

**LIVING
OPTIONS
PARTNERSHIP**

THE POWER TO CHANGE

**Commissioning Health and
Social Services
with Disabled People**



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and Social Services
with Disabled People

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Jenny Morris

Partnership Paper No.2

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The Living Options Partnership is a collaborative venture between The Prince of Wales' Advisory Group on Disability and the King's Fund Centre, with additional funding from the Department of Health.

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.



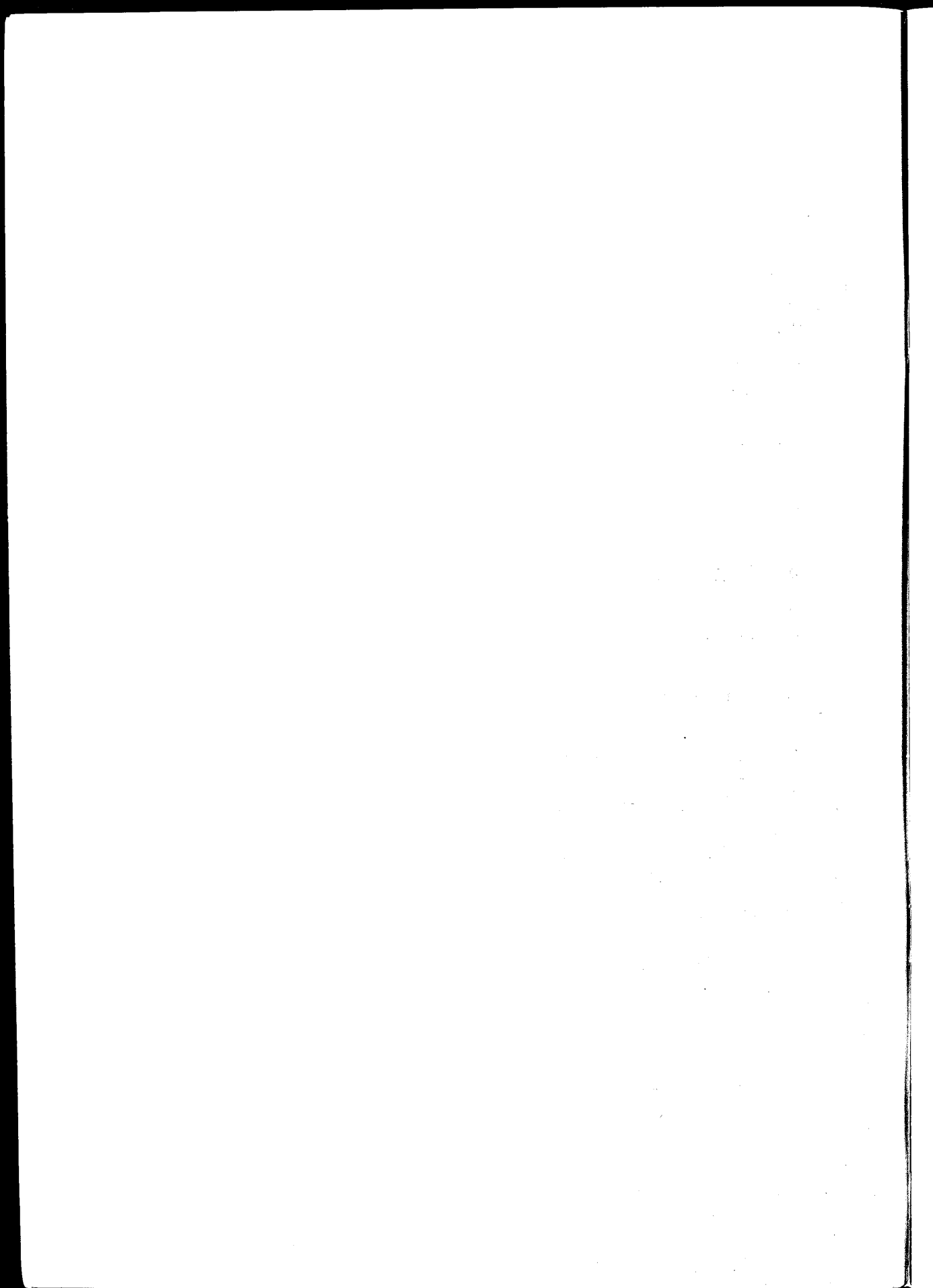
The King's Fund Centre is a service development agency which promotes improvements in health and social care. We do this by working with people in health and social services, in voluntary agencies, and with the users of these services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up. The King's Fund Centre is part of the King's Fund.

Acknowledgments

Contact was made with organisations who were recorded on the Living Options Partnership and Nuffield Community Care database as being involved in developments in commissioning services for people with physical and/or sensory impairments. Responses were received from organisations listed below and their help is gratefully acknowledged.

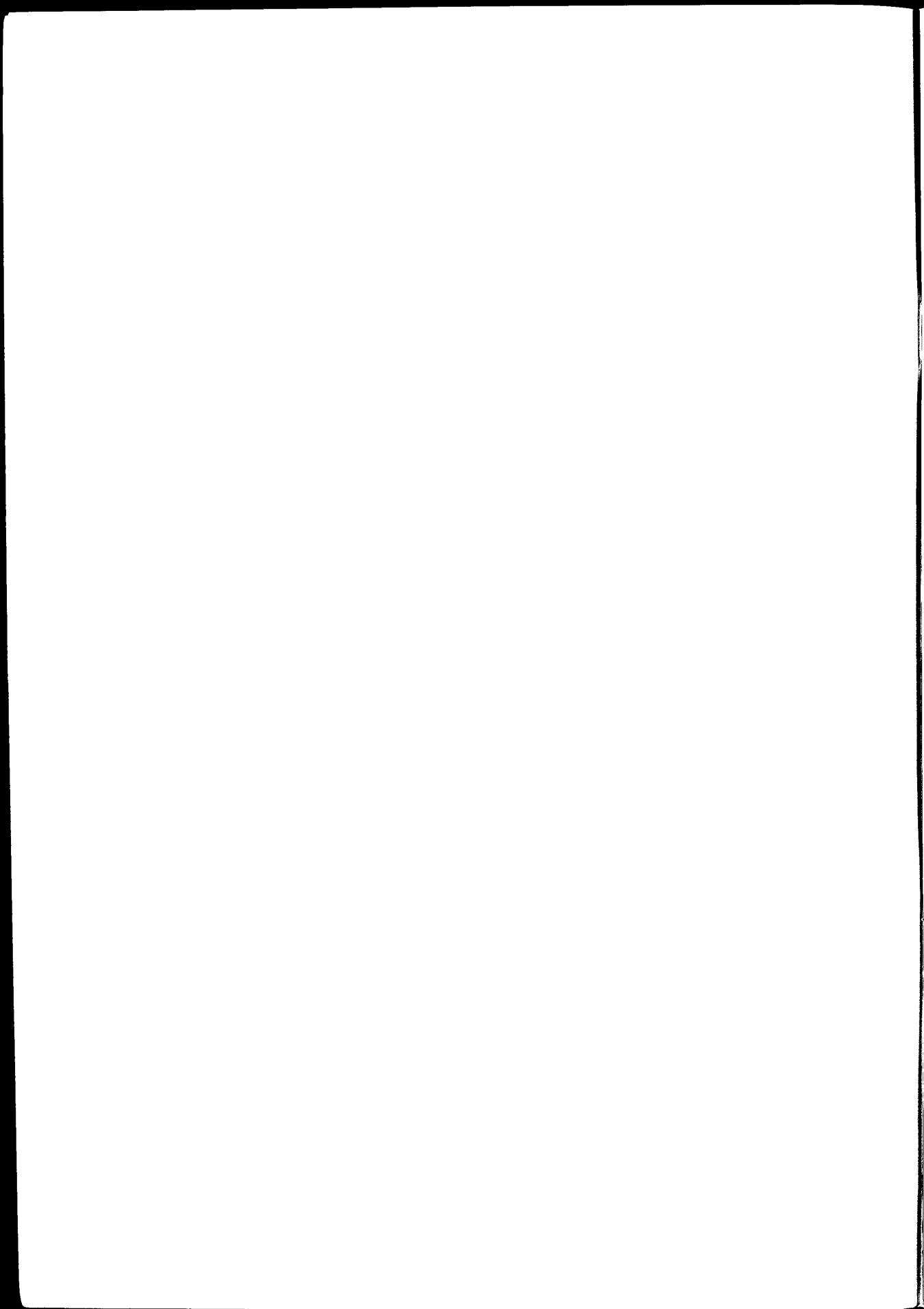
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London Borough of Merton: Housing and Social Services Department
NHS Executive North Thames
North West Regional health Authority
North Yorkshire County Council Social Services Department
West Yorkshire Health Authority
Wiltshire and Bath Health Commission
Wiltshire User Involvement Network

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Introduction

All over the country, health and social services commissioners are starting to work in partnership with each other and with disabled people to develop the kind of services that really meet people's needs, that really make a difference to their lives. This document builds on the progress being made and aims to set out some guidelines for those commissioning health and social services for people with physical and/or sensory impairments between the ages of 16 and 65.

It starts by identifying what are the general aims of commissioning activities directed at this group of people before moving on to address the different stages of the commissioning process: planning; service development; the contracting process; and looking at how a service performs. A checklist is given at the end which highlights the things which need to happen to create responsive, flexible and accessible services.

The information and ideas which form the basis of the guidelines were gathered both from published material, listed in the bibliography, and from the health and social services organisations who sent details of what they were doing.

The examples highlighted in the document are all based on current developments although most of them are not actual accounts of existing practices. Some reflect the innovative practices which are being developed by those who commission and provide services; many are also based on the creative thinking amongst service users themselves, on their knowledge of how their needs can most effectively be met.

Perhaps the most important message coming from service users and their organisations is their wish to work with commissioners, recognising as they do that how services are planned and purchased will, for many people, determine the quality of their lives.

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1 What should we aim for when commissioning services with disabled people?

Health and social services commissioners have often set out these kinds of aims when commissioning services for disabled people:

- ☐ **to purchase good quality services**
- ☐ **to fulfil requirements laid down by legislation and government guidance**
- ☐ **to use resources more efficiently**
- ☐ **to prevent unnecessary deterioration in health or impairment and to prevent secondary impairments**
- ☐ **to encourage joint commissioning and joint working by health and social services organisations.**

This section looks at these aims in more detail.

To purchase good quality services

The quality of health and social care has commonly been defined in terms such as:

- ☐ equity and accessibility: making services available to everyone that needs them
- ☐ effectiveness: whether the service achieves what it sets out to do
- ☐ acceptability: what do users feel about the service?
- ☐ efficiency: the avoidance of waste.

It is important, however, to translate these kinds of principles into a clear understanding of what a service which achieved all these things would look like in practice, of what it would feel like to receive such a quality service. Research on disabled people's experiences of receiving services indicates that three main things determine the quality of the service:

- ☐ how easy it is to access a service
- ☐ the attitudes of service providers to users
- ☐ the extent to which the service is responsive to individual and varying requirements.

Commissioners will therefore want to incorporate these issues into quality standards.

Mrs Patel, aged 55, a widow who lives with her adult son, returns home from hospital after a stroke. She receives meals on wheels, District Nursing and home care services. However, none of these service providers speak Mrs Patel's language and she becomes depressed and distressed especially as she finds the visits by occasional male service providers very difficult to cope with. Her ability to be at home on her own while her son and his wife are out at work diminishes and eventually she is admitted to residential care.

To fulfil requirements laid down by legislation and government guidance.

When commissioning services for disabled people, both health and social services authorities will seek to ensure that they fulfil their statutory duties and abide by guidance issued by the Department of Health.

Social services authorities have clear responsibilities laid down by legislation and guidance:

- ☐ there is a duty to publish information about services provided for disabled people by statutory, voluntary and private organisations (Disabled Persons Act, 1986, Section 9)
- ☐ people with physical and/or sensory impairments have a right to have their needs assessed (Disabled Persons Act 1986, Section 4)

- ❑ if a disabled person is assessed as needing any of the things covered in Section 2 of the Chronically Sick and Disabled Persons Act 1970 (which includes, for example, practical assistance in the home, aids and adaptations) then arrangements must be made to meet these needs
- ❑ assessments should be needs-led rather than service-led (Department of Health Social Services Inspectorate, 1991, *Care Management and Assessment: Practitioners' Guide*)
- ❑ assessments should be jointly carried out with health and housing professionals where appropriate (NHS and Community Care Act 1990, Section 47 (3))
- ❑ users should be consulted on Community Care Plans (NHS and Community Care Act 1990, Section 46, 2(d)) and involved in the purchasing process, for example in writing service specifications (Department of Health Social Services Inspectorate, 1991, *Purchase of Service: Practice Guidance and Practice Material for Social Services Departments and other Agencies*).
- ❑ health and housing authorities should be consulted on Community Care Plans (NHS and Community Care Act 1990, Section 46, 2(a)(b)(c)).

In order to fulfil the rights that are laid down in the Patients' Charter, commissioners and providers will need to pay particular attention to the access needs of people with physical and/or sensory impairments. This particularly applies to the rights to:

- ❑ have any proposed treatment, including any risk involved in that treatment and any alternatives, clearly explained to you before you decide whether to agree to it
- ❑ have access to your health records, and to know that everybody working for the NHS is under a legal duty to keep your records confidential
- ❑ receive detailed information on local health services. This includes information on the standards of services you can expect, waiting times and on local GP services
- ❑ to receive information about the services your GP provides and to see on request a copy of your GP's practice leaflet, which sets out this information.

(*The Patient's Charter*, 1995, pp.6-9)

One of the standards of service laid down by *The Patients Charter* concerns making it 'easy for everyone to use services, including children, elderly people or people with physical or mental disabilities' (p.6). *The Maternity Charter* also sets out rights and standards of service, while *The Health of the Nation* sets targets such as reducing smoking and premature births which are as applicable to disabled people as to other sections of the population.

Jessica Taylor has a family history of breast cancer and her GP refers her to the early screening clinic at the local hospital. Jessica telephones to find out about parking for disabled drivers and is informed that there are two designated bays but no guarantee that either will be free. Arriving at the clinic, she finds that both bays are taken, one of them by a person who is not displaying an Orange Badge. She eventually finds somewhere to park and, with difficulty, reaches the clinic's reception. Although her GP had mentioned that Jessica is a wheelchair user in the referral, the receptionist responds with surprise and the clinic nurse with consternation. "Oh dear" says the nurse, "I don't think we can do a mammogram – you would have to stand up for it". By this time, Jessica is so discouraged that she gives up and goes home.

To use resources more efficiently

Health and social services commissioners are responsible for the best use of public money. They will therefore want to purchase services which:

- ☐ meet people's needs
- ☐ are accessible to all sections of the community.

Anthony Jackson uses British Sign Language and he cannot afford to employ a Sign Language Interpreter to accompany him to the dentist. After years of never seeing a dentist he presents himself at his local Casualty Department with a tooth abscess.

An enabling service is one which starts with the individual's aspirations and responds with flexibility. In order to develop this kind of quality service it will be necessary to consult with existing and potential users to find out what their aspirations are and how they think a service can best help them to achieve these.

Users of services sometimes say that they experience services as being disabling rather than enabling. In other words, rather than being a means of achieving their aspirations (such as better health or help with daily living activities), a service has instead placed barriers in the way of the disabled person getting their needs met. This results in not just a poorer quality of life for the individual concerned but also greater costs for health and social services and for the community as a whole.

For example, a health service which is not accessible to someone, which does not enable them to get appropriate treatment for their impairment/illness, is a disabling service in that lack of treatment will result in deterioration of function and/or health – and will in the longer term result in greater costs to the health service.

A social service which does not offer appropriate support, is a disabling service in that this will result in isolation, restricted participation in family life, friendships and community life, inhibit education, work and leisure opportunities. This may lead to a deterioration in function and/or health of the disabled person and/or family member or friend who provides support in lieu of the service.

To prevent unnecessary deterioration in health or impairment and to prevent secondary impairments.

Commissioners will want to purchase services which maximise people's well-being and the quality of their lives. Disabled people need access to good services generally, but both health and social services commissioners will also wish to focus on the particular needs that disabled people have and how they can best meet these needs. For example, it is estimated that there are between 70,000 and 100,000 wheelchair users who are susceptible to developing pressure sores, and that the provision of incorrect seating for these wheelchair users could result in the

consumption of health services averaging £20,000 per person. Special cushions to prevent pressure sores cost between £35 and £350 each.¹

Preventative action can also address the health status and risk of impairment experienced by those family members and friends providing practical help to disabled people. Research on parents over retirement age who were still providing support to their adult sons and daughters found that almost four-fifths of them said they had health problems such as arthritis, angina and back pain, and two-thirds attributed their problems to the strain associated with looking after their son or daughter.²

To encourage joint commissioning and joint working by health and social services organisations

There is evidence of gaps and duplication in services provided for disabled people by health and social services organisations. The community care reforms offer a major opportunity to fill these gaps and prevent unnecessary duplication of services.

Although disabled people may sometimes have very specific needs, they often cannot divide their lives and their needs in the way that statutory agencies have traditionally distinguished between health and social care. Health and social services commissioners should therefore move beyond discussions such as when is help with bathing a 'medical need or a social care need'.

A health commissioning agency and a social services authority jointly funded an Independent Living Worker, based in the local organisation of disabled people. Following the success of the worker in supporting a number of disabled people to employ their own assistants, the two agencies decided to resource another post to make contact with people from the local Black communities, enabling those who wish it to employ personal assistants.

2 Planning to meet the needs of disabled people

When health and social services authorities are planning to meet the needs of disabled people they will want to:

- ☐ **establish their aims**
- ☐ **identify some important ground rules**
- ☐ **assess the level of need in the local population**
- ☐ **establish access standards**
- ☐ **plan for health gain**
- ☐ **develop opportunities for joint commissioning.**

This part of the document deals with all these points.

Establishing aims

Some services that disabled people use address their particular needs arising from physical and/or sensory impairments, such as rehabilitation services, occupational therapy services and so on. Other services, developed to meet the needs which exist within the population generally, will also be used by disabled people, such as family centres, acute hospital services, etc. Both specialist and general services need to establish aims for meeting the needs of people with physical and/or sensory impairments. For example, it may be agreed that specialist services will be commissioned which:

- ☐ minimise the effects of impairment
- ☐ prevent secondary impairments as far as possible
- ☐ enable people with physical and/or sensory impairments to assert choice and control in their lives
- ☐ are delivered in a way which means all sections of the community have equal access to them.

Planners will also identify that they wish to commission health and social services in general which are

- ☐ accessible to people with physical and/or sensory impairments
- ☐ appropriate and effective at meeting their needs
- ☐ delivered in a way which means that all sections of the community have equal access to them.

Some important ground rules when planning services for disabled people

Seek information about innovations in other areas

There are many new initiatives being developed. Information can be gathered from, for example, the Nuffield Institute's Community Care Division (01132 336633), Living Options Partnership (0171 267 6111), and national disability organisations, such as the British Council of Organisations of Disabled People (01332 295551).

Designate a post or posts devoted to planning services for adults with physical and/or sensory impairments below retirement age

The greatest demand for health and community care services is from older people and it is easy therefore for disabled people below retirement age to get missed out. Moreover, the needs of people with physical and/or sensory impairments have traditionally not been met by non-specialist services such as ante-natal services. Unless particular attention is paid to the needs of this group, therefore, it is unlikely that commissioners will be able to purchase services which will effectively meet their needs.

Use the expertise and experience that exists amongst disabled people themselves

The designated officer(s) should establish close contact with local organisations of disabled people and use a variety of methods to enable him/her to learn from disabled people's experiences. Both commissioners and providers have demonstrated that there are many ways of involving service users. Setting up a dialogue with local organisations is just a start; other methods include bringing together small groups of people to work on a particular task, carrying out surveys

of local users and potential users, training local disabled people to act as consultants on service issues, setting up panels of service users and enabling them to represent other users, and so on.³

A health commissioning agency and social services authority jointly funded a conference of people with physical and/or sensory impairments, where a number of people volunteered to be involved in future dialogue about commissioning services. The two agencies resourced this group of people to come together on a regular basis, provided them with training on the commissioning process, helped them to make contact with other service users to find out what they wanted from services, and incorporated meetings with this group into their commissioning procedures. Commissioners found this user involvement particularly helpful in planning services for people discharged from hospital and one result was a reduction in hospital readmissions.

Recognise that people with physical and/or sensory impairments will have varying needs and experiences.

This is a heterogeneous group of people and includes those born with impairments which are static; those born with impairments which will result in reduced life-expectancy; those who acquire a static impairment in adult life; those who acquire an impairment which is progressive and which they experience as an illness. Someone in the advanced stages of multiple sclerosis, for example, will have different needs from someone who has been blind since birth and who has no associated health difficulties.

This group also includes people with multiple impairments, which may be a combination of physical/sensory impairments and learning difficulties. Specialisation of services on the basis of impairment can mean that people with multiple impairments are 'pigeon-holed' into one particular specialism relating to only one part of their whole experience.

Commissioners will also want to take into account that people with physical and/or sensory impairments are found in all sections of the community and in all types of household.

People with physical and/or sensory impairments will need to use services which are not provided especially for disabled people as well as those that are

This applies as much to social services as it does to health services. People with physical and/or sensory impairments may also have learning difficulties or use mental health services. Social work services aimed at these groups need to take this into account.

Both general health services and other specialties may be required by people with physical and/or sensory impairments. For example, women with visual impairments need access to cervical screening; men who are wheelchair users may have cancer. Almost everyone at some time will get a common illness such as flu and need to visit their doctor.

Some impairments are associated with particular social and health care needs and it is important to recognise such needs

While disabled people have insisted that disability is not illness – and indeed it is not since disability refers to the disabling barriers of inaccessible environments, lack of appropriate support and prejudicial attitudes – people with physical and/or sensory impairments sometimes experience illness related to their impairments. For instance, they may have respiratory conditions, bladder or kidney infections, pain, pressure sores, etc. They may therefore need specialist health and social services.

Successful outcomes will often be dependent on a number of different factors

People's lives cannot be divided into the categories and needs often imposed on them by health and social services organisations. At a strategic planning level, therefore, commissioning agencies will want to think about how the services they purchase fit in with other important aspects of people's lives. Disabled people themselves have identified seven key areas of need:

- ☐ **information** to enable choices to be made
- ☐ **counselling** to help make those choices
- ☐ **housing** which is suitable, accessible, well-located
- ☐ **technical aids** or enabling equipment
- ☐ **personal assistance** when it is needed
- ☐ **transport** to function in society
- ☐ **access** to all public buildings/amenities⁴.

Successful outcomes of services purchased by health and social services commissioners may well be dependent on a range of factors and a co-ordinated approach to a person's needs as a whole person will often make it necessary for a number of organisations to work closely together.

Assessing levels of need

There are three important points to bear in mind when assessing levels of need.

There are many different methods of assessing needs and they all have a role to play

The OPCS national disability survey and local surveys tell health and social services authorities the prevalence rates of different impairments in their populations: for example, the OPCS survey tells us that 31 out of every thousand people aged 16 to 59 have locomotion impairments, 18 per thousand need help with personal care tasks, 17 per thousand have hearing impairments and 9 per thousand have visual impairments⁵.

However, measurements of prevalence rates can be confusing: one health authority, using three different surveys, estimated the number of people with significant physical impairments in their district to be 850, 1,650 and 2,000.

Needs assessments which are solely based on prevalence rates are not always the most useful way of measuring the need for a service. The number of people who actually express a need for a service will depend on things like: whether they know about it; whether it is easy to get access to the service; whether it is the kind of service they want. Needs assessments therefore have to move beyond measuring the incidence of impairment/illness and look at what people want and how they can be helped to access a service.

We cannot assume that existing services are exactly what people want and are easy for everyone to access. Therefore, needs assessments must not be based solely on measuring demand for existing services but must also include a measurement of unmet need.

On the other hand, an evaluation of who is using existing services and whether they best meet their needs can be an important part of needs assessments. For example, the need for regional rehabilitation centres for people with head injuries became evident, not so much from statistical information about the prevalence of head injuries but from evidence that such people were staying in hospital for longer than necessary, and were often placed in inappropriate health provision because there was nowhere else for them to go. Similarly, evaluation of the needs of people using day centres run by social services departments often illustrates that there are more effective ways of meeting their requirements.

Disabled people themselves are an important source of information about the nature of their needs and so too are front-line staff.

A Commissioning Agency set up a six month project to identify the needs of school leavers with physical and/or sensory impairments. Using the assessments carried out at age 14 under the 1986 Disabled Persons Act and carrying out one-to-one and group discussions with samples of 18, 21 and 25 year olds, the project found there was a need for:

- ☐ **physiotherapy in varied settings (such as College and workplaces)**
- ☐ **housing**
- ☐ **advocacy support to enable people to leave parental home/residential home**
- ☐ **help with finding accessible and sympathetic general practitioners when moving away from home/residential home**
- ☐ **access to further education/training and paid employment.**

Individual needs-led assessments have a key role

Social services authorities carry out assessments of individual's needs in their implementation of community care and these assessments should be a key source of information when planning to meet the needs of disabled people. The National Audit Office recommended in 1992 that health authorities should 'base their purchasing of services on a comprehensive assessment of the individual needs of people with physical disabilities'. There is therefore much scope for joint working here.

In order for assessments of individual needs to be useful to planners they have to be:

- ☐ separate from services; in other words staff should not be assessing the need for a service but establishing what the person wants to achieve and what would help them achieve this
- ☐ the voice of the user; disabled people need to be helped to explore what their needs are and the varying ways in which they may be met – professional expertise, therefore, is a resource to be placed at the disposal of the service user
- ☐ separate from the establishing of eligibility or priority which may subsequently be used in order to ration scarce resources.

Unmet need should be recorded, aggregated and fed into the planning process.

Reducing inequalities in access to services

Health and social services planners will want to pay particular attention to meeting the needs of people who have traditionally had less access to appropriate services, for example Black disabled people and people with invisible impairments such as epilepsy, diabetes, sickle cell anaemia.

Active community participation is the key to a comprehensive assessment of the needs of people who are less likely to be in contact with services. Some commissioning agencies find it valuable to resource outreach work which both provides a service and acts as an assessment of unmet need.

An advocacy service for Asian people was jointly funded by health and social services commissioners. Advocates engaged in outreach work, making contact with people who were not regular users of primary care services as well as those that were. They:

- ☐ **enabled people to sign up with GPs**
- ☐ **increased communications between GPs and their Asian patients about the medication they were prescribed**
- ☐ **acted as an independent advocate in the assessment and care management procedures carried out by social services staff.**

The project was evaluated and the following commissioning intentions were put into the Joint Commissioning Plan:

- ☐ **to encourage GPs to target Asian men and women over the age of 40 to attend once a year for a general health check. This was recommended following the project's identification of high rates of stroke, hypertension and diabetes in this population**
- ☐ **to request that local providers of domiciliary care recruit Asian care workers so that they can provide a culturally sensitive service to the Asian population.**

Establishing access standards

Establishing access standards for the services to be purchased will be an important part of planning to meet the needs of people with physical and/or sensory impairments.

The following suggestions build on existing practice amongst commissioning agencies and service providers.

- ⇒ **Always involve disabled people when trying to improve access to services; e.g. the local disability organisation may have an Access Group (or could be funded to set one up).**

Health and social services commissioners in one area jointly resourced a group of people with mobility and/ or sensory impairments. The group was supported by the local authority's Access Officer and received training in access issues across the whole range of physical and sensory impairments. They commenced a two year programme of inspecting health and social services premises, drawing up recommendations for changes, highlighting good access. The members of the group were paid a fee for each visit and report which they contributed to.

⇒ Make an accessible environment for people with physical and/or sensory impairments a quality standard against which each service provider's performance is measured.

⇒ All printed information should be produced in large print. It should also be available in Braille and on audio and video tapes.

⇒ Commission local relevant Black community organisation to work with professional translators to produce leaflets, videos and tapes about services and how to access them.

⇒ Information about services and how to access them to be publicised on local radio, teletext, etc.

⇒ Leaflets and tapes to be distributed in local post offices, DSS offices, Job Centres, pharmacies, libraries, local advice centres, day centres, residential establishments, health centres, Out Patients' Departments, Accident and Emergency Departments.

⇒ Clear information about services and access points to be printed in Yellow Pages and local telephone directory.

⇒ Establish independent advocacy services which enable people to be clear about their needs, to express them and to access the assessment and services they require.

⇒ Commission a comprehensive interpreting service for people from minority language communities, ensuring that interpreters receive disability equality training.

⇒ Commission a comprehensive communication service for people who are Deaf or hard of hearing and/or who use non-speech methods of communicating:

- ❑ utilising the full range of communication methods: lip speakers, British Sign Language Interpreters, Makaton, Bliss boards, communicators;
- ❑ independent communicators to be available for people being assessed, attending health service facilities, including hospital stays etc;
- ❑ the same communicator to be available during the assessment process or course of treatment or stay in hospital; and
- ❑ ensure that the communication needs of people from minority language communities are also integrated into these services. A start can be made by creating a register of communicators who speak local minority community languages.

Deborah receives a reminder to attend for her three-yearly cervical smear at her GP's surgery. Using her minicom, Deborah rings the surgery's minicom number and communicates with one of the receptionists who has been trained in using a minicom. The receptionist arranges for a Sign Language Interpreter to be available to meet Deborah before the appointment and to interpret for her during the appointment. The Sign Language Interpreter is booked through the RNID's local Communication Support Unit which has a contract with the Health Commissioning Agency to provide services for Deaf and hard of hearing users of community health services.

Planning for health gain

Health gain is not necessarily about cure or even about prolonging life. It can be about removing disabling barriers, thereby enabling people to assert choice and control in their lives. Health gain can be about improving the quality, but not necessarily the length, of life.

Whilst the traditional definition of rehabilitation emphasises 'the restoration of patients to their fullest physical...capability',⁶ disabled people's organisations have stressed the importance of services which enable people to assert control over the physical help that they might need. While everyone wants to achieve their maximum physical potential, the capacity for independent living is not limited by what you can physically do for yourself but how much control you have over the help you need. Both social services and health commissioners will therefore want to ensure that the services they purchase enhance the choice and control that people have in their lives.

Commissioning strategies will need to incorporate people with physical and/or sensory impairments in the context of *The Health of the Nation* and associated targeting. For example, targets for reducing breast cancer must include disabled women; targets for reducing suicide rates must include disabled people.

Some health gain targets, such as the prevention of pressure sores, will be specifically directed at disabled people. Targets are useful but, in order to achieve them, the services commissioned have to address the detailed reality of people's lives.

A health commissioning agency carried out a piece of work, in consultation with local disability organisations, on integrating people with physical and /or sensory impairments into the targets laid down in *The Health of the Nation*. This resulted in providers being required to add physical and sensory impairment to the ethnic origin monitoring which they were already required to do.

Disabled people's own expertise is a key resource in identifying what is important to them and how their health status might be improved.

As part of their consultation on their commissioning plans, a Health Commissioning Agency talked to a group of women who experienced paralysis from various causes. They identified that a major issue for them was chronic bladder infections leading to continence management difficulties, high use of antibiotics, and an increased risk of kidney disorders. In response, the Commissioning Agency initiated and part-funded a regional action research project which brought together disabled women to share their experiences and ways of dealing with paralysed bladders, carried out a survey of international research and produced leaflets for (a) GPs, and (b) disabled women on how to manage chronic urinary tract infections.

Joint commissioning

When health and social services work together to plan to meet disabled people's needs it is important that they set joint outcomes in consultation with services users which can be translated into people's experiences. For example, joint outcomes for the commissioning of services for people with HIV and AIDS might include:

- ☐ reducing hospital admissions
- ☐ reducing length of time spent in hospital
- ☐ increasing ability to remain at home.

John Callaghan is HIV positive and has had two recent hospital admissions. Each time he could not return home until he was well enough to do his own shopping and cooking. The hospital social worker referred him to the Care Manager at his local Health Centre who arranged a meeting with John and his GP to discuss his needs over the coming months. It was agreed that John needed extra help at home when he was unwell and also needed to call on medical or nursing help to assess what was happening and whether he needed treatment at home or in hospital. A contract was agreed with a local agency which has experience of providing home support to people with AIDS. An appointment was made for one of the Community Nurses to call round to see him to assess his needs over the coming months.

In order for these kinds of joint outcomes to happen there will need to be co-ordinated assessments and service delivery. The boundaries created by professional/organisational structures and different budgets should not impinge on the disabled person's experience of assessment and services.

There is considerable evidence that disabled people do not have enough information about services. This is a key area for health and social services commissioners to work together, for example by jointly commissioning a computer database which can be accessed in local libraries, Citizens' Advice Bureaux and other local advice centres, health centres, etc. It would also be sensible to jointly commission services for producing information in accessible formats (large print, on audio and video tape, in Braille, in minority community languages).

A joint planning approach provides an opportunity to tackle some of factors which can often act as barriers to successful service outcomes. For example health and social services commissioners could work with housing providers to develop particular schemes targeted at, say, young people with physical impairments, and also influence the Local Housing Strategy to ensure that the needs of people with physical and/or sensory impairments are generally incorporated.

Health and social services commissioners jointly set as one of their targets the reduction of the time people spent in hospital and rehabilitation centres. They jointly developed:

- ☐ a home nursing service
- ☐ an arrangement with the largest housing association in the area to nominate up to 10 households a year who required rehousing in order that a disabled person could be at home rather than in hospital or rehabilitation centre
- ☐ a fast response aids and adaptations service for people in hospital or rehabilitation centre awaiting discharge

3 Service development

Both social services and health commissioners have the important role of encouraging new services and managing the local market of service providers. In using their purchasing power, they may wish to set the following kinds of aims:

- ☐ to encourage existing and new service providers to meet identified unmet need
- ☐ to encourage services which are flexible enough to meet individual need and which are capable of responding to changes in an individual's need
- ☐ to encourage locally based community services
- ☐ to encourage a one stop contact point for access to a wide range of services
- ☐ to encourage self-assessment and self-referral where possible
- ☐ to commission user-controlled services.

To encourage existing and new service providers to meet identified unmet need

Unmet need may well be resulting in inappropriate use of services, poorer quality of life and longer-term increased expenditure. Commissioners will therefore want to stimulate the development of services to meet that need.

Care managers in one social services authority identified the need for a night call-out service which would provide irregular but familiar help to people who could not predict when they would need help at night - for example, to deal with spasms, if they were stuck in an uncomfortable position, if they needed to use the toilet or were incontinent, or if they were ill. The social service authority commissioned a night call-out service and this has enabled people who were at risk of going into residential care to remain at home.

To encourage services which are flexible enough to meet individual need and which are capable of responding to changes in an individual's needs

The fulfilment of this aim will make a major contribution to the creation of quality services - services which are effective in meeting people's needs and therefore are good value for money. Commissioners will expect service providers to consult regularly with service users and potential users about how what they provide can be truly flexible and responsive to need.

Brian Harris is 36 years old, and lives with his partner and their two children. He has a brain injury resulting from a road accident. After some months in hospital and a regional rehabilitation centre, he returned home. He rarely left his house, partly because he was so embarrassed by his communication impairment. His GP referred him to the local speech therapy service which provides both one to one treatment and a user support group. A reliable transport service to the treatment and the group meetings was provided by a local minicab company. This transport service and the support group had been set up in response to consultation carried out with users of the speech therapy service. Brian found the support group a great help and his confidence in his ability to make himself understood has resulted in his volunteering to help out at the local Disability Information and Advice Line (DIAL).

To encourage locally based community services

People prefer to remain in their own homes and within their communities. This is a general aim of both health and social policy and there is much scope for re-allocating resources which have been tied up in more traditional forms of provision.

One social services authority decided to re-allocate the resources that they had been spending on residential respite care, most of which was purchased from providers outside their area. Instead, they commissioned:

- ☐ **the local Crossroads service to provide respite care in people's homes**
- ☐ **a four bedroom unit with a local housing association to provide both emergency and short term breaks**
- ☐ **assistance with access to educational and leisure facilities**
- ☐ **support groups for people who provide help to disabled family members**
- ☐ **proper assessment of these unpaid helpers' needs.**

There is much scope for health commissioners to encourage services which are traditionally based in hospitals to be provided in health centres and GP surgeries. This applies to services which are particularly provided for disabled people, such as physiotherapy, as well as to other services such as ante-natal clinics.

To encourage a one stop contact point for access to a wide range of services

Joint working across service providers and across agencies can make this possible. For example, a Disability Resource Centre can be the base for:

- ☐ **an adaptations service (with Occupational Therapists, surveyors from housing department, and finance/administrative officer)**
- ☐ **specialist care managers**
- ☐ **the wheelchair service**
- ☐ **peripatetic physiotherapy service**
- ☐ **Disability Information and Advice Service (run by disabled people)**

- ☐ independent advocacy services
- ☐ user-controlled personal assistance agency
- ☐ Independent Living Adviser.

To encourage self-assessment and self-referral where possible

Self-referral can play a major part in helping to make services more accessible. In developing needs-led, rather than service-led, assessments the individual's own expertise and perspective is a valuable resource. Services should be encouraged to put professional expertise, together with independent advocacy support where required, at the disposal of the individual.

A social services authority commissioned training in needs-led assessment and care management for a group of disabled people who have significant personal assistance requirements and who expressed a wish to be their own care managers. Following the course, participants assessed their own needs and were 'paired' with an experienced care manager who assisted them in the early stages of organising how to meet their needs.

To commission user-controlled services

If decisions about how services are provided are in the hands of those who use them, there is very direct pressure to create and maintain high standards. Services which are developed and run by users themselves are likely to be the most responsive and flexible, the most accessible. Moreover, by encouraging user-controlled services, commissioners can also bring about an expansion of the market, an increase in the range of service providers, and thus an enhancement of their own purchasing role.

Commissioners will therefore want to think about how they can encourage the development of user-controlled services. Some of the things which are important to user-controlled services are:

- ☐ grant-aid funding for development work
- ☐ help with legal expertise
- ☐ training in management skills⁷.

Health and social services commissioners jointly funded a local disability organisation to develop an agency service providing personal assistants. The agency is run as a not-for-profit organisation, and involves its users in key decision-making. Disabled people who are experienced users of personal assistants, provide training in independent living principles and practices for new personal assistants. By the time the three year development funding comes to an end the agency intends to be self-financing through selling its services to care managers and individual disabled people.

4 The contracting process

When commissioners enter into contracts or service level agreements with providers they will wish to include some very concrete requirements which address in a detailed way people's experiences of receiving services. They will also benefit from involving service users in setting standards and specifications.

A Commissioning Agency appointed a Community Liaison Officer (Disabled People) who used a variety of methods to make contact with service users and potential users to find out what they wanted from a range of services. Regular meetings were held between disabled people and the officers responsible for negotiating and monitoring contracts. This resulted in changes to the service specifications and service users made an important contribution to monitoring the way these specifications were fulfilled by providers.

Requirements which will have a key impact on people's experiences of services.

- ⇒ The service provider must have a plan to (a) identify what difficulties people might have in using the service; and (b) to address these difficulties.
- ⇒ Services should encourage self-referral and direct access for users.
- ⇒ Services should encourage self-assessment where appropriate. They should also give full recognition to disabled people's own expertise about their needs and fully involve them in assessments and decisions taken about how to meet their needs.

⇒ Services should be able to respond appropriately and with flexibility to changes in an individual's needs.

⇒ Services should encourage users to take control and exert choice in their consumption of services.

⇒ Staff who are in direct contact with users should have information about other services available to disabled people and how to access them.

⇒ Services should comply with access standards designed to meet the needs of people with physical and/or sensory impairments.

⇒ Where any access standard cannot be achieved for an individual user, staff in service provider organisations should take responsibility for trying to overcome any barriers experienced by service users.

⇒ Service providers should give each user information - in an accessible format and in easy to understand language - about what they are entitled to expect from a service. Information should also be given about how to express dissatisfaction, informally and formally through, for example, the complaints procedure.

⇒ Services should take into account all of an individual user's circumstances and, through joint working with other agencies, seek to meet the needs of the whole person.

⇒ Service providers should be able to illustrate how they are working with other agencies to provide continuing and co-ordinated services to users.

⇒ Where service providers are contracted to provide transport for users they must demonstrate that users are satisfied with the standard of the service. Transport can be a key part of gaining access to a service but can also be a major barrier when it is provided in a disabling way.

Errol Gibson has sickle cell anaemia. Previously when he had crises, which result in great pain, he has had to go into hospital which caused him great distress. Now he is able to administer his own pain relief, intravenously and using a pump, having been shown by the District Nursing service how to do this.

A Commissioning Agency developed quality standards in consultation with users of a rehabilitation service. These standards were incorporated into the contract with the service provider and a Charter based on the standards is given to each new user.

WHILE YOU ARE AT THE CENTRE YOU ARE ENTITLED TO

- ☐ **privacy, respect and dignity**
- ☐ **be treated as a whole person: for all your needs to be addressed - physical, emotional, economic, educational**
- ☐ **full information about your diagnosis and treatment**
- ☐ **full involvement in decisions about your treatment**
- ☐ **multi-disciplinary assessment of your needs (involving community professionals as well as those from the rehabilitation centre)**
- ☐ **full involvement in this assessment**
- ☐ **co-ordinated planning of action to be taken to meet your needs**
- ☐ **full involvement in this planning**
- ☐ **help with thinking about your needs now and in the future and for your definition of your needs to be central to this process**
- ☐ **access to an independent advocate should you wish it.**

THIS IS THE SERVICE WHICH HAS BEEN PURCHASED ON YOUR BEHALF. IF YOU DO NOT FEEL YOU HAVE RECEIVED THIS SERVICE PLEASE CONTACT Ms L. BRAGG (Tel. and Minicom No. and address)

⇒ Service providers, at all levels of the organisation, should receive disability equality training which incorporates awareness of the concept of independent living as developed by the disability movement.

⇒ Service providers should be able to demonstrate that, as employers, they are able to ensure that their workforce increasingly reflects all sections of the community they serve, including people with physical and/or sensory impairments.

⇒ Service providers should be able to accommodate some users' wish to have a choice of the gender of the service provider, e.g. doctor, home carer. If this wish cannot be met through the existing personnel, it can usually be accommodated by spot purchasing.

5 Looking at how a service is performing

Assessing how a service is performing and taking appropriate action is a vital part of ensuring that people experience good quality services, which are effective at meeting their needs. Evaluating, monitoring or auditing a service are all about looking at how a service is performing. When carrying out these activities, there are a number of important things to aim for:

- ☐ **select performance measurements based on disabled people's experiences of a service**
- ☐ **consult service users when developing standards to be measured**
- ☐ **encourage and resource user-led evaluations**
- ☐ **evaluation and monitoring must be followed by action based on what is found**
- ☐ **all health and social services workers should be encouraged and supported to evaluate and audit their own work, in collaboration with service users.**

Select performance measurements based on disabled people's experiences of a service

When looking at how a service is performing we can look at:

- ☐ what resources a service has (its structure)
- ☐ how the resources are used (the process of service delivery)
- ☐ the outcome.

It is this last aspect - the outcome - which is closest to what the service user will experience and which is therefore the most important thing to

be measured. Services are purchased because they are intended to improve the quality of an individual's life and success must therefore be measured in terms of whether this has been achieved.

How outcome is measured will vary. Disabled people themselves should be involved in deciding what should be measured. Generally, when looking at how both general and specialist services meet the needs of people with physical and/or sensory impairments, commissioners will be concerned with:

- ☐ access – how easy is it for disabled people to find out about a service and gain access to it?
- ☐ equity – to what extent does the service meet the needs of all sections of the community?
- ☐ effectiveness – does the service add to the quality of disabled people's lives?
- ☐ acceptability – what do users feel about the service?

Specific measurements will be required to fit the service being monitored/evaluated. The more these measurements make sense to service users the more effective they will be at assessing whether services really make a difference to people's lives.

Consult service users when developing standards to be measured

When disabled people were asked how they would evaluate an advocacy service, for example, they responded that it should be assessed according to whether the users felt more confident with things like going out, asking for help, attending and participating in a self-help group, asserting one's rights, making choices, talking more assertively to professionals, expressing likes and dislikes, relating to people in group situations.

Similar measures could be developed together with disabled people for other services being commissioned.

A social services department convened a meeting of people who used home care services. A brain-storming session was held which came up with the following list of what happened if the home care service was what people wanted:

- ☐ the homecare worker does what I ask her to do
- ☐ I feel able to say what I like and dislike, e.g. how I want my clothes put on, what shopping I want
- ☐ the homecare worker comes at the times and on the days which are best for me
- ☐ I know each week what days and what times the homecare worker is coming
- ☐ I can rely on the homecare worker to come at the times and on the days that she is supposed to come
- ☐ most weeks it is the same homecare worker who comes
- ☐ if my regular homecare worker cannot come, I am informed in good time
- ☐ if my regular homecare worker cannot come, a replacement is usually provided
- ☐ the home care service helps me feel safe at home
- ☐ the home care service helps me feel comfortable at home
- ☐ the home care service helps me feel more in control of my life
- ☐ the home care service helps me feel less isolated.

The social services quality standards officer then constructed a questionnaire using these statements and visited a sample of users of each contracted service provider to fill in the questionnaire, asking them whether they disagreed or agreed with each statement. Each respondent was assured of their anonymity and were not visited at a time when the home care worker was present.

Encourage and resource user-led evaluations

Service providers can be encouraged to place service users at the centre of their procedures for looking at how they are performing. Commissioners should themselves ensure that monitoring of service specifications is carried out by users, for example, by resourcing user inspections of services. User-led evaluations will be the key, not just to evaluating existing services, but also to identifying where resources should be directed to future service developments; it is disabled people who know what they need in their lives and whether public resources are being best used in the current attempts to meet those needs.

Evaluation and monitoring must be followed by action based on what is found

There is no point in encouraging, enabling and resourcing user involvement in evaluation and monitoring if nothing happens as a result. When commissioners develop systems for involving users in looking at how a service is performing they should, right from the beginning, decide how they will ensure that appropriate action is taken following evaluation - and how attempts to improve services are then evaluated in their turn.

For example, when an evaluation is carried out by users, commissioners should meet with them to hear the results of this evaluation and then meet users again to report back on the action taken.

All health and social services workers should be encouraged and supported to evaluate and audit their own work, in collaboration with service users.

There is much scope for joint and on-going self-evaluation with users (and, where appropriate, their families and friends).

Jane Matthews is terminally ill and knows that she will die soon. Before her last discharge from hospital she was referred to the home hospice support team who have organised:

- ☐ counselling support for her and her family
- ☐ practical assistance (organised through the social services care management system), e.g. with picking up the children from school, help with housework, help with the weekly shopping
- ☐ regular visits from community nurses
- ☐ medical advice and assistance when required from her GP and the hospital consultant.

The Home Hospice Support Team have a quality standard which they aspire to. This includes:

- ☐ alleviation of symptoms
- ☐ pain control
- ☐ continuity of nursing care and counselling support
- ☐ meeting the patient's and his/her family's requests for information and advice as they arise
- ☐ providing opportunities for the expression of fear, grief, anger
- ☐ meeting the patient's wishes for place of death
- ☐ continuing short-term counselling support for the patient's family, should they wish it, after the patient's death and referral on to appropriate service if required.

These quality standards are made available to Jane and her partner and their Home Hospice Support Worker regularly checks with them, in an unobtrusive and sensitive way, to see whether the standards are being met. The Support Worker then feeds back to the other service providers. The Home Hospice Support Service also uses a self-evaluation questionnaire for Support Workers to assess their own effectiveness. Regular monthly meetings serve as an opportunity for Support Workers to evaluate their work in a supportive peer-group setting.

6 Conclusion

There are exciting possibilities for health and social services commissioners to use their planning and purchasing roles to ensure that public resources are used in ways which really do increase the quality of people's lives. This document reflects some of the creative work which is already being done. Small developments can often mean enormous improvements in disabled people's experience of services. All in all, those responsible for commissioning health and social services can make a real difference to people's lives.

The final section of this document comprises a Checklist which commissioners may find useful when looking at the kinds of services which will be accessible to, and will meet the needs of, people with physical and/or sensory impairments.

7 Checklist for responsive, flexible, accessible services

- ✓ Are service users and/or disabled people's organisations being regularly consulted on their views about the service?
- ✓ Is information about the service available in Braille, large print, on audio and video tape?
- ✓ Is information about the service available in minority community languages, including in accessible formats?
- ✓ Does the service have minicom/textphone facilities? Have receptionists and other key staff been trained in its use?
- ✓ Are BSL interpreters and lip speakers available, and those skilled in Makaton and other speech and nonspeech methods of communication?
- ✓ Are minority community language interpreters available?
- ✓ Are premises wheelchair accessible (ie designated parking, level access, wide enough doorways, wheelchair accessible toilets)?
- ✓ Are premises within easy reach of bus stops? Is there free parking close by for users?
- ✓ Does the service offer access to independent advocacy support?
- ✓ Have workers at all levels received disability equality training?
- ✓ Does the service vary according to the needs of the individual?
- ✓ Can the service change according to the changing needs of an individual user?

- ✓ Can the service user choose the timing of appointments/ service delivery?
- ✓ Is the service provided age appropriate?
- ✓ Does the service take account of preferences re gender of staff who have personal contact with users?
- ✓ Does the service take account of cultural/religious requirements of users? Is appropriate training provided for staff?
- ✓ Does the service's workforce reflect the community that it serves? If not, what steps are being taken to ensure that it does?
- ✓ Are measurements of quality developed in consultation with service users?
- ✓ Does monitoring/evaluation/auditing involve service users?
- ✓ Is information about complaints procedures available to all service users? Are complaints procedures easy to use?

8 Notes

1 National Audit Office (1992) *Health services for physically disabled people aged 16-64*, HMSO, p20.

2 Spastics Society (1991) *Still Caring*, Spastics Society.

3 Some examples of service users can be found in: NHS Management Executive (1992) *Local Voices: the views of local people in purchasing for health*, NHS Management Executive. Labyrinth Training and Consultancy (1993) *Responding to Local Voices: an overview of the implications for purchasing organisations*, Labyrinth Training and Consultancy/NHS Management Executive. Community Care Support Force (1993) *User Involvement in Community Care Services*, NHS Management Executive. Morris, Jenny (1994) 'Turning Rhetoric into Reality: the National User Involvement Project' *Communicare* Issue 5, December 1994.

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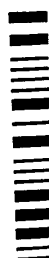
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