Putting people first:
Equality and Diversity Matters 3
Achieving disability equality in social care services

This bulletin is the third in a series of three designed to help service providers meet the personalisation agenda in social care by addressing equality and diversity matters. This bulletin focuses on achieving disability equality in social care services.

Whilst this bulletin is primarily written to assist social care providers, it may also be of interest to commissioners of adult care services and people using services.

www.csci.org.uk/professional
About CSCI

The Commission for Social Care Inspection (CSCI) was set up in April 2004. Its main purpose is to provide a clear, independent assessment of the state of social care services in England. CSCI combines inspection, review, performance and regulatory functions across the range of adult social care services in the public and independent sectors.

CSCI exists to promote improvement in the quality of social care and to ensure public money is being well spent. It works alongside councils and service providers, supporting and informing efforts to deliver better outcomes for people who need and rely on services to enhance their lives. CSCI aims to acknowledge good practice but will also use its intervention powers where it finds unacceptable standards.

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</tbody>
</table>
## Contents

**Quality issues in social care** 
4

- The Equality and Diversity Matters series 
4
- How have we developed this bulletin? 
4

**Summary of key points** 
6

**Introduction** 
9
1. What is this bulletin about? 
9
2. Important issues 
11
3. How well do social care services address equality for disabled people? 
17

**Good practice works for everyone** 
21
4. Assessments that address equality for individual disabled people 
21
5. Choice and control 
25

**All equal – key issues in equality and diversity** 
30
6. Management and leadership 
30
7. Staffing 
34
8. Tackling prejudice and discrimination 
37
9. Nothing about us without us – involving disabled people in services 
42

**Specific issues in achieving equality for disabled people using social care services** 
46
10. Addressing attitudinal barriers 
46
11. Two-way conversation – removing information and communication barriers 
51
12. Equal citizens – barriers to accessing the local community 
55
13. More than ramps – removing environmental barriers 
59
62
15. Checklist for action 
68
16. Resources 
70
Quality issues in social care

Promoting improvements in social care and stamping out bad practice for the benefit of the people who use care services are key functions of the Commission for Social Care Inspection (CSCI). The Commission has a commitment to promote equality and diversity in all that it does.

The Equality and Diversity Matters series

This bulletin is the third in a series of three designed to help service providers meet the new personalisation agenda within Putting People First by addressing equality and diversity matters. This bulletin focuses on achieving disability equality in social care services. The other bulletins cover equality for lesbian, gay, bisexual and transgender people, published in March 2008, and black and minority ethnic people using services, published in August 2008. We are producing these bulletins to:

• highlight and increase understanding of the key issues for diverse groups of people using services
• share what we have learnt about good practice in equality and diversity matters from inspecting services and from hearing from people who use services
• identify practical steps that can be taken by service providers to improve the experiences of people who use social care services.

Whilst the series is primarily written to assist people providing social care services, some of the issues raised are also relevant to commissioners seeking to ensure that the services they commission meet the diverse needs of their communities.

How have we developed this bulletin?

We have used a number of sources of information to write this bulletin, including:

• Examining the National Minimum Standards (NMS) for care services to look at the key issues relating to equality and diversity.
• A survey of disabled people available online and in a number of accessible formats, to which 307 people responded. In the survey, 11% were currently living in care homes and a further 17% had lived in care homes in the past. 29% of people were currently using home care, with a further 20% having previously used home care. People directing their own support through Direct Payments or Individual Budgets made up 27% of respondents – some of these people were using home care.

agencies for some or all of their support. Others were currently using respite care (5%), adult placement (5%) or supported living (5%), or had done so in the past.

There was targeted publicity to encourage older people to complete the survey. 15% of respondents who answered the monitoring question on age were over 65. Of the people who answered the disability monitoring question, 63% had a physical impairment, 29% experienced mental distress or used mental health services and 25% had a learning difficulty or disability. 11% of people said that they were blind or partially sighted and 9% were deaf or hard of hearing.

• Focus groups with disabled people, particularly focusing on those who may be less likely to complete a survey, including people living in residential care, older people, people with learning difficulties, people using mental health services and people living with HIV or Aids.

• A representative sample of Annual Quality Assurance Assessment (AQAA) forms (400 in total) completed by managers of home care agencies and care homes, reporting the work they have carried out to make their services accessible and appropriate for a diverse range of people.

• Discussions with service providers who are leading the way in developing work to achieve equality for disabled people and with organisations of disabled people, including corporate providers who have responded to our surveys on dignity and equality and diversity.
Summary of key points

Social care should be a means for enabling disabled people to participate in society on an equal basis to other citizens. Disabled people have long recognised that equality will only be achieved if the focus is on the barriers that disabled people face in society, rather than on disabled people’s impairments. This concept of a social model of disability and the related framework of ‘independent living’, developed by disabled people, are now accepted as key principles by government and in the personalisation agenda in social care.

Specific legislation to protect disabled people from discrimination was introduced in 1995 and covers a wide range of people using social care services, including people who have not always viewed themselves as disabled people, such as people using mental health services and older people who have physical or sensory impairments, dementia or mental health issues.

Our evidence indicates that there has been action by care providers to address physical barriers but other important barriers still need to be tackled. Social care services are so vital to equality for disabled people that if a service is not part of the solution in actively removing barriers that face disabled people, it can be part of the problem in creating these barriers to equality. Disabled people responding to our survey told us they experienced the following barriers to equality in social care services:

- **Physical barriers** were the most common barriers to disability equality addressed by

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4 Prime Minister’s Strategy Unit (2005) *Improving the life chances of disabled people*. London: Prime Minister’s Strategy Unit, Department for Work and Pensions, Department of Health, Department for Education and Skills, Office of the Deputy Prime Minister

5 Department of Health (2007) *Ibid*

6 The Disability Discrimination Act 1995
sample of services (24% of 400 services). Environmental barriers, such as poor access to or within buildings, can be significant, but they were experienced by the lowest number of disabled people (17% of the 307 disabled people taking part in our survey and 37% of people with physical or sensory impairments).

- **Communication barriers** were experienced by a majority of disabled people responding to the survey, with only 38% agreeing that all staff communicated well. These barriers were not always related to the disabled person’s impairment, for example providing information in accessible formats, but could be due to the communication skills of staff.

- **Social inclusion barriers** were also common. Only 29% of disabled people living in care homes felt that the service had helped them to challenge disabling barriers in the community, for example transport or physically inaccessible community facilities, compared to 43% of people using home care and 44% of people using Direct Payments.

- **Attitudinal barriers** were the most common barriers that people faced. 55% of all disabled people, and 65% of people living in care homes, had experiences of social care staff who did not respect their right to be treated equally with non-disabled adults; for example patronising attitudes or a lack of regard for the disabled person’s rights to make choices about how care was delivered.

Some of these barriers may be as a result of external and other factors, such as:

- The way services are procured; for example, if a disabled person is only allocated a small care package, it may be difficult for providers to work on enabling their inclusion in the community.

- Economic issues, such as the ability of social care services and disabled people using Direct Payments to recruit and retain staff, in competition with other sectors.

- Financial constraints that individual disabled people face which may influence the type, or amount, of social care services that they can access.

- An approach which focuses on ‘prevention of risk’, which limits disabled people’s choice and control and thus their equality. Services need to focus on enabling disabled people to achieve equality, including supporting people to manage any risks.

The Human Rights Act 1998 brought into UK law most of the rights contained in the European Convention of Human Rights, including a number that are particularly relevant to equality for disabled people using social care services; such as the right not to be treated in an inhuman or degrading way, the right to respect for private and family life, home and correspondence, the right to life, and the right not to be discriminated against in relation to any of these rights. A minority of disabled people reported experiences where their human rights may have been compromised, such as a lack of regard for basic privacy or dignity. Developing action on equality for disabled people goes hand in hand with a human rights approach, based on the principles of fairness, respect, equality, dignity and autonomy.

Providers should not assume that, because there are no reports of discrimination, it is
not taking place. Disabled people may not report discrimination because of uncertainty (one-quarter of disabled people in care homes were unsure whether they had experienced discrimination or not), fear of the consequences or a lack of confidence in the outcome (31% of all disabled people thought that the service they used would not deal with a complaint of discrimination well). Providers should work to ensure that disabled people know about their rights and should encourage disabled people to report discrimination and support them when they do so, as well as identifying and addressing issues of disability equality themselves.

In our sample, 94% of social care services reported that they were undertaking some general work on equality, such as policy development or staff training. However, specific work is required to remove disabling barriers and only 33% of social care services identified any focused action that they had taken on equality for disabled people. Thus, the majority of services are either providing care in a way which does not promote equality for disabled people, for example by taking a purely task-orientated approach, or are unfamiliar with the term and fail to recognise work that they are carrying out, for example in enabling disabled people to access local facilities, as contributing to disability equality. In either case, the majority of services need to prioritise equality for disabled people.

Social care services need to:
- Develop a disability equality strategy or plan, with disabled people, that focuses on barriers that prevent equality for disabled people.
- Ensure managers and staff understand approaches based on the social model of disability by providing Disability Equality Training, supported by ongoing learning opportunities.
- Base assessments, care plans and support on the life the disabled person wants to live and remove any disabling barriers to achieving this, including active encouragement for disabled people to explore independent living options.
- Ensure that disabled people have access to information, advice and advocacy.
- Increase the flexibility of services so that each disabled person has more choice and control in the support they use, including opportunities to participate in local communities on an equal basis to every other citizen.
- Audit services to remove barriers to equality and human rights in policy, practice, environmental access, information and communication.
- Encourage disabled people to have high expectations of services and deal effectively with comments or complaints that involve individual or institutional discrimination against disabled people.
- Give disabled people more control over services through a range of opportunities for effective involvement at an individual, service and organisational level.
Introduction

1. What is this bulletin about?

Equality for disabled people is central to social care services. The recent protocol Putting People First states that the values underpinning the transformation of adult social care include ensuring that disabled people have equality in relation to independent living.

The former Disability Rights Commission (now merged into the Equality and Human Rights Commission) has also stated the fundamental purpose of social care services in achieving equality for disabled people:

“The provision of health and social care are not ends in themselves. They should be seen as a means of enabling disabled people to enjoy the same opportunities for participation as any other citizen could reasonably expect.”

The first legislation protecting disabled people against discrimination in services was the Disability Discrimination Act (1995). This legislation did not put an age limit on disability discrimination, so it protects older people from discrimination based on impairment. The number of people using social care services who are protected by disability discrimination law is wider than often assumed; the definition of a disabled person in the legislation is someone “who has a physical or mental impairment which has an effect on their ability to carry out normal day-to-day activities”.

The disabled people’s rights movement has long located the disadvantage that disabled people face as barriers in society rather than differences in people’s bodies or minds. This is the fundamental principle of the social model of disability, developed in the 1960s and 1970s by disabled people, for which there is now a wide consensus of support amongst disabled people and their organisations and acceptance by government in national policy. The vast majority of people using social care services fall within this definition of who is a disabled person.

This Quality Issues in Social Care bulletin adopts the social model of disability to look at the perspectives of disabled people who use social care services and the barriers that they face. We consider how people providing social care services can both remove barriers within their services and assist disabled people to take their rightful place in society on an equal basis with non-disabled people.

10 Disability Discrimination Act 1995, subsections 1 and 2

11 For example, Barnes, C (1991) Disabled people in Britain and discrimination. London: Hurst and Company


13 Prime Minister’s Strategy Unit (2005) ibid
How to use this bulletin

All the bulletins in this series start by showing how good, personalised care can underpin the delivery of services that are appropriate to a diverse range of people. We then move on to looking at how common issues in equality and diversity for providers apply to the particular dimension being considered – in this bulletin, disability equality. We then discuss issues relevant to the particular focus of the bulletin – in this case, to ensuring disabled people achieve equality. Finally, a checklist and resource lists are provided to assist providers in achieving disability equality in their services.

Before looking at general good practice, we highlight some important issues for understanding disability equality in the context of social care services.
2. Important issues

An understanding of the different ‘models’ of disability is not just an academic exercise but is fundamental in understanding the inequalities that disabled people face and so the actions that providers must take to reduce inequality. These models have been the subject of much debate over many years. The social model of disability is still highly relevant as it underpins government strategy on improving the life chances of disabled people by 2025 and the public sector legal duty to promote disability equality as well as being widely accepted by organisations of disabled people. The box below summarises key features of the models and the definitions that follow from taking an approach based on the social model of disability.

**Thinking about disability – some definitions**

**Medical model of disability** concentrates on medical impairments as the main reason for the difficulties experienced by disabled people.

“...this model sees disabled people as the problem and thus requires them to adjust to the world as it is.”

**Social model of disability** focuses on structures and barriers that disabled individuals experience (for example, inaccessible transport, housing and education provision) and provides tools for dismantling and preventing these.

Proponents of the social model of disability do not deny that medical interventions may assist some disabled people, particularly emphasising choice and control in health services and reduction of pain or level of impairment as positive outcomes. The difficulty with the medical model of disability is that the focus is on cure or segregation, rather than equality, as the solution to the difficulties that disabled people experience.

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20 Prime Minister’s Strategy Unit (2005) *Ibid*
21 Prime Minister’s Strategy Unit (2005) *Ibid*
22 Barnes, C (1991) *Ibid*
Putting people first – Equality and Diversity Matters

The Independent Living Movement was an early development within the disabled people’s movement, firstly in the United States and then in Britain, and provided a focus for setting up alternative service provision controlled by disabled people. The concept of independent living has particular significance for considering disability equality in social care. Yet, ‘independence’ is often misunderstood, as being a measure of how much someone ‘does for themselves’ rather than how much choice and control they can exercise in their own life.

**Independent living**

The government has adopted disabled people’s own definition and vision for independent living:

“Independent living means that all disabled people have the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’ but it does mean that any practical assistance people need should be based on their own choices and aspirations.”

One important concept in independent living is personal assistance, as this provides an alternative to the more traditional models of ‘caring for’ disabled people, which can suggest that disabled people are helpless or cannot look after themselves.

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24 Prime Minister’s Strategy Unit (2005) *Ibid*
27 Prime Minister’s Strategy Unit (2005) *Ibid*
Personal assistance

“[is when people using services] exercise the maximum control over how services are organised...In particular, personal assistance requires that the individual decides:

- who is to work
- with which tasks
- at which times
- where and how

It is recognised that some disabled people, for example some people with learning disabilities, will need third party support for this.”

Personal assistance is most commonly associated with people using Direct Payments.\(^\text{30}\)

The challenge is for other types of service provision to move towards a similar level of control for disabled people requiring support.

Disabled people and diversity

- Disabled people are very diverse. Many people have viewed the main differences between disabled people as primarily an issue about different impairments. In social care this has led to the development of separate services for people with learning disabilities, people with physical impairments, people with sensory impairments and people who experience mental distress, with some services focused on people with

\(^29\) Ratka, A (1997) *Ibid*

\(^30\) Direct Payments are cash payments given to people by councils, so that they can purchase social care services themselves instead of being provided with services
specific medical diagnoses, for example multiple sclerosis. Whilst there are clearly differences in needs based on impairment, this can remove the focus from looking at common barriers, such as discrimination in employment.\textsuperscript{31} The development of impairment-specific services can also lead to a lack of equity for people for people experiencing the same barriers; for example if an audio transcription service is only available to blind or partially sighted people, and not to people with learning disabilities.

Some disabled people may be prone to questioning about their impairment:

“People don’t understand unless you are a typical wheelchair user, of exactly how you are disabled. People need to know what disabled category you fall in.”

\textit{Person living with HIV}

Differences in impairment and types of barriers faced are only two aspects of diversity amongst disabled people. Disabled people’s needs and desires will vary because of their individual mix of identity, experience, preferences and living situation.

The first bulletin in this series demonstrated that lesbian, gay and bisexual disabled people have particular needs because of both differences in lifestyles from heterosexual people and, importantly, their experiences of prejudice from other people and discrimination in services.\textsuperscript{32} In CSCI’s survey for the bulletin, 45% of lesbian, gay and bisexual people had experienced discrimination when using services – the vast majority of respondents were disabled people. The same bulletin also highlighted the particular needs of transgender people using services.

The second bulletin considered race equality in services.\textsuperscript{33} One-quarter of black and minority ethnic disabled people said that they had faced prejudice or discrimination when using services. The needs of black and minority ethnic disabled people should be responded to in ways that address differences in cultures, language and faith whilst avoiding generalisations about cultures that could lead to assumptions or stereotyping.

For this reason it is important to read the other bulletins in this series to understand the ways that disabled people may experience a variety of issues relating to equality and diversity.

Other factors also influence people’s experience of being a disabled person, including refugee status, social class, age and gender.


“Asylum seekers who are HIV+ have a lot of unresolved issues about access to financial services and support – such as transport and health.”

Asylum seeker living with HIV

People who have a higher income may be able to mitigate disabling barriers by paying for additional services, better housing, equipment or transport.

“The issues faced by a disabled child born to a lone parent in Tower Hamlets will be different from those faced by a disabled child born to a wealthy family in Guildford.”

Older disabled people may face a combination of ageism and disability discrimination, as expectations of the choice and control that older people should be enabled to exercise will also come into play:

“Disability debates are inexcusably absent from research on ageing issues and policies. This is a matter of considerable concern when the majority of disabled people are also older and suggests that the rights-based agenda promoted in recent years may be failing to affect the lives of many by focusing on the minority of disabled working age adults.”

Disabled people are often seen as ‘care receivers’ and their roles as ‘care givers’ for children, other family members or friends can often be overlooked, despite the fact that disabled people who are parents or provide support to others may face particular barriers:

“More people with learning disabilities are finding they have been transformed. From being labelled as ‘cared for’ they have become carers themselves...the Disability Rights Commission estimates that there are 70,000 people with learning disabilities who live with parents older than 70. And as more people are choosing to live independently and set up home with partners who may need support, confusion over roles and red tape is creating a forgotten group of carers.”

What disabled people using services want

Disabled people fundamentally want the same as non-disabled people – to exercise choice and control in their lives and they vary as much as non-disabled people in how they want to live their lives. However, disabled people do have the common experience of facing disabling barriers in society.

[i] Equality of opportunity with non-disabled people. This will only be achieved if discrimination against disabled people is removed from society. This involves not only discrimination by individuals, but institutional discrimination. The government target date of 2025 for “disabled people in Britain to have

34 Prime Minister’s Strategy Unit (2005) Ibid
full opportunities and choices to improve their quality of life and be respected and included as equal members of society” shows that equality for disabled people is still some distance away.

The challenge for social care services is whether their organisational values, policies and practices promote equality for disabled people or add to inequality. Social care services can be part of the solution – or part of the problem.

(ii) A legal right to equality has been a focus for disabled people’s organisations. The Disability Discrimination Act (see section 3) prohibits some discrimination against disabled people in the provision of services.

The role of social care services may be not only to ensure that they do not unlawfully discriminate against disabled people, but also that they assist those disabled people they support to challenge discrimination.

(iii) Independent living. The independent living movement has identified 12 basic needs for disabled people to achieve independence, many of which are the ‘core business’ of social care organisations:

- full access to the environment
- a fully accessible transport system
- technical aids and equipment
- accessible/adaptable housing
- personal assistance
- inclusive education and training
- an adequate income
- equal opportunities for employment
- appropriate and accessible information
- advocacy (towards self-advocacy)
- peer counselling
- appropriate and accessible health care provision.

(iv) Choice and control in the services that they use. This is an essential element that runs through all the basic needs of independent living and is examined further in section 5.

(v) Human Rights. The Human Rights Act underlines a number of key issues in equality for disabled people including “the right to be free from inhuman or degrading treatment” and “the right to life” in order to get equal treatment with non-disabled people. This is examined further in section 14.

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38 See website of Southampton Centre for Independent Living: http://www.southamptoncil.co.uk/basic_needs.htm
3. How well do social care services address equality for disabled people?

- In the sample of self-assessment questionnaires, 94% of services reported that they were carrying out some general work around equality and diversity, such as advising staff of equality policies or carrying out staff training. Some of this activity will undoubtedly include work on disability equality, as many providers have made a commitment to working on disability equality.

- Providers were asked to give examples of specific equality work, including examples relating to disability equality. 33% of services gave examples of disability equality work they have carried out. (This compares to 37% who gave an example relating to race equality and 9% to equality for lesbian, gay or bisexual people.) Looking at the disabling barriers addressed by the examples:
  - 18% of services said that they had addressed physical barriers; this was most common type of action on disability equality by care homes for older people. Examples of work by providers include providing better access to outdoor areas in care homes, and home care agencies providing appropriate hoist equipment.
  - 9% of services said that they had looked at barriers disabled people face in accessing the local community, for example transport. This was the most common action by care homes for people under 65, with 20% of services giving an example compared to only 3% of care homes for older people.
  - 9% of services said that they had carried out work to make information more accessible for disabled people, for example by putting information into large print, audio format or easy words and pictures. This was the most common action on disability equality reported by home care agencies.
  - 4% of services said they had carried out work on other communication issues, such as enabling people who do not use verbal communication to have access to appropriately trained staff or communications equipment.
  - The number of services which said they had worked specifically on disability equality was
Putting people first – Equality and Diversity Matters

The additional legal duties that councils have had from December 2006 to promote disability equality\(^{40}\) had not consistently led to actions at a service level by the end of 2007.

• The number of services saying that they had done work around disability equality was higher amongst services with an ‘excellent’ quality rating from CSCI (42%) than amongst lower-rated services.

Considering the vast majority of services are working with disabled people as the main focus of their work, it may seem surprising that only one-third of services gave specific examples of disability equality work that they had undertaken. However there are still a number of assumptions about disability equality and differences between services that may contribute to low levels of reported action on the part of service providers:

• **Assumptions that disability equality does not apply to the people that the service works with.** There is often a misconception amongst both providers and people using services that disability equality does not apply to them – particularly for mental health services and services for older people.

It may be because of the stigma associated with disability that people do not identify as a disabled person.

“I don’t see myself as a disabled person. I feel the laws don’t apply to me.”

Someone using residential mental health services

None of the older people living in a care home who took part in the focus group had heard
Putting people first – Equality and Diversity Matters

Social Care Policy and Practice

of disability discrimination laws. One person commented:

“This doesn’t seem to cover any of us.”

This does not mean service providers should ignore disability equality. Providers need to consider whether they are treating people using services less favourably because of an impairment or health condition and, if the Disability Equality Duty applies (see the box on legislation is section 3), they will also need to promote equality for disabled people using the service, whether or not those people identify as disabled people themselves.

- **Lack of understanding about what constitutes work on disability equality.** If service providers do not understand that disability equality is concerned with removing barriers for disabled people to take part on an equal basis with non-disabled people, it is harder for them to identify work that they are carrying out that does contribute to disability equality.

- **A service model based on ideas of ‘caring for people’ or ‘special provision’ rather than ‘supporting people to have equal access’.** Services with values of ‘caring for people’ or ‘special provision’ will be less likely to carry out specific work on equality for disabled people than those that have a culture based on equality and an understanding of the barriers that disabled people face.

“[If social care] is to be different, then the language, the culture, the structures and the relationships it is based on all need to change. Service users want to replace a language of ‘care’ with one of support... People simply want to be supported to live on more equal terms. They see a rights-based approach to social care – one that recognises social barriers, as well as the personal difficulties they face – as the best route to providing this.”

An organisational culture based around disabled people only needing care can affect the attitudes and behaviours of individual members of staff, who may be less likely to treat disabled people as adults, individuals or equal citizens.

- **Assumptions that disability equality is only relevant to universal services.** If a service is only provided to disabled people, there is no comparison possible with non-disabled people. This can lead services to believe that disability equality is not an issue for them. Services may struggle to differentiate between person-centred service provision and that which is specific work around disability equality. Again, an understanding that disability equality is about removing the barriers that disabled people face to equal control in their lives and equal participation in society – which is relevant to all services that disabled people use – can assist services to plan for specific action on disability equality and to evaluate their progress.

Disability equality legislation

Disability Discrimination Act 1995

Part 3, the provision of goods, facilities and services – requires service providers to make “reasonable adjustments” for disabled people. A service provider is required to take reasonable steps to:

- change a practice, policy or procedure which makes it impossible or unreasonably difficult for disabled people to make use of its services
- provide an auxiliary aid or service if it would enable [or make it easier for] disabled people to make use of its services

In addition, where a physical feature makes it impossible or unreasonably difficult for disabled people to make use of services, a service provider has to take reasonable steps to:

- remove the feature, or
- alter it so that it no longer has that effect, or
- provide a reasonable means of avoiding it, or
- provide a reasonable alternative method of making the service available.42

Disability Discrimination Act 2005

This Act places a general duty on all public sector authorities to promote disability equality. As well as this general duty, most public authorities are covered by specific duties under the Act and must publish disability equality schemes that set out how they will carry out the general duty, including:

- a statement of how they involve disabled people in developing their schemes
- an action plan setting out the steps they will take to promote equality and meet the general duty
- arrangements for gathering information about their performance on disability equality
- arrangements for assessing the impact of their policies on disability equality and ways to improve these when necessary
- details of how they are using the information gathered, in particular in reviewing the effectiveness of their action plan and preparing subsequent schemes.

Within three years of the scheme being published, public authorities must take the steps set out in their action plans (unless it is unreasonable or impracticable for them to do so) and put into effect the arrangements for gathering and making use of information.43

For social care services procured by public sector authorities:

- where services are being procured, it will be important to include in the contract specifications which ensure that the needs of disabled people for inclusive design, accessible communications, etc are addressed
- when commissioning services for disabled people, due weight should be given to the requirement to demonstrate a good understanding of the social model in the care context.44


Good practice works for everyone

4. Assessments that address equality for individual disabled people

Assessments that focus on the outcomes that disabled people want to achieve and which address the barriers that they face in doing so are the foundation which enables social care to address inequality for individual disabled people.

Good practice in assessment and care planning is not only an issue for councils, as many reviews of care plans are led by service providers. Of the disabled people who knew who had carried out their last assessment or review of care needs, 74% had assessments or reviews by their council, 6% by a home care agency, 7% by a care home and 13% by others (for example by health services). The following areas are particularly important in relation to disability equality and assessment or review.

Barriers to independent living as a focus of the assessment

Assessments that focus on disabled people’s aspirations and the barriers to achieving these – the barriers to independent living – are more likely to promote equality than ‘functional’ assessments that focus on ‘what people can and cannot do’:

“The assessment was very structured to maintaining independence in respect of impaired mobility and did not I feel fully take into account any other issues related to my disability, eg finances, emotional needs and dependence on my son for help at home.”

Disabled person responding to the survey

Sometimes assessments do not address the particular barriers people face:

“It is difficult to get a holistic approach when you are a disabled parent, and I always feel I am having to educate the professional.”

Whilst assessments should be needs led, some survey respondents described assessments that were still led by which services were on offer:

“My biggest difficulty was not knowing what kind of help I needed, yet knowing that I was not managing daily life – they said I had to tell them what help I needed before they could decide whether to offer that help.”

Person centred planning approaches, used well, can provide a basis for disabled people to identify the outcomes that they want to achieve, the barriers they face and the ways of removing those barriers. Of care homes for people under 65, 25% said that they used person centred planning approaches to promote equality, compared to 17% of care homes for older people and 14% of home care agencies. Only 1% said that they had specifically looked at disability equality issues in assessment or care planning.

Reviews carried out by providers may focus solely on reviewing how best to meet the person’s needs within the service, but reviews also need to explore alternative independent living options that the disabled person may want to consider.
“My needs are only assessed according to the home I am in... I am not offered options that allow me to think of a future that is outside a care home despite being fairly young.”

Disabled person living in a care home

Method of assessment

Disabled people need time to prepare for an assessment and need to know the implications of any discussion:

“My last assessment was done over the telephone, it took approx four minutes. Just one question, ‘is everything ok’?, I answered ‘yes’. ‘Oh good’ said the assessment officer. That was it.”

If methods of assessment are not accessible to the disabled person, this will disempower people. People with communication impairments face particular barriers:

“[I didn’t feel able to raise all the needs that I have] because I cannot talk.”

Sometimes disabled people develop their own strategies for dealing with assessment methods:

“My memory does not remember from one year to the next, so I have developed a task sheet that could be used to show any changes that have taken place.”

Advocacy

Assessment and review is a key point where disabled people can benefit from independent advocacy. Advocates can act as an ally to support the disabled person’s viewpoint, as well as assisting people to understand the assessment process.
How staff undertake assessments

How staff approach assessments, their understanding about disability equality and empathy with the disabled person can make a great difference. It is important that staff approach ‘assessment’ as a joint process with the disabled person. Being in the position of ‘being assessed’ can be difficult. Unhelpful comments or attitudes from assessors can be remembered for a long time and have an impact on both the disabled person and on their views of the organisation carrying out the assessment:

“The next time I attempted to get help I was told by one of the people who came that I seemed to want them to live my life for me – which could not have been further from the truth.”

“As a confident disabled person, with a considerable knowledge of the system and good advocacy skills, I was able to raise all my needs. However, the process itself was stressful and disempowering and attitudes paternalistic and at times offensive.”

Values that underpin the assessor’s approach can strongly influence outcomes of the assessment process, so it is important to identify and address negative judgements about disabled people from assessors, such as low expectations of what disabled people can achieve.

Self-assessment, with support from an independent advocate if requested, can help the disabled person to have more control in the assessment process.

Good practice example – Independent Community Care Management Limited

ICCM is a private home care agency based in Kettering, providing comprehensive, tailored packages of support to disabled people. ICCM also operates a nursing agency. The managers of the service recognised that access to information, advocacy and representation was a barrier for many disabled people using their support, so they appointed a disability rights advisor who works on a sessional basis.

The advisor is employed as a sub-contractor to maintain his independence and prevent conflicts of interest arising. The advisor will assist disabled people with a number of issues including liaising with the council or primary care trust about health or social care or assisting people to claim the welfare benefits that they are entitled to.

“We needed to attempt to bridge the communication gap between our clients, ourselves and public bodies. Clients now feel that they are better supported and that they have an advocate who can liaise with external organisations on their behalf if needed. Our case managers are now aware that they have a source of support around welfare and benefit rights issues when working with their clients.”

“I need an advocate when I talk to Social Services because I have found in the past that Social Services do not always hear what I am trying to say and seem to misinterpret what I am saying. I also sometimes forget to mention things that I need to say.”

Disabled person using home care
Good practice points – assessments

- Base assessments or reviews on the outcomes that the disabled person wants to achieve and the barriers to independent living that the disabled person faces, including exploring different independent living options if the person wishes to consider these.

- Enable people to have access to appropriate advocacy during assessments.

- Provide accessible information about the assessment process.

- Ensure the assessment process is accessible, particularly if the person has an impairment that affects understanding, memory or communication.

- Use self-assessments as an important element of the process – ensuring that people have access to independent advice or advocacy for completing the self-assessment if they wish.

- Ensure assessors understand the social model of disability and the role of social care services in helping to remove barriers that individual disabled people face.

- Ensure that assessors or reviewers have opportunities to reflect on any values or hidden assumptions about disabled people that underpin their approach and that these are discussed in supervision processes.

- Ensure that reviews consider how well the current care or support package works to remove barriers to independent living for the disabled person – as well as whether the person’s needs have changed.
5. Choice and control

Choice and control over services have been key themes over a number of years for disabled people working to promote disability equality.

“Independent living is about choice and control, it is not about doing everything by yourself. Nobody – whether they have an impairment or not – can do everything themselves.”

These concepts are now at the heart of the transformation of social care.

Choice of services

Ensuring that disabled people have choice about the services that they use to address the barriers that they face is a key component of care planning. When disabled people were asked how the decision was reached about which services they would use, 52% said that they “were told which services they could use”. Only 27% “chose on the basis of recommendation by others” and 21% “selected services from information that they had gathered”.

“I was not offered any information... nor was I at the original assessment that led to me being put in a care home with nursing. My family were basically told that was the only choice.”

Though Direct Payments give more control and choice to many disabled people, some people are still not informed about them. This was a common finding in the focus groups with people with learning difficulties, people using mental health services, older people and people living with HIV.

“Sometimes there needs to be a dimension of independent living. At times there are positive experiences with the idea of having people come over or friends helping [but] there is a mismatch with services offered and no promotion of Direct Payments.”

Person living with HIV

Conversely, other people feel that a Direct Payment was the only option being offered:

“The social worker kept trying to push me towards Direct Payments which I refused from experience of having them, and telling me that I will get more funding if I do. [...] Because I will not agree to Direct Payments, they have stretched the assessment out over a very long period of time in the meantime, my needs are not being met.”

Person with a physical impairment

The financial cost of services to individuals may also limit disabled people’s choice, in terms of either the type of service or the amount of support that they can afford. This could be because the disabled person’s needs are assessed as falling outside eligibility criteria or because of the person’s expected financial
Putting people first – Equality and Diversity Matters

difference that they had seen since moving to self-directed support:

“The service did not support me at all to maintain friendships. It was hard to invite friends back. Now I have friends round when I want, I have parties and my family are welcome in my new home. My PAs support me to do this.”

Person with a learning disability using Direct Payments

The concept of ‘personal assistance’, which is central to many people using Direct Payments, gives the disabled person maximum control over who is to support them, when they work, what tasks they carry out and how:

“I have a direct payment for 24/7 care plus 4 hours double handling. I would not be able to survive, or lead a normal life without this. I can do what I want, when I want and how I want. The only difficulty is the financial strain of my contribution to the ILF and having essentially one other person living with me and using my stuff.”

The challenge is for other types of services to give disabled people the same level of control and choice, in order to achieve equality.

Advocacy can be important for individual disabled people to have more choice and control in the services they use.

Choice when using services

Equally important are the choice and control that disabled people have once they start using services. Disabled people responding to the survey expressed a range of views on how much services had assisted them in exercising choice and control. Overall, 66% of people using home care agreed that services had “assisted them to live they life that they want” compared to 64% of people using Direct Payments or Individual Budgets and 43% of people living in care homes.

People living in residential care expressed a range of views on whether the service enabled them to live the life they wanted, as these two comments show:

“.not the [life] I want – but rather to follow the routine of the home.”

“Home care was very restricting – I was working around their timetables. Residential care is much better.”

It may seem surprising that the percentage of people using Direct Payments or Individual Budgets who felt that services had assisted them to live the lives they wanted was not higher. Many people were using a mix of directly provided services or commented on the amount of support as a limiting factor. Others commented on the contribution towards the cost of social care services.46

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Putting people first – Equality and Diversity Matters 3

Social Care Policy and Practice

Choice and risk

When disabled people are viewed primarily as ‘vulnerable’ rather than as equal citizens, this can lead to risk aversion – which emphasises safety at the cost of the disabled person having choice and control and therefore limits equality with non-disabled people.

“I could not live on my own – the staff have told me I cannot.”
Person with learning disability taking part in a focus group

The CSCI discussion paper Making choices: taking risks47 discusses the way that concerns about risk from social care organisations and others can prevent older people being independent and achieving the outcomes that they want. There are many similarities for other disabled people.

Service providers may be constrained in their approach to risk by national law or policy, commissioning guidelines or business considerations, such as insurance, that prevent a flexible and creative response to managing risk with disabled people:

“Legislation effectively shifts the burden of managing risk onto public authorities, who, rather than supporting people to manage risk, instead feel compelled to attempt to eliminate all potential risks. In doing so they deny disabled people the chance to lead an independent life – in which a reasonable level of risk is a normal part...Disabled people requiring community care services get caught in a mess of risk-averse policy and practice, distancing them further and further

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from any chance of independence and control over their own lives."  

The fundamental starting point must be to discuss any risks with the disabled person and then to enable the disabled person to choose the level of risk that they wish to take, and support them with managing this, providing this does not present an unacceptable increased risk to anyone else.  

Some providers have developed policies on supporting risk to assist staff.

### Disability equality, risk and the Mental Capacity Act

The following key principles in the Mental Capacity Act help to promote disability equality in relation to ‘risk’ where there may be issues of mental capacity:

- We must begin by assuming that people have capacity
- People must be helped to make decisions
- Unwise decisions do not necessarily mean lack of capacity
- Decisions must be taken in the person’s best interests
- Decisions must be as least restrictive of freedom as possible.

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**The role of user-led services**

User-led services, where disabled people are in control, have an essential role in promoting disability equality both locally and nationally. User-led organisations provide a vital voice for disabled people to achieve equality and improve services; they also provide a way for individual disabled people to come together, understand their rights and become confident in advocating for themselves. This role of ‘peer support’ is essential in user-led organisations.

The government plans to have a user-led organisation, based on existing models of Centres for Independent Living (CILs), in each locality by 2010.

Often, the focus of user-led services in relation to social care is to support disabled people with the sometimes complex and challenging task of managing self-directed support. There are a number of user-led Direct Payments support services that assist disabled people with this, often managed by CILs. However, CILs and other...
Good practice points – choice and control

- Ensure disabled people have independent information and advice on the full range of potential service options available.
- Audit services, in partnership with disabled people, to see where choice and control for disabled people could be increased.
- Consider ways of increasing service flexibility around who carries out tasks, which tasks are carried out, when, where and how to offer disabled people more choice.
- Ensure that care planning for individuals considers issues of choice and control and that people have access to independent advocates if they wish.
- Develop policies to ensure that consideration of risk does not unduly limit disabled people’s choice and control, and support staff to deliver this in practice.
- Ensure that risk assessment processes start by discussing with the disabled person the level of risk that they are prepared to take and then support the person to manage that risk.
- Ensure disabled people know about, and can access, user-led organisations or groups for advocacy, advice or peer support.
- Consider how the service works with user-led services in the area, for example in the provision of advocacy or staff training.

user-led organisations also provide services, such as advocacy or peer support, that would be useful to disabled people using directly provided services. User-led organisations may also provide services to organisations such as disability equality training or consultancy to develop disability equality action plans. Service providers should be aware of local user-led groups or organisations in their area which could provide support to people using their service.

There are fewer user-led registered care or support services but Independent Living Alternatives, an agency for personal assistance users run by disabled people, is one example (see section 11).
All equal – key issues in equality and diversity

6. Management and leadership

Managers set the aims, ethos and culture of a service. For services to embrace disability equality, it is necessary that management, at all levels, understands the social model of disability and commits to using this barriers-based approach to transform the way that services are delivered.

The Disability Equality Duty, introduced in 2006, means that councils and other statutory providers now have a legal duty to develop an action plan setting out the steps they will take to promote equality for disabled people (see the box in section 3). An earlier overview of council services in 2003 for people with physical and sensory impairments found that most council adult social services have adopted the social model of disability. However, practice did not always reflect this commitment and councils needed to review, with disabled people, their effectiveness in achieving social model approaches.55

The Disability Rights Commission guidance to the equality duty also suggests that voluntary and private sector providers delivering services commissioned by statutory bodies should have an understanding of the social model of disability in the care context.56 There can be challenges for providers in doing this, particularly if the weight given to this factor by councils and others procuring services is unknown compared to other factors, such as the cost of delivering the service. For example, providers may be reluctant to increase costs to include Disability Equality Training for staff if this disadvantages them in winning a tender.

In the survey, 59% of disabled people agreed that managers of services “took disability equality seriously”. The impact of this positive individual commitment by managers is not to be underestimated:

“I am very happy in this home in which I have lived since it opened 18 years ago. My family were horrified I should at the age of 63 choose to live in a home for the elderly. My family said ‘Mother, you will lose your independence’, to which the Head of Home said ‘if you do, we have failed you’.”

Older disabled person living in a care home


Organisational change to increase equality for disabled people

In the sample of providers, the level of reported specific management action aimed at overall change in a service or organisation on disability equality was very low, as the table below shows:

<table>
<thead>
<tr>
<th>Service Type</th>
<th>% Services saying they are taking specific management action on disability equality for people using services</th>
<th>% Services saying they are taking management-level action on general equality issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home care services</td>
<td>7%</td>
<td>19%</td>
</tr>
<tr>
<td>Care homes for people under 65</td>
<td>2%</td>
<td>28%</td>
</tr>
<tr>
<td>Care homes for older people</td>
<td>2%</td>
<td>28%</td>
</tr>
</tbody>
</table>

Examples of specific management action on disability equality included Disability Equality Duty audits, appointing staff with a specific remit to promote disability equality and using external guidance or models to review the service. Even assuming that the services taking management action across all equality issues include organisational change on disability equality, only one-third of providers reported any action that may start to address fundamental cultural change regarding equality for disabled people.

Monitoring and disability equality

Monitoring disability can be useful for service managers to measure progress on disability equality. Many social care services will only be providing services to disabled people, so monitoring that just asks people whether they consider themselves to be a disabled person will not be useful. However, disabled people with different impairments may experience different barriers, so it can be necessary to monitor outcomes according to impairment type. For example if a home care agency finds that people with learning disabilities on average use the service for a shorter length of time, they may want to investigate why people cancel the service or move elsewhere.

There has been much debate about how to describe people with different impairments. These should be based on a social model approach and words that connote a negative association with impairment, such as ‘mental health problem’, should be avoided.

There is no established national standard for monitoring disability. However, advice from the Disability Rights Commission suggests that organisations may want to consider a classification based on the barriers that the disabled person faces, rather than impairment. Two alternative monitoring systems are shown below through there are other options, such as having separate categories for blind or partially sighted people and deaf or heard of hearing people and a separate category for neurodiversity:

<table>
<thead>
<tr>
<th>Impairment categories</th>
<th>Barrier categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical impairment</td>
<td>Access to buildings</td>
</tr>
<tr>
<td>Sensory impairment</td>
<td>Written information or communication</td>
</tr>
<tr>
<td>Mental health condition</td>
<td>Verbal or audible information or communication</td>
</tr>
<tr>
<td>Learning disability/difficulty</td>
<td>People’s attitude to you because of your impairment</td>
</tr>
<tr>
<td>Longstanding illness or health condition</td>
<td>Policies or procedures such as the fire evacuation procedure</td>
</tr>
<tr>
<td>Other</td>
<td>Other barriers</td>
</tr>
</tbody>
</table>

People should, wherever possible, define for themselves whether they have a particular impairment and have the option to say that they are a disabled person but not to disclose.

their impairment. Other general good practice in carrying out monitoring applies, including defining the purpose of any monitoring exercise, obtaining consent and maintaining confidentiality of individual responses. Some disabled people may need advocacy support to explain the purpose of monitoring and to assist with completion of forms.

Organisations may need to carry out some specific work to monitor progress on disability equality. This should not only look at which impairments individuals have, but should also include establishing the barriers that disabled people face in using a service and looking at changes in outcomes as these barriers are removed; for example, levels of satisfaction.

**Good practice points – management and leadership**

- Involve disabled people using services (and other disabled people who have an understanding of the social model of disability and good practice) in developing a disability equality strategy for your services based on the social model of disability.
- Use the guidance available on the Disability Equality Duty to develop your strategy.
- Link this strategy to your business plan and allocate resources to it.
- Ensure that a disability equality approach based on addressing the barriers that disabled people face is built into:
  - the values of the organisation
  - statements of purpose for individual services
  - auditing and review of services
  - quality management systems – including spot checks, regulation 26 visits and surveys of people using services
  - staff handbook and induction materials
  - individual staff performance plans
  - methods for reporting progress on objectives
  - internal and external communications, for example newsletters.
- Discuss disability equality as a regular item at management meetings and develop managers who have a good understanding of the social model of disability and its implications for policy and practice.
- Identify and address both direct and indirect disability discrimination (see section 9) which comes to the attention of managers through informal reports from disabled people, complaints, surveys, observation by staff, regulatory activity or other means.
- Consider how best to use monitoring to identify and measure improvements in equality for disabled people.
- Management action in relation to disabled people’s human rights is covered in section 15.

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7. Staffing

Choice of staff

Half the disabled people responding to the survey felt that they had enough choice about which staff supported them, 35% did not and the others were unsure. As may be expected, a higher proportion of people using Direct Payments (59%) felt that they had choice, because they were able to employ, and if necessary dismiss, their own staff. Most of the negative comments made by people using Direct Payments were in relation to use of agencies or overall market shortages:

“I have a personal assistant but also use a care agency. The staff from the care agency change quite a lot and I don’t really have a say on who comes.”

“How can you have good choice when you pay minimum wage? I am writing a PhD and I lecture, finding ‘staff’ that can be a PA at uni and conferences and be able to clean my home and washing is impossible on this wage. So, to function I have to try to fit ‘staff’ to specific tasks, which takes a lot of juggling in an already time constrained life.”

People using home care services may have no control over which staff support them:

“I have no choice; as long as they send out a body they feel that’s all they need to do.”

Consistency of staff, as well as choice, is a problem for disabled people. Home care agencies may experience similar problems to individual disabled people employing personal assistants in attracting suitable staff and retaining them, given the low wages payable in the sector.

This creates difficulties in training a continually changing workforce in disability equality and giving individuals choice of worker and consistency of support. Councils need to consider local workforce issues in their commissioning strategies; especially attracting and retaining social care staff and personal assistants.

However, some home care services are now developing more sophisticated ‘matching’ of staff to individual disabled people’s requirements using rostering software.

People using residential care were sometimes able to choose between a number of workers available at the same time, but rarely have a choice in which staff are employed in the first place. However, some services are now involving disabled people using the service in staff recruitment.

Flexibility in staff support

Giving disabled people choice and control in when, how and with what tasks they receive support is also important. Timetabling of visits by home care agencies can limit this:

“I do live a far improved life at home but unfortunately I am still restricted to a very strict timetable leaving me no flexibility or room for spontaneity.”

Often this is a commissioning issue – it is not easy for service providers to provide a flexible service if people only have a small number of hours in their care package.

Risk aversion or health and safety concerns can also limit the flexibility of tasks carried out:

“I wanted someone to take my curtains down for me to wash every three to four months and then hang them back up again after they are washed, but [the council] say they are not allowed to – nor are their agencies – get up on anything. I have a good quality step ladder. My attempting to climb up and do it would be a serious risk, but for anyone with average mobility and balance, it would be easy. I don’t want to live in filth and squalor.”
Putting people first – Equality and Diversity Matters

Good practice points – staffing

- Involve disabled people in the recruitment of staff who will support them, including providing disabled people with any necessary training to do this.
- Find out from disabled people who they would like to be supported by, including any preferences relating to cultural heritage, gender or sexual orientation. Try to meet these preferences where possible.
- Consider ways of increasing flexibility relating to times that staff support people and negotiate with the disabled person to achieve the best timings of support possible.
- Discuss with the disabled person their priorities for the tasks that they require assistance with and try to meet these.
- Review any restrictions on tasks that can be carried out – are there any solutions that maintain essential health and safety requirements but increase flexibility?
- If employing disabled people, consider the level of influence that they will have in the service or organisation and provide them with adequate support to enable them to influence policy and practice.
- Ensure that the service complies with law on preventing disability discrimination in employment.
- Consider establishing a disabled workers’ group for consultation on employment issues and support the group in their understanding of the social model of disability – but do not use consultation with disabled staff as a replacement for consulting people who use services.

Employing disabled people as staff

Some social care organisations have employed disabled people as staff, particularly in advocacy roles, to try and promote disability equality. There has been little evaluation of the impact of these initiatives on disability equality for people using services.

A comparison could be made with strategies to employ black and minority ethnic staff to tackle racism within organisations. Evaluations have shown that this approach brings additional experiences and skills into a service but there are dangers in assuming that the presence of black or minority ethnic staff will, in itself, tackle race discrimination. Often black or minority ethnic staff are not in sufficiently senior positions to make change and find it difficult to move beyond specialist roles. There could be similar issues in relation to the outcomes of employing disabled people to promote disability equality.

Whether or not disabled people are recruited to specific roles, it is important that services comply with laws about disability discrimination in employment and give adequate support to any disabled members of staff.

61 Harris, V and Dutt, R (2004) Meeting the challenge – a good practice guide for the recruitment and retention of black and minority ethnic workers. London: Race Equality Unit

8. Tackling prejudice and discrimination

- 31% of disabled people said that they had experienced prejudice or discrimination from services. 11% of respondents were not sure if they had faced discrimination — but this rose to 26% of respondents living in care homes.
- 39% of survey respondents identified at least one disabling barrier that they had faced when using services.
- 55% of respondents had experience of at least one member of staff who did not respect their right to equality — suggesting that some people had experienced negative behaviours but did not view this as discrimination.

It should be noted that the survey was less likely to be completed by disabled people who have more significant learning difficulties or cognitive impairments, who may be more likely to face certain types of discrimination.

Types of discrimination

In sections 11 to 15, we will consider in more detail the types of barriers to equality that disabled people face when using services, and how service providers can remove these.

Some people faced direct discrimination:

“The agency carer was a bully, I think this is common. That people with a disability are vulnerable to abuse of a manipulative kind. I believe coercion to be common and I have felt it often when carers do not like certain jobs.”

Sometimes prejudice or discrimination from individuals may be unintentional:

“All staff are different, most very well meaning and try to be friendly but end up patronising.”
Others face indirect discrimination because of assumptions about impairment or the way that services are structured or resourced:

“I came to this home because am ill but some times staff struggle to attend to me because I am slow.”

“I am in a tiny room and can only drive my wheelchair into the room and have to reverse out. My wife asked if there was a slightly larger room and was told no – however, there are several empty larger rooms.”

Disability discrimination may be compounded by other types of discrimination:

“I have faced massive discrimination, partly due to being disabled, and partly due to being in a same-sex relationship.”

Disabled people may also face discrimination or abuse from family, neighbours or other people using services. In the survey, 23% of people said that they had faced discrimination from others using services. Examples were often linked to wider prejudice in society:

“Some [others using services] have internalised oppression such that they are surprised/have low expectations as to what exactly I should do and achieve in my life.”

“Some disabled people can be racist and homophobic too. Middle class disabled people seem to be heard more because they are seen to be more worthy – especially if they have acquired an impairment later in life.”

Discrimination from others may be as a result of ignorance or prejudice and may vary from a lack of understanding by other people using a service to serious disability hate crime.

**Disability discrimination, abuse and hate crime**

Some forms of discrimination, particularly direct discrimination, may constitute abuse and need to be handled through safeguarding procedures. The definition of abuse in the government *No secrets* guidance includes:

“...discriminatory abuse, including racist, sexist, that based on a person’s disability, and other forms of harassment, slurs or similar treatment.”

Even if the motivation of the perpetrator to discriminate on the basis of impairment is uncertain, disabled people may report incidents of discrimination that fall under the definition of abuse, including physical abuse, psychological abuse, financial or material abuse or neglect.

Discrimination against disabled people may also be a crime. A recent report found that:

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• Blind and partially sighted people are four times more likely to be verbally and physically abused than sighted people.
• People with mental health issues are 11 times more likely to be victimised.
• 90% of adults with a learning difficulty report being ‘bullied’.
• Disabled women are twice as likely to experience domestic violence as non-disabled women.

If the discrimination amounts to a crime, it is important that the disabled person is given the choice to report this and is supported through the criminal justice process. This report concluded that:

“The language used to describe crimes against disabled people (eg ‘abuse’ instead of ‘sexual assault’, or ‘bullying’ instead of ‘harassment’) plays a big part in concealing the prevalence and impact of disability hate crime. Adult protection policies and practices often prevent local statutory agencies taking appropriate action to stop disability hate crime... Disabled people are routinely denied access to justice by not having the crimes committed against them recognised as hate crime.”

**Reporting concerns about discrimination**

There are a number of reasons why disabled people may not report discrimination when it happens. These include:

• Uncertainty about whether discrimination takes place – reported by 11% of survey respondents and 26% of those in care homes.
• Acceptance that a level of discrimination is inevitable:
  “There is always a degree of what could be called discrimination but in the main I accept we are different and if to be fully equal then non-disabled people would suffer.”
• A view that it is the disabled person’s responsibility to handle any problems:
  “The service user has a duty to let people know what they prefer or consider unacceptable.”

Whilst disabled people should be able to express preferences, it should not be their sole responsibility to challenge unacceptable discrimination.

• A recognition that reporting discrimination will be a drain on the person’s mental or emotional reserves:
  “There are far too many occasions [of discrimination] that I could recall, but I choose not to. I want to stay calm.”
• Fear of repercussion or actual victimisation:
  “My complaints are now at the ombudsman- nothing has been changed or rectified – and I have been bullied by my social worker as a direct result of speaking up.”
Putting people first – Equality and Diversity Matters

Good practice points – tackling prejudice and discrimination

- Prevent discrimination by addressing the organisational culture and staff attitudes and behaviours.
- Ensure that service user guides make clear the organisation’s expectations of both staff and people using services around all equality and diversity issues.
- Work with disabled people to increase their understanding of their rights and to raise their expectations of services.
- Encourage disabled people to report their experiences through both informal and formal methods and ensure that any policies relating to complaints, harassment and discrimination are available to everyone using the service in a format appropriate to them.
- Ensure that all comments or complaints from people using the service, their family or friends are welcomed, treated with appropriate confidentiality and do not lead to any victimisation.
- Offer advocacy to people raising issues and always provide feedback.
- Use all complaints as an opportunity to review whether there is an element of individual or institutional discrimination and take steps to address these.
- Always check whether a report of discrimination should be dealt with as a safeguarding issue, a crime, or requires disciplinary action to be taken.
- Intentional discrimination from staff should be considered a serious disciplinary matter and included in the disciplinary policy.

Lack of confidence that reporting will bring about change – 46% of people felt confident that the service they were using would handle a complaint of discrimination well; 31% felt that they would not handle it well; the rest were unsure.

Under-reporting means that service providers cannot assume that no discrimination is taking place if there have been no reports of disability discrimination from people using services.

Developing work to handle disability discrimination

Preventing discrimination happening in the first place is obviously preferable to dealing with it after the event. However, learning from the discrimination that does take place needs to be part of any strategy to address disability discrimination. Service providers need to take action to ensure that disabled people feel confident to raise issues of discrimination and that their complaints are taken seriously. They also need to ensure that there are other ways of picking up issues of discrimination, for example by observing staff, particularly where people using the service may face more barriers in communicating their concerns.

Only 5% of service providers said that they had developed any specific action to improve reporting or handling of discrimination complaints – and none of these providers specifically mentioned disability discrimination.

• Prevent discrimination by addressing the organisational culture and staff attitudes and behaviours.
• Ensure that service user guides make clear the organisation’s expectations of both staff and people using services around all equality and diversity issues.
• Work with disabled people to increase their understanding of their rights and to raise their expectations of services.
• Encourage disabled people to report their experiences through both informal and formal methods and ensure that any policies relating to complaints, harassment and discrimination are available to everyone using the service in a format appropriate to them.
• Ensure that all comments or complaints from people using the service, their family or friends are welcomed, treated with appropriate confidentiality and do not lead to any victimisation.
• Offer advocacy to people raising issues and always provide feedback.
• Use all complaints as an opportunity to review whether there is an element of individual or institutional discrimination and take steps to address these.
• Always check whether a report of discrimination should be dealt with as a safeguarding issue, a crime, or requires disciplinary action to be taken.
• Intentional discrimination from staff should be considered a serious disciplinary matter and included in the disciplinary policy.
• Ensure staff are familiar with whistle-blowing procedures and how these relate to disability discrimination.

• Do not rely solely on complaints from people using services, their family or friends or reports from staff to root out any discrimination. Use quality assurance methods such as staff observation and quality assurance surveys to monitor whether discrimination is taking place. Use discussion in staff and management meetings to identify any barriers that disabled people may face in the service.
9. Nothing about us without us – involving disabled people in services

Disabled people have long argued that they need more say, and ultimately control, over the services that they use if they are to achieve full equality. There is now a wealth of information about good practice in involving disabled people, including an increasing amount about participation of people who are less often heard, for example people with communication impairments or people with dementia.\(^65\)

However, a recent review across a number of organisations found that despite a commitment from service providers to involve disabled people, the pace of change is often slow, in terms of involvement driving change in organisations.\(^66\)

Differing priorities and unequal power relationships between people using services and professionals, as well as funding and resources, were some of the reasons identified.

“Involvement of users is patchy and disjointed and no joined together thinking anymore... user involvement seems to rely on the good involvement at all levels – which is cultural change in itself – is the key to improving change in all other aspects of service provision.”\(^67\)

Of the disabled people responding to the CSCI survey, 56% felt that they were happy with the way that they were involved in and could contribute to the services they use, whereas 33% disagreed. Some people had never been asked for their opinion on the service, let alone been invited to participate in any other way:

“I have no idea ‘how’ I have or ‘can’ contribute to the service. I have not been happy for a long time with the service that we get.”

There are several key considerations when planning the involvement of disabled people in a service:

\[(i)\] Involvement as a separate activity or integrated into everyday service delivery

Involvement that is integrated into everyday service delivery can change the values base of a service to one which puts people using the service at the centre.\(^68\)

“Involved of users is patchy and disjointed and no joined together thinking anymore... user involvement seems to rely on the good

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will and commitment of an individual as opposed to a policy and service led initiative.”

Disabled person responding to the survey

(ii) Individual disabled people choosing the level and degree of their participation.

Involvement can be at an individual level, a service level or an organisational level. Some people’s response suggested that their priority was involvement in their own care package, rather than service change as a whole:

“I have my own rota & I am involved in my care/support plans and all meetings that concern me.”

Whilst others wanted to influence services at a wider level:

“I do contribute to some consultation processes around services for disabled people – though I don’t feel that what I – or my peers say - influences change. Though sometimes contributions are made to research projects, I feel these processes have a greater impact than dealing with social services.”

Whatever the level of involvement, disabled people may want varying degrees of participation, from being consulted about a change to being in total control. For example, a service could involve disabled people to different degrees in staff recruitment:

- **Informing** disabled people that new staff are being recruited
- **Consulting** disabled people on questions to ask in a recruitment interview
- Working in **partnership** with disabled people by having representatives of people using services on a recruitment panel
- **Delegating power** by having disabled people with a majority say on the panel
- Enabling disabled people to have **control** of recruitment by providing support for disabled people to recruit their own staff

(iii) Removing barriers to participation

These barriers will be different for individual people. They may include:

- physical barriers or transport barriers
- lack of accessible information
- access to assistance including personal assistance, advocacy or communication support
- the timing or structure of involvement activities
- opportunities to development the knowledge and skills necessary to participate
- financial barriers – such as the need to pay out of pocket expenses promptly.

“I am involved in a lot but I am interested in more, especially as an expert by experience. Transport is the biggest barrier to doing more, and then if we do too much our benefits are affected.”
Putting people first – Equality and Diversity Matters 3

Good practice points – involving disabled people

- Develop a strategy for involving disabled people that moves involvement from being an “add-on” activity to a central one in organisational development.
- Use a range of involvement approaches, that enable individual disabled people to choose the level and degree of their involvement.
- Learn from existing good practice that is relevant to the service – for example projects that have addressed involvement barriers for people with dementia.
- Put resources into involvement that builds the ability of the service and disabled people to move from the lower levels of involvement, such as consultation, to the higher levels, such as partnership and delegated decision-making.
- Ask disabled people about the barriers that they face to being more involved and involve them in developing solutions to these barriers.
- Ensure that disabled people are paid expenses promptly and consider developing a policy about paying people a fee for their time spent on involvement work to ensure consistency and fairness.
- Measure success in involvement by looking at both the benefits it has brought to individuals and, most importantly, the impact that it has had on changing services.
- Ensure that disabled people are given feedback about how their involvement has resulted in change, or if change has not been possible, the reasons for this.
- If involvement is having little impact on service change, look for the reasons why and consider whether there are organisational barriers that are preventing change from taking place.

(iv) Measuring success by outcomes, particularly service change rather than the involvement processes.

If involvement does not result in service change, it can lead disabled people to feel disillusioned and reluctant to participate in the future.

“(the organisation has) great service user mechanisms but acting on them is another story in itself!”

Disabled person living in residential care
We wanted to ensure people using services had a real voice in assessing service quality by finding an evaluation model that has people using services at the centre. People’s confidence and ability to ask for things to change has grown significantly, also some of the people involved have presented at workshops and training events. We are developing the lifestyle reviews and looking at how the model can be used with others, for example people with mental health issues.

Good practice example – St Anne’s Community Services

St Anne’s provides a range of support, care and housing services across Yorkshire and the North East including work with people using mental health services and people with learning disabilities. The organisation has a number of initiatives to increase people’s involvement in services:

- A commitment to have people using services as full Board members and development work to recruit people and support their understanding of the role, led by the Chief Executive.
- An ‘Insight group’ made up of people who receive support from St Anne’s and are interested in involvement at an organisational level but do not want to be Board Members. This group meets with the Chief Executive and sometimes Board members to hear about the work of the Board and to give feedback.

“This has created a wider expectation within St Anne’s that people with experience of using services will be full members of the Board and encourages people to consider themselves for such a role both within St Anne’s and in other organisations. One of the first Board members has used his experience to move on and develop his skills in both paid and unpaid work.”

- ‘Lifestyle reviews’ enable people with learning disabilities to assess the quality and impact of services, by supporting them to visit other services. This involves collaboration between a number of providers. Each person compares the service they visit to their own experience, using 10 outcomes set by people using services. People share the learning from their visits, devising an action plan to take back to their own service with changes they want in the way they are supported.
Specific issues in achieving equality for disabled people using social care services

This section looks at how providers can remove barriers to disabled people achieving equality.

10. Addressing attitudinal barriers

Ensuring that staff fully understand disability equality is essential for promotion of equality in day-to-day practice in social care services. 55% of disabled people in our survey had experience of staff who did not respect their right to equality and 23% said that they had experienced attitude barriers in services – the most common type of barrier identified.

Staff attitudes and behaviours

45% of disabled people thought that all staff respected their right to equality, whilst only 3% felt that no staff respected this. Around half felt that ‘most’ or ‘some’ staff respected their right to equality. The percentage of people living in care homes who felt that all staff respected this right was 35%, slightly lower than those using Direct Payments or home care services.

Negative attitudes include patronising disabled people, feeling sorry for them and having low expectations of their abilities or what they can achieve. Some disabled people felt that if they did not accept behaviours which indicated underlying poor attitudes, it was seen to be their problem:

“One carer thinks teasing us like a 7 year old is being friendly and funny. It drives me potty but no one else minds which says volumes about me maybe.”

Disabled person using respite care

“Some staff make unsupportive comments that are hurtful and do not support our equality, if I comment on this I am seen as the one with the problem when I am just trying to get on with my life, and I get distressed.”

Disabled person using home care

Many people using Direct Payments also used staff from council home care services or agencies and some contrasted the two experiences:

“Staff I select myself have respect for my needs, because I have trained/selected them. However, council staff have treated me appallingly, to the extent that I made a complaint.”

In the first large-scale survey of people using personal assistants, 79% of disabled people were very satisfied with the support provided by the personal assistants that they employed. Positive views were expressed particularly about attitudes and the respect that personal assistants showed towards them as an employer.

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70 Skills for Care (2008) *Employment aspects and workforce implications of direct payments.* Leeds: Skills for Care
Staff training in disability equality

Staff training in disability equality can provide a basis for challenging attitudinal discrimination and thus changing the behaviours and approach of staff. There is a difference between Disability Equality Training (DET), which is based on using the social model of disability to understand barriers that disabled people face and plan actions to address these, and traditional disability awareness training, which uses simulation exercises as part of the approach:

“[Simulation exercises] have been used to illustrate ‘what it is like to have a disability’. Individuals are placed in wheelchairs or blindfolded and then asked to express how they feel... This only illustrates the feelings of a particular individual who experiences an instant sudden impairment. Disorientation and awkwardness on such an occasion are inevitable. This process forms part of the medical model approach to disability and serves to reinforce the negative view that disability is only some terrible personal tragedy.”

The most recent specific guidance on Disability Equality Training for the sector is a National Framework for Disability Equality & Etiquette Learning (DEEL) for Health and Social Care Services. Other useful resources to assess whether disability equality training meets good practice are also included in the resources section.

If training on disability equality is combined with other types of equality training, there is a danger that an approach specifically based on understanding the social model of disability will not be used.

The National Minimum Standards for care homes for people under 65 state that:

“All staff [should] receive equal opportunities training, including disability equality training provided by disabled trainers.” [Standard 35.4]

Only 3% of care homes for people under 65 said that they were providing staff with specific disability equality training. This was no higher than other types of service, as 3% of all services said they were providing disability equality training, whereas 53% of services said that were carrying out training on equality issues in general.

Other ways of removing attitudinal barriers and changing staff behaviours

Disability Equality Training alone will not necessarily change staff attitudes and behaviours. This is an ongoing process that needs to be reinforced by


staff meetings and supervision sessions. Managers need to be clear about the expected behaviour of individual staff that demonstrates that disabled people are equal citizens; for example use of respectful language and treating disabled people as adults, both in communication with people using the service and in communication between staff. Intentional discrimination should be treated as a disciplinary matter.

Staff also need opportunities to translate disability equality theory into practice, when supporting individuals or developing the service.

This is best achieved through enabling staff to work with disabled people using the service in identifying barriers to equality and developing solutions to remove these.

**Challenging attitudinal barriers from outside the service**

Disabled people using services may also face attitudinal barriers from people outside the service. One common situation is where younger disabled people want to behave like other adults but their parents are concerned about safety. In the focus group of people with learning difficulties most of the people said that their parents thought it would be 'wrong' if they had a relationship, especially a sexual relationship.

These conflicts can present a challenge for services that wish to promote equality for disabled people. In the survey on dignity, providers gave a number of examples of ways to address this, such as documenting the views of others but ensuring that the person's own views are paramount, and planned conflict resolution. Where someone lacks capacity, it may be possible to use an Independent Mental Capacity Advocate to assist.
ILA carries out a number of activities that reinforce positive attitudes about equality for disabled people:

- PAs are interviewed by ILA and a significant part of the interview is based on the core differences between traditional domiciliary care and personal assistance.
- Disability equality training is provided for PAs.
- ILA encourages open communication between disabled people and PAs if difficulties arise and are able to be a neutral party in mediating difficulties, whilst recognising that sensitivity is needed because many disabled people have experienced discrimination as a direct result of needing personal assistance.
- ILA actively works to promote choice and control for disabled people, though its website and publicity as well as its work with individual disabled people.

**Good practice case study – Independent Living Alternatives**

Independent Living Alternatives (ILA) is a user-controlled organisation that places disabled people directly in control of the services that they receive. ILA is registered as a domiciliary care agency and is managed by a board of disabled people. In 2008, ILA received an 'Excellent' rating from CSCI. ILA bases its service delivery on the concept of personal assistance, rather than care. ILA takes the needs of the personal assistance user and matches services directly to their requirements, whether disabled people want to employ their own personal assistants (PAs) or not.

For people employing their own PAs, services range from providing lists of applicants who are interested in working as a PA (for people who want a high level of control and will conduct their own interviews and recruitment checks) to support in all aspects, from recruitment to providing ongoing support once the workers are in place. ILA also offers 80 disabled people an emergency personal assistance service, where ILA will find a replacement PA in the case of, for example, sickness.

ILA provides services to 24 people where ILA is the employer. This does require a level of commitment from disabled people to want to control their own services – they must be able to manage rotas, instruct PAs about tasks on a day-to-day basis and provide on-site training to PAs in their specific requirements.

“People have the same level of choice, flexibility and control whether they employ directly or ILA employs, with the exception that ILA is obviously regulated by CSCI and provides a buffer zone because if things do go wrong the PA user can fall back on us.”
Good practice points – removing attitudinal barriers

- Ensure resources are available for staff to receive disability equality training and plan a programme of training.
- Ensure that any disability equality training uses a social model of disability approach and is delivered by disabled people who have experience in this type of training. Avoid disability awareness training which focuses on impairment, for example by using simulation exercises.
- Discuss disability equality as a regular topic at staff meetings and in staff supervision.
- Discuss staff attitudes and behaviours with disabled people using the service, to get their views on where improvement is needed – but remember that some disabled people may have developed low expectations of the way that people interact with them.
- Ensure staff are clear about expected behaviour that demonstrates equality, observe staff in practice and give them useful feedback if they are unintentionally displaying poor attitudes, for example treating disabled people in a patronising way.
- If staff intentionally discriminate against disabled people, this should be considered a serious matter and disciplinary action should be taken (see section 8).
- Support disabled people who are experiencing negative attitudes from people outside the service.
- Where there are differences in views between the disabled person and their family or friends, ensure that the disabled person's views are paramount in the delivery of the service and offer ways to resolve any conflict, if appropriate.
11. Two-way conversation – removing information and communication barriers

Good communication is crucial in supporting people’s human rights.

Access to information

Of the disabled people who responded to the CSCI survey, 29% felt that information about the service was not communicated in a way they could understand. (The people completing the survey are more likely to have access to written information than some other disabled people, so this may not be a representative figure for all disabled people using services.) This figure was higher for people using Direct Payments or Individual Budgets, indicating the challenge of making information about self-directed support accessible.

Sometimes, the barrier is about having information in an appropriate format, such as audio, large print or easy words and pictures. At other times, the barrier can be an overall poor level of information provision, regardless of the person’s impairment:

“Information has been hard to get. It is not a matter of understanding it, just a matter of finding it.”

Disabled person using Direct Payments

11% of home care agencies and care homes for people under 65 and 6% of care homes for older people reported that they had carried out work to make their information more accessible. These figures are lower than might be expected; it may be that services are carrying out work on improving information but do not view this as an action on disability equality.

Communication

Only 38% of disabled people felt that all staff communicated well. This figure was lower for people living in care homes, where only 27% agreed with this statement.

Some of the communication barriers were not connected with the disabled person’s impairment but were due to behaviours of staff or their level of English:

“Some agency staff have been dismissive, slightly rude (which I do not tolerate) or no communication at all unless instigated by me.”

“There are members of staff who have no or very little knowledge of the English language and are on short term contracts.”

Deaf people and those with communication impairments can face particular communication barriers:

“My son is deaf so finding an appropriate person is very difficult. We’ve managed by finding someone with the right personality and outlook who is willing to learn basic sign language.”

Mother of a deaf man with learning difficulties using Direct Payments
“They are all very good and I have a severe speech impediment. I was upset at one point when my care agency sent me different carers all the time as I do have a problem communicating and training them to me.”

Disabled person using home care

Where people need support with written communication, this can also be problematic as it is often seen as a low priority:

“I like to use my PC but this is not available... everything relies on my family being willing to pay and this is not fair. I cannot even get help to send cards to my loved ones without them paying for additional support time!”

Disabled man living in residential care

“I am a blind person. I asked for a computer with a speech package to keep in contact with my dispersed community as I was feeling particularly isolated at the time. I was offered an old electric typewriter and no reader, human or electronic.”

5% of care homes for younger adults, 4% of care homes for older people and 3% of home care agencies mentioned specific work on developing communication support as part of their work to promote equality. Again, this may be an underestimate as providers may not link providing communication support with promoting equality.

A body of knowledge now exists about approaches and tools that can assist communication for people who communicate in different ways because they have learning difficulties or other cognitive impairments. There are some fundamental principles that enable
a positive approach to addressing individual communication needs, including:

- Ensuring that care planning processes identify communication strengths that can be built on, as well as communication barriers that could be addressed.
- Working with an individual disabled person to understand the communication that they use, for example signs and gestures, and expanding the range of these, sometimes through use of additional communication tools such as symbols, photos, communication boards, objects of reference or information technology.
- Enabling people to have 'communication passports' to ensure consistent use of people's preferred communication methods.

**Good practice example – MacIntyre**

MacIntyre is a national organisation that provides support for people with learning disabilities.

“In order to take increasing control of your life, you need to understand and be understood. We all feel more in control if we feel we are respected and listened to and have the opportunity to have our say. For many people with a learning disability that we support this is a particularly difficult and, often, frustrating aspect of their lives.”

In order to address this, MacIntyre has made a commitment to breaking down these barriers by:

- Developing a ‘Great Interactions’ policy which is being written into all job descriptions. Every member of staff in MacIntyre now has an obligation to work in a facilitative way.
- Supporting staff to do this by appointing a communications and practice development advisor who:
  - provides staff training on communications
  - develops communication tools
  - works with individual disabled people and staff who support them to find solutions to individual situations
  - evaluates services through observation and communication audits
  - enables staff to share good practice.
- Developing a DVD training module for staff on facilitated communication, covering 10 key facilitation skills. This will become part of the induction training for each member of staff.

Feedback from staff shows that these initiatives are removing barriers for people using MacIntyre services, and that many people, as well as being generally happier, are making more choices and starting to make requests of staff that they did not make previously.

There are plans in the pipeline for additional training and a DVD covering signing.
Good practice points – removing information and communication barriers

- Ask disabled people to review the content of any standard information (such as service user guides) to see whether it covers information needs and is understandable.

- Ensure that care plans identify any communication barriers that a disabled person has, but also build on their communication skills and strengths and review these as they may change over time.

- Ensure care plans address people’s written communication needs, such as assistance with reading or letter writing, as well as verbal communication.

- Ensure that all written information required to use a service is given to each disabled person in their preferred format.

- Check that each person can understand the staff they are working with and ensure that staff have a reasonable level of language skill to communicate with the people that they are supporting.

- If people face particular communication barriers, work with them to find the best solutions and find out about existing good practice that may be useful.

- Develop a range of communication tools that may be useful in meeting individual needs and develop staff skills in using in appropriate communication methods, including training and sharing good practice.

- Consider consistency of staff for people that have communication impairments.

- Ensure that disabled people who need communication support have ‘communication passports’ to ensure consistency of communication.

- Audit communication in services, though observation and specific communication audits.
12. Equal citizens – barriers to accessing the local community

A key purpose of social care services should be to enable disabled people to participate in the community as equal citizens:

- 61% of disabled people felt that services had helped them to maintain links and use services in the local community
- 58% felt that services had helped them to maintain friendships and relationships
- 43% felt that services had helped them challenge barriers in the community
- 20% felt that the availability of staff was a disabling barrier – this was often about support to use mainstream services rather than additional help with personal care or domestic tasks.

**Assistance barriers to accessing the local community**

The National Minimum Standard for care homes for under 65s states that:

> Standard 13: Staff support service users to become part of, and participate in, the local community in accordance with assessed needs and the individual plans.

However, people responding to the survey felt that this was not always given adequate priority:

> “On the whole they are poor at this unless you push and then lack of resources is always blamed. Of course if it is something that the carer wants to do that will help a lot. Again making CSCI think that they are doing a lot is more important that actually doing it. A lot gets cancelled.”

*Disabled person living in a care home*

Sometimes people who agreed that they were supported to access the community had relatively low expectations:

> “I sometimes go out with the house in the minibus. Sometimes there’s only two staff on and then we can’t go out, but we can do things in the house like playing games.”

People living in care homes were less likely than those using other services to agree that services helped them challenge barriers in the community (29% agreeing compared to 43% of people using home care).

Enabling people to access the local community was the most commonly reported action on disability equality by care homes for under 65s, with 20% of services recording this, compared to only 3% of care homes for older people, but more needs to be done to ensure disabled people can access mainstream services and local communities as equal citizens.

Assistance required to participate equally in the community needs to be addressed through assessment and care planning processes. It is important that this is carried out in an open way, rather than making assumptions about the types of activities that someone would like to do, as this may not take account of personal preferences, cultural heritage, sexual orientation or other factors.
Many disabled people using Direct Payments or home care did not see the role of ‘services’ in accessing the local community, although people requiring personal assistance for this did recognise the importance of getting an adequate number of support hours allocated in the assessment and that flexible support enables more community participation:

“On the Individual Budget I have found that I can do a lot more – like volunteer work.”

**Transport barriers**

Inaccessible transport can be a major barrier that prevents disabled people from taking part in local communities. This affects not only people with mobility impairments who require transport that is physically accessible, but also other disabled people who require personal assistance to use transport, such as blind and partially sighted people or people with learning disabilities. However accessible public transport becomes, some people will require door-to-door transport. Service providers can assist with this – to maximise equality for disabled people, transport needs to be provided in a way that is flexible and does not institutionalise people, as the good practice example below shows:

### Good practice – Prime Life

Prime Life is an independent sector provider of care homes for older people. The have developed a fleet of approximately 40 vehicles, ranging from small people carriers through to wheelchair adapted minibuses, available as a pool to their 60 care centres. Sometimes the vehicles are pre-booked for people to attend specific events, but the booking system also ensures flexibility for their spontaneous use. People who receive the mobility component of Disability Living Allowance are asked to contribute a percentage of this to the transport scheme.

“Above all don’t fall into the trap of sign writing the vehicles, in promoting your care centre or business you create an institutionalised effect, you stigmatise the users and potentially draw adverse attention.”

This is complemented by accounts with local taxi firms which offer adapted vehicles, to maximise choice and flexibility.

“The transport service has enabled older people living in our care centres to take part in activities in the community that ordinarily would be inaccessible – they enjoy vocational, educational, social and leisure activities using mainstream community resources, promoting interest, opportunity and friendship.”

### Challenging barriers in community facilities

Even if a social care service provides the assistance and transport required for disabled people to access mainstream community activities, disabled people can face barriers in the community that prevent full participation.
Putting people first – Equality and Diversity Matters

When staff heard that a new shopping centre was being developed in a nearby city centre, the manager of the service wrote to the planning team for the centre asking about plans for accessible toilet facilities and outlining what she thought would be a reasonable expectation under the Disability Discrimination Act. As a result, the shopping centre now plans to include a toilet with a hoist and changing table for adults.

“Mike currently uses a shopping centre and a swimming pool in another city. He has developed good relationships with other people using these facilities and the people who work there, but the new shopping centre, when it opens, will provide more choice – not only for Mike but for many other disabled people who live locally. Campaigning for access improvements to community facilities can assist many disabled people – we also share good practice at managers’ meetings and in our magazine for people that we support.”

These barriers could be physical, communication or attitudinal barriers. Disabled people will need to decide for themselves how they wish to deal with these situations. If services are aware of particular access issues affecting disabled people they support, they should offer support to negotiate with or challenge mainstream service providers. It can be very draining for an individual to repeatedly challenge their right to participation. People who have more difficulty in advocating for themselves may also need support, as the good practice example below shows:

**Good practice – MacIntyre**

Mike is a young man with a profound learning disability. He uses a wheelchair and requires a hoist to use a toilet. He really likes going out shopping or visiting local places but lack of suitable toilet facilities limits the length of time he can be away from home and this is a significant disabling barrier for him. When he first started living in a care home run by MacIntyre, staff did some research to identify local places for Mike to visit:

“Quite a few of the people we support require a hoist to be assisted out of their wheelchair to use the toilet or to change their incontinence aid. We find that the least commonly available services in community facilities are hoists and changing tables for adults. We did identify some local places for Mike to visit but the nearest shopping centre with suitable toilet facilities was about 30 miles away.”
Putting people first – Equality and Diversity Matters

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• Ensure that key staff have access to information about the Disability Discrimination Act 1995 to help them challenge disability discrimination.

• Share good practice and successes across the organisation, with disabled people using services and externally.

Good practice points – removing barriers in the local community

• In assessment and review processes ensure that disabled people are asked open questions about:
  – preferred leisure activities and other community participation (for example attending groups)
  – important relationships and contacts
  – education, volunteering or work goals
  – goals for the future.

• Ensure that care planning addresses barriers to the disabled person having equal participation in the local community, including assistance barriers, transport barriers or barriers in community facilities.

• Raise the expectations of disabled people and staff about disabled people’s rights to community participation on an equal basis.

• In care homes, make information about local mainstream activities, events and services accessible to disabled people and assist individuals to find appropriate activities if required.

• Consider the way that staff are deployed, to try and increase flexibility to meet the needs of individual disabled people who need assistance to take part in the local community.

• Review any transport arrangements to see if these could be more flexible to meet individual requirements.

• Support disabled people to challenge barriers to accessing mainstream services.
13. More than ramps – removing environmental barriers

If non-disabled people consider equality for disabled people, typically their first thoughts are about removing physical barriers for people with mobility impairments. 17% of disabled people, and 37% of people with physical or sensory impairments, said that they experienced physical or environmental barriers when using services.

“I am housed by a leading disability charity but they cannot even pay attention to making my room disabled friendly...the answer is not always give someone more aids and adaptations but to make things reachable for those of us who want to be independent.”

The Care Homes Regulations 2001 state that:

“The registered person shall having regard to the number and needs of the service users ensure that—

(a) the physical design and layout of the premises to be used as the care home meet the needs of the service users...

(n) suitable adaptations are made, and such support, equipment and facilities, including passenger lifts, as may be required are provided, for service users who are old, infirm or physically disabled...”

(Paragraph 23 – Fitness of premises)

The National Minimum Standards state that, from 1 April 2004, the premises of care homes for younger adults should meet the requirements of the Disability Discrimination Act 1995, Part 3; however, care homes for older people are also covered under the Act itself.

Sometimes it is the offices of providers that have environmental barriers:

“The doors are heavy and impossible to open independently. A wheelchair user cannot get from the lift to front desk because of furniture.”

Disabled person using home care services

Removing physical barriers was the most commonly reported action on disability equality by care homes for older people, with 24% of services saying that they had taken some action on this, compared to 14% of care homes for people under 65 and 8% of home care agencies (for example through the arranging the provision of equipment such as hoists).

Work on the physical environment is vital to help disabled people to achieve some equality and many service providers have made progress on this. However, it is not sufficient to consider only physical barriers, without addressing more difficult forms of institutional discrimination such as attitude or assistance barriers.

Addressing environmental barriers

Addressing environmental barriers is also not as straightforward as it may at first seem. Many disabled people face physical or environmental barriers that are not obvious; for example blind and partially sighted people face a range of environmental barriers such as cluttered layouts, poor signage or colour contrast, and people
using hearing aids may be disadvantaged in noisy environments. People with dementia face environmental barriers including appropriate lighting to assist cognitive function. Not all these barriers are covered in the building regulations covering access to and use of buildings, although these form an essential starting point and baseline.

Under the Care Home Regulations, providers only need to consider environmental access for people currently using the service, which may mean that not all disabled people who use a service in the future are considered. This is a particular issue in services that are not specifically for people with physical impairments, such as mental health services. These services may be using buildings owned by local councils or primary care trusts including older, less accessible housing stock leased on short-term contracts. These providers will need to address both short-term and long-term measures to ensure compliance with the Disability Discrimination Act with the goal of ensuring that all disabled people have full access to services.

Issues may arise when individuals have different, and sometimes conflicting, access requirements, for example around best layouts for bathroom areas. It is important to check with disabled people using a service that that buildings and outside areas, such as gardens, meet the requirements of individuals, whilst in shared areas not compromising on access for others especially if this would lead to a failure to meet building regulations.

**Disabled people controlling their environment**

Physical access is only one aspect of disability equality in care home environments; ownership of the space is also vitally important. A care home or a supported living service is the home of the disabled people who live there – providers need to consider whether the physical environment reflects this. Disabled people should be able to personalise their own rooms and collectively agree on how communal rooms are furnished and are used. Service providers need to be proactive in this respect, as explained by a provider engaged in a project to make the décor and layout of their services more like someone’s home, not a place of work:

“The impetus for this initiative has come almost entirely from us rather than the people we support. This almost certainly reflects on the inequality of power and consequent disempowerment of people that is inevitably built into the relationship between people needing support and professionals providing it – something that we must constantly be aware of and guard against. This is
often compounded by people’s personal histories of long-term disempowerment in large institutions. However people living at a property are always involved in the implementation of the initiative – in choosing the décor for their homes, in personalising communal areas so that they feel homely.”

**Good practice points – removing environmental barriers**

- Involve disabled people using a service in auditing physical environments, such as care homes or offices alongside qualified access auditors (who may also be disabled people).
- Base any audit on national standards, such as Part M of the Building Regulations, but be prepared to exceed the standards to meet individual requirements.
- Consider people who may use the service, as well as people currently using it.
- Where large-scale improvements are needed, develop a programme of work to address these barriers, including identifying resources needed and negotiating with service commissioners and/or landlords.
- Ask each individual disabled person using a service about any environmental or physical barriers they experience and take action to address these, including provision of appropriate equipment and looking for solutions where there may be conflicting requirements.
- Seek advice from qualified access professionals to find solutions to any particularly difficult access issues.

- Look at who controls the physical space in a service and develop ways of giving disabled people more control over communal areas and their personal space.
- Look at reducing the institutionalisation feel of the physical space, for example:
  - is all the signage inside and outside necessary?
  - how conspicuous is the staff room or office compared to the other areas?
  - is medical equipment stored away appropriately when not in use?
  - do bathroom areas have a clinical feel that could be reduced?
  - are furnishings in communal areas like those in someone's home or like a communal setting such as a hospital waiting area?

Human rights are based on five principles: fairness, respect, equality, dignity and autonomy. It is important not to see human rights and disability equality as separate agendas, as they are inextricably linked—partly because equality is one of the principles of human rights legislation, but also because the other principles are highly relevant to equality for disabled people. The Human Rights Act 1998 brings most of the rights contained in the European Convention on Human Rights into UK law by placing a duty on all public authorities in the UK to act in a way that respects and fits with the rights in the European Convention. Public authorities include any person or organisation “whose functions are of a public nature”. The term also covers private organisations such as companies or charities, but only when carrying out a public function.

Recent government research has shown that frequent users of health and social care services, including many disabled people, are more likely to experience poor treatment in services in relation to their human rights than people who use health services infrequently.

Awareness of human rights

Disabled people often have a low level of knowledge about their human rights, as well as their rights under disability discrimination law.

“I’ve heard about [human rights] on the news but not sure what it means.”

Focus group participant using residential mental health services

Even if people have a broad knowledge of the law, it may be difficult for people to apply the law of they feel their human rights have been breached:

“People’s understanding will be okay whilst discussing but they do not have awareness of how it affects them as an individual. It is up to the representative to apply the human rights.”

Person living with HIV speaking in a focus group

People often have a better understanding of the principles of human rights, such as dignity and respect, than of human rights as an abstract concept. There are now guides to human rights aimed at disabled people that service providers could use to increase people’s awareness of their rights.

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Putting people first – Equality and Diversity Matters

Social Care Policy and Practice

Right to life

Some disabled people have campaigned against being treated as having ‘lives not worth living’, for example by the placing of ‘Do Not Resuscitate’ notices without their consent, when they are ill. The Disability Rights Commission was granted permission to make a legal challenge where a ‘Do Not Resuscitate’ notice was placed on a disabled child against her mother’s wishes but the case was settled out of court. Social care organisations should ensure that they do not breach disabled people’s rights to life, including when they are working with health services.

Protection from inhuman or degrading treatment

Inhuman or degrading treatment includes abuse, neglect and inappropriate restraint, in some circumstances. Whether or not poor care practice amounts to a breach of someone’s right not to be treated in an inhuman or degrading way will depend on the severity of the ill treatment. Treating people with dignity is at the core of this right. Many social care services are taking action to ensure that people are treated with dignity; in a recent survey of corporate providers carried out by the Commission, 13 of the 23 organisations responding had appointed ‘dignity champions’, eight had dignity strategies in place and a further three had dignity policies. Many providers linked

Human Rights Act 1998 – convention rights and freedoms

Articles 2 to 14:

- right to life
- prohibition of torture (includes inhuman or degrading treatment)
- prohibition of slavery and forced labour
- right to liberty and security
- right to a fair trial
- no punishment without law
- right to respect for family and private life
- freedom of thought, conscience and religion
- freedom of expression
- freedom of assembly and association
- right to marry
- prohibition of discrimination.

Some examples of the rights relevant to social care providers are outlined below. The Equality and Human Rights Commission guide to social care and human rights (forthcoming) provides a more comprehensive and detailed guide than is possible in this bulletin.


82. From the Human Rights Act (1998) Schedule 1


84. The British Institute of Human Rights (2006) ibid
their work on dignity to using a person-centred approach and also prioritised training, supervision and monitoring of services. Some providers had thought through tangible outcomes for people using services that would indicate that their work to promote dignity was having an effect, such as staff asking people using the service how tasks should be carried out or all personal care being delivered in private. Some had developed ways of measuring these outcomes, for example through feedback from people using the service or improved inspection reports from the Commission.

Some disabled people reported breaches of dignity and highlighted a role for the regulator in upholding people’s human rights:

“There is also a sense that things happen in care homes and that is ok... This is the 21st century but we still have to accept communal laundry. CSCI needs to really look at what it expects for younger adults. We have many years to face in homes and some practices are way out of date. How would you feel about being made to wear someone else’s underwear because someone can’t be bothered to launder your clothes individually?”

Disabled person living in a care home

“Homes do differ in standard. [...] Specialist eating aids and protective garments are often forgotten leading to a loss of dignity... Vulnerable people out of reach of bells. Left soiled for long periods because it is too near a mealtime and staff do not want to do too much or they are short of staff.”

Disabled person using respite care

“Two members of staff [respect my right to equality] – they have both had NVQ level 2 training. The others are low paid and casual workers who have no concept of my dignity as a young disabled woman.”

Disabled person using home care

Right to liberty

The right to liberty is not absolute – it can be restricted in certain circumstances, for example if disabled people are legally detained under the Mental Health Act. The government has recently brought in safeguards to ensure that ‘vulnerable people’ are not deprived of their liberty in an arbitrary fashion. These deprivation of liberty safeguards under the Mental Health Act apply to all care homes registered under the Care Standards Act 2000 and ensure that any decision to deprive someone of their liberty is made following defined processes and in consultation with specific authorities.85

Right to respect for family and private life

Of the disabled people responding to the survey, 63% felt that their privacy was respected by the services that they used.

“At times I have been made to feel as though my home no longer belongs to me. I have

It is important that staff also respect people’s dignity by upholding confidentiality of personal information. Some disabled people reported in the survey that social care staff either discussed witnessed ‘carers’ watching TV, using the bathroom and being shown around my home without asking permission.”

Disabled person using home care
their private information with others using the service or inappropriately in public places:

“My PAs respect my privacy. Local authority staff talk about me and other disabled people without any respect for confidentiality.”

“My PA happened to be in a pub and my social worker was there. My PA heard her discussing me in the pub!”

Privacy is closely linked to dignity. Sometimes disabled people had become accustomed to undignified treatment that did not respect their privacy:

“It does depend on the care and how much privacy one wants. I don’t really insist on too much now that I am not young and shy. It is an exception but I did recently have respite when a carer wanted to wheel me through the home in my underpants. I am not bothered any more but I didn’t want to offend others.”

The right to privacy is only one element of this right. Respect for private life under the Act is wide-ranging and includes respect for personal and sexual relationships and a right to participate in community life (see section 13). For example a lesbian or gay disabled person should be afforded the same respect and support by social care services for their relationships and contact with their community as a heterosexual person. Respect for family life covers close and personal ties of a family kind, not purely blood relations – this includes friendships. This right also covers a right to privacy for correspondence.

A restriction on this right is permitted only if it is lawful, justified and proportionate.

Personal relationship policies may assist providers in ensuring that these rights are upheld – but only if these policies are non-restrictive and promote privacy and equality for all relationships. Disabled people should not have to disclose information about their family or private life unnecessarily, but there should be an open culture where disabled people are able to discuss relationships and have these recognised if they wish.

**Prohibition of discrimination**

The European Convention, and therefore the Human Rights Act, contains some limited protection against discrimination. It protects against discrimination “in relation to the other human rights contained in the European Convention” – it does not protect against discrimination in all circumstances. Disability is not specifically listed as a ground for unlawful discrimination under Article 14. There was no recognition of the concept of disability discrimination when the European Convention was drafted over 50 years ago. However, the law prohibits discrimination on the ground of any “other status”, and this has been used to cover discrimination on the grounds of disability.

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Good practice points – the Human Rights Act and disability equality

- Ensure that managers and staff understand how the Human Rights Act applies to their work.
- Provide disabled people with information about human rights and access to advocacy if they wish to pursue a potential breach of their rights.
- Consider the organisation’s statement of purpose and other key documents – do they reflect the need to uphold human rights for disabled people?
- Audit services in relation to key human rights.
- Involve disabled people in any assessment and action planning about human rights in services.
- Ensure that any work about dignity is put into a human rights context.
- Ensure that services have clear safeguards in place to prevent unlawful deprivation of liberty for disabled people or breaches of the right to life.
- Ensure that privacy is upheld when delivering services, including:
  - providing personal care in private
  - respecting a disabled person’s personal space (for example asking permission before entering their room in a care home)
  - ensuring staff treat personal information confidentially
  - having clear procedures for respecting privacy of personal correspondence, including when a disabled person needs assistance to understand correspondence.
- Ensure that services respect disabled people’s rights to a private and family life by:
  - enabling the disabled person to have choice and control over their relationships, without undue interference (see section 11)
  - supporting disabled people to have access to friendships and communities of their choice (see section 13)
  - asking disabled people who is important to them, rather than making assumptions based on the views of their family.

Social Care Policy and Practice
15. Checklist for action

This checklist gives a suggested order for putting the main good practice points about disability equality into action. Services may wish to vary the order, according to their own requirements.

<table>
<thead>
<tr>
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<th>Yes/No</th>
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<tbody>
<tr>
<td>1</td>
<td>Decide how to involve disabled people in developing a disability equality strategy and putting it into action</td>
<td>33, 44</td>
<td></td>
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<tr>
<td>2</td>
<td>Develop a strategy or plan for disability equality (linked to your business plan) using a social model of disability approach to removing barriers, increasing choice and control and addressing human rights issues. Using the guidance to the Disability Equality Duty is essential for statutory services and may be useful for others</td>
<td>33, 67</td>
<td></td>
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<tr>
<td>3</td>
<td>As part of this, develop and resource a strategy for involving disabled people that ensures that the involvement of people using services is central to organisational development and management of services (for example staff recruitment)</td>
<td>44</td>
<td></td>
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<tr>
<td>4</td>
<td>Ensure managers understand disability equality and human rights, including legal aspects and legislation, and that the application of these concepts is discussed regularly</td>
<td>33, 67</td>
<td></td>
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<tr>
<td>5</td>
<td>Audit your policies, processes and procedures to check they use an approach centred on removing barriers for disabled people, increasing their choice and control and human rights – including statement of purpose, equality policies, information to people using the service, complaints, staff handbook, and practice-based policies (such as communication, risk assessment, care planning or privacy and dignity)</td>
<td>24, 29, 33, 40, 54, 67</td>
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<td>6</td>
<td>Base assessments and care plan reviews on the outcomes that the disabled person wants to achieve and the barriers to independent living that the disabled person faces. Develop ways for disabled people to do more self-assessment</td>
<td>24, 58</td>
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<td>7</td>
<td>Consider ways of increasing service flexibility around who carries out tasks, which tasks are carried out, when, where and how to offer disabled people more choice</td>
<td>29, 36, 58</td>
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<tr>
<td>8</td>
<td>Ensure staff receive Disability Equality Training which uses a barriers-based approach and that staff learning on disability equality is developed through meetings, supervision and observation</td>
<td>50</td>
<td></td>
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<tr>
<td>9</td>
<td>Develop ways of encouraging disabled people using the service to have higher expectations of service quality and to report any concerns or discrimination informally and formally, and always report outcomes back to people</td>
<td>40, 58</td>
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<td>10</td>
<td>Ensure that complaints of disability discrimination are handled appropriately, that any hate crime, safeguarding or disciplinary issues are identified and that services rectify disabling barriers identified through comments or complaints</td>
<td>Yes/No</td>
<td>40, 50, 67</td>
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<tr>
<td>11</td>
<td>Review advocacy provision for disabled people, particularly independent advocacy at key points such as at care plan reviews and if a disabled person wishes to make a complaint</td>
<td>Yes/No</td>
<td>24, 29, 40, 67</td>
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<tr>
<td>12</td>
<td>Enable disabled people to access information, advice and support from independent sources, including putting people in contact with local user-led organisations or groups</td>
<td>Yes/No</td>
<td>24, 29</td>
</tr>
<tr>
<td>13</td>
<td>Ensure that each disabled person receives information that is in their preferred format and is accessible to them</td>
<td>Yes/No</td>
<td>24, 40, 54</td>
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<tr>
<td>14</td>
<td>Ensure that care plans identify any communication barriers that a disabled person has, but also build on their communication skills and strengths. Using best practice and a range of tools, work with people to find best solutions</td>
<td>Yes/No</td>
<td>54</td>
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<tr>
<td>15</td>
<td>Develop the communication skills of staff, including any necessary language skills as well as the range of communication that they can use with people with communication impairments or learning disabilities</td>
<td>Yes/No</td>
<td>54</td>
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<tr>
<td>16</td>
<td>Ensure that care planning addresses barriers the disabled person may face to equal participation in the local community, including assistance barriers, transport or barriers in community facilities</td>
<td>Yes/No</td>
<td>58</td>
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<tr>
<td>17</td>
<td>Review transport and staffing arrangements to see if it is possible to increase flexibility in supporting individual disabled people to participate in the local community</td>
<td>Yes/No</td>
<td>29, 36, 58</td>
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<tr>
<td>18</td>
<td>Support disabled people using the service to challenge barriers to accessing mainstream services</td>
<td>Yes/No</td>
<td>58</td>
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<tr>
<td>19</td>
<td>Use national access standards to audit physical environments but also seek the views of disabled people using the service about physical improvements to services</td>
<td>Yes/No</td>
<td>61</td>
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<tr>
<td>20</td>
<td>In a buildings-based service, consider who controls the physical space, reducing any ‘institutional’ feel and giving disabled people more control over both personal and communal space</td>
<td>Yes/No</td>
<td>61</td>
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<tr>
<td>21</td>
<td>Monitor progress through quality assurance, feedback and direct observation including measuring the outcomes for disabled people in having more control over services individually and through their collective involvement in the services that they use</td>
<td>Yes/No</td>
<td>33, 41, 44, 50</td>
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<tr>
<td>22</td>
<td>Review your progress at regular intervals and openly report progress on disability equality objectives and publish consultations and their resulting actions</td>
<td>Yes/No</td>
<td>20, 33, 44, 58</td>
</tr>
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</table>
16. Resources

Publications

Prime Minister’s Strategy Unit (2005) *Improving the life chances of disabled people.* London: Prime Minister’s Strategy Unit, Department for Work and Pensions, Department of Health, Department for Education and Skills, Office of the Deputy Prime Minister


There are two other relevant guides in this series – one *Guide for older people* and one *Guide for people living with mental health problems*


Barnes, C (1991) *Disabled people in Britain and discrimination.* London: Hurst and company

Websites

Equality and Human Rights Commission: www.equalityhumanrights.com

United Kingdom Disabled People’s Council is the UK national organisation of the disabled people’s movement, representing over 70 groups and organisations run by disabled people: http://www.bcodp.org.uk

The website of the National Centre for Independent Living includes a directory of Centres for Independent Living and other organisations of disabled people: www.ncil.org.uk

The Disability Archive UK, hosted by the Centre for Disability Studies at the University of Leeds, is an online resource containing a searchable index of key writing and research by disabled people and their allies about equality – much of which is not available elsewhere: www.leeds.ac.uk/disability-studies/archiveuk

The website of Disability Wales includes information on what to look for when purchasing Disability Equality Training: www.disabilitywales.org

Acknowledgements

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From April 2009, a new Care Quality Commission will take over the work of CSCI, the Healthcare Commission and the Mental Health Act Commission.

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