



Tackling health inequalities

The Disability Agenda

This document is one of a series of 10 giving detailed recommendations on the priorities within the Disability Agenda. The full set includes:

1. Promoting a culture of equality and human rights
 2. Bringing an end to child poverty
 3. Increasing life chances through learning and skills
 4. Ending poverty and widening employment opportunity
 5. Increasing democratic participation and active citizenship
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6. Developing a social care system fit for the future
 7. Tackling health inequalities
 8. Meeting the future housing challenge in England and Wales
 9. Meeting the future housing challenge in Scotland
 10. Building stronger, safer communities



Tackling health inequalities

Creating an alternative future

The Disability Agenda is focused on resolving the deepest and most persistent social and economic exclusion facing disabled people and their families. It aims to do this by recommending policies to reach those individuals who have felt least benefit from progress so far and by addressing those emerging issues that will become the fault lines for inequality in the years to come.

This means giving disabled people the necessary support to participate. It means expecting, in return, that disabled people will accept greater responsibilities to make a positive social and/or economic contribution.

The term 'disabled people' is used throughout the Agenda to refer to all those people in Britain who have an impairment or long-term health condition such that they are likely to meet the definition of disability in the Disability Discrimination Act 1995. This includes people with sensory and visual impairments, learning disabilities, mental health problems and long-term health conditions such as diabetes, HIV, multiple sclerosis and cancer.

The challenge

Britain faces major health challenges, including rising rates of obesity and diabetes, persistent premature mortality from cancer and heart disease, and growing health inequalities. Whilst the population on average is becoming healthier, the gap between healthy and less healthy people is growing.¹

Governments cannot meet targets to reduce premature death or reduce health inequalities without focusing on groups with the poorest health. For socially excluded groups, poor health makes it even harder to work or participate in communities; and for Britain as a whole there are potentially avoidable health and welfare costs.

Amongst those missing out on good health are disabled people – not just in relation to their primary impairment or long-term health condition but because social deprivation, unequal access to health services and other factors put them at greater risk of illnesses that in many cases could be prevented.

A Disability Rights Commission (DRC) formal investigation, for example, found that people with learning disabilities and/or mental health problems were more likely than other citizens to experience most killer diseases and risk factors, including heart disease, stroke, respiratory illness, diabetes, some cancers, smoking and obesity. They became ill younger and died faster.²

Potentially avoidable ill health creates additional barriers to achieving independence and to participation.

The challenges are set to grow as Britain's population ages. Although there are likely to be improvements in the health and well-being of older people, the likelihood of impairment and poor health increases with age.^{3 4} More disabled children and young people are also living longer with complex conditions. This requires specific focus if people are to stay as healthy and active as possible.

Improved health for disabled people and other high risk groups would result in greater participation and reduce unnecessary demand on health services. It can be achieved in part through improved opportunities in learning, employment, community activities and housing.

However, health services also have crucial roles: to ensure that routine services are provided equitably; that services are targeted at those with the greatest need, to equalise outcomes; and that services offer choice and control so that they support people's independence and participation.

The DRC investigation found that early death could not be accounted for simply by social deprivation. Other factors included differential access to health promotion, checks and treatments; failure to make 'reasonable adjustments' to ensure access to services; and staff having low expectations or not seeing past the mental health problem or learning disability to the real physical problems needing attention.⁵

While the DRC's investigation looked in depth at the experiences of people with learning disabilities and/or mental health problems, particular problems with access and attitudes have been identified in relation to other groups, including people with physical, hearing or visual impairments, travellers, lesbian women and people from black and minority ethnic communities.⁶

Unequal access and treatment in health services for disabled people should have been addressed by the Disability Discrimination Act (DDA) duties that came into force in 1999. However, many health service providers have focused narrowly on physical access rather than considering changes to how services are provided.⁷ Examples include making appointments by email or text, receiving treatment information in large print or on tape, or having phone appointment reminders.

Achieving equality means making adjustments and providing appropriate support to achieve equal outcomes – not simply treating people 'the same'. A useful tool to achieve this is the Disability Equality Duty (DED). At present, there are no systematic national data sets on health outcomes – such as premature death from cancer or heart disease – broken down by type of impairment/health condition, such as hearing impairment, visual impairment, mental health problem or learning disability. There are also no systematic data on the interventions people do (or do not) receive.

Given disabled people's level of health risk, they should form core targets for health improvement strategies across Britain. However, often they do not benefit from national programmes because of unequal patterns of access and a lack of specific targeting of groups known to be at higher risk. Health inequalities programmes tend to target geographical areas of social deprivation, rather than high-risk groups. Coupling the two approaches could deliver more effectively.

To tackle obesity among people with learning disabilities and/or severe mental health problems nationally, for example, would have greater impact than to do so for the whole of Birmingham and Coventry combined. National programmes to tackle health inequalities would not ignore whole cities like Birmingham or Coventry – yet disabled people are often ignored in national health improvement programmes.

In residential and nursing homes, the costs of contracting with GPs are sometimes passed on to residents. This denies to some disabled (and often older) people a health service free to all at the point of need.

In some hospital settings, residents have no access to primary care for their physical health and have to rely on mental health practitioners with more limited physical health training.

Some people living in supported living arrangements report difficulty in making and keeping GP appointments because their support workers are not always available or willing to assist them or to provide transport at the appropriate times. This denies some disabled people a right that other citizens have – to choose when to see a GP.

People living in residential, nursing, secure settings or hospital care should be easily able to live a healthy lifestyle, including eating the recommended five portions of fresh fruit and vegetables per day. People in residential settings are, however, sometimes under-nourished and often do not have access to a good quality diet.⁸

The adverse effects of some medication contribute to poor physical health. Anti-psychotic drugs can lead to weight gain and obesity, heart problems, low blood pressure, osteoporosis, seizures, involuntary movement disorders and in some cases sudden death. In recent inspections, nearly half the care homes in England and Wales for older people and younger adults did not meet minimum standards for providing medication.⁹

Health (and social) care resources are still tied up in services that maintain the dependence of people with long-term health conditions – nursing home provision rather than home-based nursing and support or day services for people with mental health problems, rather than evidence-based support for employment. Family and friends providing support outnumber social care workers by three to one.¹⁰ For example, 52 per cent of adults with learning disabilities live with their parents and a further 12 per cent live with other relatives.¹¹ These family members' health and support needs must be built into service improvements.

People providing informal support, especially where it is regular and substantial, experience greater ill health than other citizens. There are over 6 million informal carers in the UK, and 51,000 children in Britain provide regular and substantial support to a family member in the absence of formal services including 1,304 5–7 year olds who provide more than 20 hours support a week. There are 1.25 million people providing 50 hours support or more a week – more than that specified in the Working Time Directive.¹²

This paper proposes policy solutions for reducing health inequalities. It is part of a series offering the DRC's proposals for a future public policy agenda. Details of the series are provided on page two.

Everything in this paper should be taken as relevant to all three countries of Britain unless otherwise stated.

An alternative future?

The DRC believes that the link between disability and unequal health outcomes can be significantly narrowed. The goal is a measurable reduction in the health gap between disabled people and other citizens.

The key objectives of an effective reform agenda are to:

- Include improved health outcomes for disabled people in mainstream health targets and standards.
- Reduce inequalities through commissioning and targeting.
- Transform service cultures and staff attitudes.
- Meet people's health needs wherever they live and whatever social support they receive.
- Deliver health services that support social inclusion of families.
- Meet the requirements of the DDA.

Recommendations for action

1. To include improved health outcomes for disabled people in mainstream health targets and standards

Governments should:

- 1.1 Include expected improvements for under-served groups within the main targets to improve health (for instance, to reduce premature death from particular diseases, reduce smoking rates, tackle obesity or diabetes, reduce health inequalities) and in the targets and standards to improve services (for instance, improvements in the patient experience).¹³

Commissioners of health services should:

- 1.2 Develop effective monitoring systems that identify disabled people, including those with long-term health conditions, and track their health experiences and outcomes against those of other citizens.

Standard-setting and good practice bodies should:

- 1.3 Support implementation of the targets, for example by including the requirements of different groups of disabled people in clinical guidelines on subjects such as tackling obesity and treating heart disease.

Inspectorates should:

- 1.4 Track the experience of different groups of disabled people through patient surveys.

2. To reduce inequalities through commissioning and targeting

Governments should:

- 2.1 Ensure that national policies and frameworks explicitly address the requirements of groups at high health risk, including disabled people, through health promotion and screening programmes, national standards, commissioning guidance and contracts (including general practitioner (GP), consultant, dentistry and pharmacy contracts). This will help to target resources to the greatest needs. Targeting should also include children (with specific reference to transition services), older people and people from black and minority ethnic communities, to prevent the perpetuation of unequal access and treatment.
- 2.2 Subject new policies to disability equality impact assessments to ensure that new developments (including in choice and diversification in England) do not disadvantage disabled people.

Commissioners of health services should:

- 2.3 Analyse the health needs of their community and then commission for their whole population on the basis of need, including identified health needs of different groups of disabled people. The objective must be to focus on who needs support to better manage health. Commissioning should be creative to ensure health services reach those who need them, including through new service models and partnerships.
- 2.4 Monitor and report on health service interventions, outcomes and core standards, such as trends in referral, screening, disease incidence and mortality (including age at death) and use of standard interventions by disability (including by broad impairment group).¹⁴

Inspectorates should:

- 2.5 Inspect whether commissioners use data on local population need, including high risk groups, directly to commission effective and accessible service models.

3. To transform service cultures and staff attitudes

Governments should:

- 3.1 With partners, spearhead evidence-based training for health professionals and managers at key career points, with particular attention to raising the expectations of disabled people and countering diagnostic overshadowing. Since evidence shows that attitudes change most through contact with disabled people on equal terms, training led and delivered by disabled people is particularly useful.
- 3.2 Spearhead programmes to enable disabled people to share knowledge and skills on rights and how to negotiate for improved services, including through patient and public involvement initiatives. They should encourage programmes to support disabled people to manage their condition and/or service (for instance through individualised budgets).

Health service commissioners and providers should:

- 3.3 Support increased employment of people who are disabled or have long-term health conditions in health services.¹⁵ This could help change NHS culture, especially if those at more senior levels are encouraged to be open about their experiences.

4. To meet people's health needs wherever they live and whatever social support they receive

Commissioners of health and social services should:

- 4.1 Ensure GPs do not charge, and residents are not asked to pay, for healthcare within residential care settings, whether as 'retainer' fees or under some other label. Regulators must ensure that charges are not passed on.
- 4.2 Ensure all citizens can access quality healthcare services in the setting in which they live. People living in care homes must have equal access to healthcare and people in psychiatric care must have access to trained physical healthcare professionals, not mental health staff alone.

Inspectorates of health and social services should:

- 4.3 Measure institutional provision against human rights and independent living criteria: residents' enjoyment of freedom, choice and control over the services they receive, respect, equality and dignity, including in access to healthcare and opportunities for healthier living.
- 4.4 Enforce minimum standards in nutrition and medication to ensure healthier lifestyles are encouraged and unnecessary and harmful use of medication to manage behaviour is reduced.

5. To deliver health services that support social inclusion of families

Governments should:

- 5.1 Base policy on long-term conditions on the principles of independent living, choice and control.
- 5.2 Incentivise movement of resources, from services that sustain dependence to services that support social inclusion.
- 5.3 Use individual budgets across Britain to better meet the needs of disabled people and their friends and families. This could have potential cost-benefits in the longer term, through reducing health crises and inappropriate or long-term hospital use, and through avoiding injuries.¹⁶

6. To meet the requirements of the DDA

Providers of health services should:

- 6.1 Meet their duties under the existing DDA to make reasonable adjustments, such as providing information in accessible forms. Done well, this can lead to citizens taking better care of their health; gaining access to services earlier, before health problems escalate to require more costly interventions; and having trust and confidence in services.

6.2 Offer people the option of recording their access needs on the patient record to ensure those needs are routinely met. This should be factored into developments in health records.

Commissioners of services should:

6.3 Commission advocacy services. Some people with learning disabilities need accessible information, support and advocacy to understand diagnoses and prescriptions. Other disabled people may need advocacy to support them in negotiating their choices. Meeting this access need could mean fewer expensive crises caused by misunderstandings of diagnosis or medication use.

6.4 Build disability access standards into all contracts with health providers, in the public, private or voluntary sector.

6.5 Identify and tackle patterns of health inequality in the community they serve, as required under the DED.¹⁷ Disabled people should not just be treated ‘the same’ as others but, in order to achieve equal outcomes, they should, when needed, be treated differently. The DED also requires disabled people’s involvement in the development of policy and practice.

Measuring change

1. To measure health outcomes of disabled people in mainstream targets and standards and to reduce inequalities through commissioning and targeting, governments should:
 - develop improved baseline data on disabled people’s health outcomes, including premature mortality from major diseases such as heart disease and cancer. They should track outcomes over time and report on them under the Secretary of State and First Minister Duty under the DED.
 - require achievement of health service standards to be broken down by disability where relevant (in particular, access to screening and core treatments, and improvements in the patient’s experience)
 - build the recommended categorisation of broad impairment group into the electronic health record.
2. Providers should:
 - improve recording of people’s impairment/long-term health condition status, so this can be matched against incidence of health problems, health outcomes (eg age of death) and access to key interventions (from screening to heart disease treatment).

3. Commissioners should collate the above data at local level.
4. Inspectorates should ensure that patient surveys regularly assess disabled people's experiences – including those in relation to dignity, respect, access to services, information, reasonable adjustments and level of support for social participation – broken-down by broad impairment group.
5. Inspection bodies should assess whether commissioners effectively analyse local need, including the physical health needs of disabled people and other under-served groups, and whether they use this data to commission services to close gaps of inequality for these groups. In Wales, regulators should assess whether local Health, social care and well-being strategies have been used effectively to address the health inequalities faced by disabled people.
6. All the above data on outcomes and standards should be reported to the Board of every NHS organisation to drive improvement. It should be collated by the inspectorates nationally and used to judge performance.
7. To measure transformation in culture and staff attitudes:
 - patient surveys and inspectorate reports should assess whether health service providers meet standards, including dignity and respect, and whether specific problems, like diagnostic overshadowing, reduce over time
 - governments should ensure that appraisal of health service professionals assesses respect for disabled people and understanding of disability equality.

8. To measure whether people's health needs are met wherever they live, and whatever social support they receive, inspectorates in health and social care should measure residential, nursing, secure hospitals, prisons and other facilities against standards, including effective health promotion and access to healthcare, to quality and outcome framework standards.
9. To measure how well health services support social inclusion of families:
 - governments should set standards for services for people with long-term conditions based on user-and carer-defined outcomes, including social participation
 - inspectorates should measure progress in meeting these standards.
10. To measure performance in meeting requirements of the DDA:
 - inspectorates should work with the Commission for Equality and Human Rights (CEHR) to report regularly on progress in the CEHR's State of the Nation report.
 - the Secretary of State for Health, Scottish Ministers and the Wales Assembly Government First Minister should report under DED requirements. Reporting should relate findings to other personal characteristics, such as gender, ethnicity, sexual orientation, religion and age.

Footnotes

- ¹ Department of Health (2005) 'Tackling health inequalities: Status report on the Programme for Action'.
- ² Disability Rights Commission (2006) 'Equal treatment: Closing the Gap, a formal investigation into health inequalities experienced by people with learning disabilities and/or mental health problems'.
- ³ The Family Resources Survey 2003–2004 suggests 45 per cent of people over the age of 65 have an impairment or 'limiting long-standing illness'. In the next 20 years, the number of people aged 85 and over is set to grow by two-thirds, compared to a 10 per cent growth in the overall population.
- ⁴ Welsh Assembly Government (2006) 'Fulfilled Lives, Supportive Communities: the Strategy for Social Services in Wales over the next decade': "In Wales 23 per cent of all adults report having a limiting long-term illness, compared to 18 per cent in England and 20 per cent in both Scotland and Northern Ireland. The proportion rises sharply in the older age groups. The trends suggest that by 2016 there will be a 12 per cent increase in the number of adults with at least one chronic condition and a 20 per cent increase in those aged 65 and over."

- ⁵ For example, a woman reporting breast cancer symptoms dismissed due to her mental health problem.
- ⁶ Disability Rights Commission (2006) Discussion paper on implications of investigation findings for other disabled people; Stonewall (2006).
- ⁷ Disability Rights Commission and Department of Health (2005) evaluation of 'You Can Make A Difference' initiative.
- ⁸ Around one in six care homes in England do not meet minimum standards for meals: Commission for Social Care Inspection (CSCI) (March 2006), 'Highlight of the day? Improving meals for older people in care homes'.
- ⁹ CSCI (2006) 'Handled with care?'; Care Standards Inspectorate Wales (2006) Annual Report.
- ¹⁰ See 'The Future: Who Cares?' Disability Rights Commission, Equal Opportunities Commission and Carers UK commissioned Ipsos-MORI survey (2006) for further information. There is also a 6:4 gender imbalance of women to men in providing care and support, limiting women's life chances, employment and pension opportunities.

- 11 Emerson, E. et al (2005) 'Adults with Learning Difficulties in England, 2003–2004', Health and Social Care Information Centre.
- 12 National Statistics Office 2003.
- 13 Specific targets may be required: for example to improve cervical screening of women with learning disabilities.
- 14 For guidance on monitoring please see www.drc-gb.org/health
- 15 There is evidence of barriers in the health service to the employment of disabled people: British Medical Association (2004) 'Career barriers in medicine: doctors' experiences'; Disability Rights Commission (2006) 'Interim report of a Formal Investigation into Fitness Standards in Teaching, Nursing and Social Work'.
- 16 The Audit Commission has estimated that £130 million could have been saved by health services if just visually impaired people received adequate adaptations to their homes, to avoid injury for example. This is just one group of disabled people.
- 17 This came into force from December 2006.

Copies of these documents, including alternative formats, are available to order from the Disability Rights Commission's Helpline: 08457 622 633
Textphone: 08457 622 644

They are also available online at: www.disabilityagenda.org

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