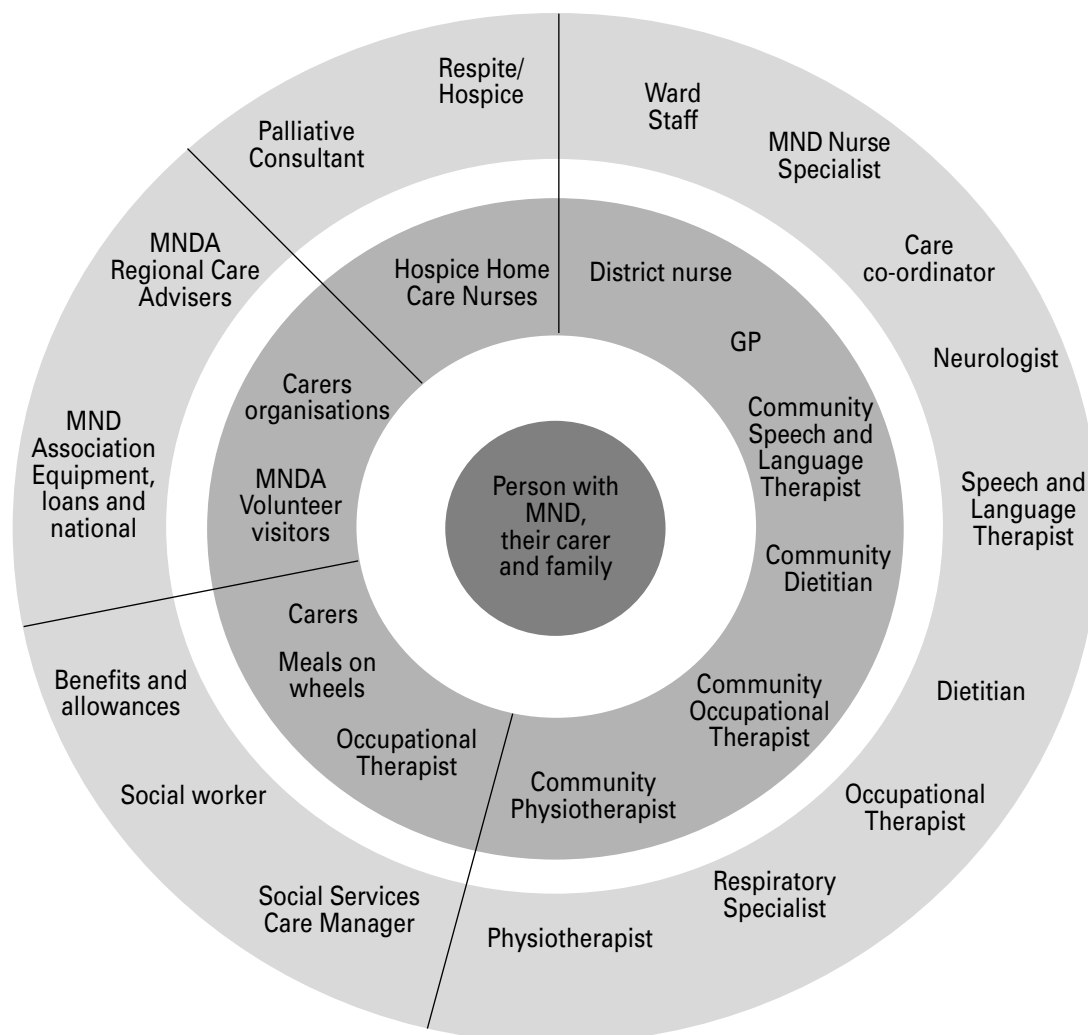
- Many people with MND can rapidly become dependent on others for daily activities such as washing and dressing; they may also be dependent on assistive equipment to enable them to communicate.
- There are usually no psychological or cognitive changes but a minority of people with MND may experience difficulties with planning non-routine activities and solving problems. A few people experience dementia.
- MND causes a shortened lifespan because nerves controlling respiratory muscle action become affected at varying points in the course of the illness. An additional life-threatening symptom is difficulty eating and swallowing as the muscles of the face and throat are affected.

Services for people with MND and their carers

Due to the various ways in which people with MND become disabled, and the rapid progression of symptoms, people with MND and their families may be in contact with a number of different services. Figure 1 illustrates the wide range of services a person with MND may be in contact with at any point in their illness.

A multidisciplinary teamwork approach is needed to counter fragmentation across organisational boundaries and find ways of ensuring that equipment and adaptations are jointly provided (Corr *et al.*, 1998). There are few formal agreements on service levels or joint working practices, and the resources to enable co-ordination of such teams are not available within statutory services. There is some evidence that multidisciplinary working can be experienced by users as fragmentary, burdensome and only patchily effective (MNDA, 1998, 1999b, 2001, Leigh *et al.*, 2003).

Figure 1 Health, social care and voluntary organisations who may be involved in working with someone with MND



Services for people with MND vary widely. Some areas do not have multidisciplinary teams or neurologists with a specific remit to support people with MND. There are currently no statutory care standards for people with MND, although there are suggested practice parameters for healthcare professionals (Miller *et al.*, 1999).

The Motor Neurone Disease Association (MNDA), the representative organisation for people affected by the illness covering England, Wales and Northern Ireland, has developed standards for care (MNDA, 1999a) emphasising:

- timely and appropriate support
- flexibility and speed in response to need

- co-ordination and co-operation between service providers
- access to a range of specialist and community-based health and social care agencies.

User involvement: the policy context for BUILD

Throughout the past decade, central government has published policy documents (e.g. DoH/NHSE, 2000) and produced legislation requiring statutory bodies to involve existing and potential service users in planning, developing and monitoring service provision (e.g. Health and Social Care Act 2001, s. 11, which came into force on January 2003). Discussion papers from the Commission for Patient and Public Involvement in Health (e.g. DoH/NHSE, 2001) and the Patients Forum focus explicitly on ways in which people in local communities, particularly those from marginalised or minority groups, can be empowered to assert their views and influence change.

A further initiative has been the government's introduction of national service frameworks (NSFs) which list a series of national standards, what each will aim to achieve and how they should be developed and delivered. NSFs to date have included frameworks for services relating to mental health, older people and children. An NSF for Long-Term Conditions, to be published early in 2005, will focus on improving health and social services for people with neurological conditions such as MND and other long-term conditions. Using a standards approach this will provide greater equity and coherence of services across the UK.

Acute and community-based neurological services are responding to these policy and legislative requirements to involve users, but:

- with the exception of mental health services, experience of user involvement has been limited
- patient satisfaction surveys and other consultative strategies have only become more widely developed in the past five years
- more work has been undertaken to develop user involvement in planning services for chronic conditions such as diabetes or asthma
- there has been little experience of involving users with terminal illness receiving palliative care.

The BUILD project was a timely response to policies and legislation focusing on user involvement. At King's MND Care and Research Centre, where the project was based, the director and other senior managers strongly supported the development of user involvement. Redefining their services in response to users' views was seen as an appropriate means of strengthening the existing provision.

User involvement and community development

The physical effects of MND described above, and the coping strategies that people develop in response to increasing disability, must be understood in order to develop appropriate ways of enabling users to participate in the planning, development and delivery of MND services.

Individuals with MND can have a range of coping strategies which may involve complex shifts between different emotions and behaviours. Coping strategies may vary at different times in the course of the illness, and very different feelings can be experienced simultaneously (Hogg *et al.*, 1994):

- people may search for information enabling them to understand more about the probable cause(s) of MND and the treatments and therapies available
- denial of the diagnosis and the likelihood of premature death can create forms of stability in people's lives, giving people time to plan their futures
- anger about the illness but also acceptance of it can be experienced simultaneously
- some people express the hope that treatment will have a positive outcome and focus on maintaining a positive outlook.

Analysing the complexities of user involvement in palliative care, Small and Rhodes (2000) consider the possibility of setting up user involvement groups, building on existing social networks or creating new ones. As they recognise, however, local MND networks can be difficult to establish and maintain, and typically have low membership. The MNDA, for example, has experienced difficulties in setting up local support groups and branches, particularly in inner-city areas. As Small and Rhodes point out, this raises questions about the legitimacy of such groups in representing a wider constituency (2000, pp. 50–1).

The findings of Small and Rhodes suggest various possible reasons for the low numbers of people with MND currently participating in local groups:

- the rapidly progressive nature of the illness can make it difficult to sustain a viable group
- the low incidence of the illness means there are few people with MND living in a local (geographical) community at any one time
- willingness to participate in local user groups may change as coping strategies shift, for example, people with MND may have mixed feelings about meeting others with the same illness for fear of causing distress to themselves or others.

As Small and Rhodes point out, the situation leaves 'a sense of vulnerability or powerlessness in people who feel they cannot fight on their own but are also ambivalent about seeking the support of others' (2000, p. 214). They go on to suggest that harnessing information technology could be an alternative approach to user involvement. Participation in a virtual forum (i.e. an online discussion on the internet) could potentially overcome some of the problems inherent in bringing together people with MND:

people isolated by geographical distance, illness, mobility or communication difficulties can make contact with others in similar situations and with similar experiences with whom they would not normally meet. Such electronic forums enable people, who would otherwise be excluded ... to identify and discuss issues of common concern.

(Small and Rhodes, 2000, p. 89)

Feenberg and colleagues (1996), who reviewed the content of forum discussions, noted that 'computer messaging diminishes the sense of vulnerability that often inhibits discussion and behaviour in [a] face-to-face setting'. There is evidence too (e.g. Ferguson, 2002) that patient-led online services could provide valuable expertise and peer support. Taking this further, Feenberg *et al.* (1996) note the potential for forums to consider and discuss service provision, having reviewed one group who 'established a list of priorities' for service provision and research priorities.

However, concerns have also been expressed about using information technology to form a representative group of people. Small and Rhodes (2000, p. 82) warn that computer links may

run the risk of creating a well-informed elite who are in regular contact with each other and a relatively ill-informed and disempowered, albeit decreasing, majority who do not have access to the Internet.

Concerns that the relatively elderly population of people with MND might not be well placed to access information technology may be offset by recent findings (Hardey, 1999) that over half of internet health information surfers are family members and carers seeking information and online support communities on behalf of someone else.

The work by Small and Rhodes has been valuable in highlighting some of the issues which may affect the chances of involving users in planning services for people with MND, but their research may also indicate possible ways forward, such as using the internet for involving service users.

If it is possible to demonstrate that a representative group of people affected by MND can be enabled to participate in planning services, then this has relevance not only for statutory service providers but also for voluntary organisations such as the MNDA who experience these challenges for user involvement on a national scale (but particularly in inner-city areas).

Although there are no universally agreed definitions, it is possible to distinguish two broad approaches to user involvement in service planning, development and delivery. The summary below is drawn from Richard Lewis's discussion paper which looks at stakeholder engagement in foundation trusts (Lewis, 2003):

A 'consumerist' approach seeks to enable service users to shape services through the exercise of choice. This may include users 'voting with their feet' by turning to alternative service providers or users may be invited to express their views on levels of satisfaction (as defined by the provider).

An 'empowerment' approach seeks to challenge the power relations existing within a given community, to the advantage of disadvantaged groups. Users are enabled to define their own agenda and to build democratic structures to express their views and participate with service providers if they choose to do so.

With the BUILD project, we adopted an empowerment approach:

- to see whether a user-defined agenda raised previously unstated issues
- to see whether this approach would enable a local user group to be established when a more traditional approach to setting up a user group has failed
- because a previous patient satisfaction/opinion survey from the Centre had yielded little useful information and patients had expressed some frustration with this approach which is widely used in market research

- because the Centre team felt that a democratic approach which sought to empower the most marginalised within the MND community was more appropriate to the Centre's ethos of patient-centred care.

Community development can offer a framework for empowering individuals and groups and our thinking underpinning the BUILD project was informed by key principles set out by the Standing Conference for Community Development:

Community development does not seek to impose solutions or structures, or to provide services or events for people. Rather it is about working with people to define and deal with problems and assert their interests in decision making. This requires empathy and an ability to engage with individuals, working to develop and maintain appropriate forms of organisation. It may also involve changing existing organisations so that their practices and culture embrace the empowerment of communities ... By helping communities to develop informal and formal organisations, the worker will inevitably challenge and re-negotiate existing power relations.

(SCCD, 2001)

Empowerment is central to the community development approach espoused by BUILD and it was always envisaged that the project would evolve directly from the input of people affected by MND.

Overview of the report

The first two chapters set the scene for the rest of the report. This chapter has explained why the BUILD project was undertaken, the nature and impact of MND, the policy context for user involvement and the relevance of community development. Chapter 2 provides an overview of the project.

Chapters 3 and 4 capture the learning from the research interviews with users and professionals. Chapter 3 describes the impact of living with MND, experiences of services and suggestions for improving current provision. Chapter 4 reports on users' and professionals' views on user involvement, the proposed local group and the virtual forum, and explores possible barriers which the project would need to address.

Chapter 5 describes the ways in which BUILD and users worked together to lay the foundations for the local group meetings and, returning to themes in earlier chapters, Chapter 6 discusses barriers to user participation, users' reasons for wanting to join a local group or network, their experiences of service provision and their suggestions

for service change and development. Chapter 7 describes the practicalities of organising local group meetings and offers a glimpse of the early meetings and the activities of some of the local network members.

Alongside these local activities, BUILD developed and launched a website with a forum, testing out the possibilities for user involvement at a national level and this is the subject of Chapter 8.

This report concludes with Chapter 9 which seeks to capture the learning from the BUILD project.

Summary

- The starting point for BUILD was the recent work of Small and Rhodes (2000) on user involvement and palliative care which included personal accounts of the 'lived' experiences of people with MND.
- People with MND may need a wide range of health and social care services, although provision varies widely and multidisciplinary teamwork is not always effective. There has been little research into service users' experiences of organising what are often complex packages of care which can be problematic.
- There are currently no detailed care standards based upon the needs and wishes of people with MND, but the government will publish a National Service Framework for Long-Term Conditions in early 2005 which will focus on neurological conditions, including MND, and aims to raise awareness of best practice.
- The low incidence of MND and the rapidly progressive nature of the illness can make it difficult to establish viable local groups.
- MND service users may experience significant challenges to becoming involved in planning services and there are few practical examples of where this has happened.
- The internet may be used to bring together a geographically dispersed community of interest to influence service planning, but there was little information about whether this would be an effective model for people affected by MND.

2 Overview of the BUILD project

This chapter describes:

- the aims of the project
- the project's base
- the project team
- the project participants
- the project activities
- capturing the learning.

Aims

The BUILD project set out to explore the barriers and potential for developing representative user involvement in planning national and local services for people with MND, their carers and family members. The initial aims of the project were:

- to develop two different and possibly complementary methods of user participation in shaping services – a local user-led group and a ‘virtual group’ using the internet
- to assess the effectiveness of the two approaches in delivering change and the resources required to sustain them
- to develop a partnership approach across service agencies to improve the scope, co-ordination and delivery of services
- to assess the user projects and service partnership against the objectives initially set by the participants.

To work towards meeting these initial aims, BUILD's activities were:

- *the research interviews*: a series of interviews with people with MND, their carers and family members, and professionals from health, social care and voluntary agencies working with people with MND
- the development of a local user-led group (referred to in this report as *the local group*)

- the development of a local network which emerged from the early states of setting up the local group (referred to in this report as *the local network*)
- the establishment of an internet-based virtual group (referred to in this report as *the virtual forum*).

A separate overview of each activity is included later in this chapter.

BUILD was working simultaneously in, and with, two different kinds of community:

- the ‘geographical community’ of South East London where the project team was based and where the local group and local network developed
- the ‘community of interest’ – in this case people affected by MND (who participated in the local group, the local network and the virtual forum).

Local group and local network members were a community of interest and were also a part of their local geographical community. Virtual forum participants were also a community of interest but in this case they belonged to a geographically dispersed community.

The project’s base

The BUILD project team was based at King’s MND Care and Research Centre in South East London (see Chapter 1). As a specialist centre, it accepts referrals from across South East England but has a particular responsibility for people with MND in the London boroughs of Lambeth, Southwark, and Lewisham.

Funding from the Motor Neurone Disease Association (MNDA) enables the Centre to employ a co-ordinator, whose remit is to support patients to access services and reduce potential fragmentation between hospital- and community-based services. The Centre hosts monthly case study and educational meetings for community services in Lambeth, Southwark and Lewisham.

Lambeth, Southwark and Lewisham have a total population of 754,000. This is one of the most deprived areas in the UK, with considerable pressures on services. Approximately 30 per cent of the population describe themselves as coming from black and minority ethnic backgrounds and the area’s ethnically diverse population also experiences problems of access and uptake of health and social care services (LSL Health Authority, 2001).

The project team

The project team consisted of:

- two researchers based at King's MND Centre, who carried out the research interviews and analysed the data
- the project worker who undertook home visits and other preparation prior to servicing the local group, and developed the virtual forum
- a volunteer (a bereaved carer of a person with MND) who accompanied the project worker on home visits and participated in the local group.

The project worker had previously been the Centre's patient care co-ordinator. With BUILD, she was able to draw on knowledge, skills and experience acquired through working with people affected by MND, but she was also able to use her previous experiences of community development with a community regeneration project.

Project participants

People with MND, their carers and family members living in the boroughs of Lambeth, Southwark and Lewisham were invited to participate (and are described in this report as 'users').

Recruitment of participants aimed to ensure that the users would reflect their local and national communities in terms of:

- their needs and abilities in relation to communication and mobility
- age and gender across the MND population
- the cultural and ethnic diversity of the local community
- a balance between people with MND, their carers and professionals.

The research interviews

The interviews were undertaken to:

- understand the lives of people with MND and their carers
- ascertain their experiences of using services and their suggestions for making changes to services

- obtain participants' views about the BUILD project (including the proposed user group and virtual forum).

We recruited participants by approaching everyone with MND from the three boroughs who was known to the Centre, although we excluded anyone who had significant cognitive problems or who was medically assessed as possibly within a few months of death and so too unwell to be approached. Two people were excluded at this stage but although the Centre usually knows of about 20–25 people at any one time, when the project started this had fallen to nine. (Numbers can fluctuate considerably if a number of deaths occur at around the same time, but increase again as others are newly diagnosed.)

People were sent a letter, information sheet and interview response form and those interviewed were then invited to pass on introductory letters from the Centre to carers and professionals.

Nine people with MND and five carers were interviewed and Table 1 provides more information about their characteristics.

Table 1 Characteristics of people with MND and their carers interviewed

Characteristics	People with MND	Carers/family members
<i>Sex</i>		
Male	6	1
Female	3	4
<i>Ethnicity</i>		
White British	5	4
British Caribbean	1	—
White Irish	2	1
British Italian	1	—
<i>Age groups</i>		
30s	1	1
40s	1	—
50s	—	—
60s	1	—
70s	6	4
<i>Marital status</i>		
Single	1	—
Married	6	5
Divorced	1	—
Widowed	1	—
<i>Length of diagnoses</i>		
Less than one year	4	2
More than one year	1	1
Two years or more, but less than three	—	—
Three years or more	4	2
<i>Living arrangements</i>		
Alone	3	—
With spouse	6	5

Table 2 Characteristics of professionals interviewed

Characteristics	Professionals
<i>Sex</i>	
Male	2
Female	13
<i>Age groups</i>	
20s	3
30s	3
40s	7
50s	2
60s	–
<i>Service setting*</i>	
Hospital	8
Community	4
Social services	3
<i>Length of service</i>	
Less than five years	5
More than five years	6
Ten years or more	4
<i>Estimated number of MND contacts</i>	
Less than five	2
More than five but less than 50	7
More than 50 but less than 100	1
100 or more	5

* Occupational roles in each setting include nurses, other clinicians and managers.

BUILD contacted health, social care and palliative care professionals with a range of roles, responsibilities and experience, and representing front-line and strategic interests in MND across the three boroughs. A total of 15 were interviewed and Table 2 describes their main characteristics.

Semi-structured interviews lasted between 25 and 90 minutes for users and between 30 and 80 minutes for professionals. Users were interviewed in their homes and professionals at their workplace. Further information about the research can be found in a later section of this chapter ('Capturing the learning').

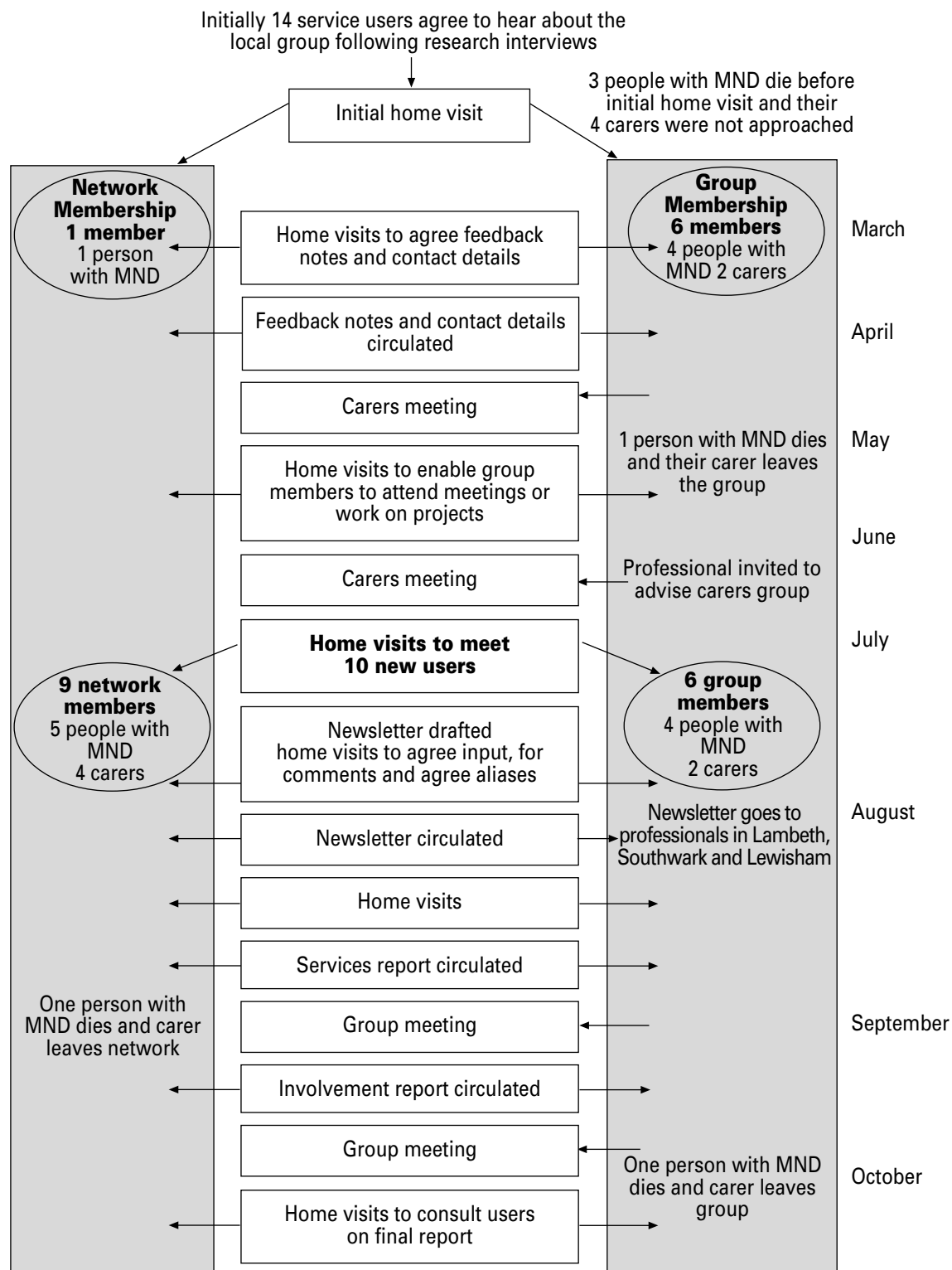
At this stage in the project, three people died unexpectedly shortly after participating in the research interviews and their carers and family members were not approached to take any further part in the project.

Chapters 3 and 4 set out the findings from the research interviews which are presented according to the main themes to emerge from analysing the data.

The local group

Figure 2 outlines the development stages of the local group.

Figure 2 Development stages of the local group



Initial home visits

Each user who had been interviewed was also offered a home visit from the project worker to learn more about BUILD. All the interview participants agreed, and between March and June 2002 a first set of seven users met with the project worker, accompanied by a bereaved carer who was a volunteer with the project (see above and Chapter 5). (Three people with MND died before a meeting could take place and their carers were not approached.)

This first set of people with MND were predominantly wheelchair users with considerable mobility difficulties and two also had significant communication difficulties. Most had been diagnosed with MND between four and ten years previously.

From July 2002, the project worker made initial home visits to a second set of ten users, the majority of whom went on to form the local network.

Feedback notes recorded the discussion and learning from these meetings which were circulated to other users.

Further development work on the local group

After the initial home visits, the project worker and volunteer made further home visits to discuss the content of feedback notes, agree the content of a proposed project newsletter and discuss arrangements for local group meetings.

At this point, the project worker met two carers to enable them to subsequently participate in the local group when it started meeting.

Other work undertaken during this phase of the project included the production and distribution of a BUILD newsletter (see Appendix 1) which was circulated to users and to relevant/interested professionals in Lambeth, Southwark and Lewisham.

Meetings of the local group

Two meetings were held (September and October 2002), which were chaired by users and serviced by the project worker. Users shared information and gave advice, expressed emotional support and talked about how services could be improved. More about these meetings can be found in Chapter 7.

The local network

The characteristics of the second set of users who had home visits differed from those of the first set. They had all been relatively recently diagnosed, were generally less severely disabled, and lived with partners who were also their main informal carers.

These users also differed markedly in their response to the proposed project activities. Although the majority chose not to meet up with other people in a similar situation, they all wanted to remain in touch with BUILD and hear more about the project as it progressed. With one exception, these users became members of what we have described as the 'local network'.

Further information about the local network's involvement in the project can be found in Chapters 5 and 7.

The virtual forum

The second strand of user involvement was to create a 'virtual group', using the internet to draw together a community of interest across the UK. This part of Chapter 2 provides an overview of the development of the virtual forum (see Figure 3) and a fuller description can be found in Chapter 8. The project also explored ways in which the local group and the virtual forum could relate to one another and how ownership of the site could be adopted by local group members.

Existing MND sites

Existing MND websites were reviewed to assess the most appropriate format for a UK-based site.

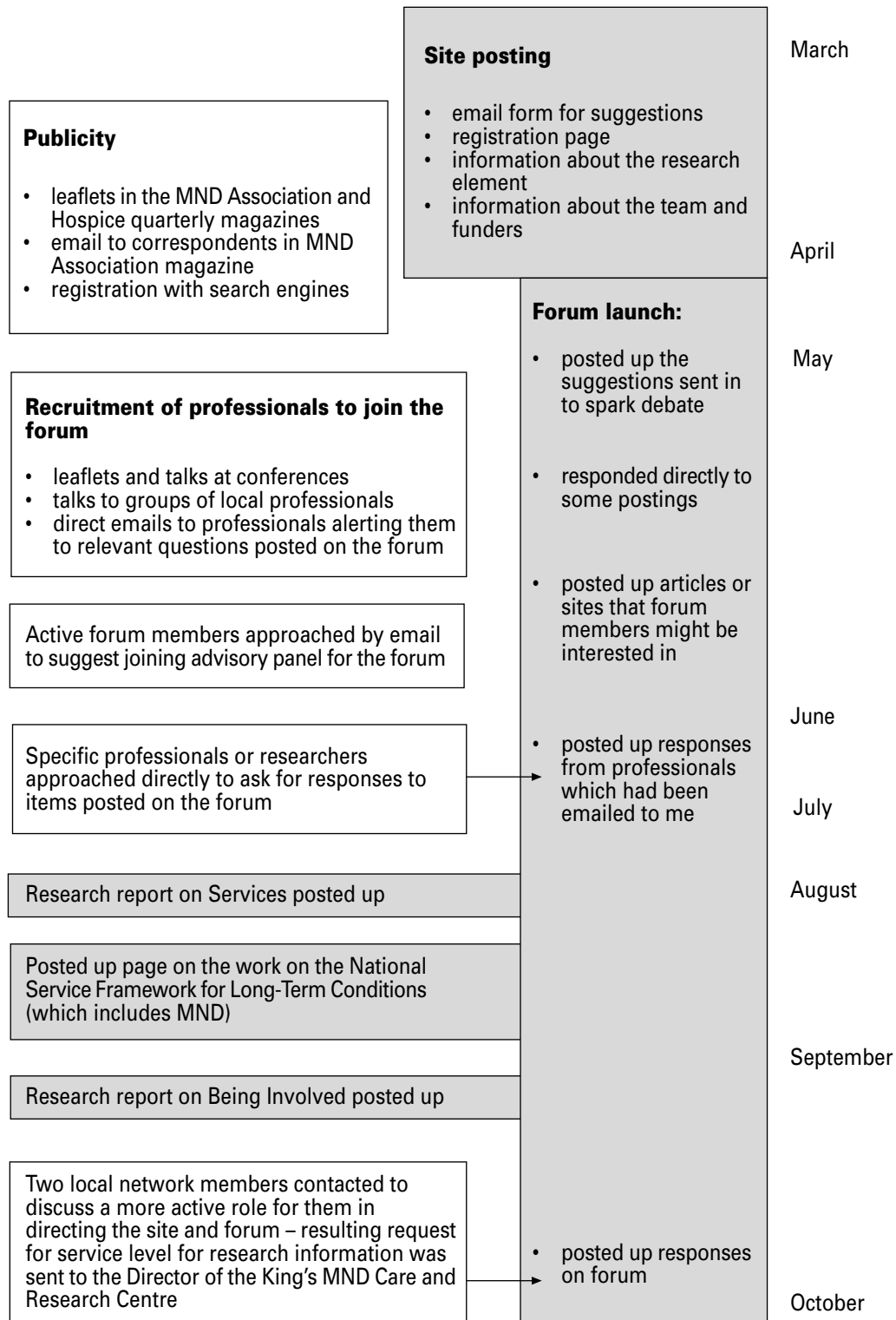
Publicity and recruitment

This was undertaken with a modest budget and a limited amount of time.

People with MND and carers were targeted through: a leaflet in *Thumbprint* (the MND magazine); emails to people with contact details in *Thumbprint*, an article in *Help the Hospices* magazine; and registration of the site with the main search engines (e.g. Google). Twenty-eight people who registered gave details of how they heard about the BUILD site: the majority through *Thumbprint* or from search engines.

Professionals were recruited to join the forum through: leaflets and talks at conferences; talking with groups of local professionals; and emailing professionals about relevant questions posted on the site.

Figure 3 Development stages of the virtual forum



Launch of the BUILD website and forum

The site went live in early April 2002 (see Figure 4) and included:

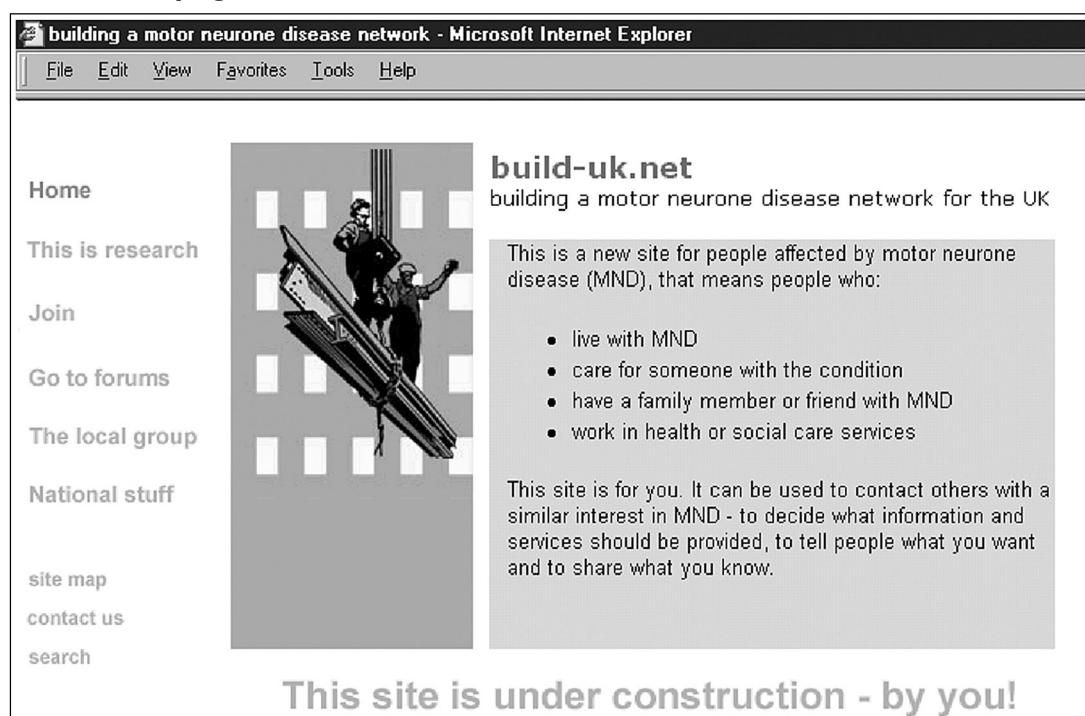
- a description of the project
- an explanation of how site postings would contribute to BUILD's research
- a (voluntary) registration page
- an online form for users to respond to suggestions for development of the site.

The forum operates as a bulletin board, with messages posted and replies displayed. Because, initially at least, we would only be reaching a small number of people, this was chosen rather than a chat room which would have needed a large number of active site users to be viable.

Registration was voluntary and site users could post messages without having to use a password. Where people did choose to register, however, their basic details helped the project find out whether we were working with a wide range of people affected by MND.

The forum was launched at the beginning of May 2002 and information about the site users can be found in Chapter 8 (see Table 3).

Figure 4 Front page of BUILD website



Service provider partnership

One of the project's initial aims was to explore how partnership with service providers could lead to improvements in the scope, co-ordination and delivery of services. Drawing on a model widely adopted in local government and regeneration initiatives, it was envisaged that a partnership board would be established where service providers' representatives would meet with users to hear their recommendations for service change and discuss the impact of MND and service providers' responses.

There were several reasons why these meetings did not take place. A distrust of some service providers (particularly social services care management), together with a lack of information on how services operated or what services were available, led users to express little interest in meeting with such a group at this stage. Group members would need to become more confident about establishing their agendas and negotiating with service providers before this would be viable.

There were also 'external' reasons why this aim could not be more vigorously pursued during the life of the project. The local primary care trusts (PCTs) had only recently been established and user consultation and involvement strategies were still being developed. Few resources or structures were in place at this point, although the project worker attended meetings of the Southwark Public Involvement Group – a partnership between hospital- and community-based health services, social services and the voluntary sector.

Despite these difficulties, the two meetings with carers (see Chapter 5) did provide some insights into the development of partnership working. At the first meeting, the carers agreed that, in partnership with a local occupational therapist, they would explore the issue of assistive equipment and ask why there were problems accessing equipment and what potential solutions he could suggest. At the second meeting, attended by the occupational therapist (OT), it was agreed that he would work with the local group to draw up guidelines to which all OT services in the area would be asked to respond.

Capturing the learning

BUILD used two main approaches to capturing the learning from the project. The team were open to finding out which approach might be more fruitful or which might offer insights into what was happening as the various activities described above were taking place.

The researcher interviewed service users and professionals using a semi-structured interview guide to enable participants to raise issues that may not have been

anticipated by the project team. These interviews were recorded and transcribed, and field notes were also written by the researcher to capture her reflections. The transcriptions and field notes were then analysed, allowing common themes to emerge which were then grouped for further exploration.

Analysis of the interviews took some time to complete and summary reports were made available, although after the project worker had started her home visits. This meant that the research findings did not inform early work on developing the local group and virtual forum, but they enabled users to rehearse their thoughts and were subsequently available as a description of the group's concerns when they started meeting.

The project worker used audio recording and field notes in her discussions with users and with the volunteer and also to record her reflections on her work. Transcribed audio recordings also enabled her to identify further issues. This was particularly useful for discussions with users with speech difficulties which required more active and less reflective listening on her part. The field notes also proved to be a key resource when drawing together the learning from the project in Chapter 9 of this report.

Summary

- BUILD aimed to develop representative user involvement of people affected by MND.
- There were four main elements to the project: interviews with people with MND, carers, family members and relevant professionals; setting up a local user group; working with a local network of people with MND; and establishing a BUILD website with a virtual forum.
- A community development approach was used to explore the most appropriate methods to build community activity and involve people with MND, their carers and families in shaping services.
- The project, which was based at a specialist MND Care and Research Centre, was undertaken in three London boroughs with an ethnically diverse population and significant social deprivation.
- A wide range of participants were recruited to ensure that they reflected the local community and were representative of the MND community nationally, in terms of age, gender, and needs and abilities in relation to communication and mobility.

- The development of the virtual forum was exploratory in nature and intervention levels were continually assessed and changed in view of site users' responses.
- There was an aim for the local group to meet a panel of representatives of local service providers on a formal basis. This did not appear to be relevant to the local user group and the disruption caused by the development of the primary care trusts also meant it was unlikely to happen.
- Although research findings did not inform early work on developing the local group and virtual forum, it enabled users to rehearse their thoughts and reflect on potential action before meeting the community development worker.

3 Living with MND: findings from the research interviews

Drawing on the research interviews with users and professionals, this chapter describes:

- the impact of MND on people's lives
- the experience of using services
- suggestions for improving services.

The impact of MND on people's lives

As MND progresses it has debilitating physical effects. People with the illness recognised that it affects people in different ways and this man described how:

You can be alright one day and maybe the next week or two you might be all wrong. You see, I'll get up from the chair ... but sometimes I have a job to get up from the chair. A month ago I could hop up from the chair. It's getting through to my back, I can feel that, it's walking up the stairs too I can feel it. My legs are pretty good so far, but once it gets your back, that's the worst.

And another person said:

When you stand up like that [and stands to demonstrate] you imagine there's something pushing me into the ground ... or either you're carrying a lot of weight on your back, you know what I mean? ... You can imagine if it were a fifteen or twenty stone weight, you imagine you have to carry it on your shoulder that's the way it feels.

MND can therefore limit travel, hobbies and pastimes. This recently diagnosed older man described how the illness had affected him and his wife:

I used to be reasonably active, even though me age, I could get out quite easily and everything. But now it has restricted us ... even from going out socially and dancing or anything like that. I've had to give up driving and it has made a lot of difference to us also, like you can hear me voice and breathing and everything like that ... I feel that every so often I know things are slowing down and I can feel muscles in me body gradually deteriorating.

We interviewed many older people and it was sometimes difficult to separate out the impact of MND and the effects of ageing. However, one younger person continues with his previous social activities but had also had to make some compromises:

I pretty much do everything I used to do anyway, but perhaps fatigued a bit earlier now ... I've just continued socialising, doing what I used to do anyway, so ... uh suppose it's not nice knowing that sort of you tire easily, whereas you have to leave people a bit earlier than normal. But you just get used to it.

As the illness progresses people can become increasingly dependent on close family members which in turn affects their relationships. This man was left feeling:

a little bit uptight about things but other than that I try to conceal it you know ... it's just the fact that I can't do things for her [his spouse] now which, you know, she has to do it for me and it's, it's completely in reverse.

Although his wife was coping with daily life, she felt very uncertain about dealing with practical matters, including finance, should he die:

I'm just hoping we'll carry on for years ... I hope I go first, you know, or when he comes along saying about the money – he's always managed it – he says, 'you're alright you don't have to worry about anything'. But I believe it doesn't matter how many times he's telling me, I'd be useless. I just depended on him so much for that.

Some individuals described how they 'got used' to living with the illness, as this man had found:

It seems to just come natural ... and you're lumbered with this thing and you've got to get over it and try and do your best you know.

Whilst people with MND and their carers described considerable uncertainty about the future, they also discussed the importance of coping. As this recently diagnosed man found:

I said to [his son], 'I don't know how I'm going to finish up'. He said, 'well, Dad, you know, some are progressive and at your age I don't think it's progressing so quickly'. I don't know whether they're trying to flannel me off, but okay I accept that. And I was worried about that, but then I thought, well if you've got it and you've got to cope with it, so you try and, the best way you can. I mean, I don't know how I'm going to finish up.

Despite this uncertainty, people of different ages and at all stages of their illness discussed the issue of acceptance. In the words of this newly diagnosed young person:

I think 'cause there's no cure or anything, you accept it, with MND it's so final as it was. I think one thing is you tend to think, it's just not worth worrying about. I can spend the next few years of my life worrying about this illness, it's gonna eventually gonna kill me, or I can just go out there and enjoy it and you know, let it do its worse. I think, having a positive attitude, it helps you in the long run anyway.

An older man who had been living with MND for many years drew attention to the importance of memories in accepting the illness:

I think you know, now I'm literally wheelchair bound ... I think you live a lot on memories really ... I think adapting and accepting your lot is quite an important part.

Some people ignore their illness as much as they can. One person who had only told his close family about his recent diagnosis and who continued to work said:

Well ... to put it crudely I've tried to say, 'cobblers to it', because I didn't know how to handle it, so I've tried to ignore it.

Some, such as this carer, were reluctant to find out more about MND:

I've not been very good in that I haven't found out much about MND because I can't bear to face, I'd rather just take it one day at a time ... I don't want to know what his prognosis is, I think to read the grimmest facts are too much, I couldn't.

To protect themselves and their loved one from distress, carers would sometimes restrict available information. One person, for example, discussed their response to the media coverage of Diana Pretty:

The first time we heard of it was what we saw on television. That's it, and if I saw anything in the newspaper I take it out, say nothing, just hope he didn't notice the pages missing! ... I thought if he sees it, it might upset him and if he got upset I'd be upset.

Professionals recognised that individuals experienced many different emotions and used a variety of coping strategies. As this health professional who had worked with people with MND for six years suggested:

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

Recognising how MND affected people, professionals such as this community services manager sometimes described this in terms of quality of life:

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

Although some professionals understood the impact of MND, some people living with the illness described an overall lack of understanding which had affected their experiences of services. As this woman found:

You see nobody really understands it or knows how you feel ... because I'm not so good now, but I was always quite bright. I've got nobody to do my hair or make my face up how I used to. But it's because from the neck up I'm alright.

Experiences of services

Many people affected by MND were unsure about their entitlement to services. This carer felt at a loss as to where to turn to obtain:

things like wheelchairs and things like that ... I don't know what's ... because I know that [the person with MND] will need more equipment, and you know my question is where does he get that equipment? Does he get it from the hospital? ... I don't know what the situation is ... is it something that [professional] helps us with, do we get them from the hospital or is it the occupational therapist?

Some professionals recognised that users could be confused by different information from different sources but even getting hold of information could be difficult as this carer had found:

I mean if you're coming in blind and you have no idea ... where do you start? ... I was phoning up the town hall ... we were just sort of like plopped in, I didn't know where to get any help from at all.

MND care services were sometimes prioritised because of the rapid progression which can occur. According to this person who had worked for eight years in social services:

I think MND is given an extra priority because of the nature of the disease and the rapid progress. So that we would visit – the target is within a month, the government's target – but we actually try to visit ... or at least contact the person within a week.

Users also described encounters with professionals' attitudes. Some felt that professionals were distant and divorced, such as this person's experience:

He'll give you the facts and that ... as I found out at first I felt quite strange ... not cold but the clinical representation of it to begin with. But then I came to terms with that. When you're actually sitting down opposite a doctor he'll tell you what you want to hear, you know, but generally they deal in specifics don't they? You're a subject to them rather than a patient.

Similarly, some users were concerned about gaps in professionals' knowledge and understanding of MND. This carer explained how little her social worker knew:

because it's so rare ... the social worker seemed quite surprised, I'm sure she didn't know, she wasn't aware of what it was. Then we said, 'well this is what happens', and she was like, 'oh my god!', you know ... we had to explain to her what would happen. Which is fair enough because it's not every day she'd be seeing somebody with the illness so I don't blame her for that ... Yes she said, 'I have to go back to the office and find out what it is'.

Like this carer, others also felt that professionals' lack of knowledge about MND was possibly due to its low incidence. One professional who had worked with over seventy people with MND said:

Most therapists don't have a high exposure to it and as you know most GPs don't have a high exposure to it so you may not see that many ... The reality is ... a lot of these therapists, that some of them may go through their whole professional career and only see a few, unless they work in a very specific neuro-degenerative, neurological team.

This lack of knowledge about MND led to problems with accessing service entitlements, such as social security benefits. This was the experience of one person caring for her husband:

He's been turned down for Disability Living Allowance which I think is absolutely outrageous ... it's the lack of foresight in that decision by the benefit offices.

Some professionals' apparent lack of understanding and knowledge about MND or their attitudes to users meant that people, like this carer, were reluctant to ask them questions:

I never hear anybody say, well, how long it would take or how long he could live or anything like that. I suppose that's a question at the back of my mind. I'm not too scared, but I don't want to ask ... But I wouldn't mind asking you [the researcher].

These kinds of situations left users very dissatisfied, as this man caring for his wife found:

I don't remember getting anything that was worthwhile to tell you the truth. As a matter of fact I've had nothing worthwhile since [person with MND] got this.

Problems with obtaining the right information at the right time led some users to seek out information themselves. Most people read books and leaflets, some followed stories about MND in the media and one person was a regular internet user. However, users, such as this carer, appreciated the complexities of presenting information and the challenges for professionals:

because you've either got the person who wants to throw themselves into it, find out as much information as possible, or the ostriches like me who just want to bury their heads in the sand. So I mean you've got to decide what sort of person you're dealing with really before you give them the information.

Suggestions for improving services

Not surprisingly, users' suggestions for improving services related to their experiences of the illness and the services they received. Professionals' views stemmed from their experiences of providing care to people with MND.

Some users identified the need to improve information and communication between professionals and users. This recently diagnosed person wanted to find out what to expect in the future:

Well I think maybe the doctor should tell you. I mean in some ways, you know, instead of reading bits and pieces about it's a terminal disease ... So they're straight, you know, or even the therapist, you know, you go and see them, they can explain, 'well you'll you know eventually you'll get worse', or whatever. It would, it would help people I'm sure.

Newly diagnosed people often required practical information about the illness and their entitlements to services. One carer, for example, drew on her experiences of contacting social services to highlight the need for efficient service responses:

especially if you've got something like MND ... it took about seven or eight phone calls to actually get an appointment to see the social worker, each time you're talking to somebody else ... and the last time I phoned she said 'yes we have got you in mind, we are getting an appointment, we will arrange for you to see someone' and then I phoned up two weeks later and the woman said, 'sorry we've got no record, what did you say your name was?' This sort of, this is all frustrations that you could well do without.

People who had been living with MND for longer were also keen to receive information about treatments, therapies and research. As this person suggested:

It's more sort of information about the new, the research I mean of course one's avidly interested in all that and with improvements and whether things are going to develop in the future.

Some people needed specific information but, as this older man suggested:

A professor or a doctor could actually give you a verbal lecture and I think that a lot of what he said would be based on the medical aspect of it ... I don't think he can actually say to you, what's the best way to handle serious muscle cramps ... These are all little specifics that seem irrelevant until you actually get them, so unless they had a series of tapes that you could just borrow ... some leaflets or books.

Professionals recognised they needed more education and training to increase their knowledge about MND and, as this person working in health services pointed out:

I think sort of increasing people's knowledge through the use of the MNDA and courses and stuff like that ultimately helps the people with MND because the people that are dealing with them know more about it.

As this professional suggested, co-ordination and information exchange needed to improve, especially between hospital- and community-based teams with the latter having a key role to play:

I think it would be good if the community teams could be supported and it's probably a financial reason why they can't keep people on review ... but as I

don't work in the community I don't know why they don't keep people on review. So that would be something to investigate ... the main treatment needs to be done in the home environment so the community team is probably the most key team to be involved anyway. So I think that they probably need more support to be able to provide what we would think as an ideal for patients with MND.

Some professionals believed services should be restructured to reduce demarcations between providers and enable professionals to follow up their caseload between hospitals and the community. This hospital-based professional felt that:

There could be a better service to people with MND if they didn't have to have this constant hand-over of patients to community teams, if, if more therapists could be able to cross the hospital-community divide and do outreach and follow-up.

Other people identified a need for more support, not necessarily from professionals, but from people who understood MND. A woman caring for her husband had this to say:

When you're first told, it would be nice to have someone to talk to. I mean, you don't really know what to expect. I mean, I suppose some people have never heard of motor neurone disease – I hadn't – you know, if you could talk to someone – not a doctor, 'cos they're busy people – but ... someone that knows about the disease ... if you knew that person was there and you could go to them if you had any problems or if you wanted to ask them anything.

Meeting other users in similar situations could help reduce social isolation, as this family member said:

But I still say that they should associate more, it seems as though they isolate them instead of fetching them together. I mean you don't hear of many people with MND people all meeting in certain groups.

Having considered the lives of people affected by MND, their experiences of services and suggestions for improving services, the next chapter focuses on views about user involvement and the BUILD project.

Summary

- The impact of MND on people's lives including their experiences of using services and suggestions for service informed the project's subsequent development of user involvement.
- The physical effects of MND vary between individuals but it affects their lifestyle and their relationships, particularly with their family carers.
- Older people with MND can find it difficult to separate out the effects of the illness from the ageing process, although their symptoms usually progress more rapidly.
- People respond differently to having MND and can use a range of different coping strategies to adjust their lifestyle.
- Accepting the illness can often enable people to cope and achieve some stability in their lives.
- Users can find it difficult to access clear practical information about service provision and entitlements, although some obtain this through leaflets and booklets.
- People affected by MND wanted information about research, treatments and therapies.
- Both users and professionals are aware of gaps in professionals' knowledge and understanding about MND and wanted to see more education and training opportunities.
- Users and professionals identified the need to improve co-ordination of hospital- and community-based services.

4 User involvement and BUILD: findings from the research interviews

Continuing the previous chapter's focus on findings from the research interviews, this chapter sets out users' and professionals' views on:

- user involvement and the proposed local group
- the roles and functions of a local group
- potential barriers to involvement in a local group
- the establishment of a virtual forum.

User involvement and the proposed local group

Users and professionals were invited to discuss their views on the proposed local user group. Users' views suggest that this would provide an opportunity to voice concerns and complaints about services. As one man said:

I'd just like to see somebody of authority from the hospital ... because if you don't make a noise about things you're just left to lie by the side of it.

Professionals noted that people diagnosed with MND are often unaware of the potential impact of this disease until they begin to experience some of the symptoms. They raised concerns about how this might affect people's involvement in a local group. As this physiotherapist working in the health service explained:

I think we often see patients when they are first diagnosed and I don't think they have really have quite grasped exactly what condition they have and what impact it will have on their life.

Alongside this, some users saw themselves as having little knowledge and few skills to deal with the illness and only a minority felt that they had any expertise to share with others. Like this man, they did not feel they had anything to offer a group:

I don't mind doing it ... but I don't ... I think to myself that I've got nothing worth listening to.

Professionals emphasised the value of user involvement to improve communication and consultation with users, thus contributing to more user-informed and user-shaped services. In the words of a health service-based psychotherapist:

Apart from the fact this is now very politically correct ... I think it must be the best way to go about creating anything ... where else ... can you get the information about what it's leading to if not from the users? I can't think of any other way really of pitching services at the right level. So I am a hundred per cent behind the idea of consultation and users' involvement.

Professionals like this were generally supportive of a local group but also emphasised that users should be aware that professionals had limited resources and so needed to prioritise their workloads. According to this health service manager:

You need to be realistic with people, and honest with people about what you can and cannot do. And what the timescales are, and I think patients who participate in user involvement things, need to understand that we're on a journey, and that some things we just can't change overnight. I think it's also about being equal players in the discussion.

Given these finite resources, professionals such as this manager of a community-based service expressed the view that an inability to implement recommendations arising from user involvement could disappoint or frustrate users:

... there's nothing worse ... in raising people's expectations to what services are going to be available, what they're going to be able to have, and when you're front-line staff and you have to say 'well actually no we can't do that' ... it suggests we're saying that you're not important.

Whilst professionals felt that users may be unaware of resource limitations, this carer expressed understanding and empathy towards professionals:

They're very busy, so you've got to be patient and understand that, I mean they've got hundreds ... thousands of people to look after and you're just, you're just one of many.

Users and professionals were generally supportive of a group, but also discussed its function as a means of sharing information and providing support.

Roles and functions of a local group

Sharing experiences, information and support

Users and professionals saw the proposed group as an opportunity to share experiences and information, particularly (though not exclusively) amongst users. As this man suggested:

If you could get two [people with MND] there, they probably might be worse than me, and they could tell me their experiences of how they're coping with it and how they get by and what they do, which is beneficial for one another really.

Users, such as this man, saw the benefits of sharing information:

Well, I'd like to talk to people that have it [MND], you know, that's why I joined in the long run. I wasn't going to bother because there's nothing they can do for you ... But if you get out and talk to other people it might be a help ... to get other people's opinions.

Mutual support

Professionals' views on a group highlight the importance of mutual support. As a social services manager described it:

They're not on their own, that's the same with any group like that isn't it? ... you can share problems with and your anxieties and concerns.

This nurse expressed the view that although professionals could offer support, more could be gained by people living with MND sharing their experiences, a view echoed by other professionals:

Sharing experience comes better from the individual, than from professionals telling them what we think is going to happen. My experience is that when a carer tells – or a patient who has gone through the experience before – tells another member what they have experienced, they're sharing experiences, and that always goes down a lot better from those individuals.

Learning from users and professionals: a two-way process

Professionals, such as the occupational therapist quoted here, saw information sharing as an opportunity for professionals to learn from users:

We learn a lot from them about the day-to-day problems that they face ... What they need and when they need it I think is a really important lesson to learn and what's appropriate and what's not appropriate, what works well, what doesn't work well ... I think there's a lot that we assume that goes on that sometimes doesn't go on.

Users like this person also saw the group as an opportunity to question and learn from professionals:

People try so many weird, different concoctions, remedies ... Everyone's sort of seeking this thing to help them a little bit ... I mean if people do find things, there's nowhere really where you can fire it back to someone, or how do I get this checked.

Users like this man recognised that people with MND and carers might have different perspectives and different requirements in terms of seeking information about MND:

Perhaps a lot of carers are not quite sure what's in store for them ... what the future holds so how do they care. I think that's maybe one area where information does lack. Or, what does someone who's either going to be a part-time carer or a carer need to know or you need to know what to expect.

One man with MND also made the point that a group could offer both emotional and social support as well as information sharing:

It could be pleasant that you've actually come across another soul, another person ... So a proportion of it is friendly and a small proportion of it is informative.

Users and professionals also emphasised the need for the group to be properly convened, rather operating solely as a social group:

First of all it must be very professionally run ... It must be known it is not a social club.

Potential barriers to user involvement

Users identified a number of potential barriers affecting their willingness to join a group – some because they recognised that not everyone wanted to discuss their situation with other people and others because they felt they would be ‘moaning’ or talking about their problems. As this carer said:

I mean that's my own, my personality and I, I've never been a great one for speaking about my problems really, you know, just deal with it.

Users saw age as an important influence on any group composition with some older people reasoning that younger people may be more willing to regularly attend a group than older people.

Some users, particularly those who were severely disabled, were concerned whether participating in a group would involve too much fatigue and disruption. One woman with MND put it like this:

I would have been very interested, and I could be very interested, but I haven't got the strength and the 'go' that I had. Whether I'd still be fit to go ... I just don't know.

As the illness progresses, its effects increasingly absorb people's time and energy and users were reluctant for the group to take up a disproportionate amount of their time. Getting ready to go to appointments could be a strain and carers were concerned about leaving patients on their own, even for things like shopping. It is not surprising therefore that some carers voiced their concerns:

I wouldn't want to go every week. Now and again perhaps ... it all depends on the person you're caring for ... I mean, if he can't be left for long.

Because of previous difficulties, some users mentioned transport as a potential barrier to joining a group. Transport was also mentioned by professionals, who added that the low incidence of MND could result in low group membership. This led some professionals, such as this social services manager, to question the feasibility of groups:

I should imagine it would be difficult, just because again of the nature of the disease and the process and pattern of it, to include service users. And for loads of reasons like transport and you know people in wheelchairs getting access to a building.

Some newly diagnosed people were concerned about meeting others at a more advanced stage of the illness, and suggested separate groups. If this were not feasible, professionals believed it would be necessary to forewarn users. As this speech and language therapist said:

If you've got somebody who's got very severe and you've got somebody else who's coming who's quite in the early stage of the disease they can be horrified by what they see and won't come back. So you have to think quite carefully about whether you're doing a group for people with mild difficulties, moderate difficulties or severe difficulties. Or whether we're going to make it clear to people before they come that they might meet people at that group that are in the end stages.

Some users too felt that meeting others at a more advanced stage of the illness could affect them. As this man with MND said:

If you were a newly diagnosed person probably the last thing you want to see is someone who's um ... at the sort of endgame. Because that's going to spook you.

Professionals also identified communication as a possible barrier to group participation. It can be difficult, even distressing, to not understand the speech of people with MND, and use of communication aids affects conversation flows. As this physiotherapist pointed out, people can be excluded from groups or even from services:

Because they can't communicate, they're housebound, they're unable to get access to any normal computers, telephones and that type of thing.

Professionals' previous experience of user involvement highlights the challenges as well as the benefits, as this nurse had found:

A lot of people will be there with their own agenda, and that's quite often very personal and very painful, and, but I still think, in principle, they're right and good. And years back when I worked with [illness] they were a very angry group. But maybe that's what gets things done.

Users like this carer, whose previous experience of a similar group had not been positive, were less prepared to become involved in an MND group:

I'm not a great fan of these support groups. I have to say I think some people find them absolutely useful ... I went to an [illness] group and I went once because I have to say I felt nothing but depression [laughs], it depressed me to discuss the illness ... I didn't want to see other people with my illness.

One man with MND, who had been involved with an MND support group in another area, had found it frustrating that all the others were carers:

You don't find any sufferers there. So you can't sit down next to somebody and say, 'Oh, how do you find the top button of your shirt?'

Establishment of a virtual forum

Users and professionals were asked for their views on establishing a computer-based discussion forum. Because of the nature of MND, they were generally

supportive of this 'virtual group' which could enable people to contribute to service planning. As an occupational therapist working in social services commented:

For those [who] have access to the facility ... that would enable those very disabled people to also be commenting on the, what's going on.

Many issues relating to a local group were also relevant to a virtual forum, including the way MND could affect people's physical ability to use computers. A physiotherapist pointed out that:

Often patients have problems being able to communicate in a normal way and so that may pose a problem if they are trying to communicate with others. That's why computers may be good but then people may not have the hand function even.

Unfamiliarity with computers was also identified as a significant barrier to involvement. As one professional said:

I think the internet is a fantastic thing, but I think it's limited because so many people ... they're not that way inclined ... or they're physically not able to use those facilities.

The majority of users interviewed did not own a computer and had never used one, often seeming reluctant to do so in the future. One man with MND explained:

Well I'm not into the internet or, it's good if you can handle it, great, if you're brought up with it it's fine.

Some users recognised that younger family members were conversant with the internet but others such as this man were already familiar with it and valued it:

I think the internet's the most powerful form of communication for users. I think that's, I mean that's the way everything's going.

Accessing computers was also mentioned by professionals but, as this speech and language therapist had found when she had tried to organise them for people with communication difficulties:

Even if you sort of assist them with funding and give them a computer, that's not to say that they're going to learn how to use it, and going to be happy using it.

Summary

- A local group and a virtual forum were seen as having the potential to meet users' needs for support, information exchange and advice which might enable them to address difficulties in their lives and with services.
- Professionals generally supported the development of a local group, but emphasised that users needed to be realistic about the level of available financial and staff resources for service provision.
- Potential barriers to user involvement in a local group were identified including: transport difficulties; demands on users' limited time and energy; some people's unwillingness to share their experiences; previous unhelpful experiences in similar groups; and communication difficulties within the group.
- Users and professionals generally supported the establishment of a virtual forum which was seen as enabling people who might be reluctant to meet up in a local group to engage in user involvement.
- Some interview participants (mainly professionals) mentioned potential barriers to user involvement in a virtual forum including: lack of previous experience with computers; physical difficulties with operating a computer; and difficulties with obtaining computer equipment and using the internet.

5 Developing a local group

The main aim of this part of the BUILD project was to explore whether it was possible to develop and sustain a local group of people affected by MND. This chapter describes the stages involved in setting up the group including:

- the values underpinning the group
- the home visits to users (people with MND and carers)
- meetings with carers
- feedback and information sharing with users
- the project's advocacy role
- the emerging local network.

Key values

The community development approach, emphasising user expertise and empowerment (see Chapter 1), was seen as central to how the local group would develop and function. In the early discussions with users, the project worker explained how these values could inform the way the group ran.

- Users would be free to participate in the group at whatever level and in whatever way they chose.
- Users could choose to end their involvement with the group at any time.
- The project worker's role was to enable users to present their views, obtain information for them and help them pursue their concerns.
- Irrespective of disability, age or ethnic origin, all potential group members would be welcomed and represented by the group, and enabled to have their views heard.
- Individual experience and expertise would be valued and seen in the context of a wider MND community agenda.
- Users might have different and conflicting agendas, but the group would be supported to discourage a sub-group dominating the agenda.

The home visits

Between March and July 2002, the project worker and the volunteer met with two sets of users.

- Five people with MND and two carers who had participated in the research interviews and who were interested in finding out more about the project. Most of this set decided after the first home visit to become group members.
- Five people with MND who had been diagnosed after the research interviews period plus five carers were contacted; most decided not to meet up with the group.

Meetings were held in users' homes at their invitation. These visits enabled the project worker to get to know users by listening to their accounts of their experiences, hopes and needs, and users were able to find out more about the project. These exchanges were important in building trust, in enabling some users to feel more confident about their expertise and skills, and exploring how they might contribute to the group.

This process was particularly fruitful with those users who felt disregarded and lacking any control over the services they used. It also enabled some users to feel confident to assert their views on service provision. Their views and experiences, together with their suggestions for service change, are described in Chapter 6.

Involvement of a volunteer/previous service user

The project worker was accompanied on some home visits by a bereaved carer for someone with MND who had been involved in the project from the outset and was keen to support the formation of a local group.

This was invaluable: as a previous service user, she could encourage users to assert their right to have their views heard, while also making it clear that she understood the barriers which might prevent them doing so. Unlike the project worker, she could talk to users as someone who had experienced the illness and death of her partner from MND. By sometimes relating her own experiences of caring, she was demonstrating how this could be emotionally supportive. As she told the project worker:

But then ... if you say 'Yes I can understand, I've been through it, I've worked hard to move on ... If I have done it, there is hope for you as well', you're not giving them hope that there's going to be a miracle recovery, but you're giving them hope that they can cope with their situation the best they can.

Framework for the visits

After several initial visits, their duration and timing became an important issue which would also need to be considered when arranging the group meetings. This was because:

- fatigue is very common amongst people with MND
- many users had numerous home visits from health and social care professionals so the project was 'competing' for their time
- users with agency carers coming in were not available for meetings before mid-morning
- people with speech difficulties needed more time to communicate their views.

To accommodate these factors, meetings were limited to a maximum of an hour and more frequent home visits were made.

Most visits were recorded by audio taping or note taking, although one user chose not to be audio taped. Additional records of home visits were made by the project worker's field notes after visits, and following discussions with the volunteer.

Sharing the feedback from visits

The home visits were beginning to lay the foundations for a possible agenda for the local group, but various practicalities (e.g. finding a venue, organising transport) also needed to be addressed before the first meeting could take place and these are discussed in Chapter 7.

To maintain momentum and start developing a group agenda, it was important for the project to find ways in which group members could be in touch with one another. About half the initial set of users had speech difficulties, but communicating by email or telephone was not feasible. Circulating written material from the research interviews would have been another possibility, but this was not yet available.

The project worker reluctantly decided that for the time being she would have to be the link or 'messenger' between group and network members until they chose to be more directly in contact with one another or could meet up. At this point, group members agreed that feedback notes would be a way of sharing their comments, thoughts and experiences.

After each initial home visit, the project worker drafted feedback notes which were then agreed by the user concerned. These were then circulated to other group members, together with a contact sheet with the user's name, borough, preferred means of contact and, if they chose, a photograph. Some users were anxious about direct approaches from other group members which might make demands on their time and energy. For these users, the project worker acted as the initial contact point.

Although the arrangements for feedback notes had to be carefully negotiated, their circulation had several advantages.

- Individual issues could be flagged up as part of a developing group agenda.
- They clarified situations and helped users identify priorities for action.
- Seeing their words in print enabled people to make more informed consent for wider dissemination and negotiate how their views were represented.
- Users had a concrete sense of being part of a group, with some talking about meeting up before the full group met, and several offering their own homes as a venue for meetings.
- Two or three users offered help to other group members or to pass on information.

There were, however, one or two drawbacks. Seeking amendments from the user concerned and obtaining their consent to the final draft and their contact details could involve up to three home visits, so this rather resource-intensive method was not used for the second set of users visited, partly because the group was about to start meeting.

Meetings with carers

During the home visits, it emerged that:

- some carers took a back seat when the person with MND was present
- others contradicted or talked over the person with MND
- carers and people with MND could have different perceptions of services

- some carers felt anxious, resentful or distressed about their situation, including the prospect of progressive disability and the early death of their partner, but could find it difficult to talk about this in their presence.

The volunteer suggested that a separate carers meeting could help resolve some of their difficulties with organising care, provide an opportunity to 'offload' feelings and perhaps enable them to feel more positive about their caring role.

During the home visits, two carers had expressed a willingness to meet other carers, but then indicated that they had some reservations about this. They were unsure about the benefits of meeting other carers, only felt able to leave their partners for short periods, but also felt there would be extra work if their partners came to the meetings as well.

It was important that users did not feel that their carers were meeting 'behind their backs' and the reasons for these separate meetings were explained. As a result, two meetings between these carers were held (in May and July 2002) before the first local group meeting in September, at a venue within 15 minutes' walk of their homes.

An account of these two meetings can be found in Chapter 2, in the section on 'Service provider partnership'.

Sharing information

To facilitate contact between members of the local network (see Chapter 2 and below) and the local group, a BUILD newsletter was produced in consultation with group members. Contents included quotes and views from the feedback notes, and users' names were changed to avoid potentially defensive reactions from service providers. A copy of the newsletter can be found in Appendix 1.

The newsletter also had a wider circulation, including: people with MND and their carers attending the clinic; professionals who had participated in the research interviews; and other professionals in the locality.

Although producing the newsletter placed further demands on the project worker during this one-year project, it seemed to raise awareness about the group. The response from the local group and the network was an increased curiosity about other group members and, as with the feedback notes, some users again offered advice and information.

Two reports of findings from the research interviews were also produced. The first analysed users' and professionals' comments on services, and the second looked at users' and professionals' views on being involved in a group of MND service users. Both were sent to local network and local group members with the suggestion that users may want to talk about the reports at the group meetings.

The project's advocacy role

Although it had not been envisaged that the project worker would have a formal advocacy role, representation and referrals were made to service providers on behalf of two users. Both had significant problems with their service provision and, without some kind of assistance, it was unlikely that they would have had sufficient energy (or trust in the BUILD staff) to attend the group meetings.

This was a short-term intervention to help resolve individual crises. The project worker agreed with the users that she would draft letters to service providers on their behalf, based on the discussion she had with them. The next step was to agree with users how they felt the systems of service provision or communication could be improved so they would initiate their own problem solving in future and have regular access to professionals.

In both cases where advocacy was needed, the result was an improved package of care, but more importantly users felt they could once again be actively involved in organising their care. They described feeling less isolated and seemed more able to make a positive commitment to the project.

An emerging local network

One of the first set of users did not want to meet other local users and four of the five users in the second set also declined to join the local group, but they all wanted to stay in touch with the project. They therefore became members of the local network. Why they opted for only an arm's-length involvement is not entirely clear, although there are a number of possible reasons for this.

- They may have preferred not to see people at a more advanced stage of the illness.
- Being younger, they may have assumed that other local group members would be predominantly elderly.
- Some were able to continue leading relatively normal lives, although some seemed to be in a state of shock as their symptoms progressed rapidly.

- Those using services were generally overwhelmingly grateful for their support, and were not motivated to campaign for service change.
- Some were still struggling to accept their diagnosis and seemed reluctant to identify themselves as part of an 'MND group'.

Summary

- A series of home visits to users covered similar issues to those raised in the research interviews (see Chapters 3 and 4).
- The impact of living with MND, and users' experiences of services and suggestions for improvements, raised issues which informed the local group's priorities and agendas.
- Home visits were made to one set of users who had participated in the research interviews and to a second set who had been diagnosed after the research interviews had been completed.
- Characteristics of the two sets of users differed. The first set were mainly older and were more severely disabled. The second set were younger, had been more recently diagnosed and experienced fewer symptoms.
- Key community development principles were explained to users wanting to join the local group who agreed that they would inform the way the group operated.
- A bereaved carer accompanied the community development worker on many of the initial home visits, sharing her first-hand experience of living with a person with MND.
- Feedback notes from individual visits were circulated to other users, together with their contact details.
- Users were also kept in touch with the project before the local group started meeting, through a BUILD newsletter which was also circulated to relevant professionals.
- Reports on the research interviews were circulated after the first local group meeting.

- The project undertook some limited advocacy for two users experiencing significant problems with service provision, to enable them to participate in the local group.
- Two meetings with carers were held before the local group started meeting, to discuss ways of overcoming potential barriers to their joining the group.
- The majority of the second set of users chose not to join the local group but formed a local network to remain in touch with the project.

6 The local group and network: barriers, motivations and emerging agendas

This chapter describes the contents of the discussions during the home visits to users (described in Chapter 5) which explored:

- their existing involvement in the 'MND community' and their informal support networks
- the potential barriers to involvement in the local group or network
- the reasons which motivated them to participate in the local group or network
- their experiences of service provision which could form the basis of an agenda for local group meetings
- users' suggestions for service improvements.

Involvement in the MND community and informal support networks

Before the BUILD project, most users did not know anyone else in their neighbourhood who was affected by MND. One or two people shared the same care agency staff, but there was no direct contact between them and the hospital-based specialist clinics for people with MND did not offer opportunities for people to be introduced or meet one another.

No one was involved in consultation arrangements about services for disabled people or in any of the carers organisations. Some people knew of previous attempts by the MNDA to develop a local branch, but this had been unsuccessful because of transport difficulties. Several people had enjoyed the MNDA's national events but were now too disabled to attend.

Service users described strong social support networks of friends, neighbours and members of their church. In addition, several relied on friends and neighbours who supplemented their paid care staff, responded to emergency alarms and provided legal and financial advice and advocacy.

Users also described how relationships with friends and extended family became strained. As the illness progressed, they became more housebound, hobbies and activities outside the home were often given up and a couple of people limited activities outside the home because of anxiety or embarrassment about their

physical symptoms. Despite these restrictions, many users were keen to join a local group, although several made it clear that with an 'army of friends' they did not see the group as a replacement social life.

Barriers to user involvement in a local group

Users identified a series of barriers which prevented them from participating in activities outside the home, including the local group meetings. Although barriers sometimes overlap, they could be loosely categorised as physical (e.g. lack of ramps), practical (e.g. unreliable transport), or emotional/psychological (e.g. professionals' unsympathetic attitudes). These barriers needed to be identified and addressed when considering how the local group could function, but they also impact more widely in terms of restricting users' ability to participate in activities outside the home – whether these are for hospital appointments or for social and leisure purposes.

Transport

The first set of users were more severely disabled than the second set and almost all were wheelchair users. Problems with transport could have a knock-on effect. Not only were users becoming more housebound, but it could also block their access to specialist healthcare such as hospital appointments, therapy reviews and care co-ordination. As this carer found when trying to prepare for hospital visits:

It is such a job to get ready, but transport hadn't turned up two times and on the third time it was late ... and so I didn't really feel that it had been worth it.

Even when special transport was organised, this could still be very tiring and physically painful if it involved sitting for long periods waiting for transport to arrive, being bumped over traffic-calming humps and lengthy round trips with several people travelling together.

Physically inaccessible environments

Even when people did manage to go out, they could encounter a lack of suitably adapted toilets with raised seats (known as 'polo mints') and several users dealt with this by eating and drinking less the previous day.

A lack of ramps outdoors and in buildings could also make some environments inaccessible, despite generally increased awareness of the need for accessible environments.

Fatigue

Fatigue is a common symptom of MND that circumscribes people's lives, though this person explained how she had learned to pace herself:

... and then you struggle. I think 'You should push yourself to keep things up!' but I've learnt that if you overdo things then the next day you've used up your supply of energy – to struggle is not good.

Having found this to be an issue with the home visits, the community development worker recorded for each user the most appropriate time of day to contact them and the times when they would be resting (see also Chapter 5).

Fluctuating patterns of health

People affected by MND can have 'good' and 'bad' or 'less good' days which are often impossible to predict. This meant that some users were worried about whether this would mean letting other members down when a local group meeting was scheduled. As one person said:

You see I could feel fine all week and then the day of the meeting you wake up feeling like jelly. I wouldn't like to let people down.

Changing needs for services

As well as these day-to-day fluctuations, the progressive nature of MND means that people's needs will also change over time, requiring specialist reassessment and advice and, in some cases, new assistive equipment or other changes to their service provision. For one person, when her changing needs were unmet, this had a major impact on both her and her carer (see box).

Adele was keen to join the local group but there were some barriers to be overcome before this would be possible. Adele had previously used two wheelchairs supplied by her local occupational therapy services, after which her file was closed, but as these became unsuitable and needed replacing, the 'system' broke down. The upshot of this was that for nine months Adele was unable to leave the house and lived mainly in one room.

There were several reasons why Adele was unable to organise a reassessment of her needs: she was unable to use her arms so could not organise her diary or

continued overleaf

maintain her address book; she could not remember which provider was responsible for equipment; her elderly carer, who undertook much of her physical care, had limited energy and felt unable to organise her care at this point. His previous attempts to do so had left him feeling unconfident and powerless to act and he relied on other supportive services to resolve problems.

The project worker discussed various solutions but Adele didn't feel able to use a voice-activated phone; and even if the local care co-ordinator were to phone regularly, Adele found she couldn't rely on recalling the issues she needed to discuss. The approach which did turn out to be workable was for Adele to receive regular home visits from professionals.

Communication

Three people who had home visits used a computer and communicated via email. Two had speech disabilities which made telephone conversations difficult or impossible but only one logged on regularly enough for email to be a practical way to arrange meetings or consult other users.

Concerns about meeting others with MND

One recently diagnosed user was afraid of meeting other people whose MND had progressed further. For another user, though, this had changed over time. Having backed away from meeting other people with MND she now felt that:

It would be quite a comfort to talk to other people with MND. I thought this would make me depressed, but over the course of time I have accepted I have MND, I know what's going to happen.

The majority of the second set of users (see Chapter 5) opted not to join the local group, though one person from this set chose to do so because:

You have to die of something and I don't have children to worry about.

The majority of the first set of users were older and had been living with MND for some years, so perhaps this was less of a barrier than it would have been for the second set. However, because these older users were more severely disabled, they experienced additional barriers such as problems with physical access, reliance on specialist transport and needing to organise more complex packages of care.

Barriers for carers

Although similar barriers could be encountered by people with MND and carers, several ‘carer-specific’ issues were raised during the home visits. This led to the decision to have meetings for two carers from the first set of users, to facilitate their participation in, and commitment to, the local user group.

- The time and energy expended on providing not only physical but also emotional support can leave carers with little energy and motivation for joining a group:

Because when you’ve got somebody with a terminal illness, living with it, and hearing them saying ‘I wish I was dead, why can’t I go to sleep and not wake up’, I mean [laugh] it’s not the type of thing you want to be living with.

- Where carers are mainly or wholly responsible for organising care, liaising with service providers can take up a great deal of their time and energy.
- Carers could be inhibited from speaking openly when the person with MND was present, particularly if they wanted to talk about the future and their partner’s death.
- Carers were sometimes resentful that their needs were not addressed by professionals and indicated that the local group meetings might reflect this imbalance:

You don’t have opportunities to raise your head and think about ... what might be good for you in the long term in quite a sort of calculating way, in terms of coping as a carer. Particularly in the face of the fact that you will be left outliving your partner.

- Older carers, in particular, might find it especially difficult to fulfil a caring role because of their own ageing, making it even more difficult for them to participate in a local group.

It’s ridiculous that they expect me at 77 to be doing the work of a carer of about 30 or something like that.

Organising care

Even for users who did not experience significant fatigue, the physical and emotional requirements of organising complex care inevitably took up much of their available time and energy. As one person commented, comparing this to their working life:

Getting all this organised costs more energy than running a business and many of the skills that are needed are the same.

During the home visits, people often apologised for raising yet again the problems they were having with organising care. This agenda seemed to sap their energies which might otherwise have been focused on maintaining a normal lifestyle.

Not all users' experiences of the service system were negative but the time and energy required to organise appropriate services and ensure their effective delivery could be a potential barrier to their active participation in the local group. At the same time, though, negative experiences could be used in a more positive way by forming the basis for a shared action plan and agenda for the local group meetings.

The next part of this chapter explores users' reasons for joining the local group or network and it was sometimes their anger and frustration with services which motivated them to join a group which would be seeking service change.

Motivation for participating in a local group or network

The majority of the users in the first set instantly welcomed the project and agreed to join the group. As the home visits and discussions proceeded, a number of reasons emerged which motivated people to join a local group (although with individual variations).

Seeking emotional support and information sharing

Most of the users who were opting to meet up talked of their need for emotional support and information from people in a similar situation. There was a desire to share thoughts and feelings with others affected by MND.

Anger and frustration about service provision

People who felt dissatisfied with their existing services or unable to obtain services they needed were strongly motivated to join the local group. Some were wanting support to resolve their individual problems with services and were more likely to become actively engaged in a group if they were angry about specific issues. Most of this stemmed from what they perceived as inadequate or substandard services. One person with MND explained how he wanted a campaigning group and he felt this to be more important than any research function; he was clear about not participating for 'sentimental' reasons:

No sympathy, I would not be here if I was being sentimental for my participation. We have to be a very high pressure group alongside researching as the latter is time consuming.

Users also hoped that the community development worker and other users would be able to contribute information, advice and advocacy which could help resolve their individual problems.

Awareness of models of good practice

Some users had experience of informed professionals who provided them with information and offered them options and guidance. Sharing these ‘models’ of good practice more widely motivated them to join the local group in the hope that this would improve services and educate other professionals.

Altruism

Group and network members were altruistic, displaying a concern for those they perceived as ‘worse off’, or ‘following on behind’. One user from the first set who chose not to meet up with other users was still keen to be involved as she didn’t want others to go through ‘hellish years’ of trying to deal with social services.

Using their skills and experience

Most users who joined the local group were motivated to become involved by using their experience and skills to improve services. They offered other group members (and professionals) advice on how to improve equipment and deal with social services. They also offered MND awareness-raising training for professionals. Users also suggested a workshop for local professionals at which they could raise problems and suggest ways of dealing with them (either as a ‘live’ exercise or by using video).

Users’ experiences of service provision

Users’ difficulties with service provision, which they described during the home visits, served as a starting point for the local group’s agenda and echoed many of the concerns raised in the research interviews.

Lack of information

Users can require inputs from many different services but, because of this, most had no idea who provided what, whom to contact and what kind of service they might

need. Many users were concerned that they would have changing needs and most were unsure how to access the advice and information about how to meet those needs.

Users' attempts to obtain information from agencies providing paid carers were often unsuccessful. They were unable to ascertain what services they could expect, what the schedules would be and who their carers would be. With one exception, care agencies' files in people's homes were insufficiently detailed to effectively share information with wider multidisciplinary teams or even with users themselves.

Vulnerability

People living alone had experiences of unfamiliar agency carers coming into their homes and alleged that on occasion they had been assaulted and victimised. Users with speech difficulties felt particularly vulnerable because they felt that this made it more difficult for them to be believed when they reported these incidents.

Professionals' attitudes, and lack of knowledge and understanding

Users were angry when they encountered professionals who apparently neither understood nor cared about the impact of MND on their lives. In this carer's words:

I feel that people think that this is a game that we're playing here with motor neurone disease, and it's no game. There's very, so many people down there on the council and social services who don't know what it's all about ... the sooner they become educated in it a bit better, the sooner they realise the kind of problems I've got. But at the present moment, I wouldn't trust any of them as far as I could throw them.

As this person pointed out, professionals' lack of understanding about MND could be painful:

It's nice for professionals to be honest, but they should then make the point to go away and find out what MND is about if they don't already know. It makes you feel lonely when people don't know about MND.

Loss of contact with specialist services

Users who were housebound and no longer able to attend the specialist clinic at the Centre often felt angry, unsupported and lonely at the loss of input from informed doctors and therapists they had come to rely on. Not only were they unable to

access specialist advice and assistive equipment but they became anxious when new symptoms appeared as the illness progressed. As a result they were reliant on their GP and the primary care teams, some of whom, users felt, were unconfident and under-resourced.

Lack of choice or shared decision making

Some users were angry when professionals offered services, treatments or interventions which they did not want to accept. This person, for example, felt there was a mismatch and that she was under pressure to accept something she did not want:

She's said to me several times over the years 'Have you ever thought of having a catheter?' and I say, 'I don't want a catheter, I don't need it' and I feel in the end they'll get me.

Although users recognised that professionals may have few resources, they often described their failure to listen to their views as part of a deliberate policy to limit their demands to what professionals could cope with. Users did not want ready-made solutions and some described meeting professionals who they felt came with a thinly disguised task list to be completed. One person with MND asserted that institutions were self-serving rather than patient or client centred:

Person with MND: *When you're ill you don't expect to have to fight, it's the last thing that you need.*

Project worker: *What did you expect when you became ill?*

Person with MND: *Well I expected people to help me, not to be given other people's idea of help.*

Lack of continuity

Users found it difficult when, for example, an occupational therapist would 'close down' their case or leave a phone message saying 'Call me if you need anything'. Users knew when they had a particular problem, but didn't always know what help was available, whereas a therapist who was in regular contact would be able to recognise what advice or equipment would be available.

Many users had the experience of phoning a therapist several times, only to be told that they had left the department and the user would have to join the queue to be reassessed.

Users' suggestions for service improvements

The empowerment of people affected by MND was a fundamental principle underpinning the BUILD project which sought ways of enabling users to put forward their views. Because this was a short-term project, many of their proposals for service change could not be followed through with local service providers. Nevertheless their suggestions, based on their 'lived' experience of MND, can be seen as a valuable contribution to the national agenda for improving service provision for people affected by MND.

Access to services

- When people are diagnosed with MND, all services should clearly state how they can be accessed and what they can offer.
- Services should state what they can provide for informal carers and should not assume that a person's partner, family or friends will make up any shortfall in paid support or care.
- Services should allow their staff to make home visits to users who are too disabled to leave their home, This should include hospital staff and social services management when necessary.
- All therapy services, and particularly occupational therapy, should not 'close down' people's files but should remain in regular active contact with users to ensure that with changing needs they can access assistive equipment, advice and other services.

Information about services

- There should be a clear and effective point of contact for users needing to access a service.
- Information should set out how entitlement to the service is assessed.
- There should also be contact details for alternative and complementary sources of support.

Communication

- Services should ensure that their staff are allowed sufficient time to meet with users who have speech difficulties or who have difficulties with organising their care.

Transport

- Users need access to reliable and appropriate transport, in order to be able to attend hospital appointments and other specialist services including therapy reviews and care co-ordination.
- Users should have access to their local community transport schemes to enable them to continue with social and leisure activities outside the home.

Relationships between users and professionals

- Users should be able to share their problems with professionals and be supported by them to find possible solutions, even if these do not involve professionals' more conventional or more orthodox approaches.
- Professionals should be able to offer users medical interventions, services or support, but should recognise that users should be able to choose whether to accept these suggestions.
- Although there is no cure for MND, users would appreciate the support of professionals so that they feel accompanied while facing the impact of MND.

Professionals' knowledge and understanding of MND

- Health and social care professionals should have access to information and training and development activities, to increase their awareness, knowledge and understanding of MND and the ways it impacts on people.
- This is particularly important for community-based professionals such as members of primary care teams and home carers who are unlikely to come across people with MND on a regular basis.

Organising care packages

- Some users will need support to organise complex care packages.
- Even where users are being supported by family or friends, they may still need additional administrative assistance with writing letters, making phone calls, and organising their diaries, contact books and other paperwork.
- Users may need face-to-face discussions in their own home to explore options for treatment or equipment before reaching a decision.

- Services should ensure that users have written records of discussions and service agreements which can also be shared with other multidisciplinary team members.
- Short-term or longer-term advocacy should be available, where appropriate, to assist people to access the support services they may want and need.

Equipment and adaptations

- When new assistive equipment is supplied, services need to ensure that it is suitable and that users know how to use it, in order to avoid equipment lying around unused.
 - Services need to ensure that their premises are fully accessible to disabled users, including the provision of suitably adapted ('polo mint') toilets.
- Some users need wheelchair reassessment and provision to be arranged.
 - Transport had to be identified which was reliable and comfortable and which could take users to meetings without delays or lengthy round trips.
 - The location of meetings had to be no more than a quarter to half an hour away from users' homes. This was necessary for carer meetings in particular, but people with MND who used wheelchairs were often unable to spend a long time travelling to meetings.
 - Users were reluctant to attend meetings more than an hour long.
 - Background material might need to be recorded onto audio tape for people who had difficulties holding or turning papers.
 - Some users were exhausted and cynical about service providers. It became clear that it would be necessary to work with some users to resolve problems before they were willing and had the energy to attend group meetings.

Summary

- Users had had little or no contact with others in their locality affected by MND.
- Some users experienced barriers to social activity but there was no apparent correlation between social isolation and choice to become involved in the local group.

—— The local group and network: barriers, motivations and emerging agendas

- Users identified barriers which needed to be overcome if they were to be able to participate in a local group. These were: transport difficulties; problems with physical access; fatigue; limited available time due to frequent appointments with health professionals and agency carers; fluctuating health; changing needs for services; communication difficulties; and concerns about meeting others with MND.
- Other barriers to user involvement identified by carers included: the time and energy needed to organise formal care services; the time and energy expended on providing physical and emotional support; potentially different agendas; concerns about leaving the person with MND at home; limited free time to pursue their own interests and activities; and resentment that professionals were unsupportive and did not recognise the burdens of caring.
- Key motivating factors for user involvement were: anger and frustration at inadequate or poor quality service provision; their own expertise and skills; their awareness of good practice; a desire to improve services and educate professionals; hoping that their individual problems with services could be resolved; wanting to help those worse off or less severely affected; wanting to share information; and mutual support with others in a similar situation.
- Users described the impact of organising a complex package of service provision which appeared to be as disabling as their physical symptoms. Few services seemed to recognise how their practices exacerbated this impact.
- Users' experiences of service provision which formed the basis of a group agenda or action plan included: lack of information about services and entitlements; physical and psychological vulnerability to harassment and abuse; professionals' attitudes and lack of knowledge about MND; loss of contact with specialist services; lack of choice and shared decision making with service providers; and lack of continuity of contact despite users' changing needs requiring changes in service provision. This seemed to create distrust of all local authority and social services and also served to motivate involvement in a user group.
- Users made suggestions about ways in which current services could be changed and improved. These focused on access to services, information about services, communication, transport, professionals' attitudes and knowledge, care packages, and equipment and adaptations.

7 The local group and network: getting going

This chapter describes:

- the practical arrangements for local group meetings
- the local group meetings
- the activities of the local network.

Practical arrangements

The home visits had enabled users to consider the practical arrangements which would need to be made before the group could meet. The original planning and some adjustments made after the group started are described here.

Venue

Many users had offered to host meetings in their own homes but as three or four people who used wheelchairs wanted to attend, no one had sufficient space to accommodate them. Users might also feel they could discuss their experiences more freely if they met in a 'neutral' venue.

Proximity was also a major consideration as some users were unwilling or unable to travel long distances. Carers also preferred to limit their time away from home to not more than one and a half hours. To also allow for travel time, this meant finding a central venue but fortunately group members lived relatively close to one another so no one had to travel for more than half an hour to meetings.

Users were unwilling to meet in a venue associated with service provision and a community hall was found which was relatively central and had access for disabled people and wheelchair-adapted toilets.

Groups using the community hall had to have their own public liability insurance and this was arranged by the project worker at a cost of about £200 for one year.

Transport

Reliable and comfortable transport was an important consideration for the group. Minicabs were considered but, although they would be suitable for carers, the people with MND would have to remain in their wheelchairs throughout the journey. Some users had found black cabs useful, as they are wheelchair adapted, but others had found them unreliable.

On the recommendation of one group member, the borough's community transport scheme was booked but the appropriate kind of van was not available for the first meeting, so private transport was arranged. For the second meeting, a lack of volunteer drivers meant the community transport was again unavailable so private transport was used again.

At the first meeting, private transport brought people to the meeting an hour early, with the result that they almost decided not to come again. For the second meeting, specific pick-up times were requested, which was satisfactory for users, although it was an expensive option (two half-hour return journeys costing £100).

Meeting times

Most users could get to a mid-morning meeting although the project had to organise additional paid carers to enable some people to be dressed and ready for the transport. One person used paid carers from the council's in-house agency which offered no flexibility but an offer of help from the MNDA enabled the user to negotiate carer assistance for the day of the meeting.

Personal care assistance

We were concerned that some people would need assistance to use the toilet (or, for men, to use bottles). This can affect people's dignity and even be a barrier to attending meetings and one user asked a paid carer to attend to provide personal assistance.

At the first meeting it became clear that some users would need occasional personal assistance. For one person, their relative provided this support, and for another they were too ill to attend the second meeting although they had hoped to be present.

At the first meeting, the personal assistance arranged for one user who felt he would need it fell through, but with this person's consent, the volunteer assisted. At the second meeting the group member had again arranged personal assistance, which again fell through and the project worker assisted.

Communication

Before the meetings started, it was necessary to consider how people with speech difficulties who used lightwriters¹ would be able to put their views forward and generally participate in discussions. It had been anticipated that people using lightwriters would need someone to assist them to put their views forward.

At the first meeting the chair found it difficult to ensure that users with speech difficulties had an equal chance of their views being heard. To address this, the project worker monitored how the group member who used a lightwriter was following and responding to the discussion and alerted the group to the user's wishes to have their views heard. She also had to remind the group what the user's comments referred to as they related to issues which had been discussed several moments earlier. To resolve this difficulty, the group agreed that people using lightwriters would have someone at the meeting to assist them.

The group also agreed that there would be five minutes at the end of each meeting to plan the next meeting's agenda to allow lightwriter users to record their comments on particular topics which would be played at the next meeting.

Roles in the group

The community development worker acted as secretary to the meetings, noting down key points on a flip chart. She was there to work at the group's direction although she would advise how the group might want to establish itself and develop, and how it might wish to put forward its views to other organisations.

The suggestion was made that the group nominated a chair. At the first meeting, group members were asked to nominate a chair who would facilitate discussion and ensure everyone had a chance to have their views heard. With the group's consent, the volunteer chaired this meeting. At the second meeting, one of the carers acted as chair.

The meetings

An account of how some of the practicalities which arose at the two meetings of the local group has already been given. This part of the chapter provides an account of these meetings.

During both meetings, social connections were made, particularly between two people with MND who realised that they had known each other slightly several years before getting MND. On the users' behalf, the project worker put in a request to the Centre's care co-ordinator to arrange for them to meet socially.

At the end of the first meeting, one of the members produced some champagne and asked the group to toast the inaugural meeting, stating that he felt that forming the group would help individual members who were suffering real problems with their care services. This and other comments from users indicated that the group felt a fair

degree of ownership of the group, despite the relatively high level of facilitation that was required by the project worker to enable members to attend meetings.

The project worker and the volunteer (who chaired the first meeting) agreed that she would adopt an open style of chairing, not pursuing an agenda but enabling group members to raise points and describe their own situation. As the discussion developed from these descriptions of personal situations, a possible group agenda began to emerge and points were noted down by the project worker on a flip chart (see box).

Flip chart from the first meeting

- The BUILD group is our group
- To swap ideas about services like: occupational therapy: how do you get it? transport: Dial-a-Ride can be good, but the telephone booking line is always busy
- To swap information like: warnings about bad services
- Decide how to change bad services: give them our expertise; ask for individual treatment; professionals need to go to people's homes
- Use a good professional to put our ideas into recommendations and get them to listen
- Housing – a nightmare if you need housing off the Council (paperwork mountain) (chain ourselves to the railings to protest – one suggestion)
- Do professionals help?
- Responsibility is put on the carers
- Tell each other how to cope with the authorities.

This open style of chairing was continued at the second meeting, chaired by a carer, and many of the same concerns about service provision were discussed and support offered to group members who were experiencing particular problems.

During both meetings, members commented that there were services they had not known about and would then pursue for themselves. This comparison of individual situations also led members to say that they felt that the services they received were relatively good or bad compared to the experience of other users.

In this way, local inequalities between services became apparent and users suggested that boroughs where services were not working so well could learn from those considered to be models of good practice. At the second meeting, the chair, who had attended the meetings of carers with the local occupational therapist, suggested that the project worker invite him along to the next meeting to work with the whole group and advise them how services could be improved across the three boroughs.

At the first meeting, one user described his lack of appropriate housing which led another group member to offer to go and chain herself to the town hall's railings and demand a better service for him. The group laughed, comments such as 'anarchist' were made and the discussion moved on.

After the first meeting, the project worker recognised that she could have suggested to the group that they supported this as part of an action plan. She confirmed with the user that she was in fact willing to go down to the town hall and at the second group meeting asked the group if there were any other users willing to join in and make it a group outing. This was agreed on the basis that the user who was awaiting housing needed the support.

At the end of the first meeting, all the group members attending agreed that, if funding for the project worker was not continued, they wished to meet up monthly.

Local network activities

The nine users who formed the local network wanted to be kept in touch with the local group's agendas. Nicola, one of the most active of these network users and someone who had a wealth of experience and expertise, worked with group members in a variety of ways.

I wish I was not so ill I could do some more work ... I think this is really important work that you are doing but it's a really hard one, that you've taken on.

Although unwilling to attend group meetings, Nicola's contributions to the project, described here, demonstrate how network members can participate in user involvement in their local MND community.

Offering advice and consultancy

Nicola suggested she could offer advice and consultancy, and the project worker approached her at the request of a group member to ask about the Social Services Department and the care agencies which the group member was having to deal with.

Drawing on her knowledge and experience, Nicola offered the following advice:

- persevere with complaints, 'Fight, fight, fight'
- treat good carers like gold dust
- cut the Social Services Department out when they've agreed to fund an adequate care package
- organise details of your care package directly with the care agency's managers.

Exploring possible initiatives

Nicola suggested exploring two possibilities: developing a group of (formal/paid) carers specifically trained to work with people with MND; and drafting an advert to raise funds for MND work, describing the rapid progression of MND from the perspective of someone with the disease.

Planning a training video

The project worker made several home visits to Nicola during which she dictated a script for a training video highlighting the need for specialist carers and the vulnerability of those living alone and experiencing care agencies' bad practices. The project worker wrote an initial draft and Nicola worked this up further.

MND research

Nicola was interested in research techniques and, at the project worker's suggestion, she met a researcher at the Centre to discuss her ideas and find out about his work. Nicola thought others would be interested in this and, again at the project worker's suggestion, she asked the researcher to write something which she would read to ensure it was understandable to an informed lay audience before it was posted on the BUILD website.

Other local network activities

Two other network members, both with young-onset MND, shared Nicola's interest in research and were regular internet users.

The project worker asked what information about research they would want access to and how they would like to contribute to the research process. A letter setting out

their requests was sent to the Centre's director and the response sent to these network members and posted on the website.

These two local network members also discussed amendments to the BUILD website with the project worker and suggested ways of retaining site users' interest (see Chapter 8).

Local network members' interest in research activities and wanting to obtain information about research on an international scale appeared to be rather different from local group members' concerns about community health and social care support.

Summary

- Practical considerations for enabling people with MND and their carers to attend group meetings have to be responsive to the restrictions experienced and priorities set by users. Practical arrangements were made before the first meeting but needed reassessing once the group had started meeting.
- Contrary to expectations, the group that decided to meet were mostly severely disabled and supported by complex care arrangements. Making arrangements for the meetings therefore required time and resources but, having met up, the local group was committed to meeting once a month.
- A venue had to be found which did not involve users making lengthy journeys, with premises which were physically accessible for wheelchair users including suitably adapted toilets. Users also wanted a venue which was independent of service provider organisations and which could enable them to speak more freely than meeting in each other's homes. A public liability insurance policy also needed to be obtained.
- Reliable and comfortable transport is essential for enabling severely disabled users to attend meetings. The local community transport scheme was not able to meet these requirements so the project used the more expensive alternative of a private company.
- The timing of meetings had to accommodate some people's use of paid carers to be ready to go out, and the length of meetings needed to allow for users' available energy and the amount of time carers could be away from home.

- Some users requested personal care assistance during meetings although the arrangements for this could sometimes fall through.
- Users with speech difficulties had to be considered and practical solutions offered to enable them to participate in meetings, particularly if they used lightwriters. They needed to be able to raise issues and to respond to issues raised by others in the group, with volunteers to assist this process.
- The project worker acted as secretary during group meetings and implemented action points at the direction of the group. Users nominated one of the members to chair each meeting.
- Social connections, exchange of information, advice and suggestions for campaigning needed to be followed through by the project worker reflecting these back to the group to consider as options for action.
- Network members who chose not to meet up with other group members had a fund of experience and expertise to offer the group, and one local network member was able to provide advice.
- It was possible to link in work with some local users to activity on the virtual forum. Further work would be needed to enable local users to have greater ownership of the virtual forum.
- Some local network members were particularly interested in finding out more about current research into MND and wanted to have more input into the research process. This contrasted with the local group members who were more concerned about shortfalls in current service provision.

Note

- 1 A lightwriter is a tool for communication which consists of a keyboard, a screen and a speech synthesiser. The user types in what they want to communicate, the screen displays this and the synthesiser 'speaks' the words.

8 Developing the virtual forum: early experiences

This chapter describes the development of a virtual forum for people with MND, carers and professionals, and highlights emerging issues from the first few months:

- mapping and reviewing existing MND sites
- users' views on development of a UK site
- the characteristics of BUILD site users
- how the virtual forum was used
- sustainability of the site
- the involvement of professionals
- implications for hosting the site
- users' suggestions for the BUILD site and virtual forum.

Mapping and reviewing existing MND sites

The first step was to map and review existing English-language MND sites to assess the most appropriate format for a BUILD site. Two main types of site were identified (although a host organisation may provide both).

- Static sites usually have information provided and controlled by the host organisation. This remains largely unchanged, apart from updates, although there are usually regularly changing 'news and events' pages.
- Dynamic sites use forums, chat rooms or galleries which enable site users to post information, messages and images, allowing community activity and exchange. The host organisation is an active partner in this relationship, creating an ethos and distinct brand.

The majority of dynamic sites reviewed are USA-based with a predominantly American audience so this chapter uses their terms for site users which are:

- PALS for people with MND/ALS
- CALS for carers and family members of people with MND/ALS.

Our search of dynamic sites found three fairly distinctive types of hosting: national/regional patient representative organisations; academic and clinical organisations; and sites initiated individually or collectively by PALS/CALS.

This review highlighted a number of issues relating to BUILD's proposed development of a UK-focused site. From a positive viewpoint: many users of these sites appreciate the emotional and social support offered by other site users; sites are available to any English-language user of the internet; support often includes advice about treatments and access to healthcare; and some sites support discussions about preliminary research findings and clinical trials, prescriptions and complementary drugs, treatments and supplements.

However, there were some drawbacks to these sites – mainly because of their limited relevance to the UK with its different health and social care services and systems. In addition, the USA has a larger virtual community of PALS/CALS and we were concerned that a UK site might not attract sufficient users to be sustainable (an issue we return to below).

Views on the development of a UK-specific site and virtual forum

Having reviewed existing sites, we explored further the 'market' for a virtual forum. Early suggestions which were either posted to the site or emailed to the project indicated that PALS/CALS supported the proposed virtual forum. This carer, for example, liked the idea of contacting others in a similar situation:

This seems like a good idea to provide ways and means of coping with this, also it's important to be able to speak with others that understand the problems, I hope I can help in some way.

Some users were interested in finding out about research and although some wanted space to talk among themselves, others, like this person, wanted discussion with professionals:

I particularly like the idea of hearing about research projects and getting information on progress and I would like to be able to exchange views and ideas with people with MND etc., particularly with the involvement of professionals.

Several people suggested that the site should include an element of humour and issues should not focus solely on MND:

I have found that it is easy to let mnd take over your entire life, with physio's district nurses occ. Therapist speech therapist hospital visits, mnd conferences, group meetings, fund raising etc. so I think for the site to remain popular it needs to offer hope, practical advice and some light hearted relief.

Subsequent postings further confirmed support for a UK-specific site as these messages indicate:

thank you for your email, I am a carer for my partner who has mnd and we both find talking to other people with mnd is a big help, my partner has come to terms with his illness more since we found a page of live chat to other pals and cal's. Mostly hundreds of miles away, so to have another site to chat to people who live closer, I think is a wonderful idea and I would like to say thankyou.

Just discovered this site tonight, it's very good and a UK site for MND was really needed ... My Husband died from MND last year and I used the ALS site a lot but this one is more pertinent to this country. Well done.

Site users had given a great deal of thought to the format and content of the site and their suggestions can be found at the end of this chapter.

There is clearly support for a UK-specific site but some site users had difficulties using their computers (although they were still able to post their views):

... SORRY FOR TAKING SO LONG TO REPLY my hands do not work too well and as I use speech synthesis this uses most of my energy most days.

People registering on the site were asked if they had any concerns. This single response came from a professional who wrote:

Not really. I am often involved in supporting people with MND. There is potential for difficult situations if for instance professionals became the focus of adverse (fair or unfair) critical attn.

Characteristics of site users

Table 3 lists the characteristics of site users registering with the BUILD site.

Table 3 Characteristics of registered site users, May–October 2002

Registrations received	52	
People with MND	28	
Carers or family members	12	
Bereaved carers or family members	2	
Professionals	9	7 professional role only 1 bereaved carer additionally 1 current carer additionally
Academics	1	
Country of residence		
United Kingdom ^a	44	23 people with MND 10 carers or family members 2 bereaved carers or family members 9 professionals Ethnicity ^b : 39 White British 3 White Irish 1 Black African 1 Indian
United States	5	2 people with MND 2 carers 1 bereaved carer (2 White Irish 1 White Anglo-Saxon 2 White)
India	1	1 person with MND (Indian)
Italy	1	1 carer (Italian)
Canada	1	1 bereaved carer and also professional (French-Canadian)
Characteristics of people with MND (28)		
Gender	21 men 7 women	
Age ^c : 20–30 years old	1	
31–40	4	
41–50	6	
51–60	10	
61–70	4	
over 70	2	
Unstated	1	
Living with spouse or partner	24	
Living with family	2	
Living alone	2	
Under 2 years from diagnosis	7	
Over 2 years–under 5 years	13	
Over 5 years–under 10 years	3	
Over 10 years	4	
Unstated	1	

^a Geographical range was from across the UK with three from London.

^b Definitions taken from the 2001 Census.

^c 18 per cent of site registrants were under 40, compared to an average of 13 per cent of the MND population being under 40.

Table 3 Characteristics of site users, May–October 2002 – *continued*

Types of professionals	9	2 nurses 1 research doctor 3 therapists 1 regional care adviser for the MNDA 1 care co-ordinator 1 retired
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How the virtual forum was used

In the first few months after the forum was launched, PALS/CALS posted several different kinds of messages which are described here (although there are overlaps) with examples of postings.

Introductory messages

People often posted up an introductory message, sometimes including a brief synopsis of their experiences of services and passing on advice and expertise. For example:

I have MND and was diagnosed in Oct 2000 ... My walking was getting very difficult, until I was prescribed a FOOT ORTHOSIS to correct the drop-foot problem that was constantly tripping me up. I would strongly recommend this to anyone with MND affecting their legs, but you may have to ask for it. I received it maybe 12 months after I needed it.

Requests for advice and/or information

Some postings requested information about the nature or cause of MND which would be relevant to a wide community of people affected by the illness. This carer for someone with bulbar MND posted the following request for advice:

When one has no speech, limited communication, Question: what can the carer do to help you in a positive or social way?

Jellyhead (the username for a site user with MND), for example, asked for advice about accessing equipment and adaptations:

With this in mind (everything taking about 6–12 months to happen), what advice could someone give me about modifying my flat. I want to get my flat prepared for when I'm more disabled. This things I need are, small ramp for 2 entrance stairs, removal of bath in small bathroom and refurb into a shower cubicle with

bars, seat, etc. Bed lift etc. Do I need to wait until I cannot cope before action is taken or is there a possibility of getting this work done in advance. Tips from people in similar circumstances would be appreciated.

Sharing information

Many site users shared information as a way to help people subvert or get around the system of service provision, as with this posting from a carer:

Our neurologist said we could claim under special rules regardless of the 6-month 'peg it' clause ... he said that no one can predict exactly what the course will be in any individual and so the social services people accept claims from anyone with MND even if they are doing ok ... I advise you to claim under special rules anyway. Out of interest, have other people done this? Maybe we were breaking the rules.

Sharing information also revealed inequalities experienced in service provision and the inadequate resources that some people received.

Campaigning

Campaigning on issues affecting people with MND in the UK is primarily organised by the MNDA and Jellyhead suggests they might help people obtain discounts on vitamins:

Who would like to see this? Maybe if there is enough of us groaning something will be done.

Site users also direct people on the forum to contact the MNDA in connection with campaigns. For example:

have you contacted the MND association I seem to remember an article about meeting with government dhss and mnd to sort problems with claims.

Countryboy, who is involved in the campaign for fast-tracking benefits payments in Wales, responds to Jellyhead who had asked for advice about claiming benefits:

At the conference I provided details of your problems to people from [the MNDA] HQ in Northampton. I stressed the urgency of your case but the answers I got were not very promising. It seems there are quite a few people in the same boat as you ... The outcome of the conference has been passed to the group in

England who are fighting like us in Wales for the automatic payment of the top level of DLA, etc. At this time the only thing I can suggest is for you to ask Northampton to take the matter up with the minister for Social Security at Westminster, they do have contact with his office.

Moving between US and UK sites

Some UK site users who were really active surfers used multiple sites and dipped into the BUILD site from time to time. As the site developed, some postings, such as this one, discussed the strengths of US-focused sites:

*By the way I've also logged on to a US site started by Steve Holly:
<http://www.alschat.com/echat43/putlic/index.html>. It's very popular and chatty, extremely chatty, but I for one had a lot of 'Hi ron' greetings, but few answers to questions posed. Could be my awful questions, or may be that they know each other but not me. You probably know that one anyway.*

Some site users gave advice about vitamins and supplements based on information gathered from other websites. This person, for example, relayed information about the possible benefits of taking prescription drugs:

Although there are reports to suggest they may help (as they have in mice with MND), the problem is getting hold of them. Some people like to try anything! What have they got to lose? Speak with your consultant or GP if you wish to try some 'unproved' drugs, they may be sympathetic and prescribe. PLEASE NOTE I AM NOT A DOCTOR.

This concerned one of the staff involved in setting up clinical trials at the local specialist centre. Widespread and covert taking of prescription drugs obtained via the internet amongst trial participants would effectively make these trials null and void. Researchers were aware that 'lack of compliance to trial protocol' probably happened anyway on a small scale and was unavoidable, but they were concerned that sharing information and encouraging non-disclosure of use of prescription drugs might increase the problems.

Clinical trials and research

A few months after the virtual forum was launched, several clinical trials were about to start and Jellyhead posted a question which stimulated debate:

I understand there are some trials on the horizon. How do you feel about 1 in 3 of candidates receiving a dud. Personally I disagree. Surely they must have enough historical data on how people who receive nothing progress. Why is it that people with terminal diseases are made to be put in a lottery, even when there is a glimmer of hope.

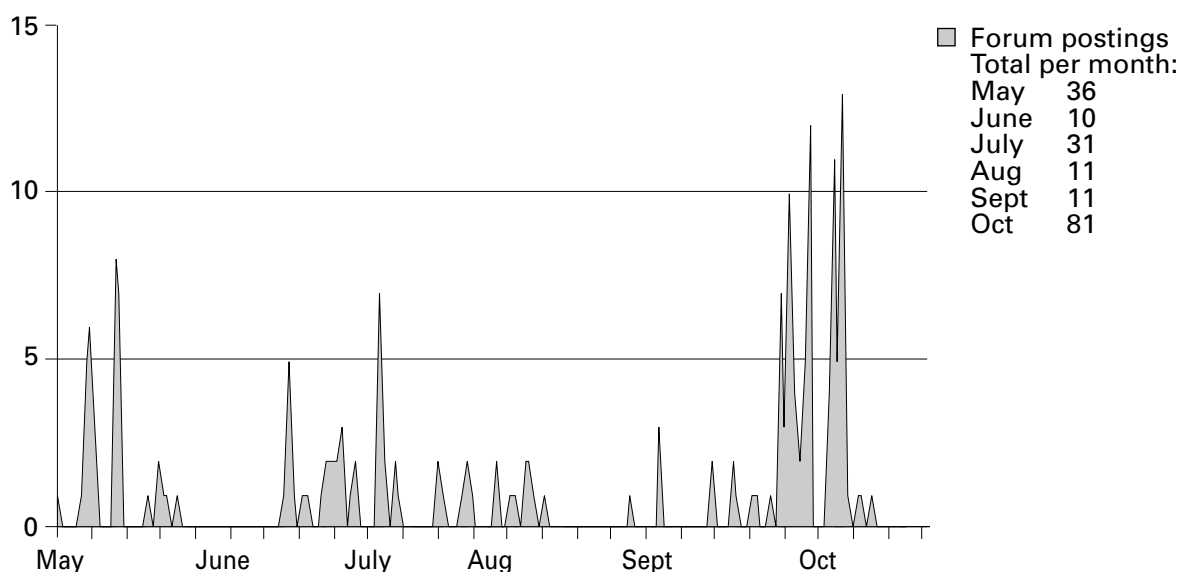
This questioning of the use of placebos led to a posting from a professional, reluctantly justifying their use from an academic/research viewpoint. This prompted a further response from Jellyhead:

Thank you Animal for your reply, and I understand many of the points you have raised. But who determines 1 in 3, why not 1 in 4 or 6. At least give us terminally ill people better odds. Is it not also possible to use persons not on the trials as reference's? ... To my knowledge no trials have been conducted for the past two years. This time could have been used to collect data for future trials. In this day and age I feel the placebo trial process is outdated.

Sustaining the virtual forum

As Figure 5 indicates, the level of activity on the virtual forum fluctuated considerably. After an initial flurry, the number of postings reduced markedly through June and again in September, raising questions about the sustainability of this method.

Figure 5 Level of site user activity, May–October 2002



Some site users obviously felt a sense of ownership of the site and some responsibility for ensuring its success as these postings indicate:

This afternoon I had an appointment with my GP. While I was with him I tried to tell him about the new site. He was very pleased at the news but because I did not have my lightwriter with me I was unable to explain all the details to him. Would you or any members of your team have any objections to me showing him a copy of your original email, and a copy of the draft I sent you ...

Hi Keren, well the forum works ok, but traffic seems to have diminished, I hope its not me!

Sometimes requests for advice went unanswered, perhaps because few people were using the site or because site users lacked relevant expertise:

Do any health professionals have advice or thoughts about the use of non-invasive ventilation – the NIPPY. I got no replies from people with MND to a previous post, so would like to hear from the medics or researchers please.

When the site became quiet, regular site users appealed to others to continue using the forum:

Hi anyone I am sure this forum could be helpful but it seems no one is using it, please feel free to talk I have 2yrs. exp. caring for my father who has just gone into a nursing home and I was thrilled to talk to someone in the same language someone who knew what I was talking about re MND bye.

Where a posting was unanswered, some site users emailed the project worker directly who responded by encouraging them to post comments about diminished traffic on the site. For example:

I have looked at the messages for several days and there has been no additions at all, whats up?

This provoked the following response from another site user:

Until a big enough audience is captured, people will stay with braintalk and discussals ... I feel for this site to succeed it needs to be aimed predominantly for European/UK sufferers and MND charities in Europe should be pointing people to this board. Remember some people just read and don't post, so although some advice may not get responded to, I guarantee it would have been

read (and maybe used). I would be interested to hear from others as to what they would like to see on this site.

After a particularly quiet period, Jean, a young woman with MND, left five messages, the last one appealing for responses:

hi im new to all this I have wrote no end of messages on the forum and no one seems to write back I thought we were all in this together

The next day there were two replies. Ronnie and Jellyhead both posted messages introducing themselves and the exchanges between Jean and Jellyhead were the first that seemed like a conversation:

Thanks for replying, keep positive I do, I don't class my self as dyeing as I have everything to live for I just blank it out I use to cry a lot but not no more I feel better than ever apart from stiffness and a wobble take care love Jean.

To which Jellyhead replied:

I'm the same ... whats the use in worrying, I'm starting to walk a little bit like a thunderbird puppet. What medicines and vitamins do you take?

When, as in this case, two people made particular connections this often prompted offers to email directly, bypassing the more public arena of the forum.

Interaction with professionals

Professionals were circulated with publicity material about the virtual forum locally and at national conferences, and early postings from site users indicated that they would welcome the opportunity to discuss issues with them.

The level of postings from professionals was low, but they were almost invariably in response to a direct approach by the project worker to registrars and clinical trial staff at the Centre, asking them to respond to questions posed online by PALS/CALS. This moderation on the project worker's part elicited quite a high response rate.

There was an issue about how professionals should identify themselves, bearing in mind that they could be seen as representing their organisation. Some chose to post under a pseudonym, some used their own name and some postings were made as an anonymous contribution from a professional. Some professionals described

themselves as carers for people with MND who also had a professional role but others used the site solely because of their professional interest.

The reasons why some professionals might be reluctant to post directly to the site are not entirely clear but this message highlights some of the issues:

My own bias has been towards pragmatic openness but folks are different & as a practitioner it is clear we have to err on the side of caution & build a rapport before being able to discuss the very practical issues honestly & with any humour.

As this example shows, sometimes site users wanted opinions from neurology registrars about the potential value of suggested treatments they had found on other sites:

Subject: Professional opinion pls:

Please give me an opinion on Scleronet, there are claims of 80–100% improvement to patients [link to site given]. please go to the following site for more info [link to site address given] THESE ARE SOME BIG CLAIMS, MEDICAL OPINION WOULD BE APPRECIATED

This led to a series of detailed discussions about supplements and trial drugs between UK neurologists, research registrars and the trial nurse at the Centre which became increasingly informal. Jean asked:

What is your advice on this new supplement LUTIMAX, Do you think it is worth taking, or will it harm us?????

To which the Centre's clinical trial nurse replied:

Can't find much info on it Jean – you know any more about it? The only site I can find had a personal account from someone with ALS... but without knowing what is actually in Lutimax, we can't advise on the safety of taking it.

Discussions between PALS/CALS and professionals on the BUILD site seemed to be a way of disseminating information about the 'system', but occasionally the professionals' responses seemed to close down discussion – perhaps because of the weight of information, or their 'expertise'. Also perhaps there was a mutual assumption of a role for professionals that left site users without sufficient space to create a role for themselves.

Implications for hosting the site

BUILD, including its website, was based at King's MND Care and Research Centre, so did the fact that some site users would also be using the Centre's services affect what they might post on the site, particularly if it was critical of service provision or research linked to the Centre?

There were some indications from the BUILD site that some assertive users were wanting to debate the best ways of sharing information about research, securing treatments and discovering a cure for MND, but there was also evidence that site users might edit their postings, aware that the site was connected to the Centre.

Other postings on the BUILD site suggest that appearing to criticise the host organisation could be problematic. As this BUILD site user said, referring to the MNDA:

I'm having problems with them [the MNDA] as well but I don't like to criticise as they probably help some people.

This raises the question as to whether a response similar to this would have been posted on an MNDA-hosted site.

Users' suggestions for the BUILD website and virtual forum

The website should be available to:

- people with MND
- carers
- doctors (including GPs)
- district nurses
- home care staff.

Newly diagnosed people who are not in contact with the MNDA should be informed of the website by their neurologists.

Information and advice

More detailed information and links to other sites should be available and targeted at the following groups.

People with MND need information and advice on:

- MND, different types of MND, its effects on the body, and possible causes
- medication and symptomatic treatments (e.g. ventilation, gastrostomy feeding)
- potentially beneficial dietary supplements and vitamins debated on the internet, with pros and cons, and how to access them (even if the benefits are not scientifically proven)
- potentially beneficial drugs prescribed for conditions other than MND (even if the benefits are not scientifically proven)
- advice on appropriate exercises and exercise levels for self-help
- self-help fatigue management
- dietary information including food preparation and products such as those used to thicken drinks and soups
- therapy services and widely used equipment (e.g. ankle/foot orthosis)
- equipment guides, particularly newly developed assistive technology with reviews by users
- symptom management at home, particularly the less life-threatening but worrying symptoms (e.g. spasticity, clonus, emotional lability)
- financial and welfare benefits advice
- the scope of services, including speech therapy, physiotherapy, home care services, respite care, etc.
- strategies for dealing with speech difficulties
- adaptations to housing, funding sources and possible solutions (e.g. through-floor lifts), with indications of time required to install these

- mobility-related information (e.g. car finance, assessment centres)
- reminders of monthly events diary for fundraising events etc. (e.g. from the MNDA).

Carers need information and advice on:

- all the suggestions (above) for people with MND
- lifting and handling people and equipment to assist with these
- how to use medical equipment (e.g. ventilators, suction machines)
- strategies for communicating with people with speech difficulties
- carer support services, including carers' breaks, and the costs of these.

Doctors, including GPs, need the following information and advice which could be provided through their health authority:

- early symptoms
- referrals to neurology services
- diagnosing MND
- research
- new drugs
- strategies for communicating with people with speech problems.

District nurses and other primary care team members need information and advice on:

- MND and its impact on patients and families
- care techniques
- strategies for communicating with people with speech difficulties.

Other suggestions:

- people with MND and carers should be able to use the forum to exchange experiences and pass on tips which might be of help to others
- the website should be accessible to people from black and minority ethnic communities whose first language may not be English
- the website should offer 'entertainment' as debate and satire, even if this risks offence (e.g. the most ridiculous statement by a professional, the most embarrassing communication gaffe)
- site users should be able to campaign on specific issues such as increasing the number of neurologists, linking with MNDA's ongoing campaigns, improvements to pay and conditions of home care staff
- online petition forms could be used to gauge support for new campaigns
- people with MND should be able to participate in monitoring and reviewing the benefits of supplements and vitamins, even if this is not acceptable to the research community
- there should be information on previous and current clinical trials with information about their location, their rationale and procedures and protocols, progress to date and contact details for recruitment of participants.

Summary

- BUILD found no existing UK- and MND-focused websites offering dynamic formats such as virtual forums. There were numerous US sites with discussions covering a range of relevant issues and accessed by a large and active virtual MND community, though some of the content was more relevant to US health and social care systems.
- Site users expressed an interest in a UK-focused forum and several users provided the project with information and advice on technical issues, design, content and recruitment.
- With limited time available and modest financial expenditure, a BUILD site was launched with a virtual forum format and optional registration.

- In the first six months, 54 per cent of those who registered were people with MND, 27 per cent were carers/family members, and 19 per cent were professionals/academics. Eighty-five per cent were from across the UK. Of those with MND, 18 per cent were 20–39 years old and 58 per cent were aged 40–59.
- Many of the forum postings by site users had a specific relevance to the UK MND community, focusing on their experiences of service provision.
- The BUILD virtual forum was used for introductory messages, requests for advice/information, sharing information, campaigning, and information about clinical trials and other research.
- Some site users culled information from US sites and translated it to the UK context, specifically regarding clinical trials, novel treatments and supplements.
- The level of postings fluctuated. The reasons are not entirely clear. There was only a limited publicity budget and some site users reduced their involvement if their messages received a poor response. It also proved difficult to engage professionals and some did not have access to the internet at their workplace.
- The project worker found that the most productive way of encouraging site activity was to recruit users and professionals to respond to messages, rather than responding directly as moderator of the site.
- Some site users appeared to be aware that the site's hosting organisation was also a service provider and modified their postings accordingly.
- Some people with MND debated with neurologists and researchers using the site about access to novel and unproven treatments for people with MND, clinical trial protocols and the use of placebos. They also challenged researchers' commitment to finding a cure for MND.

9 Capturing the learning

BUILD looked for common ground between a disparate set of people affected by MND and examined whether this potentially overwhelming experience shared between people of different ages, cultures and backgrounds would transcend differences between how users identified themselves and the communities to which they belonged.

What about the original aims?

During the project, BUILD's original aims (see Chapter 2) changed, partly because of the relatively short time available, but also for other reasons.

Capturing the learning from the wealth of material about the process of developing the local group and virtual forum became more relevant than assessing the effectiveness of both approaches in delivering service change. Agendas emerging from the local group and virtual forum did include a concern about services, but there was the equally important issue of testing the relevance of these newly established groups.

Our original aims of establishing a local group and virtual forum also changed with the unforeseen development of the local network which enabled us to consider the benefits and disadvantages of this 'user-suggested' approach to engaging with a group that was always going to be particularly challenging to involve.

The aim of developing a service provider partnership panel to respond to a user-defined agenda was discarded, partly because the PCTs' user involvement strategies were still in their formative stages. The local group had also not yet reached the point of defining its agenda although several of the group suggested the alternative of working with trusted professionals to define a set of priorities for consideration by service providers.

Although BUILD moved away from some of its original aims, we saw this as an indicator of success, being true to the project's ethos of allowing users to begin to define their own agendas.

Who sets the rules?

To what extent was this a user-defined project? It wasn't for most of the project. The original agenda was defined by the project team with advice from the volunteer, the JRF Advisory Group and committed professionals. One 'rule' was that the project would develop in response to users' participation, but as with any project there is an

impetus to continue with the aims agreed with managers – and possibly with funders. When a project is under way, it can also be difficult to find time to review and possibly amend the original aims. Publicity about BUILD, the topics covered in the research interviews and the issues discussed during the home visits inevitably provided a framework of aims, methods and possible outcomes.

As the project developed an agenda began to emerge. When a campaign about one member's housing problems was suggested at the first local group meeting, this took the project worker by surprise, although any member could have suggested abandoning the idea of a group or changing its aims and ways of working. There were, however, indications that local users felt ownership of the agreed aims and methods. In postings to the site, virtual forum members also indicated that they were committed to BUILD.

What could you get for your money?

BUILD found that in order to support meaningful user involvement, resources must be provided to enable a representative range of people affected by MND to take a full and active role. Without adequate funding, the involvement of the most severely disabled people with MND will inevitably be overshadowed by carers (including bereaved carers).

Our actual resources were, effectively, a project worker for about three days a week and a few thousand pounds. Emotional and peer support was provided by a volunteer. A considerable amount of the worker's time was taken up with the research aspect of the project, managing the fieldwork material, considering research practice, drafting the research findings and drafting grant applications for further funding.

Drawing on our experiences, we outline in Table 4 the resources needed to set up and sustain a local group and network.

This may seem like a long list of resources, but what do you get for this? Compared with patient satisfaction surveys, for example, BUILD's learning about service delivery and recommendations for service improvement which emerged during the research interviews, home visits and group meetings indicates that rich and useful information can be gained.

Table 4 Requirements for setting up a local group and network

A local group and/or network: resource considerations	
Staff	<ul style="list-style-type: none"> ■ One full-time worker to serve an area of about 20 square miles or three or four inner-city boroughs (with 25–50 people with MND) ■ A salary commensurate with the challenge of the post, and the degree of project leadership needed to broker service change and negotiate a shift in project aims ■ Some experience of MND or similar terminal neurological conditions: a professional and/or someone with MND, or a current or former carer ■ Experience of community development theory and practice
Finances	<ul style="list-style-type: none"> ■ Long-term funding (minimum three years) ■ Hardware costs (computer, printer, camera and scanner) ■ Sufficient funding to enable the active participation of the most disabled users, to meet costs of personal assistance, appropriate transport and venues, substitute carers, other expenses ■ Cost of public liability insurance policy ■ Small grant for the group to further its aims (e.g. minute takers, social activities) ■ Publicising group activities; dissemination of recommendations; for communication and recording members' views using supplementary media such as video or audio recording
A local group and/or network: additional considerations	
Support structures	<ul style="list-style-type: none"> ■ Support for worker (e.g. peer support network via local PCT, or local authority's public involvement network, or internet) ■ Formal arrangements for emotional support for worker (e.g. for bereavement issues, boundaries, etc.) ■ In-house training on: issues relating to MND; how service providers work; technical issues such as video production; aspects of community development
Host organisation	<ul style="list-style-type: none"> ■ Needs credibility at local level as a service provider to people with MND ■ Confidence to allow independence of local group
Commitment of key local service providers	<ul style="list-style-type: none"> ■ Responding to a user-defined agenda which might mean reallocating budgets/staff to new or altered services ■ Empowering front-line staff to define workable responses to users' recommendations ■ Recognising that challenge and confrontation are integral to the process and require management rather than a defensive reaction ■ Working with other providers by pooling staff and budgets if necessary
Group structures, constitution/rules	<ul style="list-style-type: none"> ■ To enable the group's views and recommendations to be credibly disseminated within service provider organisations ■ To have a clear relationship between the group and its host organisation(s) and other service providers and agreed remit on the group's objectives ■ To enable those least able to present their views to do so and prevent domination of the agenda by any sub-group ■ To enable a succession of users to enter the group and play an active part in the group

Table 4 Requirements for setting up a local group and network - *continued***A local group and/or network: additional considerations**

Evaluation/outcomes	<ul style="list-style-type: none"> ■ Developed in relation to user group's defined aims and objectives rather than those of the host organisation ■ Evaluation by active users and users choosing not to participate, plus assessment by other stakeholders such as service provider professionals
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Furthermore, a project is unlikely to be viable without the additional considerations listed above, though they seem to require a considerable investment of time and effort. The BUILD project indicates that investing in a user involvement programme in a local area can also provide a continuing context for exploring innovative solutions, new services and amended delivery of services which can then be rolled out to similar patient groups within a location or to other MND service users across the country.

Table 5 lists the resources needed to set up a website with virtual forums. The BUILD website was built with minimal expenditure and by inexperienced staff with little technical expertise, so a virtual forum may initially seem to require fewer resources in terms of both funding and staffing. However, as we subsequently learned, this created technical barriers. Users mentioned long delays in logging in and lost postings which contributed to a reduced use of the site. On a more positive note, the potential for different forums became apparent, with users volunteering to moderate specialist forums (e.g. on bereavement), but lack of time did not allow these suggestions to be acted on.

A virtual forum would be likely to cost less than a local group, particularly once set-up costs had been met. A site could potentially draw together users' recommendations for service delivery or proposals for research trial design and delivery. It could also be a consultation tool for organisations, particularly if they wish to contact younger users or get a rapid response to any proposals.

Is user involvement too burdensome?

This question, raised by Small and Rhodes (2000), was kept in mind during the BUILD project and there were clearly pressures on local users experiencing difficulties in organising their care while also being asked to become involved in BUILD. Because the project was associated with King's MND Care and Research Centre, users may also have felt under pressure to join the local group in order to continue using the Centre's services.

Table 5 Requirements for setting up a website with virtual forums

A website with virtual forums: resource considerations	
Staff	<ul style="list-style-type: none"> ■ One part-time website technician (three months) to establish the site and create forum structures and an administration facility, and create databases and middleware scripts which allow for registration functions, automatic password responses and remote data input for site users ■ One part-time (2.5–4 days p.w.) community development worker to design the appearance and content of the site, moderate forums initially, recruit site users and voluntary moderators, create publicity and shape the site to respond to site users' agenda ■ Contract technical support after the three-month set-up period (about two days a month) to provide maintenance support and further middleware scripts, etc.
Finances	<ul style="list-style-type: none"> ■ Website hosting and software costs ■ Hardware costs: computer, printer and scanner ■ Recruitment publicity through national events and organisations ■ Dissemination of virtual forum's recommendations ■ Alternative media to enable a wide range of site users to participate, e.g. disposable cameras for logging users' photo diaries, tapes for audio diaries ■ Possible costs of meetings of a user-led advisory or decision-making panel ■ Expenses incurred by users taking on roles such as moderators, editors, newsletter contributors
A website with virtual forums: additional considerations	
Support structure	<ul style="list-style-type: none"> ■ Community development peer network support through internet networks ■ Emotional support ■ Training on MND issues, technical developments, community development practice
Hosting organisation	<ul style="list-style-type: none"> ■ Needs credibility at national level to broker decision makers' commitment and response ■ Confidence to allow independence of virtual group
Commitment of national service provider decision makers	<ul style="list-style-type: none"> ■ To respond to a user-defined agenda which might mean consulting with a wider group of representatives on the virtual group's recommendations ■ To recognise that challenge and confrontation are integral to the process ■ To feed consultation about developments in service policy and practice through the website in addition to other forms of consultation
Group structures, constitution/rules	<ul style="list-style-type: none"> ■ Not as relevant as with local group, but if site users choose to run the site, a constitution may be needed
Evaluation/outcomes	<ul style="list-style-type: none"> ■ Similar to those for the local group

Pressures on site users to participate in the virtual forum, on the other hand, were minimal, since this required potentially less time and energy. However, internet communication is limited by access to computers, and the limitations of technology can make downloading or inputting information tedious or impossible. For disabled people, inputting information, such as responding to a request posted on the site, can be a drain on users' time and energy. The project worker made some direct email appeals to people affected by MND to participate in the project, and they might have felt under pressure to respond. As with the local group, some site users were aware that the hosting organisation was also one of their service providers so may have felt under pressure to continue involvement with the site to maintain their support from that organisation.

In order to minimise the likelihood of users feeling that their participation in BUILD was too burdensome, the following measures were taken:

- local service users were able to choose how and to what extent they participated in BUILD (e.g. they could participate at arm's length as network members)
- the project worker sometimes advised users on how to pursue their complaints with service providers (including her employing organisation)
- the website and forum were made as accessible as possible, within technical and budgetary limits
- the project worker phrased emails to highlight that potential site users were free to choose whether or not to respond
- site users could post without registering and, when registering, no identifying details were required.

The limited timescales meant we were unable to carry out a second round of research interviews to obtain users' views on the local group and virtual forum. This made it difficult to find out what impact the project may have had on their lives, but some conclusions may be drawn from the following.

- Large numbers of users in the local area expressed the wish to be involved in all aspects of service planning and delivery.
- Group members persevered with meeting up and overcame barriers to involvement.

- Network members showed varying levels of input to a group agenda.
- No users dropped out of the local group.
- Some users expressed satisfaction at the resolution of individual problems.
- Some users were more able to manage their care packages and were more committed to the local group because of the project worker's support.
- At group meetings users described the importance of the emotional support, information and advice they gained from contact with other local users.
- Some site users demonstrated considerable commitment to ensuring that the project continued and that it responded to their needs, while others openly discussed the merits of the site in comparison to other forums and expressed concern and disappointment at the occasional low level of postings.
- Some site users felt that lack of activity on the site did not offer enough benefits to make the site sustainable, while others expressed satisfaction when postings increased and an engagement with professionals on the site provided advice they were unable to get elsewhere.

Is representative user involvement possible?

Although the samples for the local group and virtual forum were relatively small, contrary to expectations users who were severely disabled, recently diagnosed and from black and minority ethnic communities chose to participate in the project.

Both the local group and the virtual forum appealed to particular sections of the MND community and not to others. Users who became most active in the local group were severely disabled, had been living with MND for several years and in some cases were approaching death.

The project worker found that several of those who chose to join the local group were characterised by their 'acceptance' of the illness – a word which seemed to encompass acknowledging the life-shortening nature of MND and accepting the physical symptoms and their increasing dependence on others.

The fact that recently diagnosed people chose an arm's-length involvement with BUILD was more in line with our expectations.

The virtual forum engaged people across the whole age range of the MND population, but a relatively large percentage of registered site users were under 40 and several who chose not to register stated in their postings that they were in this younger age range. Professionals were initially concerned about the use of new technology, given that the MND population is relatively elderly, but registration details indicate that many over-50s visited the site including two users over 70. Local group members said that family members were using the internet to search out information and community support on their behalf and this was supported by other registration details on the site.

BUILD secured the involvement of local users who broadly represented the cultural diversity of the local area. Over half the local group members were from black and minority ethnic communities, perhaps because the project team had similarly diverse backgrounds and, because we used an outreach approach, all the users from black and minority ethnic communities took an active part in the project.

Only one person from a black and minority ethnic background registered on the project website, but wider publicity (e.g. advertising in *The Voice* and on local radio) might have attracted more culturally diverse users.

In the face of the early deaths of many of the participants, is user involvement sustainable?

Any (local or virtual) group of people with MND will have to sustain the impact of the death of its active members; this is a reality for people living with MND. The emotional impact can be greater than with other groups, as remaining members are forced to confront issues around their own death or that of the person they love.

For a local MND group the deaths of successive generations of members can make the group unsustainable: they lose the experience, skills and learning of users who would otherwise have been 'senior' members in a group, mentoring and providing role models for recent recruits.

Although individual members discussed their 'acceptance' of MND, the local group was only beginning to discuss this. One person with MND died during the early part of the project; other carers were distressed to hear of the bereavement. The local group had not been meeting for long enough to be able to discuss how it could accommodate the loss of an active member and the ways in which it wished to support bereaved group members.

The loss of existing group members may be offset by an influx of new users but BUILD did not allow the time to see whether network members might go on to join the local group. Any local MND group seeking to sustain its membership would need to explore ways of enabling recently diagnosed users to contribute to a group agenda. Newsletters, videos of group meetings and social or campaigning events could perhaps allay their concerns about meeting others with MND and encourage them to meet existing group members.

Unsurprisingly, many local groups for people affected by MND have high numbers of bereaved carers and few active members with MND and we were aware that building the sustainability of a group through the involvement of disproportionate numbers of carers or bereaved carers might lead to fewer people with MND choosing to become involved. This raises concerns about the relevance of a group's agenda to the wider MND community and we raised this as an issue early on, to try and establish the characteristics of the group as led predominantly by people with MND and with separate carers meetings, so that the main group meetings could focus on the concerns of people with MND.

Building a (local or virtual) group must enable its members to develop their capacity for action. To do this, resources must be controlled by the group and responsibility for carrying out roles needs to be established and kept within the group. If a disabled group member takes responsibility for minuting meetings but has difficulty doing this, when the group controls the funding, it can decide to bring someone in to do this but the group member retains management responsibility and retains the skill. If someone outside the group takes responsibility for minutes but then withdraws, the group is left deskilled and unsustainable.

While BUILD demonstrated that provision of adequate resources enabled severely disabled users to attend the local group, there was insufficient time for members to take on responsibility beyond chairing the meeting. For a virtual group to become sustainable it would need to take over responsibility for running the site even if this was after completion of the technical work of creating easily maintained forums.

Were the methods used fruitful?

BUILD employed research and community development methods to explore the advantages and disadvantages of both approaches.

The research interviews and the project worker's home visits raised many similar issues, including concerns not previously discussed with professionals. Both approaches contributed to developing an agenda for the local group, although

analysing and writing these up took a considerable amount of time which meant that summaries of the research interviews were only available after the first local group meeting, so the agenda focused on the dynamics of meeting together. Despite this, the group was not sufficiently cohesive to start engaging in detail with the research findings.

What were the challenges?

BUILD faced challenges from participants and service provider professionals in the local area. These were partly due to the project's ambitious aims with relatively limited time and resources to achieve them. The emergence of demands with their perceived criticism of professionals and service providers posed further challenges.

Ensuring the representative involvement of local users was time and energy intensive. The unanticipated emergence of the local network and the project worker's 'linking' role increased her workload and meant she had less time for reflection and listening to users. However, by the end of the project, the project worker was able to start reducing her support, to allow the group to become more self-supporting.

It was less easy to resolve the tensions between the project worker and professionals who had previously been colleagues, although these are inevitable at the interface between service providers and users. Compared with organisations more familiar with user involvement, it seemed that some professionals felt disproportionately undermined by the mild assertions and challenges offered by some local group members.

For two front-line staff, it was important for managers to reassure them that challenges were to be expected, signalling BUILD's progress rather than a deteriorating service. Professionals found it particularly difficult to deal with users when their employing organisation did not allow them to respond to suggestions for improving services.

As discussions on the virtual forum demonstrated, the virtual group became increasingly empowered. Professionals demonstrated their engagement by listening and responding to users' concerns, and the anger initially expressed by users became more clearly articulated and focused. Without a positive response to what could otherwise appear to be quite unfocused anger, groups would be unable to develop a relationship with service providers.

What were the lessons for service improvement?

As Chapter 6 indicates, both groups, but particularly the local group, were able to begin developing approaches for commenting on service development. Although these had not yet reached the stage of a set of recommendations from an established user group together with the research interview findings, they arose from individuals' experiences of services and their consideration of service improvement.

In addition to the suggestions at the end of Chapter 6, the project worker was also aware that gaps in services could have such a negative impact on several users' lives that they had reached the point where they no longer wanted to live.

The complex arrangements and range of professionals involved in the care of someone with multiple and severe disabilities require considerable time and energy to organise. This leaves some users with no time or energy for enjoying any leisure or social life, while others are too powerless and exhausted to organise even their basic care. Many users were angry that it was left to them to keep in touch with professionals and to actively search out equipment and treatments as new symptoms appeared. Users unable to move or speak stated that they needed a personal assistant to help them with these tasks, but also to keep contact with family and friends.

The limited amount of advocacy undertaken by the project worker led some users to express disproportionate relief and lifting of their mood. The effectiveness of the approach was clear as people with MND and their carers assumed greater control over their care arrangements in the following weeks. There seemed to be no programme allowing users to apply for personal assistants or advocates. One user was put in touch with an advocate but was only able to use this for six weeks. Users may need ongoing assistance from a personal assistant or advocate to organise their support from a multidisciplinary care team.

What were BUILD's broad outcomes or achievements?

BUILD was planned and funded as a one-year pilot project, but developing the local group and virtual forum meant there was limited time for writing the necessary grant applications for continued funding. Some organisations we approached were unused to funding and evaluating user involvement projects and their funding structures were also problematic.

The project team was concerned that when the short-term funding ended, the loss of support for the local group and virtual forum would leave users possibly disillusioned, making subsequent attempts to engage with them more difficult. Despite failing to secure further funding, however, it is still possible to identify BUILD's achievements.

One approach to evaluating the effectiveness of both groups is to look at their ability to define and pursue a collective agenda and establish a group ethos by assessing their potential for effectively delivering change which might include:

- how easily individuals were able to contribute their views and have them acknowledged within the group agenda or action plan
- how the group set its own ground rules and established a group ethos
- how individuals subsumed their individual concerns to put forward those agreed by the wider group
- the connection of the group agenda to the concerns of the wider community it represented (but who may not have active membership).

There are differences in how individual group members within the local and virtual forum were able to set their concerns within an emerging group agenda. For both, there were early indications that individuals acknowledged other group members' concerns and that the priorities for group action plans were adjusted accordingly. Some early ground rules were set between users to establish how individuals should behave in the group setting.

During discussions at local group meetings various concerns were aired by group members with particular support given to one member whose housing situation left him unable to enjoy a good quality of life. Although other group members had pressing concerns, they recognised this as a priority and decided to adjust their emerging action plan to focus on this issue. Users also initiated discussion about how to acknowledge and support users who were upset in meetings, framing one user's tears as a positive sign that they had strong feelings about the group which would enable things to get done.

Within the virtual group, individuals were able to voice their views freely although some became disheartened when they did not receive a response. There were early signs of forum members pressing other members to alter their views, which began to establish a group ethos. At various points site users acknowledged the cause of frustration and anger expressed by fellow site users but suggested a moderation of tone or a refocusing of the target of their anger to reflect the situation more fairly.

With both groups, if it had been possible for them to develop further, it would have been useful to work with members to formalise some of these ground rules to allow clear terms of reference to be drawn from emerging practice. This might enable the

group to pursue their agenda more effectively and support individual group members to influence the group.

BUILD has demonstrated that a representative group of people affected by MND can be enabled to participate in planning services. This has relevance not only for statutory service providers but also for voluntary organisations such as the MNDA which experience challenges for user involvement on a national scale but particularly in inner-city areas.

The project showed that people with MND have extensive knowledge and experience through which MND services can be improved. It has demonstrated the need to involve MND service users in developing an improved model of care. The initial series of research interviews and work between the project worker and users highlight difficulties with the current model of service delivery by a multidisciplinary team. There are concerns that, particularly for severely disabled people, this can prejudice their quality of life and their involvement in social and community activity.

References

- Anderson, C. (2002) *The Charles Anderson Diaries: Living a Life with Motor Neurone Disease* and audio diaries. BBC Three Counties Radio website at: http://www.bbc.co.uk/threecounties/read_this/2002/06/charles_anderson/book.shtml
- Corr, B., Frost, E., Traynor, B.J. and Hardiman, O. (1998) 'Service provision for patients with ALS/MND: a cost-effective multidisciplinary approach', *Journal of the Neurological Sciences*, Vol. 160, Suppl. 1, pp. 141–5
- DoH/NHSE (Department of Health/NHS Executive) (2000) *The NHS Plan: A Plan for Investment, a Plan for Reform*. London: DoH/NHSE
- DoH/NHSE (Department of Health/NHS Executive) (2001) *Involving Patients and the Public in Healthcare*. Response of the Listening Exercise. London: DoH/NHSE
- Dyer, C. (2002) 'Final right to die rejected by court', *Guardian*, 30 April
- Eadie, A. (2002) 'Living with MND', *Telegraph* (Weekend), 9 November, pp. 1–2
- Feenburg, A.L., Licht, J.M., Kane, K.P., Moran, K. and Smith, R.A. (1996) 'The online patient meeting', *Journal of Neurological Sciences*, Vol. 139 (Supplement), pp. 129–31
- Ferguson, T. (2002) 'From patients to end users: quality of online patient networks needs more attention than quality of online health information', *British Medical Journal*, No. 324, pp. 555–6
- Hardey, M. (1999) 'Doctor in the house: the internet as a source of lay health knowledge and the challenge to expertise', *Journal of Sociology of Health and Illness*, Vol. 21, No. 6, pp. 820–35
- Haverkamp, S., Appel, V. and Appel, S.H. (1995) 'Natural history of amyotrophic lateral sclerosis in a database population. Validation of a scoring system and a model for survival prediction', *Brain*, Vol. 118, pp. 1311–23
- Hogg, K.E., Goldstein, L.H. and Leigh, P.N. (1994) 'The psychological impact of MND', *Journal of Psychological Medicine*, Vol. 24, No. 3, pp. 625–32
- Lacomblez, L., Bensimon, G., Leigh, P.N., Guillet, P. and Meininger, V. (1996) 'Dose-ranging study of riluzole in amyotrophic lateral sclerosis'. ALS/Riluzole Study Group II. *Lancet* Vol. 34–8, pp. 336–7
- Leigh, P.N., Abrahams, S., Authors (2003) 'The management of Motor Neurone Disease', *J Neurol Neurosurg Psychiatry*. Vol. 74 (Suppl 4), pp. iv32–iv47

Lewis, R. (2003) *Foundation Trusts: A New Era for Stakeholder Engagement?* London: The New Health Network. Available at <http://www.newhealthnetwork.co.uk>

LSL (Lambeth, Southwark and Lewisham) Health Authority (2001) *Health Improvement and Modernisation Programme*. London: LSL Health Authority

Miller, R.G. *et al.* (1999) 'Practice parameter: the care of the patient with amyotrophic lateral sclerosis (an evidence-based review): report of the Quality Standards Sub-Committee of the American Academy of Neurology', *Neurology*, Vol. 52, pp. 1311–23

Miller, R.G., Mitchell, J.D. and Moore, D.H. (2001) 'Riluzole for amyotrophic lateral sclerosis (ALS)/motor neurone disease (MND)', *Cochrane Database Syst. Rev.*, No. 4, CD001447

MNDA (Motor Neurone Disease Association) (1998) *Annual Tracking Survey of Views and Experiences of People with Motor Neurone Disease*. Northampton: MNDA

MNDA (Motor Neurone Disease Association) (1999a) *Standards of Care*. Northampton: MNDA

MNDA (Motor Neurone Disease Association) (1999b) *Annual Tracking Survey of Views and Experiences of People with Motor Neurone Disease*. Northampton: MNDA

MNDA (Motor Neurone Disease Association) (2001) *Annual Tracking Survey of Views and Experiences of People with Motor Neurone Disease*. Northampton: MNDA

SCCD (Standing Conference for Community Development) (2001) *Strategic Framework for Community Development*. Available to download from http://www.quest-net.org/view_external.asp?ID=1269

Small, N. and Rhodes, P. (2000) *Too Ill to Talk? User Involvement and Palliative Care*. London: Routledge

Turner, M.R., Bakker, M., Sham, P., Shaw, C.E., Leigh, P.N. and Al-Chalabi, A. (2002) 'Prognostic modelling of therapeutic interventions in amyotrophic lateral sclerosis', *Amyotrophic Lateral Sclerosis and Other Motor Neurone Disorders*, Vol. 3, No. 1, pp. 15–21

Appendix 1: The BUILD newsletter



THE BUILD NEWSLETTER

Keeping you up to date with what's happening on the BUILD project in Lambeth, Southwark and Lewisham - working with people with motor neurone disease, their carers and families

Building **U**ser **I**nvo**L**vement in MND

Issue No.1, June 2002



Devi

Seenundun

reviews the BUILD project after its first six months

We're getting there

Welcome to the first issue of The BUILD Newsletter and a massive thank you to everyone in Lambeth, Southwark and Lewisham who's given their time and thoughts to Anu Sinha, our BUILD researcher.

Anu spent January to May visiting people in their homes to hear what they had to say about living with motor neurone disease. She's also visited local professionals, GPs, social services, therapists and hospital staff to hear their views. Now she's beavering away, analysing all these comments. She'll shortly be able to give us our first report which will tell us the most important issues for our local BUILD group, the problems, opportunities and things we feel could be done better. The report will also tell us the strategies and skills that group members have used to keep living their lives the way they want.

Why bother doing the research?

'Research is time consuming' - Tony

There's been hardly any research done to ask people with MND and their carers to describe in detail what's important to them, what they want and what they know. At the moment professionals who commission and plan services are having to work with little information. They're making a good guess based on their training and their experience of working with individuals who have MND or similar illnesses.

Local BUILDers Get Involved

Local group members employ an alias when quoted in print:

Nicola offers tips 'Ask your social worker to ascertain your rights and use this as a basis for getting your caring needs met'

Anne says 'its difficult to explain how it affects family relations'

Tony warns 'we have to be a very high pressure group'

Yvonne is perplexed at priorities 'it seems they have marvellous machines for diagnosis and to find out the facts, but nothing to do anything with the illness'

Adele 'I was one for walking in the countryside or we took the car to Wiltshire or Scotland and that's what I miss the most'

John explained that 'it's like in the old days when people weren't told they had cancer, but it's up to us to deal with the information'

Bill is frustrated 'I mean, to think that all the care that's supposed to be going about and we can't get any at all.'

Planning services means allocating budgets and deciding how people work. If people with MND, their carers and families want to be treated as equal partners in planning services, then they need to make a strong case. The BUILD research can help us to do that.

Our first research report will document what people said, anonymously. The local group will draw up an action plan based on this report. We hope that service planners and commissioners will respond to the action plan, changing their services or providing new services.

Tips from old fighters



**Keren
Down**

sees the local BUILD group getting interested and reports the highs and lows

Since Devi and I have been meeting the local BUILD group we've been amazed at how generous everyone is with their time and their advice.

In our travels around Lambeth, Southwark and Lewisham, Devi and I've talked about how many issues are shared. How one person we've met asks a question that the next person we visit can answer. Often people ask us how other people deal with social services, or benefits or talking to family members.

Group members have told us how their lives have changed after they or the person they care for has been diagnosed with MND. Many of these experiences will be highlighted in the research report and group members have started thinking of ways to develop an action plan based on the research report.

But first I think it's important to listen to some comments made to Devi and me by the group.

Carers are not just for Christmas

Nicola identified that although everyone with MND has different requirements, one thing they usually have in common is that they will require carers and often these are provided by social services department. **Nicola** is very happy with her current social services carers. However, she has only reached this position after a lot of effort and fighting, this took 4 years. 'All people with MND need compassionate carers. They also need carers with a sense of humour and patience'. She advises that, if you have a good carer, treat them like gold dust.

Adele and Bill dread the unfamiliar carers who come at the weekends 'the weekend girls just don't know enough about the situation - they need to be trained by their agency' - **Bill**

'I'd like to know how other people manage, am I the only person in Britain in this predicament, where I've got to go to the loo and there's nobody to help me? Am I the only person?' - **Adele**

Despite having had some good carers in the past, **Tony** had difficulties with his current team 'pseudo carers .. trying their best to accumulate as much pay for doing sweet fanny adams'

Some of the frustrations felt by the local group:

'It's getting to be like Victoria Station with people coming and going" **Anne**

John couldn't find anyone who can sit down and work through applications and give advice about benefits.

'Getting all this organised costs more energy than running a business and many of the skills that are needed are the same', advises **Nicola**.

Yvonne used to work as a health professional but recently had to find someone to help her sort out problems with equipment. She lives alone and found this exhausting. 'There was not enough support or answers to problems.'

Tony cautions other group members to get agreements about services in writing. He says staff 'have an escape habit of transferring to other government agencies' leaving promises unfulfilled.

Bill and Adele had two wheelchairs, a zimmer frame and lots of other equipment that no-one wanted to take back. 'Someone told me that they throw these things away, I've tried lots of times to get them to take this stuff away, it takes up room, but they're not interested.' - **Bill**

Yvonne was given a freezer by Social Services Occupational Therapists to keep microwave meals in 'but I couldn't use it, the handle was too stiff, and I phoned (*the social services occupational therapist*),.. 'well we don't take equipment back once it's allocated', so my neighbours use it at Christmas for the turkey. It does seem a waste.'

But beware of the horrors of recycling if it's done without consideration. **Nicola** tells of a horror story which happened after phoning social services to get a replacement bath seat. 'She told me that it was not important to have a bath and after some weeks she sent me a filthy, dirty, broken bath seat that still had people's pubic hair in it even though it had been wrapped in new cellophane.'

Who are you?

A common frustration is not knowing who does what, and who's responsible for bits of equipment. The situation is not helped when you phone up and the person who's name you've been given has left.

People describe how busy their lives are and how their energy reduces. Instead of finding more support, some people say that they get left alone to sort things out by themselves.

Any old iron?

Many of the group are confused about why social services and the wheelchair services leave them with equipment and seem reluctant to take it back.

Some of the occupational therapists and physios get top marks from the group because they phone up regularly and adapt or take away equipment that's no longer useful.

If you want to comment, or submit an article, please write to:

The BUILD Editor
PO Box 41
Institute of Psychiatry
De Crespigny Park
London SE5 8AF

Remember this is research



Anu Sinha
On how your comments will be used as part of the research project.

After interviewing people with MND, their carers and family members, I also interviewed professionals working in health services and social services.

I heard about people's views on the impact MND has had on their lives, how they have coped and their views on services they receive. It's been great to meet with everyone as each person has had something valuable to contribute. I am writing up these interviews into a report for MND service users and professionals in order that they can develop an action plan for improvements.

As the groups meet up and grow I shall be observing their development. We hope that BUILD will be able to identify important lessons for other groups around the country.

Building a network across the UK

The BUILD project is also working directly with people across the United Kingdom. People can join a lively discussion forum and chat to others in a similar position for advice, exchanging information or just to be social. Professionals are also joining the forum, so if you have a question, try logging on (no wait for passwords) and ask your questions.



www.build-uk.net

building a Motor Neurone Disease network for the UK

This is a new site for people affected by Motor Neurone Disease (MND), that means people who:

- live with MND
- care for someone with the condition
- have a family member or friend with MND
- work in health or social care services

Everyone is welcome to log on to share information and views.

You are welcome to join BUILD or find out more about us

Please contact me to tell me more about the BUILD project:

Name

Address:

Telephone or email details:

Post to:

Keren Down
The BUILD Project
PO Box 41
Institute of Psychiatry
De Crespigny Park
London SE5 8AF

Appendix 2: Handout for users about local group meetings

Building **U**ser **I**nvo**L**vement in MND

Working with people with Motor Neurone Disease,
their carers and families to plan services

Group meetings

The BUILD project has a small budget to enable group members to attend (and enjoy) meetings. Please contact Keren or another BUILD team member to let us know any requirements.

Transport:

If you need a mini-cab, adapted mini-bus or ambulance transport, we will be happy to arrange it, or we can refund the travel expenses you incur coming to the meeting.

Carer cover:

If you need someone to take over your caring duties, whether this is for elderly relatives, your children or a person with MND while you attend a group meeting, this can be arranged. We can either arrange to pay one of your normal carers, or a family member. We can also help you to find suitable alternative carer cover.

Language and communication needs:

If English is not your first language and you need interpreter assistance, we can arrange for this, or cover the expenses for a family member to assist you. If you have a speech or hearing impairment and need technical assistance, we can help you with this. If you would like to bring someone with you to assist you to communicate, we may be able to cover their expenses.

Physical assistance:

If you require assistance with physical needs during the meeting, please speak to a BUILD project member prior to the meeting to arrange for someone suitable to be available to assist you.

Refreshments:

We will normally make tea, coffee, juice and biscuits or sandwiches available during meetings, but are happy to provide other refreshments depending on what people would like. Just speak to a BUILD project member to let us know.

Venue for meetings:

We will try to find venues that are central to group members and are a pleasure to visit. We're always happy to hear your ideas and recommendations. In the meantime, we will try some venues and ask you whether you find them suitable.

