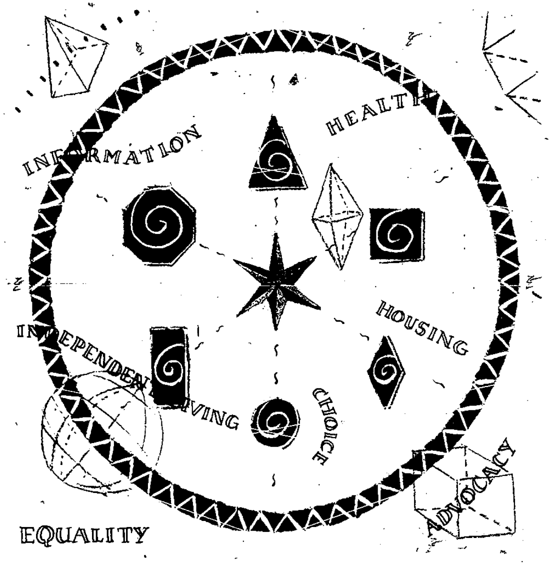
IMPROVING DISABILITY SERVICES

The way forward for health and social services



Nasa Begum and Sheila Fletcher

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Partnership Paper No. 3

Nasa Begum and Sheila Fletcher

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Introduction

Community care has heralded a climate of rapid change, new opportunities and some real challenges for improving services for disabled people. The principles of flexibility, choice, value for money and needs-led services have become the bed-rock of developing health and social care.

There has been a plethora of literature on community care but very little attention has been paid to the implications of the reforms on meeting the needs of people with physical and sensory impairments.

This publication aims to provide a quick guide to improving disability services for senior managers in health and social services, who may have overall responsibility for services for adults with physical and sensory impairments, yet not have a detailed involvement at an operational level. The guide is written primarily for commissioners and providers in the statutory sector, but it should also be helpful for those in the independent sector.

The agenda for improving disability services is potentially very large and does not all fall on the shoulders of health and social services. Housing, education and other agencies also have a large role to play. Nevertheless, the ability of disabled people to live in the community often depends on essential services accessed through health and social services. This guide therefore highlights the basic ingredients necessary for implementing community care.

Since services for people with physical and sensory impairments cross the boundaries between health and social care, they demand a great deal of co-ordination and flexibility from those agencies. This has sometimes presented difficulties for statutory agencies where both the organisation and the delivery of services can vary substantially. Consequently, services for people with physical and sensory impairments have been described as being ‘piecemeal, fragmented and inflexible’ (Beardshaw 1988, Fiedler 1988).

Disabled people are not a homogeneous group and their needs are very diverse. This presents problems for many statutory agencies as they often find it difficult to achieve the degree of flexibility required. Also there are certain groups of disabled people whose specific requirements are excluded from the realms of disability services, such as Black disabled people, disabled women, and disabled lesbians and gay men. The philosophy of needs-led services should help to ensure that the requirements of *all* disabled people are addressed.

In recent years, disabled people have focused public attention on how, as a result of attitudinal, institutional and environmental barriers, disabled people are discriminated against. There is increasing pressure for civil rights legislation, and disabled people are starting to assert their right to services under existing legislation, such as Section 2 of the Chronically Sick and Disabled Persons Act 1970. Statutory agencies find themselves working in an environment where, on the one hand, disabled people are asserting a right to appropriate services, while on the other, there are many constraints on resources and competing demands for budgets.

Over the past ten years, Living Options Partnership has worked to improve services for people with physical and sensory impairments by promoting their involvement in planning, implementing and evaluating services. There have been some important developments in terms of improving services for disabled people. Resources are being reallocated and new initiatives are emerging thanks to the direct involvement of disabled people. For example, wheelchair services have been redesigned, independent living schemes have developed as an alternative to residential care, and housing associations have started to address disabled people's needs within the community.

There are a number of key principles which need to underpin both policy and practice in disability services. The Living Options Partnership principles have already been adopted by the Association of Directors of Social Services (ADSS), and recommended to local social services departments as the basis for developing disability services in partnership with disabled people. These principles also need to be adopted by the NHS Executive as the baseline for developing more appropriate and effective health services for disabled people. Their adoption by both local health and social services will give disabled people the confidence that services are being designed and delivered with a common approach.

Living Options Principles

- *Participation in the life of local and national communities is the right of all disabled people as equal members of society.*
- *Recognition that discrimination occurs as a result of the barriers disabled people face. Action needs to be taken to tackle discrimination on the grounds of disability, race, gender, sexuality or poverty.*
- *Autonomy is disabled people's freedom to make informed choices and control their own lives.*
- *Partnership between disabled people and service agencies to enable them to work together on an equal basis to plan, implement and evaluate services.*
- *Consultation to ensure services meet the needs and choices of all disabled people.*
- *Information clearly presented in a way which is accessible to all disabled people.*

Section 1 – Access to services

Access to health and social services is dependent upon people's ability to identify and use appropriate points of entry into the service system. This can range from individuals presenting themselves to a service provider directly (i.e. a general practitioner), to going through a formal referral and assessment procedure. In order to improve disability services, the first area that needs to be tackled is the mechanism by which people access services.

For many disabled people, the greatest barrier to receiving the services they require is a lack of information about what is available, the conditions of entitlement and the process which they have to go through to secure such services. Alongside this, there is a strong demand by disabled people to have a more active involvement in deciding the most effective way of meeting their needs. Consequently, many disabled people want direct control over the information and decisions that affect their lives.

The NHS and community care reforms provide a procedural framework for ensuring that information about services is available and users are involved in determining their own needs. The next step is to ensure that, in such a climate of limited resources as the present one, the process of allocating resources is fair and equitable.

Information

AGENDA FOR CHANGE

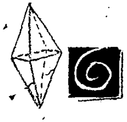
Readily accessible information is crucial for enabling disabled people to find out about the services available, eligibility criteria and how to go about obtaining services.

Considerable resources are invested in producing information, but there are still great difficulties in ensuring that it reaches disabled people in a format that they can use. The main problems with a lot of the information currently available include:

- an emphasis on printed information;
- too much use of jargon;
- limited availability of literature in Braille, tape, large print and other community languages;
- rarely takes account of the access needs of Deaf people who may rely on sign language interpreters, video-tapes with sign language, etc.

FRAMEWORK FOR ACTION

- **Produce information in Braille, tape, large print and sign language interpreted videos (possibly by pooling resources with neighbouring areas).**
- **Provide a sign language and community language interpreting service to work with the Deaf community and disabled people whose first language is not English.**
- **Use local media, particularly the 'free' newspapers and community radio stations.**
- **Use Ceefax and Teletext.**
- **Distribute information through disability groups, a range of community organisations, as well as places where services are provided, such as GP surgeries, advice centres, post offices.**
- **Provide a mobile information service with workers who can help people make effective use of the information.**



Advocacy

AGENDA FOR CHANGE

Disabled people may feel powerless when dealing with statutory agencies, particularly when negotiating with people like doctors, care managers and other staff.

Advocacy services have played an important role in helping disabled people identify their needs and access the most appropriate services. They have also been valuable in terms of developing disabled people's self-advocacy skills.

Not everyone requires advocacy services; however, even the most confident and articulate person can find it extremely difficult to deal with statutory agencies when it is a personal matter.

Equally, there are certain groups of disabled people, for example Black disabled people and people who have been institutionalised for a long time, who may need to use advocacy services to a much greater degree.

Difficulties have arisen with advocacy services because of confusion about the distinction between the role of interpreters (both sign language and other community languages) and the role of advocates.

Advocacy is often perceived by service agencies as quite threatening and adversarial, rather than as a means of ensuring that practitioners and disabled people can work together more effectively.

The reality is that advocacy services are in short supply, but in great demand. Improvement in the provision of independent advocacy services is high on the service development agenda.

FRAMEWORK FOR ACTION

- **Prepare a short document on the role of advocates and interpreters, and how to work with them. Circulate this widely, particularly to staff dealing with the public.**
- **Train care managers and other staff working with the public on the role of advocates. The training needs to stress that advocacy is not about being adversaries, but about ensuring that practitioners and users can work together more effectively.**
- **Fund training for disabled people to develop self-advocacy skills.**
- **Offer disabled people the opportunity to become advocates for other disabled people by providing resources.**
- **Fund advocacy projects and promote the importance of the services on offer.**

Assessment

AGENDA FOR CHANGE

Assessment is an important tool for considering the best way to enable a disabled person to live in the community. In order to ensure that the assessment process is useful, a number of problems need to be addressed, including:

- a tendency to compartmentalise different aspects of a disabled person's life, rather than take a holistic approach.
- assessments are sometimes undertaken when people are not in a position to identify their needs. For example, when people are imminently due to be discharged from hospital, or are in the middle of a crisis.
- assessors and care managers are in the process of learning a new way of working. They are not always aware of how to work with a needs-led approach or of the best way of costing and designing innovative care packages.
- disabled people can feel uncomfortable with the fact that someone else has to do an assessment on their behalf, when they would prefer to do the assessment themselves.

FRAMEWORK FOR ACTION

- **Develop resources (e.g. training materials or workshops) to help practitioners adopt a more holistic approach.**
- **Provide practical examples of how a needs-led approach differs from traditional assessment methods.**
- **Run regular training sessions on needs-led assessment and user involvement.**
- **Encourage care managers to share ideas, exchange information and network with others in order to learn more about how to cost and design innovative care packages.**
- **Offer an independent advocacy service to enable disabled people who require support during the assessment process to have it.**
- **Ensure that speech therapists, deaf/blind communicators, and any interpreters required are provided during assessments, reviews and other relevant meetings.**
- **Phase the timing of assessments so that they are not done at inappropriate times.**
- **Let disabled people do self-assessments if they choose to.**
- **Provide training for disabled people to be their own care managers if they wish to.**

Section 2 – Key components of disability services

In the past, particularly before the NHS and Community Care Act 1990, services for disabled people tended to regard disabled people as a uniform group. There was little scope for offering flexibility and choice to users. A service-led approach meant that considerable resources were being invested in services which did not necessarily meet the needs of disabled people. Users were expected to fit into the service, rather than the other way round.

Statutory agencies are working in an environment of limited resources, therefore priorities have to be established over which and whose needs can be met. Nevertheless, the philosophy of community care cannot work unless some of the essential ingredients are in place for enabling disabled people to live in the community.

Accommodation

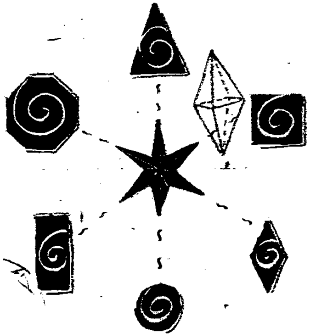
Although housing is a central feature of community care, it is often missing in discussions about disability services.

The general shortage of public housing stock and the high cost of property have had a particularly devastating effect on the availability of affordable accessible houses.

Although a small number of disabled people may choose to live in a residential home with other people, most want to live in their own house in the community. However, the current design of many homes presents access problems for disabled people.

The accommodation needs of disabled people are complex, and there are a number of problems that need to be addressed, including:

- practical problems of availability and cost in the public and private sectors;
- a reluctance to include housing in community care assessments;
- a tendency for housing departments/agencies to work in isolation from health and social services;
- uncertainty for both statutory agencies and disabled people about who to work with to improve both public and private sector housing;
- limited choice and information in terms of residential homes.



- Identify the housing needs of disabled people locally, particularly taking account of disabled people who may be living in hospitals or residential homes because there is no suitable housing available. This may be done by conducting a survey or bringing disabled people together specifically to discuss housing needs.
- Adopt existing guidance on what are the basic ingredients for a house to be considered accessible (recognising that the detail will vary according to individual disabled people's needs).
- Investigate how much accessible housing stock there is locally in the public and private sectors, and prepare a register of accessible housing.
- Encourage the Department of Environment and local planning bodies to adopt standards for newly built accommodation which meet the requirements for lifetime housing.
- Provide incentives for housing associations and other house builders to establish new accessible housing projects in the area.
- Set up projects where disabled people and housing agencies work together to develop housing schemes.
- Work with local estate agents to ensure that they are able to respond to the needs of disabled people. This may mean preparing a checklist of things to think about to help disabled people who may want to purchase a property.
- Ensure housing advice agencies have appropriate knowledge and skills to work with disabled people. This may be achieved, for example, through training initiatives.
- Establish a checklist of activities for use before a disabled person is offered a place in a residential home. This should look at the range of information and options provided, independent advice, long-term plans and choice of accommodation.

Aids and Adaptations

Sometimes disabled people can have the bricks and mortar of a house, but the lack of appropriate aids and adaptations can mean that they become trapped within their own home, and unnecessary dependence is created.

Appropriate aids and adaptations are vital for enabling disabled people to maintain maximum independence in their home environment.

A simple adaptation, such as installing a flashing doorbell for a Deaf person, or a more complex programme of work, such as building a ground-floor bathroom, will have a major effect on how well disabled people are able to function within their own home.

Similarly, the availability of a range of equipment which enables people with limited movement to control their environment (e.g. POSSUMs), and the provision of minicoms, tape-recorders or a Perkins Brailler, will determine the degree of independence disabled people can exercise over their lives.

The provision of aids and adaptations is problematical for a number of reasons, including:

- lack of clarity about different sources of funding;
- confusion about the responsibilities of different agencies;
- difficulties with the administration of disabled facilities grant;
- lengthy timescales involved when adaptation work is required;
- limited opportunity to try out equipment before a commitment is made.

- Produce a basic checklist on aids and adaptations with information on:
  - sources of funding;
  - easy to understand eligibility criteria;
  - where people can go for information and advice;
  - where people can try out different equipment.

- Provide direct access to basic items of equipment (i.e. a jar opener) so that people do not have to wait a long time to go through an assessment and then obtain the equipment required.

- Develop a more co-ordinated approach to the administration and use of disabled facilities grant by providing clear guidelines and training and establishing a joint forum where relevant agencies can come together to explore more effective ways of working.

- Identify a lead officer who takes responsibility for overseeing adaptations and who acts as the link between all parties.

- Set performance targets for the length of time adaptations should take and quality standards.

- Establish an agency (if not already available) within the local area that can:
  - provide lists of approved builders;
  - supply sample building contracts;
  - negotiate with builders;
  - oversee any building work;
  - enable people to try out different forms of equipment.

Independent Living

For disabled people to live and participate fully in community life it is essential to have services which enable them to do everyday tasks, such as getting up, dressing, eating and childcare.

'Independent living' is a term that disabled people use to describe the support they require in order to live in the community. It is a concept which stresses the importance of disabled people retaining maximum control over their own life.

'Independent living' usually refers to a situation where disabled people either directly employ personal assistants, or go through some form of agency to obtain personal assistants.

Personal assistants are a popular form of service provision because there is a one-to-one relationship between the disabled person and the personal assistant, and there is a much greater degree of choice, flexibility, accountability and quality control within the service provided.

Disabled people are increasingly using a range of financial resources to set up independent living schemes. Initiatives such as personal assistant agencies, independent living trusts, third-party arrangements and the principle of direct payments have become widely accepted as a mechanism for offering disabled people control over the services that they use.

A number of user-controlled organisations provide training, advice and practical support in setting up and running independent living schemes. Nevertheless, there are difficulties due to uncertainty about direct payments, and practical problems arising from a lack of emergency cover or back-up services.

Disabled people want a range of options available in terms of accessing statutory or independent sector services. For example, some people may want to buy in a service from an appropriate agency, others may choose domiciliary services provided by social services.

Domiciliary services are in short supply and disabled people often find them unreliable, inflexible and unable to provide the quality of service required.

- Investigate the number of disabled people who may want to use independent living schemes locally.
- Provide information on how independent living schemes may prevent disabled people remaining in hospital or living in residential homes unnecessarily.
- Identify ways of building in independent living schemes into purchasing plans.
- Explore how joint commissioning can be used to support independent living schemes.
- Pilot or establish independent living schemes.
- Fund user-controlled organisations to recruit independent living support workers or advisers who can:
    - help a disabled person explore the different options available;
    - provide training;
    - offer practical support on recruitment and selection of personal assistants;
    - supply model contracts of employment;
    - give guidance on employment practice;
    - help disabled people to negotiate with different agencies if they choose to buy in domiciliary services rather than employ personal assistants.
- Establish an emergency cover service which disabled people can use whether they employ their own personal assistants, or rely on statutory or other independent sector services.
- Make statutory domiciliary services more flexible and responsive to the needs of disabled people by:
    - having more staff available at peak times;
    - incorporating realistic travel time in work schedules;
    - providing a written contract stating the time a worker will attend, the service to be provided and what to do if this proves unsatisfactory.
- Stimulate the independent sector to develop good-quality services which reflect the diverse needs of local disabled people. For example, services need to be sensitive to the specific needs of disabled lesbians and gay men and Black disabled people.
- Work with disabled people to establish quality standards for a range of independent living schemes and other domiciliary services. These standards need to be built into service specifications and contracts.
- Monitor the quality of services with disabled people and make any appropriate changes.

Day Services

Living in the community can be an isolating and negative experience if disabled people are stuck at home all day without anything to do.

Some disabled people have used independent living schemes to obtain the support required during the day to take up employment, go to college, pursue leisure activities or do whatever else they want to do. However, a much larger proportion of disabled people go to day centres.

Traditionally, day centres have been the only activity available for unemployed disabled people who require some support during the day.

While such establishments may have played an important role in terms of reducing isolation and offering disabled people something to do during the day, many concerns have been raised about their ability to meet disabled people's individual needs and encourage personal development.

The specific difficulties associated with day centres include:

- tendency to be paternalistic;
- institutionalisation;
- limited range of activities available;
- inability to provide an individualised personal service;
- high capital and running costs;
- lack of user involvement.

- Encourage experienced disabled people to provide training and facilitate user groups within day centres to help overcome institutionalisation.
- Provide disability equality training and other support to staff in day centres to encourage them to empower disabled people and not feel threatened or deskilled by a change of emphasis within day services.
- Explore how independent living schemes can be used as an alternative to day centres in terms of supporting disabled people during the day.
- Use day centres more as a resource which disabled people can use as a base for other community-based facilities.

- Ensure that care packages incorporate financial resources which enable disabled people to purchase the activities that they wish to pursue.
- Set up inclusive projects where education and leisure providers work to make their services more accessible to disabled people.
- Work with local employers to open up employment opportunities for disabled people. Initiatives such as employment training, work experience placements, and targeted recruitment may be helpful.

Primary Care Services

While disabled people's lives do not revolve around their medical conditions, they will have everyday health concerns (e.g. flu) and sometimes some very specific requirements.

Disabled people are users of all health services, but often their needs are overlooked within general health settings. For example, many general dental practitioners are based in inaccessible premises; a lot of screening services find it difficult to respond to the needs of disabled women; and often general health settings do not have a minicom or sign language interpreter available.

In addition to physical access problems, there are real difficulties with the fact that practitioners in general health settings tend to have limited experience of working with disabled people. Negative attitudes combined with an inclination to be paternalistic and patronising in one's responses create extra barriers between practitioners and disabled people.

For many disabled people, particularly those from Black communities, it is likely that primary health care teams (PHCTs) will be the only point of contact with statutory agencies. Although the numbers of disabled people in any single PHCT may be relatively small, disabled people are likely to rely on PHCTs on a much more regular basis than non-disabled people. For example, disabled people may need on-going prescriptions, treatment and other primary care resources. Also disabled people may have to rely on GPs for access to a whole range of services or activities, ranging from social security benefits, housing and social services provision, to employment and leisure facilities.

At the moment, there are considerable demands upon PHCTs, and as their role continues to go through a process of change, a number of practical concerns have to be addressed:

- limited information, training and resources available to help PHCTs work more effectively with disabled people;
- access and attitudinal barriers;
- the extent to which GPs are required to provide letters to endorse everyday activities (such as leisure and employment);
- a reluctance on the part of some GPs to register disabled people as patients.

- Produce information and resources which professionals in general health settings can use to raise their level of awareness of the needs of disabled people.
- Provide disability equality and other appropriate training to all staff.
- Encourage health service staff to take up training and other resources by offering a range of alternative options, such as short workshops, seminars and video material.
- Incorporate disability equality issues into any organisational audit, service specifications and quality-assurance initiatives.
- Work with disabled people on an access survey of health service premises.
- Provide incentives for health providers to make their services more accessible. This may need to include issues such as transport, waiting times and attitudinal and physical barriers.
- Ensure minicoms are operational in all health settings.
- Recruit speech facilitators, sign language and other community language interpreters for use in general health settings. Ensure that staff, Deaf people and others who may require the service know how to access it.
- Remind GPs that it is part of their terms of service to enable patients to avail themselves of services. Provide them with practical advice and guidance on making their services accessible.
- Monitor whether disabled people are not being allowed to register with GPs, or are being removed from GP registers.
- Ensure an explanation is provided as a matter of good practice when a disabled person is refused registration or removed from a GP's list.
- Work with disabled people to establish needs and identify priorities for incorporation into purchasing and business plans.
- Pilot development initiatives to promote good practice in primary care, such as using outreach workers to provide information directly to local community and disability groups or running a particular surgery for disabled women to have cervical smears and other health checks.

Hospital Services

Many of the problems discussed in terms of primary care are also echoed within hospital settings. For example, accident and emergency departments or maternity wards sometimes find it difficult to accommodate the needs of disabled people because of poor facilities, or a general lack of knowledge about the needs of disabled people.

Some disabled people will rely on particular specialisms, (e.g. rehabilitation services, physiotherapists, or orthotics services). Therefore it is important to explore some of the specific issues that emerge in relation to specialist services.

The tendency to compartmentalise people's needs, rather than take a holistic approach, creates particular difficulties for disabled people who may be in contact with many different services. For example, a disabled person could be seeing a neurologist or a gynaecologist, and being treated by an ENT specialist at the same time, yet there may be very little co-ordination and discussion between the different specialists. This lack of collaboration between different experts has an adverse effect on the treatment that disabled people receive.

Referral processes and lengthy waiting times mean that disabled people who need access to specialist services can suffer unnecessary pain, deterioration and/or a loss of independence. There is very little recognition of the health gain achieved if services are provided in an appropriate way when requested by disabled people.

The availability of specialist expertise within a reasonable travelling distance is a cause for concern for many disabled people because, as new contractual arrangements are introduced and an emphasis is placed on community-based services, it is likely to become much more difficult to obtain the specialist services required.

A lot of disabled people fall through the net after leaving school. The transition to adulthood often means that young disabled people lose contact with any specialist provision. Similarly, disabled people who leave hospital can encounter considerable difficulties. Sometimes disabled people may be discharged from hospital without appropriate follow-up arrangements, such as physiotherapy or domiciliary support.

Debates about the primary and secondary care interface take on a special significance for disabled people who use both elements of the health service regularly, yet the needs of disabled people are rarely taken into account in the debate, and their experience of primary care and hospital services is rarely addressed within organisational audits, consumer surveys or other quality-assurance initiatives.

- Employ a link worker to offer support to disabled people when they are being admitted into hospital. The link worker's role could be to provide (or where necessary seek out) appropriate advice, information and access to specialist resources for both the disabled person and hospital staff.
- Implement the *Charter for Disabled People Using Hospitals* (1992).
- Work with other health service providers to develop ways of making the services more responsive to the needs of disabled people. For example, ante-natal clinics could have a qualified sign language interpreter available on a particular day, or accident and emergency departments could have information available in Braille to give to blind patients.
- Encourage providers of specialist services to develop a flexible service which can respond to a range of requirements. For example, the wheelchair service may offer an evening clinic one day a fortnight, or the spinal injuries centre may offer a seven-days-a-week advice and information line.
- Set up a mechanism so that if there are a number of different health professionals involved, someone takes the lead responsibility for a co-ordinated approach and keeping the patient properly informed about what is happening.
- Investigate how referral systems can be made quicker and simpler. Try piloting a self-referral scheme, or establish special contractual arrangements so that disabled people who require a specialist service gain quicker access.
- Work with disabled people to obtain consumer feedback on a complete range of health service provision, especially specialist health services.
- Commission independent research to examine the impact of changes in hospital provision on disabled people.
- Conduct research to identify the needs of disabled school-leavers and chart their progress over a period of several years. A longitudinal study would be useful for exploring how the transition to adulthood has occurred and identifying areas for improvement.
- Establish guidelines for working with disabled adolescents, so that essential services do not stop if disabled people wish to use them beyond school-leaving age.
- Use joint-finance money to develop a project which actually looks at ways of supporting disabled people who are discharged from hospital. This may take the form of a service focused on co-ordinating inter-agency work, or it may be another form of practical support, such as a mobile counselling or speech therapy service.
- Fund some independent work so that disabled people can establish quality standards and participate in quality-assurance initiatives, organisational audits and other evaluation activities.

Personal Development

AGENDA FOR CHANGE

An essential element of community care consists of the opportunities available for disabled people to participate in everyday life. All too often services have focused on meeting disabled people's requirements in terms of accommodation and support services, and very little attention has been paid to disabled people's personal development in broader terms.

Access to work, education, leisure, transport and an accessible environment are all vital ingredients for promoting disabled people's personal development. This is not the sole responsibility of health and social services, but, in developing community care, work needs to be done with the appropriate agencies to ensure that disabled people's needs in terms of personal development are met.

In order to pursue work, education and leisure, an accessible environment is essential. This should not simply concentrate on physical access to buildings, but also incorporate the communication needs of Deaf people, blind people and disabled people whose first language is not English.

FRAMEWORK FOR ACTION

- **Establish links and joint development initiatives with education providers, employers, leisure facilities and transport organisations to enable disabled people to use such resources.**
- **Provide disability equality training to key departments and organisations responsible for education, leisure, employment and transport.**
- **Work with planning departments to assess the accessibility of existing public buildings and monitor new planning applications.**
- **Work with key departments and organisations to fund an interpreting service with sign language interpreters, deaf/blind communicators and community language interpreters that can be used beyond the realms of health and social services.**
- **Ensure that a service is provided, in either the independent or the statutory sector, to run a Braille tape-and-transcription service.**
- **Explore how personal assistants can be used to support disabled people's participation in community life.**

Section 3 – Developing services with disabled people

Traditionally, disabled people have only been the recipients of services. The opportunity to shape the way services are designed and delivered has not been available. However, community care legislation, policy documents and good practice now highlight the need to involve disabled people in developing services.

In a climate of increasing user involvement in various spheres of life, there has been a recognition that community care services cannot be developed effectively without the involvement of the people who use them.

User involvement requires time, commitment, resources and a shift in traditional ways of working. However, the only way to ensure that services are developed in a way which responds to disabled people's needs is to work with disabled people on the design and delivery of services.

Over the past few years, some progress has been made in terms of accepting the principles of user involvement. There is, however, a danger that user involvement could become an end in itself, rather than a means to an end. In order to prevent this, it is important to tackle a number of issues.

Defining User Involvement

AGENDA FOR CHANGE

Over the past few years, the term 'user involvement' has become part of everyday language for policy makers and practitioners alike.

Although most people would be able to explain the basic premise behind the notion of user involvement, it is clear that the term has come to mean all things to all people.

In the context of improving disability services, 'user involvement' is defined as:

'Disabled people being involved in many different ways in planning, implementing and evaluating services.'

There is a whole spectrum of user involvement, ranging from providing information, consulting disabled people either individually or within a group, through to joint working and delegated control where disabled people actually manage and run services.

FRAMEWORK FOR ACTION

- **Be clear about what 'user involvement' means in terms of your work.**
- **Produce some information for workers on the different types of user involvement with examples about when it may be appropriate to use them. For example, it is inappropriate to ask someone visiting an accident and emergency department to join a working party; similarly, disabled people using the district nursing service may prefer not to give their individual experience, but work with other disabled people to design a service specification and determine quality measures.**
- **Select an area of work that needs to be looked at, such as the provision of information or disability equality training for staff, and work with an organisation of disabled people to tackle it.**
- **Find out whether there are any local user-controlled services, and what they may be able to offer.**

Resourcing User Involvement

There are many benefits to be gained from involving users in the design and delivery of services. The knowledge, skills and expertise provided by disabled people significantly contribute to the development of good-quality and appropriate services.

However, disabled people are often expected to participate in a range of consultation and joint-working initiatives without any financial or practical resources being made available.

User involvement cannot be developed effectively unless there is a recognition that disabled people who share their knowledge, skills and experience are providing an essential service.

In order to work with service agencies on the development of community care, disabled people need access to:

- practical resources (e.g. facilitation, training, transport, meeting venues);
- financial resources to cover costs and provide remuneration for the service offered.

Similarly, it is important to try to deal with any resistance to user involvement within service agencies, otherwise professionals may feel threatened and hostile to working with disabled people. There is a grave danger that user involvement could be seen as a passing fad unless all professionals are encouraged to recognise and value the contribution that disabled people can make to improving services.

- **Identify organisations of disabled people and set up contracts for joint working which cover core costs as well as the cost of any development work that may be required. For example, an organisation of disabled people can be an ideal position to conduct a review of services.**
- **Work with disabled people to establish user groups in areas where there is no existing representative forum.**
- **Provide transport, sign language interpreters, speech facilitators, etc. for any meetings or events.**
- **Offer training to help disabled people develop their skills or acquire knowledge in a particular field, such as service specifications.**
- **Provide training on user involvement for staff.**

Integrating User Involvement

User involvement in terms of the development of community care plans or other planning structures has become widely accepted. This has been a significant move forward; attention now needs to be paid to how users can be involved in the implementation and evaluation of service development.

Involving disabled people in implementation means that, wherever appropriate, disabled people should be able to run services or put into action the recommendations made in community care plans or other similar documents. For example, disabled people might run an independent living scheme, or actually work with PHCTs to make services more accessible.

Disabled people can be involved in the evaluation of services through a number of different approaches, ranging from taking part in a consumer survey or a focus group, to being commissioned to do a user-led evaluation, where disabled people actually conduct an evaluation of a particular area of work, such as assessment and care management.

The whole spectrum of user involvement needs to be integrated into every stage of service development.

- Go through all current and future work plans to examine whether it is appropriate to involve users and, if so, what may be the most suitable form of user involvement. For example, it may be sufficient to invite a local organisation of disabled people to comment on a purchasing plan, or alternatively it may be more sensible to ask them to put in a bid for a particular area of work that has been identified.
- Be clear about any reasons for not involving disabled people, and also be aware that there are very few circumstances where user involvement is not appropriate. For example, while disabled people may not want to run the service provided by orthopaedic surgeons, they could be in a very good position to evaluate aspects of orthopaedic services.
- Establish local guidelines for integrating user involvement into the different stages of service development. While it is difficult to prescribe at a national level minimum standards on user involvement, as requirements can vary according to local circumstances, some basic standards could be built into local community care charters.
- Find out what user-controlled services are available in the area, and identify whether there are any particular services that disabled people may be in a position (with appropriate support) to run. For example, African-Caribbean disabled people may want to run a counselling or advice and information service for people with sickle-cell anaemia and thalassaemia.
- Devise methods of enabling disabled people to monitor the quality of services. These may include visiting residential homes, maternity units or day centres. Alternatively, a group of disabled people could come together to share their experiences and make recommendations in a quality circle focusing on the service provided at, say, an eye clinic.

Evaluating User Involvement

User involvement requires time, effort, resources and hard work on the part of both disabled people and service agencies. This is usually paid off by the fact that there are improvements in the way services are designed and delivered.

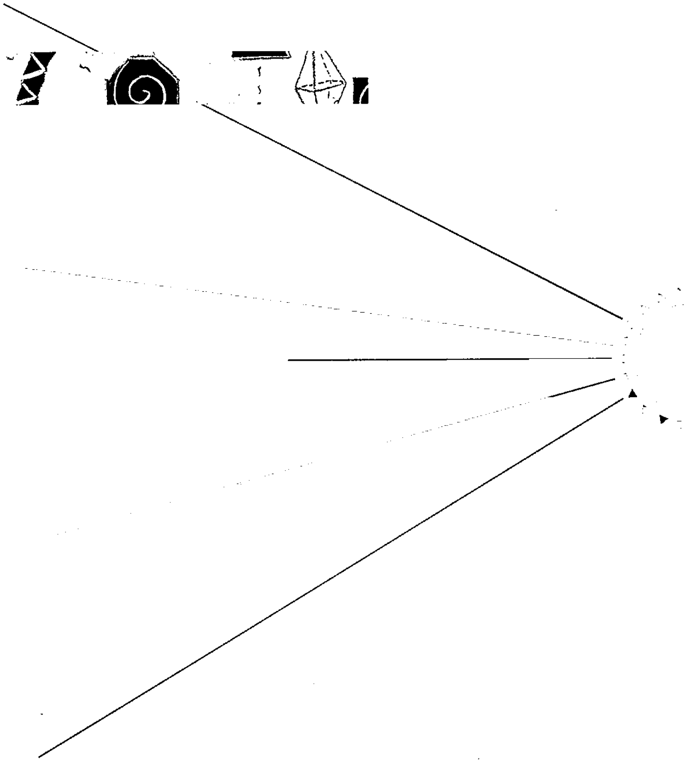
Sometimes it can be difficult to see any tangible benefits or improvements from the process of user involvement. People can be left feeling frustrated and disillusioned. On the one hand, service agencies could be inclined to try to avoid user involvement as much as possible, or at least use more superficial, tokenistic approaches. On the other hand, disabled people may decide that as they do not seem to be getting anywhere, their involvement is a pointless exercise and withdraw or use more direct lobbying tactics.

There is a danger that user involvement may become an end in itself, rather than a means to an end. Therefore it is extremely important to review the effectiveness of the approaches used and assess the impact that they are having on the areas of work in question.

In order to evaluate the effectiveness of user involvement, one needs to be clear about what the initial aims and objectives were and why a certain type of approach was adopted. This needs to take account of the perspective of all the people involved, and ensure that the views of disabled people are not marginalised.

Unless the evaluation is managed sensitively, there could be difficulties with disagreements, competing priorities for all the stakeholders and fears about the demands or expectations that may be placed on the different people involved.

- Agree basic ground rules for user involvement work which incorporate the concerns of everyone involved, and respect the skills and expertise of disabled people in a meaningful way. The ground rules could cover issues such as confidentiality and dealing with any disputes.
- Agree a timetable of work with tangible targets. This will need to incorporate short- and long-term goals, so that all the stakeholders know what they are trying to achieve.
- Be clear about the aim of a particular area of work and why a certain approach has been used.
- Review the achievements of any work and identify outcomes.
- Set up a meeting, training or review forum which comes together once every six or twelve months to discuss how well user involvement is working, to identify future priorities, and to explore alternative options if there are difficulties.



APPENDIX – Legislation and guidance

Chronically Sick and Disabled Persons Act 1970

Community Care Support Force 1993: *User Participation in Community Care Services*

Department of the Environment/Department of Health 1992: *Joint Circular on Housing and Community Care,* Circular 10/92 & LAC (92)12

Department of Health 1989: *Discharge of Patients from Hospital.* Booklet to accompany Circular HC(89)5

Department of Health 1990: *Community Care in the Next Decade and Beyond: Policy Guidance*

Department of Health 1991: *The Patient's Charter.*

Disabled Persons (Services, Consultation and Representation) Act 1986

Local Government and Housing Act 1989

National Assistance Act 1948 (Choice of Accommodation) Directions 1992

National Health Service and Community Care Act 1990

Social Services Inspectorate 1991: *Care management and assessment: Practitioners' guide*

Social Services Inspectorate 1991: *Care management and assessment: Summary of practice guidance*

Social Services Inspectorate 1991: *Getting the message across: A guide to developing and communicating policies, principles and procedures on assessment*

Social Services Inspectorate 1991: *Purchase of service: Practice guidance and practice material for social services departments and other agencies*

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LIVING OPTIONS PARTNERSHIP

The Prince of Wales' Advisory Group on Disability exists to assist HRH The Prince of Wales in unifying perspectives and acting as a catalyst to enhance the values, attitudes and practices of society as they relate to disability.

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