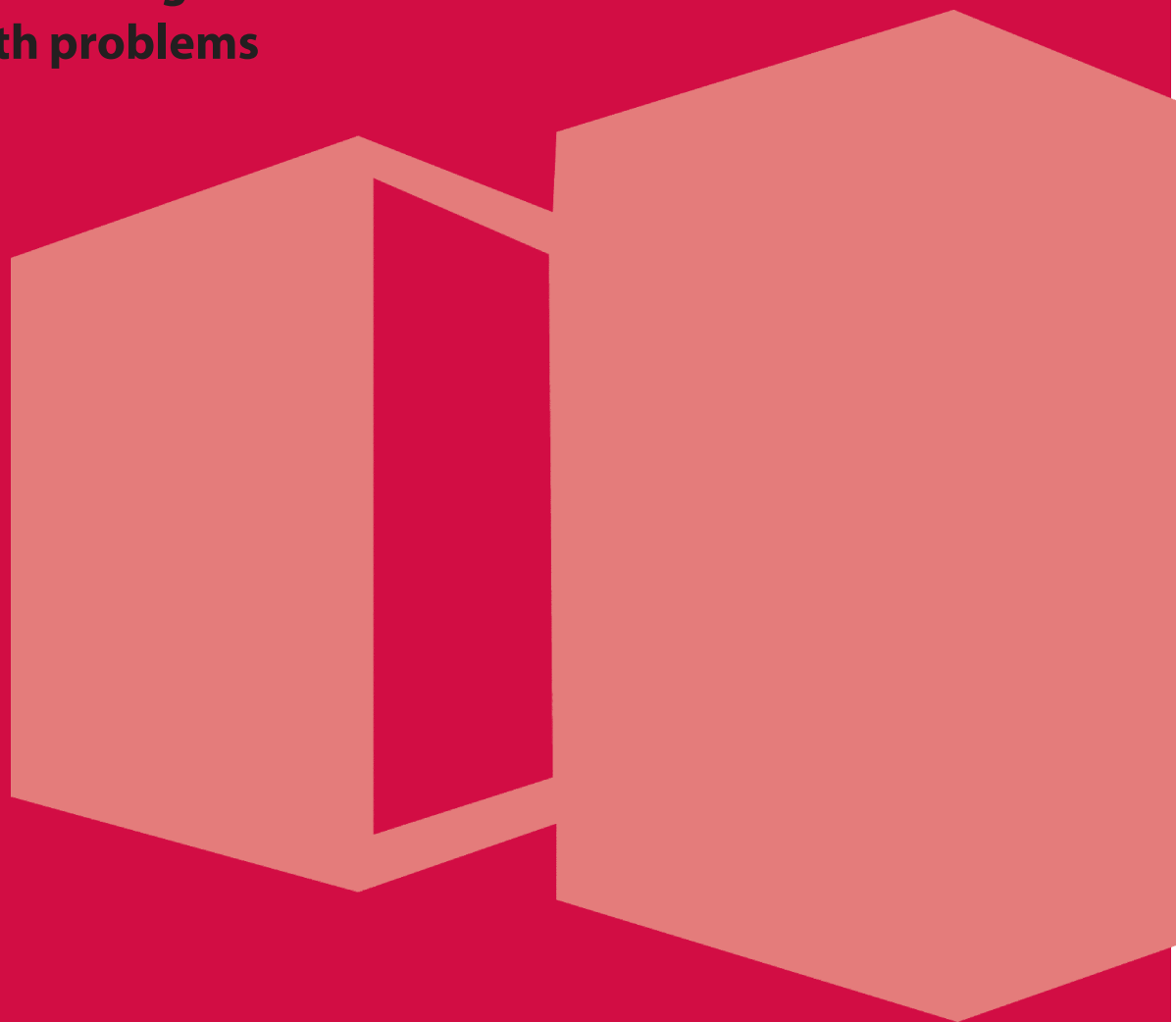


PART 1 OF THE DRC'S FORMAL INVESTIGATION REPORT

# Equal Treatment: Closing the Gap

**A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems**

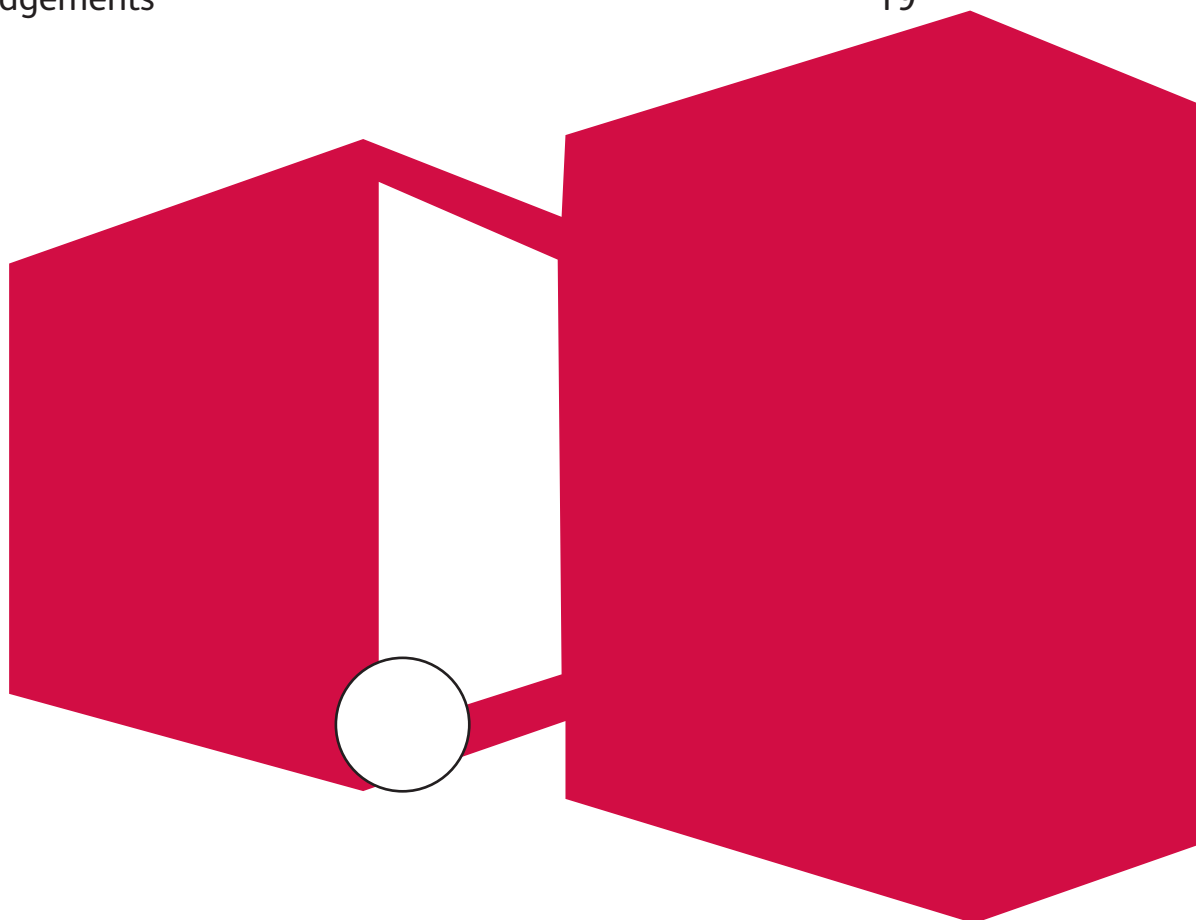


**Disability  
Rights  
Commission**



# Contents

<b>Foreword</b>	<b>1</b>
<b>Executive summary</b>	<b>3</b>
<b>1 Introduction</b>	<b>13</b>
The DRC and formal investigations	13
Purpose and scope of the formal investigation	15
Methodology	17
Formal investigation Inquiry Panel	19
Acknowledgements	19



Details of all Health Formal Investigation publications are listed on the back cover.

<b>2</b>	<b>The imperative for action</b>	<b>21</b>
	Health inequalities, access and disability equality	21
	Disability Equality Duty (DED)	24
	The absence of an effective policy response	27
	Taking forward our recommendations	31
<b>3</b>	<b>What's the problem? Ill health and early death</b>	<b>33</b>
	People with mental health problems	33
	People with learning disabilities	39
<b>4</b>	<b>The causes of health inequalities</b>	<b>41</b>
	Health inequalities and socio-economic factors	41
	The effects of medication	43
<b>5</b>	<b>The 'journey' through primary care: the experience of people with learning disabilities and/or mental health problems</b>	<b>45</b>
	Stage 1: Recognising health need	47
	Stage 2: Seeking and accessing primary care	51
	Stage 3: Checks, screening and health promotion support	65
	Stage 4: Diagnosis, treatment and support	69
	Stage 5: Seeking feedback and involvement	72
<b>6</b>	<b>Different people, different journeys</b>	<b>75</b>
	Children and young people	76
	Older people	78
	People from black and minority ethnic (BME) communities	79
	People with multiple impairments and challenges	83
	Family carers of adults with learning disabilities and/or mental health problems	85
<b>7</b>	<b>Conclusion, recommendations and action</b>	<b>87</b>
	<b>Appendix 1</b> Terms of reference	105
	<b>Appendix 2</b> Principal conclusions of the Inquiry Panel	106
	<b>Appendix 3</b> List of research reports for this investigation	109
	<b>Appendix 4</b> Members of the formal investigation Inquiry Panel	112
	<b>Appendix 5</b> Table of responsibilities for action	114
	Notes and references	115

# Foreword

Despite having spent most of my career working to redress inequalities experienced by disabled people I was shocked to learn the results of this formal investigation. It provides new evidence that people with learning disabilities and people with mental health problems are more likely to experience major illnesses, to develop them younger and die of them sooner than other citizens. They are less likely to get some of the evidence-based treatments and checks they need, and they face real barriers in accessing services. In the course of the investigation we sometimes encountered a complacent attitude that these excluded groups ‘just do’ die younger or ‘just won’t’ look after their health or attend appointments. These low expectations must be challenged.

1

I am enormously impressed by the innovative practice being developed in primary care services in pockets around England and Wales; and by the work of champions in mental health and learning disability policy and practice who have worked to get these issues addressed by mainstream primary care. The evidence reviews carried out for this investigation show there are models that can and do work. It is imperative that these become the norm across the health services.

Improvements in access for these groups of excluded citizens will drive up the patient experience for everyone. Improved early intervention will reduce unnecessary costs and ill health later. Planning now to reduce inequalities in health will mean health organisations meet their new duties under the Disability Equality Duty.

I am extremely grateful to the high level Inquiry Panel chaired by Dr David Wolfe with experts from general practice, other major health professions and people with learning disabilities and mental health problems, who drew on the new evidence to come up with powerful

recommendations and actions for specific organisations. The Inquiry Panel comments that the early deaths in these groups are ‘not acceptable’ and that it is ‘a great disappointment’ that primary care services have not taken action to improve access to these groups of disabled people, as has been required by the Disability Discrimination Act since 1999. Also, that in the absence of systematic national action to close gaps of inequality, service users ‘remain caught in a policy Catch 22 situation’ and that there are ‘no excuses at all’ for changes not to happen. I can only agree. The implementation of the Disability Equality Duty provides the impetus to remedy this neglect through a strategic and proactive approach to tackling the health inequalities described in this report.

There are also lessons for the disability sector: the Panel notes that historically generic disability equality and awareness training have been very weak on learning disability and mental health issues. We need to put that right. We can support and empower people with learning disabilities and/or mental health problems to expect and demand more from health services, through better information and choice.

If all the relevant organisations act concertedly on these recommendations, with strong leadership to drive change, we should find we look back in years to come on a scandal of health inequalities that, once revealed, were tackled. I hope that all involved will accept the challenge.

**Bert Massie CBE**

Chairman, Disability Rights Commission

# Executive summary

The acid test of a national health service is not whether it works for people who are generally healthy but whether it benefits those with the shortest life expectancy, the greatest problems accessing services and the biggest risk that poor health will stop them taking part in society. This investigation has revealed an inadequate response from the health services and governments in England and Wales to the major physical health inequalities experienced by some of the most socially excluded citizens: those with learning disabilities and/or mental health problems. This includes the one million people with learning disabilities, 200,000 people with schizophrenia or bipolar disorder and six million people with depression in England and Wales.

3

It identifies practical recommendations that could make a significant difference to reducing those inequalities and to meeting the present government's overall objectives, including to reduce premature mortality and deliver earlier, more cost-effective interventions.

A step change in the delivery of health services to these groups is needed. The Disability Equality Duty (DED), in force from December 2006, is designed to provide the impetus for the public sector to improve outcomes for disabled people. This investigation provides an invaluable resource for health organisations working to meet their new duty, not least by setting out a clear evidence base for proposed actions.

This investigation is unique internationally in bringing together three powerful sets of data to inform robust recommendations:

- New research – the most comprehensive study of primary care records and mental health issues in the world (eight million primary care records), coupled with Area Studies in four areas, extensive consultation with service users and providers and evidence reviews. This enabled us to undertake detailed exploration of health inequalities, barriers to services and potential solutions. The evidence and main recommendations are outlined in Chapter 7 of this report (and all the primary research is available at [www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation)).
- Written and oral evidence analysed by a high level Inquiry Panel, who generated recommendations designed to work practically in the newly configured national health services. The Inquiry Panel's full conclusions form Part 2 of this report and are available on the CD-ROM which accompanies it.
- Collation of existing evidence through literature review, available at [www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation)

## Findings

We found that in England and Wales, people with learning disabilities and people with mental health problems are much more likely than other citizens to have significant health risks and major health problems. For people with learning disabilities, these particularly include obesity and respiratory disease; for people with mental health problems, obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke.

This investigation has also made an internationally completely new finding – that people with schizophrenia are almost twice as likely to have bowel cancer as other citizens.<sup>1</sup>

Both groups are likely to die younger than other people. People with serious mental health problems are also more likely than others to get illnesses like strokes and coronary heart disease (CHD) before the age of 55. Once they have them they are less likely to survive for more than five years.

There are several reasons for inequalities, including social deprivation. However, the differences cannot be explained by social deprivation alone.

Despite these stark findings, the response from primary care services and from governments has been very patchy.

In primary care, these high risk groups are actually less likely to receive some of the expected, evidence-based checks and treatments than other patients and efforts to target their needs specifically are ad hoc.

- For people with mental health problems, although annual health checks have been incentivised through the General Practitioner (GP) contract, some standard treatments and tests – for example cholesterol checks and statins for people with heart disease, and spirometry for respiratory illness – are received less often than for others with heart disease or respiratory illness.
- For people with learning disabilities, some checks are given less often. People with learning disabilities who have diabetes have fewer measurements of their body mass index than others with diabetes and those with stroke have fewer blood pressure checks than others with a stroke. They have very low cervical and breast



cancer screening rates. We found that health checks identify significant unmet health needs amongst people with learning disabilities; and that when a second health check is given one year later further significant unmet need is identified, some of it serious. Despite this, regular health checks have not been introduced in England (although they are being introduced through incentives in Wales).

- Both people with learning disabilities and people with mental health problems experience ‘diagnostic overshadowing’, that is reports of physical ill health being viewed as part of the mental health problem or learning disability – and so not investigated or treated. This could mean that levels of ill health are even higher than our figures suggest.
- There is little or no evidence that information on the physical health needs of people with learning disabilities and/or mental health problems is either regularly collated or used locally by commissioners to develop improved services.
- There are some impressive examples of positive practice in primary care. There is also extensive evidence that primary care services are not generally making ‘reasonable adjustments’ – simple things like making appointments by email, providing treatment information in alternative formats or sending text or phone appointment reminders. These have been required by the Disability Discrimination Act since 1999.

At government level, these groups have not been systematically targeted by programmes to reduce health inequalities which have mainly focused on socially deprived areas. Whilst important, this alone does not meet the needs of people with learning disabilities and/or mental health problems, who will only attain more equal health outcomes through targeted attention in health improvement, promotion, access to services and equality of treatment.

To give one example, there are more obese people with learning disabilities and/or mental health problems than there are obese people in Birmingham and Coventry combined. To tackle the problem of obesity among people with learning disabilities and/or serious mental health problems would thus have a greater impact than to do so across these two cities. A national programme to tackle health inequalities in England would not ignore whole cities like Birmingham or Coventry and yet people with learning disabilities and/or mental health problems have, to date, been ignored in national health inequalities programmes.

Despite positive policy and practice developed by mental health and learning disability specialists, the lessons have not become part of mainstream health programmes or primary care delivery on the ground.

7

The evidence we have obtained from primary care records is startling. We are aware however that these records are sometimes incomplete and that some health needs, particularly among people with learning disabilities and/or mental health problems, may remain unidentified and unrecorded. If anything, the data we present may under-estimate the true level of physical health needs.

### **Ways forward and recommendations**

Governments in England and Wales should now set in motion measures to meet the health needs of these most excluded, high risk groups. This will help meet national targets to reduce health inequalities, to reduce premature death from cancer and coronary heart disease (CHD), to reduce smoking and obesity rates and to improve employment and social inclusion amongst disabled people.

Our evidence clearly indicates that implementing changes in primary care would be straightforward, inexpensive, would reduce ‘Did Not Attend’ rates, improve early intervention for high risk groups and improve standards of service for everyone.

This report sets out major recommendations for change (see Chapter 7). The top level recommendations are:

**1. Governments in England and Wales** should make closing these gaps of health inequality part of their Departmental objectives, at the highest level, and lead improvements in:

- Primary care access and health checks (through the GP contract, commissioning guidance and screening programmes).
- Equitable treatment, by spearheading health professional training at key career points, to tackle ‘diagnostic overshadowing’ and inequality.
- Health, by targeting these high risk groups in national health inequalities programmes.
- Expectations, by supporting a partnership of people with learning disabilities and/or mental health problems to spread knowledge on rights and how to negotiate for improved services.

Progress should be driven through performance management and inspection. It should be tracked by breaking down Public Service Agreement (PSA) targets in England and Health Gain Targets in Wales (like early death from CHD and cancer) by broad impairment group – so we know who is dying young from CHD or cancer, over time. The Secretary of State for Health in England and the First Minister in Wales should report on progress in tackling health inequalities as part of their Secretary of State Duty under the DED.

**2. Commissioners of services** (practice-based commissioners, primary care trusts, local health boards and local authorities) should analyse the physical health needs, experiences and views of people with learning disabilities and/or mental health problems in their area as part of their local strategic assessments of needs (in England) and health needs assessments in ‘health, social care and well-being’ strategies (in Wales). They should use this data directly to commission services to close gaps of inequality by:

- Identifying groups who may need outreach or new service models to ensure they get primary care, to at least the same standard required for everyone (for instance, people in residential and hospital provision receiving primary care to Quality and Outcomes Framework standards).
- Building robust disability access and quality standards into all contracts with providers, in the public, private and voluntary sectors.

Progress should be tracked by monitoring trends in morbidity, survival rates, diagnosis, condition management and patient experience.

Guidance is available at [www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation)

**3. Primary care providers** should improve equity of access and treatment for people with learning disabilities and/or mental health problems by:

- Providing the option of recording their access needs so they appear on patient records and can be easily identified and met. Providing a range of personalised adjustments including different appointment times and lengths, text or telephone appointment reminders, accessible appointment cards, telephone consultations and specific waiting arrangements can all help.

- Offering regular evidence-based health checks, and close monitoring of the physical effects of any psychiatric medication, and taking extra care to ensure they receive the health promotion, screening and physical treatment they require, as well as information and choice in relation to physical effects of psychiatric medication.
- Making direct contact with local disability groups and involving them in advising on improvements, for instance through delivering training to the whole primary care team so that everyone engages in improving systems.

Progress can be tracked by including people with learning disabilities and/or mental health problems and their organisations in patient and public involvement initiatives.

The DED provides an essential framework for taking these recommendations forward: by involving disabled people, collecting evidence, action planning and disability equality impact assessments. Guidance on the DED for health organisations is available at [www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation).

There are also vital roles for inspection, performance management and good practice organisations; and for specialist mental health and learning disability services.

Across all organisations it will be important to take a targeted approach to ensure that people with learning disabilities and/or mental health problems who do not have easy access to a GP or who experience exclusion on multiple grounds receive full and proper primary health care services, for example, people from some black and minority ethnic (BME) communities, older people, children and people with multiple impairments. For action points relating to these specific groups please see Chapter 7.

Implementing our recommendations will ensure existing resources are better targeted on the greatest needs. They will drive progress towards equal treatment, not only for people with learning disabilities and/or mental health problems – including people with autistic spectrum disorders – but also other disabled people.

If these recommendations are implemented the complacent attitudes we have encountered at times in this investigation – that people with learning disabilities or mental health problems ‘just do’ die younger, that they ‘just won’t’ look after their health or attend treatment – could become a matter of history.

The Disability Equality Duty provides an essential framework for taking this report's major recommendations for change forward: by involving disabled people, collecting evidence, action planning and disability equality impact assessments.



# Introduction

## **The DRC and formal investigations**

The Disability Rights Commission (DRC) is an independent body established in 2000 by Act of Parliament to stop discrimination and promote equality of opportunity for disabled people.

13

**Our goal is ‘a society where all disabled people can participate fully as equal citizens’.**

The DRC is empowered by the Disability Rights Commission Act 1999 to conduct a formal investigation for any purpose connected with the performance of our duties under section 2(1) of the Act.



Those duties are:

- To work towards the elimination of discrimination against disabled people.
- To promote the equalisation of opportunities for disabled people.
- To take such steps as we consider appropriate with a view to encouraging good practice in the treatment of disabled people.
- To keep under review the working of the Disability Discrimination Act 1995 and the Disability Rights Commission Act 1999.

On 10 December 2004, we announced our intention to conduct an investigation into the health inequalities experienced by people with learning disabilities and/or mental health problems in England and Wales. We called the investigation 'Equal Treatment: Closing the Gap'. The terms of reference for the investigation are set out in Appendix 1.

The Equal Treatment investigation has now been completed. This report presents our findings and recommendations and is published in accordance with paragraph 7(4) of Schedule 3 to the Disability Rights Commission Act 1999. Our principal recommendations are listed in Chapter 7 of this report.

## Purpose and scope of the formal investigation

We undertook this investigation because significant international research evidence showed that people with learning disabilities and/or mental health problems are more likely than other citizens to die young and to live with physical health problems, many of which are potentially preventable. We wanted to understand this experience in England and Wales so that we could recommend changes to primary care policy and practice that would help ‘close the gap’ in physical health inequalities.

We found that the experiences of people with learning disabilities and/or mental health problems in Wales and England were similar. Differences between the two countries became more apparent when we considered potential solutions, because of very different policies and organisational structures. Our recommendations and action points take account of these differences.

15

It is clear that barriers to equal access span both primary and secondary healthcare. However, for the purposes of this investigation, we deliberately chose to focus on how the primary care services provided by GPs and practice staff meet the physical health needs of people with learning disabilities and/or mental health problems. Primary care is the gateway to health services and we found less pre-existing evidence on primary than on secondary services. We drew on evidence of wider determinants of health as a backdrop and, whilst recognising the importance of dental and optical services, these were not the focus of our investigation.

We focused on the experiences of people with learning disabilities and/or mental health problems because of particular evidence internationally that health inequalities are pronounced for these groups, yet they may also be likely to miss out on some necessary health services. Disabled people with other impairments experience health inequalities too with some causes of inequalities being shared across impairment groups. We therefore expect the conclusions and recommendations of this investigation to be relevant beyond the particular needs of its immediate subject groups.

The terms ‘mental health problem’ and ‘learning disability’ cover a very wide range of impairments with varying degrees of severity. For the purposes of the investigation, we have looked at the experiences of people who, by virtue of their mental health problem or learning disability, would be likely to be protected from discrimination by the Disability Discrimination Act (DDA). Essentially, therefore, we focused on people with conditions which are long term and have a significant adverse effect on the person concerned. This would include, for example, people with severe depression or schizophrenia, and people with autistic spectrum disorders.

Different people encounter different barriers when accessing primary care, and the appropriate solutions vary accordingly. Nevertheless, there are solutions which, if implemented effectively, would improve the accessibility of primary care for disabled people irrespective of their particular impairment and, indeed, improve the patient experience for all.

## Methodology

This has been a wide-ranging investigation employing multiple methods to assess the existence and extent of inequalities in health and health service interventions experienced by people with learning disabilities and/or mental health problems as compared to other citizens. We approached the task from a range of perspectives in order to obtain a full and rounded picture of people's health, the healthcare they received, their views and experiences, and the views of practitioners, planners and third parties, including specialist professionals and family carers.

Following our initial review of the available evidence, which we published at the outset of the investigation, we consulted service users by means of a questionnaire on their positive and negative experiences of primary care as people with a mental health problem or learning disability. Over 1,000 people with learning disabilities and/or mental health problems responded. We also consulted practitioners and planners, including a discussion group with GPs. Focus groups were convened with groups of people whose voices we might not otherwise hear, such as deaf people with mental health problems and people from BME communities.

We then commissioned a series of analyses by QRESEARCH, at the University of Nottingham, of the health records of eight million primary care patients from 488 general practices in England and Wales held on the QRESEARCH database, in order to analyse quantitative evidence of ill health and health service interventions, amongst our target groups as compared to other citizens. We believe this to be the most comprehensive study of primary care records and mental health issues in the world.

Detailed Area Studies were then carried out in four localities across England and Wales by the Sainsbury Centre for Mental Health in conjunction with Mentality, Central England People First and the University of Lancaster. The studies examined local clinical data and explored, through interviews and focus groups, different perspectives on experiences of primary care. A study in Wales by the Welsh Centre for Learning Disabilities included further analysis of the results of health checks for people with learning disabilities, focus groups with service users and interviews with healthcare professionals and planners.

Two literature reviews (by the University of Manchester and the Sainsbury Centre for Mental Health) examined the effectiveness of interventions to improve physical health. An investigation Inquiry Panel took written and oral evidence from government departments and standard setting, professional and inspection agencies, as well as voluntary organisations and service users, in order to generate robust recommendations.

Throughout the course of the investigation, our work was informed by the views of a Consultation Group of disabled people, and by the Equal Treatment Investigation Reference Groups in England and Wales. The latter comprised a broad range of organisations and individuals including leading medical and nursing organisations, disability organisations, academics, good practice and inspection bodies, and health officials from England and Wales.

The strands of work which have been brought together to inform the conclusions of this investigation comprise an important body of new evidence about health inequalities. The principal findings are summarised in this report and the full range of evidence and the studies referred to above (listed in Appendix 3) are published at [www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation)

## Formal investigation Inquiry Panel

As a key component of this investigation we convened an Inquiry Panel of experts from general practice, other major health professions, people with learning disabilities and people with mental health problems. A full list of the Inquiry Panel's membership is in Appendix 4.

The Inquiry Panel was a lens through which to focus the results of our earlier evidence-gathering work. Its conclusions form Part 2 of the report of this investigation. The DRC endorses in full the 11 principal conclusions of the Inquiry Panel, listed in Appendix 2. We also endorse the comprehensive set of action points which the Panel has proposed as a framework for action. That framework is set out in Part 2, and summarised in Chapter 7 of this report.

We have also included tables, in Appendix 5, outlining the roles which we believe that governments and others concerned in the planning, commissioning and delivery of primary care services must play in implementing this framework.

## Acknowledgements

We have been assisted in this formal investigation by a great number of individuals and organisations, without whose efforts and expertise the completion of the investigation would have been impossible. We are indebted to all those who contributed to the project, including:

- Those who took the time to complete consultation questionnaires or to participate in our focus groups.
- The authors of the formal investigation research reports and studies listed in Appendix 3.

- Members of the investigation's Reference Groups and of our Consultation Group of disabled people.
- The DRC's Mental Health Action Group and Learning Disabilities Action Group, whose personal and professional experiences triggered our initial review of evidence which provided the basis for the investigation.
- Those who gave oral or written evidence to the investigation's Inquiry Panel.
- The members of the Inquiry Panel.

We would also like to express our gratitude to a number of individuals whose participation and expert guidance have been central to the investigation: Dr Philippa Russell, DRC Commissioner with lead responsibility for this formal investigation; Dr Alan Cohen, Director of Primary Care at the Sainsbury Centre for Mental Health; Professor Eric Emerson, Institute of Health Research at Lancaster University; and Dr Huw Lloyd, Provost of Welsh Office of Royal College of General Practitioners (RCGP) and Chair of RCGP's Mental Health Task Force, all of whom gave their time to sit as members of the DRC's Project Steering Board for the investigation; and Dr David Wolfe, barrister at Matrix Chambers, who chaired the investigation's Inquiry Panel.

Finally, the DRC wishes to pay tribute to all those members of its staff in England and Wales, whose efforts have been instrumental in the conduct of this formal investigation and in the delivery of its findings and recommendations. The core team comprised Joanna Owen (project manager), Jonathan Holbrook, Andrew Nocon, Laura Jerram, David Groves, Carly Wong, Sue Pratt, Katie Grant and Liz Sayce (director).

# 2

## The imperative for action

### Health inequalities, access and disability equality

Government objectives – to reduce premature death from cancer and coronary heart disease, to reduce smoking, to reduce health inequalities – cannot be met if the needs of those with the greatest risk of premature death are not addressed. Disability needs to be placed at the heart of policy on health inequalities.

People with learning disabilities and/or mental health problems are particularly likely to live in poverty. This in itself means their health will be worse than that of other people – even before taking account of specific health needs or disability-related barriers to accessing healthcare. Tackling poverty must therefore form a key part of any efforts to address health inequalities.



However, work to reduce inequalities, currently targeted mainly at geographical areas of high social deprivation, will not meet disabled people's specific health and access needs 'in passing', through general health promotion and treatment programmes. Indeed there is a real risk that new services, like walk-in centres or choice of GP in England, will exacerbate the inequalities they face: they could be left behind as others, better equipped, exercise their choices.

While programmes designed to tackle health inequalities have tended to ignore disability-related inequalities, programmes to support the health of people with learning disabilities and/or mental health problems have under-played the impact of poverty. There is a need to build bridges between policies on learning disability, mental health, health inequalities, poverty and social exclusion. This will entail making disability-related inequalities central to the Department of Health and Welsh Assembly Government's mainstream programmes on health inequalities.

‘I’ve just had a road to Damascus moment.  
I’ve often written and given presentations  
on health inequalities, focusing on race  
and poverty, but I’ve just understood  
what a rough deal these other groups are  
having too’

(Professor David Haslam – President Elect of the Royal College of General Practitioners, National Clinical Adviser to the Healthcare Commission and DRC Equal Treatment Investigation Inquiry Panel member)

Disability also needs to be placed at the heart of access initiatives. Primary care 'access' now relates to the whole experience of accessing primary care (from appointments being made by email to having services at more convenient places and times). However, walk-in centres at central railway stations or longer opening hours are not sufficient in relation to our target groups. There is a need proactively to take physical health information and services out to where the most excluded people are.

Similarly, disability 'access' is about much more than ramps and changes to the physical environment. It is about 'reasonable adjustments' for people with learning disabilities, mental health problems, sensory impairments and other disabled people. These 'reasonable adjustments' are not optional; they have been required under the DDA since 1999. Improved access – for instance, accessible information for someone with a learning disability, so she knows when to attend, or that she will need a repeat prescription – can reduce unnecessary costs, Did Not Attend rates and other avoidable health crises.

### **Disability Equality Duty (DED)**

The DED, in force from December 2006, requires all public services to actively promote disability equality, by involving disabled people and working towards equal outcomes. Progress in closing gaps of inequality will need to be tracked over time at local and national level. The duty applies to all areas of activity from employment to governance, procurement, service delivery, public consultation, research, partnership working and policy development.

The Duty requires public authorities to produce Disability Equality Schemes by December 2006. These schemes must indicate how progress in closing gaps of inequality will be tracked over time, for example by breaking down existing indicators and targets by disability group. They must set out plans for actions to close these gaps, and put in place processes for ensuring that disability equality considerations are given proper weight in future decisions. Finally, they will need to show how disabled people have been involved.

Health organisations will find the recommendations of this investigation an invaluable resource for the preparation of their schemes. One of the initial problems for them may be the difficulty in compiling an evidence base of the health outcomes of disabled people. This report for the first time provides this base for people with learning disabilities and/or mental health problems. Most of its recommendations (see Chapter 7) conform to particular aspects of the DED: action planning, evidence gathering, involvement and impact assessment. Guidance on the DED for health organisations is available at [www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation)

The Secretary of State for Health in England and First Minister in Wales will be required to produce a report every three years from December 2008, on progress towards disability equality in the health sector, and proposals to co-ordinate future work by public authorities. Our recommendations to the Government will assist with this task, and the Secretary of State and First Minister's report should review the implementation and effectiveness of this investigation's recommendations.

‘People with learning disabilities face particular health inequalities. The National Health Service (NHS) has historically not served such people well’

(‘Our Health, Our Care, Our Say’, White Paper)

## The absence of an effective policy response

### In England

‘It is remarkable how some targets will drive us to intense activity while others lie forgotten. It would be interesting to know how many GPs are reading this editorial work in practices where each of their learning disabled patients has had a health action plan composed for them with the help of a health action facilitator.’<sup>2</sup>

The White Paper ‘Valuing People’, launched with a foreword from Prime Minister Tony Blair in 1999, set positive targets to improve the health of people with learning disabilities. All were to be registered with a GP and to have a health action plan by set dates. Despite strenuous efforts by the Valuing People Support Team these targets were never built into mainstream primary care targets. There is no way of knowing whether they have been achieved or not, although it is generally thought that progress has been patchy.

The White Paper, ‘Our Health, Our Care, Our Say: a new direction for community services’, acknowledges frankly that:

‘People with learning disabilities face particular health inequalities. The National Health Service (NHS) has historically not served such people well.’

It goes on to state only that it will explore ways of delivering on an earlier commitment to introduce regular health checks (without committing to doing so in a set timescale).

The formal investigation Inquiry Panel notes that ‘Valuing People’ commits government to addressing health inequalities affecting people with learning disabilities; but the Health Inequalities Status

Report of 2005 makes only one reference to people with learning disabilities, which refers the reader straight back to 'Valuing People'. This is circular. Nowhere does the commitment move forward into imperatives or incentives that reach primary care commissioners.

There has effectively been no inclusion of the high risks to physical health amongst people with learning disabilities in mainstream targets or health policy.

In mental health policy too, there are some excellent developments. The Quality and Outcomes Framework (QOF) in the new GP contract includes measures to review the physical health of people with serious mental health problems. The need to address physical health inequalities is also included in the Mental Health National Service Framework, with a focus on reducing smoking rates and improving services for long term physical health conditions. However, these have not been translated into wider health policies like the primary care access initiative or relevant National Service Frameworks (NSF) like the NSF on diabetes. The Chief Nursing Officer's review of mental health nursing recommends that mental health nurses should promote the physical health and well-being of people with mental health problems. And the commitment in 'Choosing Health' to learn from eight pilots on improving physical healthcare for people with mental health problems and roll lessons out in Spearhead Primary Care Trusts (PCTs) is a helpful step. But these are not matched by national programmes to reduce physical health inequalities, tracked over time.

This failure to mainstream is repeated at local level. Research for this investigation found that the health needs of people with learning disabilities and/or mental health problems were often ‘off-loaded’ onto specialist services rather than addressed through regular primary care.<sup>3</sup>

The Inquiry Panel found that many organisations were willing to act – if others did. There has effectively been no one driving action through the system.

### In Wales

There have been important changes to the GP contract in Wales which provide incentives to general practices to provide regular health checks for people with learning disabilities, annual health reports for people with mental health problems (in addition to the existing health check for people with ‘severe mental illness’) and changes to services to make them more accessible to disabled people. The progress that these contractual arrangements represent and their impact on health inequalities, if taken up across the country, should not be underestimated. However, in Wales as in England there is still a lack of a coherent policy response at a national level.

The Welsh Assembly Government’s Learning Disability Strategy guidance ‘Service Principles and Service Responses’ (2004) acknowledges health inequalities faced by people with learning disabilities and provides very positive statements of principle for tackling them. However, this document lacks a robust action plan or rigorous enforcement mechanism and, issued as section 7 guidance to local authorities, it is less than forceful in relation to the health service. Without a National Service Framework (NSF) or Health Gain Target dedicated to learning disabilities, there appears to be a vacuum at a strategic level.



The Mental Health NSF in Wales does refer to the health inequalities faced by people with learning disabilities and/or mental health problems and makes welcome reference to the need to take on this investigation's recommendations. We appreciate that it is crucial to improve mental health services and promote mental health in Wales. However this should not detract from improving the physical health of people with mental health problems. This is clearly a challenge. For example, the National Public Health Service's 'Vulnerable Adults' team states that its key aim in relation to people with learning disabilities is to tackle health inequalities, but in relation to mental health it is mental health promotion.

Many health, social care and well-being strategies in Wales refer to learning disability and mental health services but very few make specific reference to improving the physical health of people with learning disabilities and/or mental health problems. At the time these strategies were drafted there was nothing to compel Local Health Boards and local authorities specifically to address the health inequalities faced by these groups.

The investigation has found excellent examples of innovative local projects in Wales, a number funded by Welsh Assembly Government programmes including 'The Health Inequalities Fund' and 'Equity Training and Advocacy Grants'. This illustrates a commitment to address the issues faced by these groups of disabled people, but without a clear policy framework it is likely to be harder to extract maximum national benefit from localised good practice.

‘Designed for Life’ (2005), the Welsh Assembly Government’s ten-year strategy and vision for the health service must benefit disabled as well as non-disabled people. The fact that ‘Designed for Life’ schedules a review of health inequalities strategy is very welcome. This will immediately highlight the absence of a comprehensive health inequalities strategy for Wales. Implementation of ‘Designed for Life’ represents an excellent vehicle for the Assembly Government and NHS Wales to develop such a strategy (paying due attention to disability-related health inequalities) and to provide national direction to drive changes through the system.

### Taking forward our recommendations

Inequalities in health have multiple causes; there is no single intervention that will ‘close the gaps’. We need a multi-faceted approach – but one which is nonetheless focused, to deliver results. The first, and central, conclusion of our Inquiry Panel process was that:

**All professionals and organisations with a role in the provision of primary care health services to people with learning disabilities and/or mental health problems must act now to tackle the inequalities in physical health and primary healthcare services they experience.**

We agree – everything we have discovered in the course of this investigation causes us to return to this one overarching conclusion.

We will reconvene the formal investigation Inquiry Panel one year on to assess progress in implementing the recommendations and embedding the new Disability Equality Duty in the health sectors in England and Wales. From 2007 onwards the new Commission for Equality and Human Rights will have the role of assessing progress in its 'State of the Nation' report on equality in Britain, across disability and other equalities dimensions, from race to sexual orientation. It will promote and enforce equalities legislation.

What follows is an analysis of our findings and recommendations.

# 3

## What's the problem? Ill health and early death

International evidence shows that people with learning disabilities or long-term mental health problems on average die 5 to 10 years younger than other citizens, often from preventable illnesses.<sup>4</sup>

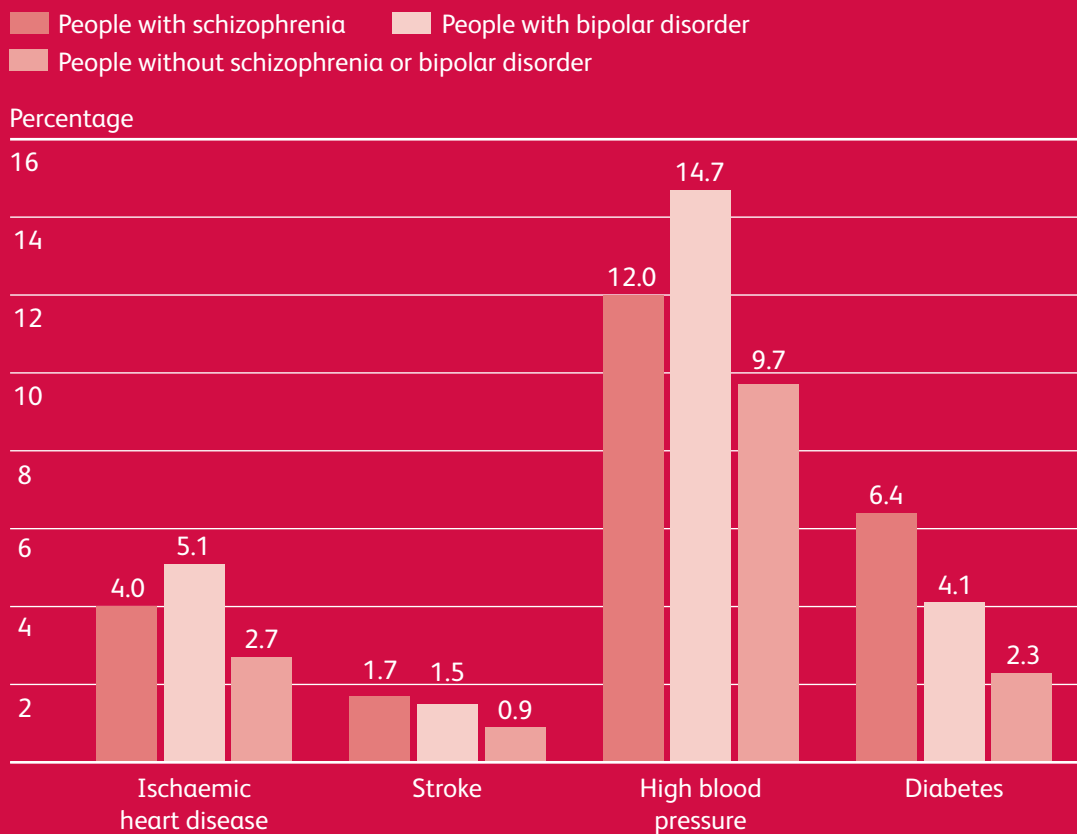
They also live with poorer physical health, which means people who are already exceptionally socially excluded – on every measure from education and employment to housing and social networks – often face the additional challenge of diabetes, heart disease or other long term physical illness. This makes it harder to participate socially and economically and harder to play an active, valued role in family and community.

### People with mental health problems

We commissioned the largest clinical data analysis of primary care and mental health records so far in the world. We also looked in more detail at primary care records in four areas in England and Wales (the 'Area Studies'). Both studies revealed very high rates of physical ill health.

The results of the national data analysis (which covered England and Wales) are shown in the following graph, which illustrates higher rates of ischaemic heart disease, stroke, high blood pressure and diabetes among people with schizophrenia or bipolar disorder compared with the rest of the population.<sup>5</sup>

### Prevalence of physical health conditions among people with schizophrenia or bipolar disorder



(Source: Hippiusley-Cox and Pringle 2005)

These figures are similar to those found internationally.

We also, however, looked at cancer and found:

- Women with schizophrenia are 42 % more likely to get breast cancer than other women.
- People with schizophrenia are 90 % more likely – ie nearly twice as likely – to get bowel cancer (the second most common cause of cancer death in Britain).<sup>6</sup>

This is a completely new finding internationally. It has significant implications for services and for targeting of the bowel cancer screening programme.

Not only are people with major mental health problems more likely than other citizens to develop some significant health problems, they are likely to develop them at a younger age. They are also likely, once they have them, to die faster than other citizens.

- 31 % of people with schizophrenia and CHD are diagnosed under 55, compared with 18 % of others with CHD.
- 41 % of those with schizophrenia and diabetes are diagnosed under the age of 55, compared with 30 % of others with diabetes.
- 21 % of those with schizophrenia who have a stroke are under 55, compared with 11 % of others who have a stroke.
- 23 % of those with schizophrenia and respiratory disease are diagnosed under the age of 55, compared with 17 % of others with respiratory disease.<sup>7</sup>

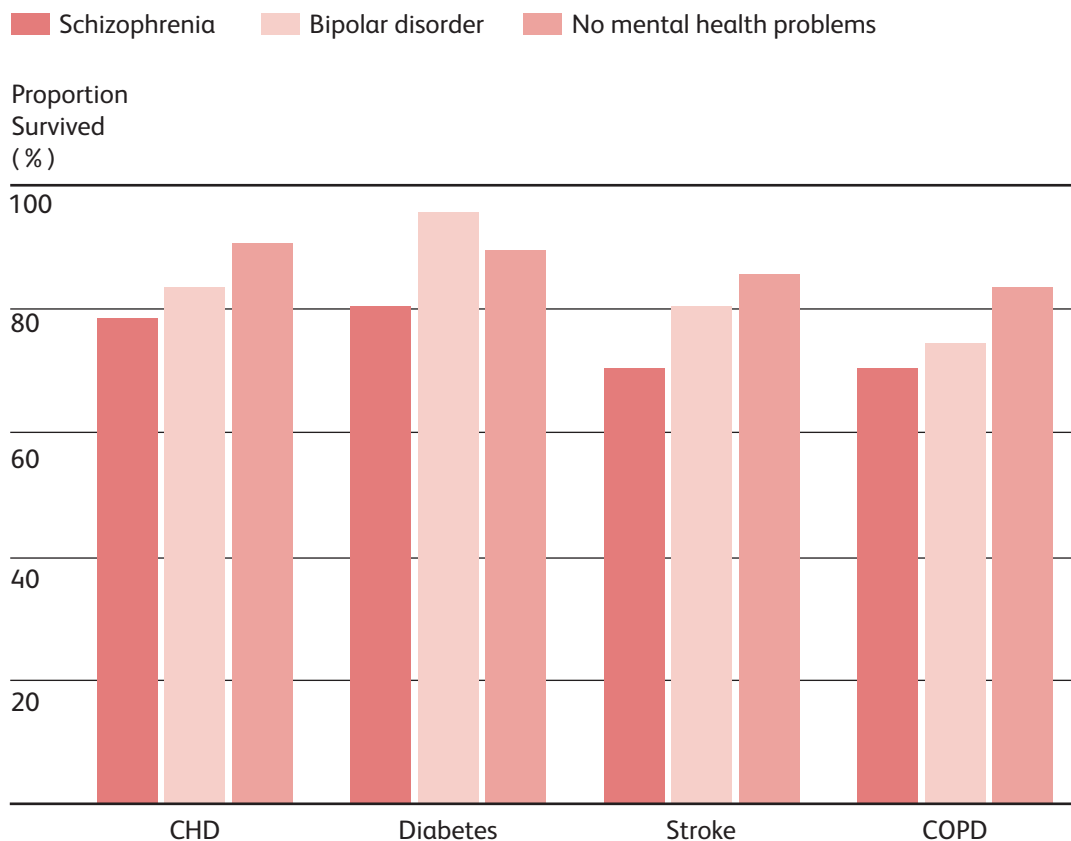
Our clinical data analysis concluded that:

‘Five-year survival rates show lower survival rates for patients with mental health problems for almost all key conditions’ (including stroke, diabetes, respiratory disease).<sup>8</sup>

After five years, and adjusting for age:

- 22 % of people with CHD who have schizophrenia have died, as have 15 % of people with bipolar disorder, compared with 8 % of people with no serious mental health problems.
- 19 % of people with diabetes who have schizophrenia have died, as have 4 % of people with bipolar disorder, compared with 9 % of people with no serious mental health problems.
- 28 % of people who have had a stroke and have schizophrenia have died, as have 19 % of people with bipolar disorder, compared with 12 % of people with no serious mental health problems.
- 28 % of people with respiratory disease, chronic obstructive pulmonary disorder (COPD), who have schizophrenia have died, as have 24 % of people with bipolar disorder, compared with 15 % of people with no serious mental health problems.

## Five-year survival rates for people with and without mental health problems



(Source: Hippisley-Cox and colleagues 2006)

In summary, someone with a major mental health problem is more likely to develop a significant illness like diabetes, CHD, stroke or respiratory disease than other citizens, more likely to develop it before 55, and – once they have it – more likely to die of it within five years. This combination of facts means that people with schizophrenia die younger than other citizens, even after accounting for suicide. The same is true for people with bipolar disorder in relation to CHD, stroke and respiratory disease. People with depression also have higher risks of key physical illnesses than other citizens. The impact on them, their families, friends and fellow service users should not be underestimated.



‘Far too many people affected by severe mental illness are dying in their 40s, 50s or even younger – far more than in the wider population. Whenever I hear of someone else dying young I always wonder what could have been done to prevent it’.

(Cliff Prior, Chief Executive Rethink and DRC Equal Treatment investigation Inquiry Panel Member)

## People with learning disabilities

The recording of learning disability in primary care is poor. Practices use a range of different codes to identify learning disability. Some are not exclusively associated with learning disability (as in the case of dyslexia), while terms for general educational or learning problems (eg special educational needs) that should capture learning disabilities also include a wide range of people with other needs. In addition, the proportion of people with learning disabilities who are known to services is estimated to be around one quarter of actual prevalence. For these reasons, it is difficult to be confident that any data will fully capture the needs of all people with learning disabilities.

With these provisos, our Area Studies did, nonetheless, attempt to obtain the best available evidence, which showed that:

- People with learning disabilities had higher rates of respiratory disease at 19.8 % than the remaining population (15.5 %).
- People with learning disabilities were more likely to be obese. The rate of obesity in all those with recorded body mass index (BMI) was 28.3 % in people with a learning disability, as compared to 20.4 % for the remaining population.<sup>9</sup>

For other health conditions such as diabetes, stroke and ischaemic heart disease, rates were lower amongst people with learning disabilities than in the remaining population. However, the figures in the analysis may be under-estimates: it is known that diabetes, for instance, is often under-diagnosed, primary care records may not accurately reflect the extent of health problems, and the health needs of people with learning disabilities often remain unidentified.

People with learning disabilities die younger than other citizens. They also have high rates of unmet health needs, which may contribute to early death.

Improved recording of learning disabilities in primary care is essential to achieving a better understanding of health status and outcomes; and in order to track progress over time. It is notable that we have no way of knowing whether the targets set in 'Valuing People' in England have been met – for instance, for people with learning disabilities to be registered with a GP and to have a health action plan. The latest revision to the GP contract which rewards practices having a register of people with a learning disability, provides a vital first step towards understanding and meeting their health needs. The introduction in 2006 of a Directed Enhanced Service in Wales, designed to encourage general practices to offer people with a learning disability a regular health check, represents the second step. But neither step ensures full identification of all people with a learning disability or monitoring of their healthcare or health outcomes.

# 4

## The causes of health inequalities

### Health inequalities and socio-economic factors

The causes of health inequalities are multiple and include deprivation, lifestyle, access to health assessments and treatments and side effects of anti-psychotic and mood stabiliser medication.<sup>10</sup> Social deprivation is a major contributory factor and people with learning disabilities and/or mental health problems are at very high risk of living in poverty. Our clinical data analyses reveal a clear correlation between having serious mental health problems and living in socially deprived areas. Recent data from Lancaster University suggest that around 20–33 % of the increased risk of poor health faced by children with learning disabilities in the UK can be attributed to their increased risk of exposure to socio-economic disadvantage.<sup>11</sup>

The health problems experienced by people with learning disabilities and/or mental health problems are shaped by broader social inequalities, and tackling poverty must form a key part of any efforts to address those problems. The impact of socio-

economic inequalities is starkly spelled out in a paper we commissioned for this investigation from Professor Hilary Graham,<sup>12</sup> which is available at [www.drc.gb.org/healthinvestigation](http://www.drc.gb.org/healthinvestigation)

Our own specific concern, however, has been to focus on those issues that are usually omitted from broader debates. Social deprivation alone does not account for the poorer health of people with learning disabilities and/or mental health problems. Our clinical data analysis demonstrates what the Equalities Review, chaired by Trevor Phillips, calls a ‘disability penalty’. It shows that, even after accounting for social deprivation, people with schizophrenia or bipolar disorder who have major physical health problems are more likely to die sooner than other citizens with those health problems.<sup>13</sup> Also, deprivation may be experienced differently by someone with a learning disability and/or mental health problem, because of compounding difficulties of social exclusion, discrimination and isolation. This is therefore rightly a matter of disability equality, to be addressed through the new Disability Equality Duty, which requires public sector organisations to work positively to promote equal outcomes for disabled people. Targeting at risk groups is also a matter of effective health policy, of concern to anyone seeking to redress inequalities in health.

Lack of health promotion, service access and equal treatment can reduce opportunities for health. The remainder of this report focuses on the role of primary health services.

## The effects of medication

The adverse effects of some medication also cause poor physical health.<sup>14</sup> Anti-psychotic drugs can lead to major weight gain and obesity, heart problems, low blood pressure, osteoporosis, seizures, Parkinsonism, tardive dyskinesia (involuntary movement disorders) and a range of other problems. In some cases, it can lead to sudden death. Anti-depressants are a risk factor for heart disease in particular.

Our Area Studies examined this issue in detail and noted that many people with mental health problems experienced weight gain, which they attributed to the psychiatric medication they were taking. They were aware that this made them more susceptible to other health problems.<sup>15</sup>

43

A respondent to our consultation questionnaire said that:

‘I am dismayed and surprised that my consultant psychiatrist has advised me to remain permanently on anti-depressants. I have been taking this drug for six years (with unpleasant physical side effects). He has never suggested that an alternative anti-depressant may be a better option. It is my experience that some psychiatrists are oblivious to the negative response in the elderly to certain drugs. I feel I am living in a permanent fog – simply existing and not living.’<sup>16</sup>

Studies have also estimated that between 20 % and 66 % of people with learning disabilities are given psychotropic medication. It is often used as a form of chemical restraint for behaviour management rather than to treat mental health problems. Its effectiveness in addressing challenging behaviour is questionable and there are strong arguments for stopping or reducing its use for many people.



# 5

## The ‘journey’ through primary care: the experience of people with learning disabilities and/or mental health problems

45

We wanted to see how the ‘journey’ through primary care impacted on the problems identified above and, in particular, how the high physical health needs of people with learning disabilities and/or mental health problems were being addressed. We found both examples of good practice and substantial evidence of barriers at every stage of the individual’s journey into and through primary care: from first recognising a health need, to seeking help, making an appointment, screening, health checks, health promotion, treatment and onward referrals. At some stages we found new, quantifiable evidence of unequal treatment.



**For instance:**

- **Although people with schizophrenia are more likely to have coronary heart disease, and to die of it younger, than other citizens, they are less likely to be prescribed the main evidence-based treatment: statins, which lower cholesterol. As the authors of the investigation's clinical data analyses put it:**

**'CHD patients with schizophrenia have higher risks (as reflected in the higher prevalence of smoking), but are less likely to be screened for raised cholesterol and less likely to be in treatment so there is a need to raise awareness among GPs and consider ways in which this shortfall can be addressed.'**<sup>17</sup>

- **Although people with learning disabilities are more likely to be obese than other citizens, when they get diabetes they are less likely than others with diabetes to have their weight (body mass index) checked.**<sup>18</sup>

In analysing the journey we have drawn on qualitative evidence from consultation questionnaires, Area Studies interviews and focus groups. This helps us understand the experience of primary care from the perspective of those who use the services, those who provide them and others who know about them (for instance, professionals in learning disability or mental health teams and family members).

There is no doubt that some people with learning disabilities and/or mental health problems receive an excellent service from primary care. However, over half of the 1,083 people with learning disabilities and/or mental health problems who responded to our consultation questionnaire reported problems, linked to their disability, when accessing decent primary care. The Area Studies reported some systemic problems requiring concerted action.

## Stages of the journey:

### **Stage 1: Recognising health need**

For health need to be met it has to be recognised: by the individuals themselves, by family or paid carers and others (like probation officers or voluntary sector staff) who may have day-to-day contact and act as 'gatekeepers' to services. Crucially, health need must also be recognised by primary care services so they can plan and commission services at both an individual and population level.

People with serious mental health problems have higher than average rates of diabetes, respiratory disease, heart disease and cancer. People with learning disabilities have higher rates of respiratory disease. We also found risk factors to be high. 61% of people with schizophrenia have a recent history of smoking (among those whose smoking status is recorded), as do 46 % of people with bipolar disorder. This compares with 33 % in the rest of the population. In addition 33 % of people with schizophrenia and 30 % of those with bipolar disorder are obese, compared with 21% in the rest of the population.<sup>19</sup>

We also found high levels of unmet health needs. Of 181 people with learning disabilities in Wales who received a health check, half (51%) had newly identified health needs and 9 % had serious health problems; subsequent checks over a year later identified further new health needs among 68 % of people, with serious problems in 11% .<sup>20</sup>

We found concerns expressed by practitioners that people with high levels of health needs often failed to seek help, for instance:

**‘Maintaining contact becomes a problem when an individual becomes increasingly unwell or has significant disability. Trying to be proactive for this vulnerable group can be almost impossible with our current resources.’<sup>21</sup>**

We heard from people with learning disabilities and/or mental health problems that it was difficult to attend because information and appointment systems were not accessible. Some people living in supported living arrangements reported that they had difficulty in making and keeping GP appointments because their support workers were not always available or willing to assist them, or able to provide transport at the appropriate times. This denied these people the right other citizens have – to choose when to go to the doctor.

Specialist learning disability and mental health service providers are important gatekeepers. Our review of the effectiveness of interventions to improve physical health of mental health service users highlighted the value of an integrated approach between primary and secondary care, and of good liaison between primary care and mental health professionals, in improving physical health.<sup>22</sup>

Examples of successful collaboration include:

- The North Warwickshire Primary Care Trust, where a graduate worker specialising in primary care is placed with an assertive outreach team and works with primary care practitioners to improve access to smoking cessation, better drug information and choice. People with mental health problems said this scheme made them feel more able to attend GP appointments and access physical health services and as a result they had managed to change their lifestyles.
- In Rotherham, community learning disability nurses supported people with learning disabilities to share health promotion messages about healthy hearts with their peers (the ‘Healthy Hearts’ project).
- In Birmingham, learning disability practitioners are involved in mainstream Primary Care Trust groups to discuss implementation of the National Service Frameworks.

- In the London Borough of Barnet, learning disability staff are involved in PCT commissioning, health development, clinical governance, and locality management.
- In Wrexham, the ‘Hearts and Minds’ project aims to improve access to screening, health promotion and healthy living for people with learning disabilities and/or mental health problems, through inter-agency work. Its work has included funding the provision of gym facilities in a psychiatric hospital.
- In Powys, the ‘Healthy Friendships’ project, run by a range of voluntary and statutory organisations, provides advocacy and befriending to support people with mental health problems attending medical appointments and participating in leisure activities.

Practices are more likely to have developed databases of patients with mental health problems than learning disabilities, because the GP contract offered financial incentives to create databases of people with mental health problems before it did so for people with learning disabilities (in 2006). These databases have huge potential for commissioners who need to analyse local health needs in order to design locally appropriate services. However, use of this data at practice or Primary Care Trust/Local Health Board level as an aid to commissioning services was not in evidence.

In Wales, where government has decided to incentivise annual health checks for people with learning disabilities, we hope that information gathered will be used effectively – for monitoring take-up of the check and as a source of data on health interventions and outcomes.

These findings suggest a need to strengthen planning and commissioning in relation to physical health and to improve knowledge in service users, family members and gatekeepers.

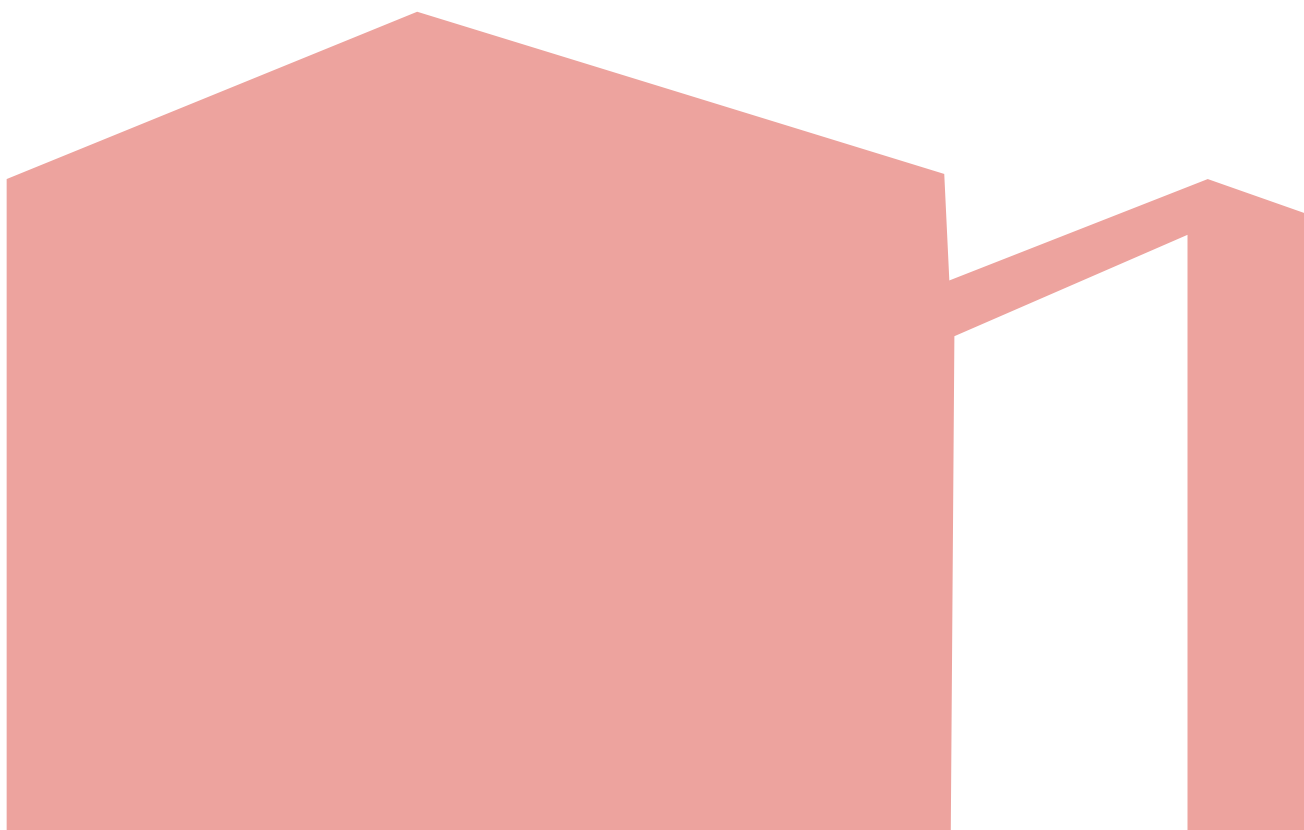
## Stage 2: Seeking and accessing primary care

### Being registered with a GP

Our investigation identified a small number of people living in the community who are not registered with a GP at all. Whilst numbers seem relatively small, the problems for the individuals concerned are considerable. A common theme was the impossibility of ‘clearing your name’ if removed from a GP’s list following allegations of being difficult, overly demanding or aggressive. People with learning disabilities and/or mental health problems tended to view these allegations as born of prejudice, on grounds of disability or race or as victimisation, following complaints made. For instance, respondents to our consultation stated:

51

‘I believe allegations have been exaggerated to say I was violent, and although I have police witnesses prepared to state I was not, I cannot defend myself from these allegations as I have not been informed in writing of the exact allegations against me, despite numerous requests.’<sup>23</sup>



‘My doctor struck me off her list last week because she sent a letter saying I was upsetting her staff. I try to put my points across clearly but none of them listen to me... She told me “you people are always the same” – she is Asian and I am an African Caribbean male.’<sup>24</sup>

The Parliamentary and Health Service Ombudsman in England also provided evidence to the investigation of a person who was unfairly removed from a GP’s list and our Area Studies gave the example of someone who was labelled a violent patient after refusing to tell a receptionist what his problem was, and why he needed to see a doctor. After this he and his partner were struck off and had great difficulty getting treatment such as asthma medication.

A vicious circle can occur whereby the individual becomes frustrated at being viewed as difficult and denied a service. This frustration further confirms the GP’s view that this is a ‘difficult patient’. This suggests a need to ensure decisions on removal from a GP’s list are free of prejudice and stereotyping – and follow principles of natural justice by giving people reasons and allowing appeals. Otherwise some people with significant health needs may end up without any general practice support, and with a deep mistrust of services.

## Trust or fear

Trust in services is important but variable. Some people have huge confidence and trust in primary care staff. However, where they lack confidence, this can impact on their preparedness to seek help. For instance:

‘The effect is that I avoid contact now... When I do attempt contact, usually in real desperate need and naively trying to trust them, I am disappointed.’<sup>25</sup>

Fear and mistrust can work in both directions. As the authors of the Area Studies carried out for this investigation put it:

‘The subtext from the interviews with primary care staff and practitioners was a mix of fear, anxiety and some impatience combined with paternalism and kindness. Even though some of the interviews described the provision of awareness training in both mental health and learning disability, there was still a sense that patients from these groups were like time bombs ready to go off at any moment.’<sup>26</sup>



A respondent to our consultation with practitioners said:

‘I have to say that my colleagues speak about the residents with fear and ignorance and will do their best to avoid visiting people with learning disabilities if I am not on duty.’ (learning disability nurse)<sup>27</sup>

Fear and anxiety may simply reflect the fear of people who are ‘different’ that occurs across society. It is not helped by a lack of adequate training for many primary care staff. For instance:

‘I personally do not feel that I have had adequate training in providing care for people with mental health problems. I only qualified three years ago and I had a grand total of seven weeks working on an acute ward. I am a district nurse and many of my patients have mental health problems. I do my best to liaise with CPNs (community psychiatric nurses) but I feel ill-equipped to care for them.’<sup>28</sup>

Our evidence suggests that service users can sense the fear and anxiety and be very hurt by it. For instance:

'I hate going to see him, it makes me so anxious because of that awful wariness that he seems to have, as if I am a leper and might do something unexpected at any minute. My knee just seems to be crumbling over the past year and when I finally went to see him he couldn't hide the discomfort he felt at having to examine my knee. I wished I could have just assessed it myself to not have that look. Everything always comes back to me being mental/anxious and I felt such a fool when I left the surgery... It just hurts to see how people are so wary.'<sup>29</sup>

Given the mistrust on the part of some service users, opportunities for staff to understand first hand the experiences of people with learning disabilities and/or mental health problems are important. Effective attitude change is fostered by personal contact, as long as it is on equal terms.<sup>30</sup> Increased understanding is therefore likely to be most effectively delivered through patient involvement initiatives that bring practitioners and service users together and by training led and delivered by people with learning disabilities and/or mental health problems.

## Primary care in residential, nursing and inpatient psychiatric settings

In residential and nursing homes, the costs of contracting with a GP are sometimes passed on to residents. We heard various viewpoints on the patchy application and legality of ‘retainer fees’ (the fee paid to GPs – indirectly – by residents). Organisations responsible for commissioning residential care need to ensure that GPs do not make, and residents are not asked to pay, charges (whether as ‘retainer fees’ or under some other label) for services which, for everyone else, are free.

Good practice in providing primary physical healthcare in residential and inpatient settings exists. In at least one Local Health Board area in Wales, a GP and pharmacist are contracted to visit nursing homes to undertake health checks and check people’s medication. Some psychiatric hospitals offer ‘inreach’ primary care services, commissioned by PCTs. One such service identified a range of physical health problems, almost all patients received health promotion advice and one in five needed referral to other specialist services.<sup>31</sup> However, demand so exceeded capacity that access to the service had to be restricted. Our Area Studies reported that in one medium-secure unit, all residents were registered with a GP. But in psychiatric hospitals generally, psychiatrists and psychiatric nurses are the first port of call for physical health problems, without the same levels of training and expertise as primary care staff. This constitutes unequal treatment.

## Receptionists

Receptionists are of enormous significance in the primary care experience, and featured prominently in the evidence we received. Some receptionists are excellent. Others, however, are not. This is not just a matter of poor reception practice generally: it is a very specific issue faced by people with learning disabilities and/or mental health problems. The Area Studies reported that:

‘Those we talked to often felt there was a lack of understanding among reception staff about their needs due to their learning disabilities and/or mental health problems or the challenges they faced as a carer... People with mental health problems felt that reception staff often didn’t understand their condition and the effect that it had on their lives and functioning. They felt these receptionists didn’t take this into account when insisting that people phone early in the morning to book appointments or when they booked individuals into early consultations.’<sup>32</sup>

## Making appointments

Our Area Studies reported that ‘the process of making appointments was a frustrating experience for most of the people we talked to’, often for reasons relating directly to the impairment. For example, the requirement to book appointments in advance was difficult for people who found it challenging to organise. Also:

‘It is difficult to make an appointment because you have to be good on the phone and that is too hard because people always talk too fast on the phone and you can’t think quick enough to answer them.’<sup>33</sup>

Making adjustments to appointment systems is possible and often fairly straightforward. Many practices have built in flexibility to accommodate people with different needs. The Area Studies cite an example of a practice where the doctor or nurse makes the next appointment at the end of the patient consultation for someone with a learning disability, rather than the appointment having to be made via a receptionist.

Some people with learning disabilities said they did not seek appointments even when ill because it was too difficult. But others we spoke to told us about changes that would make appointments easier – eg making appointments by email or fax. None of these particular suggestions are difficult to arrange and would be likely to be required by law as ‘reasonable adjustments’.

## Information

The lack of information in accessible formats and Easy Read text can be a fundamental barrier to primary care. If a person with learning disabilities is sent a letter inviting them for a standard screening appointment, the letter may well be useless if they have no support worker or family member on hand to read it to them.

Inaccessible information in surgery waiting rooms is equally useless. The Area Studies found that in many waiting rooms ‘the writing in leaflets was often small, the language complicated and there were rarely illustrative drawings or photographs that can aid understanding of such information by people with learning disabilities’.

Producing information in accessible formats for people with learning disabilities is not an optional extra. The DDA makes it an obligation for providers of primary care services.

## Waiting rooms

We found that surgery waiting rooms can in themselves create barriers to primary care. Research for the investigation highlighted the following experience: ‘One woman who had three sons with autism spoke of how long waits in the waiting room could lead to her children becoming hyperactive and difficult to control. This resulted in her children becoming very distracted and challenging to communicate with once in the consultation room with the doctor. This same mother spoke of how the doctor at this surgery used to call her sons “the little bastards” due to their behaviour at the surgery. Whilst this woman felt hugely insulted by this comment she never felt able to confront the doctor about it.’<sup>34</sup>

Providing quiet side rooms, offering first appointments or seeing people immediately if they cannot wait are all examples of simple and imaginative approaches introduced by some practices. One respondent to our consultation who was not able to wait in waiting rooms told us of an arrangement she had whereby she would wait in her car until the doctor was free. The receptionist would then call her mobile to let her know she could come in.

Making reasonable adjustments to waiting arrangements are also required by the DDA.

### The views of practitioners

It was remarkable from our evidence that many practitioners did not realise or acknowledge that such significant barriers to accessing their services existed. Whilst some practices are taking great strides to improve access arrangements, many do not seem to understand the need. For instance:

‘Some practice staff expressed bewilderment as to why there should be any issues for people with learning disabilities and/or mental health problems getting their needs understood. This view came from staff who are doing their best to be kind and considerate. However it could create problems for people trying to make an appointment or getting their needs met once they are attending for an appointment.’<sup>35</sup>

In a similar fashion, practitioners responding to our consultation often noted that they treated everyone ‘the same’. For instance:

‘As a practice we do not discriminate, any patient is welcome to use the practice services in the normal way.’<sup>36</sup>

This suggests that practitioners do not generally understand that:

- Achieving equal outcomes often means needing to treat people differently – by making adjustments.
- The DDA has, since 1999, required all service providers – including primary care practitioners – to make reasonable adjustments. As the formal investigation Inquiry Panel put it, ‘there is no excuse at all for the changes not to happen’.

### Some practitioners attributing barriers solely to individual impairments

When practitioners interviewed for the purposes of our Area Studies, or responding to our consultation questionnaire mentioned access difficulties, they often attributed them to the individual’s impairment itself ie ‘diagnostic overshadowing’. Some practitioners had taken action to make access easier by, for instance, holding drop-in sessions with no appointment needed or arranging regular health checks. But others simply did not seem to have made the jump from seeing the access problem as intrinsic to the person (part of their chaotic lifestyle, or inability to read the 24 hour clock) to seeing access as the responsibility of the service provider. Similarly, providers noted people were not taking treatments prescribed – without making the jump to considering why and what might be done about it:



‘In almost all interviews with primary care staff we heard about patients from these groups who don’t follow advice as given, don’t attend for appointments and who can’t cope with the implications of the advice they have been given. There did not seem to be any strategies in place to support these groups to follow any advice or guidance they might have been given.’<sup>37</sup>

This failure to make adjustments so that services are accessible or to develop strategies to provide inclusive primary healthcare services is a waste of resources. Inaccessible services lead to missed appointments and medication not being taken.

A recent evaluation of targeted health sector information materials on the DDA duties showed that health service managers saw access almost entirely in terms of physical access: eg ramps and lifts. The message that access arrangements are essential to meet the requirements of disabled people, including people with learning disabilities and/or mental health problems, has not yet penetrated primary care. ‘Access’ in a primary care context is understood as seeing a GP within 48 hours or, if disability is considered, in terms of wheelchair users being able to get through the door.

In Wales, Disability Access Criteria have been introduced into the GP contract – so that participating general medical practices will be incentivised to show that they are making their services more accessible to disabled people. This is welcome recognition, in Wales at least, that accessibility means more to disabled people than seeing your GP quickly. It is to be hoped that greater expectations will encourage general practices to deliver more accessible services year on year.

There is a significant difference between the view primary care practitioners have about the effectiveness of their services and the view of disabled people that fundamental improvements are needed. Our Area Studies expressed this difference as follows:

‘There is a clear-cut perception gap between primary care practitioners and staff and not only people with learning disabilities and/or mental health problems who use services, but also a range of key stakeholders in primary, secondary and voluntary sectors. The former have a sense from their individual interactions with their patients that they are providing as good a service as possible, but the latter think that services could be much improved, even allowing for multiple demands on primary care.’<sup>38</sup>

This evidence highlights the need to ensure registration in practice, to take measures to influence staff understanding and attitudes, and to increase ease of access to services.

Some practitioners had taken action to make access easier by, for instance, holding drop-in sessions with no appointment needed or arranging regular health checks. But others simply did not seem to have made the jump from seeing the access problem as intrinsic to the person (part of their chaotic lifestyle, or inability to read the 24 hour clock) to seeing access as the responsibility of the service provider.

### Stage 3: Checks, screening and health promotion support

The research carried out for this investigation revealed a complex picture of healthcare provision in relation to checks, screening and health promotion support:

#### Standard tests

- People with serious mental health problems generally had as many standard tests (relating, for instance, to blood pressure, cholesterol, urine analysis and weight) as the rest of the population.<sup>39</sup>
- However, the Area Studies data showed that people with learning disabilities who did not have a previously identified health problem were less likely to receive such tests.<sup>40</sup>
- The clinical data analysis carried out for our investigation found the uptake of cervical screening to be lower for women with schizophrenia (63 %) than for those without serious mental health problems (73 %).<sup>41</sup>
- For women with learning disabilities, cervical screening uptake rates were much lower – variously estimated at 13 % and 47 %, as compared with 84 – 89 % in the general population.<sup>42,43</sup>  
The reasons for the variation among women with learning disabilities are not known but may be linked to small sample sizes and the less reliable estimates which they produce.

## Annual or regular health checks

Health checks for people with severe mental health problems have been incorporated into the systems of the majority of primary care practices thanks to GP contract financial incentives. An analysis of data from the first year of the contract, carried out as part of this investigation, showed that 76 % of practices reported having provided health checks to at least 90 % of their patients with severe mental health problems (who had agreed to be on a register). We do not know the quality and outcomes of these health checks.

It will be important for this to be audited, particularly given evidence that disabled people are less likely to get some important treatments for problems like heart disease than other citizens.

Health checks for people with learning disabilities are not incentivised in English GP contracts. But progress on health checks in Wales is more impressive and, as of April 2006, there will be a financial incentive for general practices to offer regular health checks to people with learning disabilities. This is an addition to the standard contract, in the form of a Directed Enhanced Service. Practices have to compile their own registers of people with learning disabilities known to social services, invite them for checks, and carry out the check using a standard format. Extra funding has been provided by the Welsh Assembly Government. Our review of the effectiveness of interventions for people with learning disabilities noted that such checks are an effective way of picking up physical health problems.<sup>44</sup>

To ensure the best chance of physical well-being for people with learning disabilities and/or mental health problems, the need for health checks arises at key points, not just annually or regularly. For example, health checks based on evidence about health needs, carried out by appropriately trained staff on hospital admission, or by pharmacists in relation to medication changes, would have the likely effect of cutting down on inappropriate prescriptions that may exacerbate underlying conditions or interact with other medication. Ensuring when people are first seen by a Community Learning Disability Team or Community Mental Health Team that the individual can register with a GP and access a health check could be made routine through health action plans (for people with learning disabilities) and the Care Programme Approach (for people with mental health problems). A check at the point of leaving hospital or prison can also be useful.

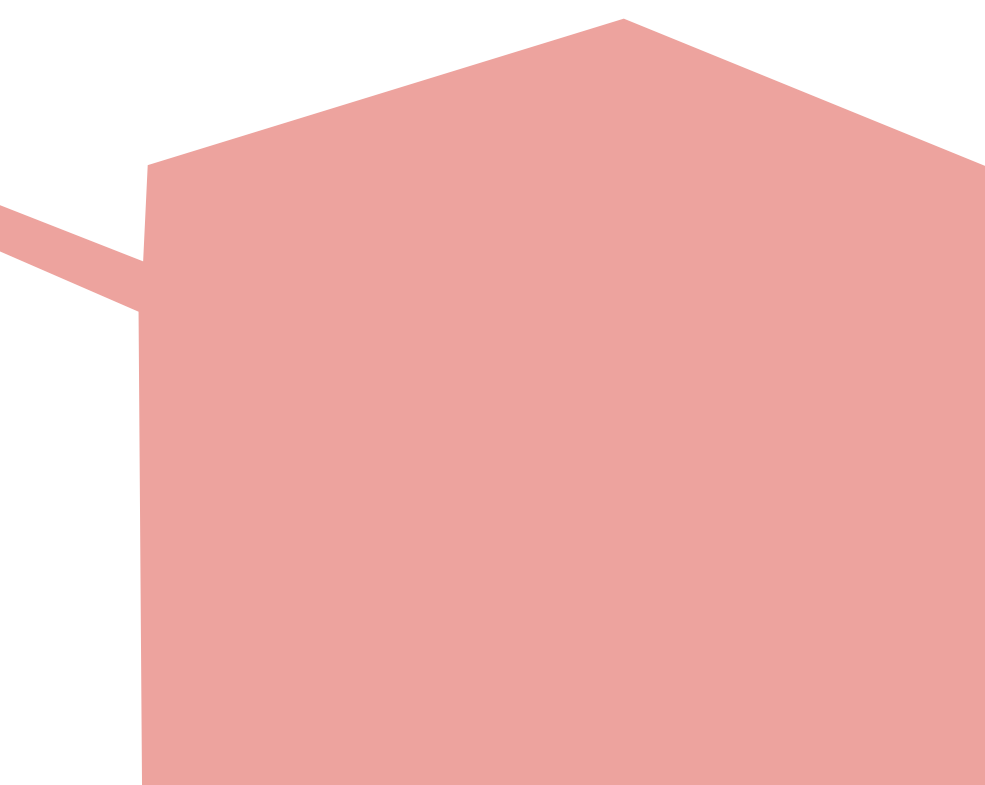
### Health promotion

The extent of health promotion available to people with learning disabilities and/or mental health problems is very variable. While clinical data indicate that obese people with schizophrenia or bipolar disorder received a similar amount of dietary advice to the rest of the population, those with depression received less – as did the obese people with learning disabilities whose records were examined in the Area Studies. More people with serious mental health problems were recorded as receiving smoking advice and smoking cessation medication as compared with the general population, but rates of cessation treatments were low.

However, only a minority of the people who were interviewed in the Area Studies said they had received advice on health promotion or been offered an intervention. This corresponds with the views of some practitioners who responded to our consultation questionnaire and expressed doubt about the value of smoking cessation advice for people with mental health problems. This lack of enthusiasm is likely to translate into health promotion being near the bottom of the priority lists in consultations.

The review of the effectiveness of interventions for people with mental health problems notes that smoking cessation does work for people with mental health problems.<sup>45</sup> The evidence also indicates that structured approaches to weight management are effective in improving the health of people with learning disabilities and/or mental health problems.

This suggests a need to target evidence-based health promotion and support at those at greatest risk to raise expectations.



## Stage 4: Diagnosis, treatment and support

### ‘Diagnostic overshadowing’

Many of the people who took part in our consultation referred to problems in communication with healthcare staff. This could be a failure by staff to listen or understand and a tendency to attribute health problems to a person’s learning disability and/or mental health problem. This tendency, known as ‘diagnostic overshadowing’ was reported to us particularly by people with mental health problems. However, people with learning disabilities and their families also reported that when they told health professionals about changes in their physical well-being, they were sometimes explained as behavioural but turned out to be caused by pain or a significant physical illness.

69

Some staff do not speak directly to the person making the consultation, make no attempt to use alternative ways of communicating where communication is difficult, and do not check if their understanding of symptoms is correct.

Diagnostic overshadowing also impacts on trust and can mean that people may not make or attend appointments.

‘It has got to the stage where I avoid the doctor when I am ill as there seems no point.’<sup>46</sup>



Our clinical data analysis found that people with schizophrenia were less likely to receive a diagnosis of chronic obstructive pulmonary disorder (COPD) on the basis of spirometry – the standard recommended method to diagnose lung problems.<sup>47</sup> This is worrying. It may mean that other health problems are being missed through practitioners not using standard procedures.

### Rates of interventions once physical health needs have been identified

Even where specific physical health conditions have been identified, the care that people receive is sometimes poorer than for the general population. According to our clinical data analysis, people with schizophrenia and heart disease have fewer blood pressure or cholesterol tests than people with heart disease but without serious mental health problems (86 % and 68 %, compared with 92 % and 80 %).<sup>48</sup> And people with schizophrenia who have had a stroke have fewer cholesterol tests than other people with a stroke (48 %, compared with 63 %).<sup>49</sup> The Area Studies found that people with learning disabilities and diabetes have fewer BMI measurements than other people with diabetes (78 %, compared with 95 %), and those with a stroke have fewer blood pressure checks than others with a stroke (78 %, compared with 99 %).<sup>50</sup>

On the positive side, our clinical data analysis also found that people with schizophrenia and bipolar disorder do not experience any difference in investigations following postmenopausal or rectal bleeding, both of which can be symptoms of cancer as well as of non-malignant conditions.<sup>51</sup> And records of lung function and inhaler technique checks indicate no significant difference for people with serious mental health problems who have respiratory disease.<sup>52</sup> However, 63 % of people with schizophrenia who have had a stroke are on aspirin (either prescribed or over the counter) compared with 68 % of other people who have had a stroke.<sup>53</sup> 66 % of people with schizophrenia who have coronary heart disease (CHD) are likely to be prescribed statins to reduce lipids (fats) in the blood, compared with 81 % in the case of other people with CHD.<sup>54</sup> These facts were recorded during the first year of the new GP contract, during which 76 % of practices reported that they were carrying out health checks for 90 % of their patients with a serious mental health problem. The checks in their current form do not appear to result in the expected interventions in relation to need.

### Why fewer interventions?

It is difficult to pinpoint reasons for there being fewer interventions even when physical health needs are diagnosed. It may be due to diagnostic overshadowing; or because disabled people press less hard for further interventions than other patients; or because their health is accorded less value and priority than other patients. The result is unequal treatment.

These findings suggest a need for service users to know their rights and how to negotiate for services; for improved training, particularly to tackle diagnostic overshadowing and the need for equality; and for improved planning and commissioning.

## Stage 5: Seeking feedback and involvement

We found little evidence of effective ways of seeking feedback in primary care from people with learning disabilities and/or mental health problems; or of people being involved to help improve services. People who consistently experience barriers to services develop low expectations of what those services will be like in the future, which in turn feeds in to the low expectations providers have of what they can offer.

Research carried out for the investigation noted that ‘those who shout the loudest’ get the most out of the system. This is a truism that applies in many circumstances, and is likely to refer to middle class, affluent people who know their rights and feel confident about complaining. People with learning disabilities who have communication difficulties may find it difficult or impossible to obtain the support they need. Those with advocates or family carers may fare better. Family carers told us that they ‘had to constantly battle to make sure that our sons and daughters got a decent service’. Similarly, people who are depressed may find it hard to feel confident about asserting themselves.

A common reason for not complaining, especially in residential settings, is that people are afraid of rocking the boat or being singled out as troublemakers. A woman with learning disabilities giving oral evidence to the Inquiry Panel spoke about independent inspection visits to the home she lived in:

‘They ask me, “Is everything all right?”... quite often there are staff there and you don’t want to answer if there are staff there. Quite often, certainly in our house, the staff will stand there when questions are being asked by inspection.’

A recent report in England on older people in residential and hospital settings said that they ‘find it difficult to challenge against attitudes and their reluctance to complain can often mean nothing changes’.

The investigation Inquiry Panel received some very constructive evidence from the Parliamentary and Health Service Ombudsman in England whose strongly expressed view is that access to formal complaints procedures needs radical improvement, especially for people with learning disabilities and/or mental health problems.

‘I have commented on the problems of the fragmentation of the relevant complaints procedures in my report on the complaints procedure ‘Making things better?’ published in February 2003. I am sure that people with mental health problems and learning disabilities, who are often reluctant to complain at all, find the inter-organisational aspect a particularly confounding factor.’

At the moment, people with learning disabilities and/or mental health problems seem to lack choice and power when accessing primary care services. There also appears to be a lack of understanding about the potential reach of disability legislation. This needs to change in order that disabled people can engage as effective partners in improving services.

‘In the view of those outside primary care services, diagnostic overshadowing was a significant obstacle to people with learning difficulties and also with mental health problems getting their physical health concerns taken seriously in primary care. We heard many stories of a range of conditions being missed or overlooked, often with profoundly negative consequences’.

# 6

## Different people, different journeys

We have listened to many different voices during the course of our investigation: women and men, people with physical or sensory impairments and a learning disability, black, Asian and refugee mental health service users, parents of children with autism, people of different ages, people with learning disabilities living in sheltered accommodation. There are both similarities and differences between the experiences of people with learning disabilities and those with mental health problems. There are also differences according to living situation.

Government is committed to introducing single equalities legislation which would simplify the law and produce equal coverage across all equalities strands: age, religion/belief, sexual orientation, race, gender and disability. This means that health services will need to provide equitable services to positively promote equality across the strands. It may also help address some of the intersecting issues which have been raised with us during our investigation.

## Children and young people

It is estimated that around 748,000 children and young people aged 5 to 16 in Great Britain have mental health problems (including emotional and conduct disorders); around 78,000 of these have autistic spectrum disorders,<sup>55</sup> around 132,000 have learning disabilities<sup>56</sup> and 51,000 of these also have mental health problems.<sup>57</sup> About 60 % of children and young people with both learning disabilities and mental health problems live in poverty.<sup>58</sup> There is a continuing upward trend in the numbers of disabled children (usually with associated learning disabilities) who have complex multiple disabilities and who may also be technology dependent.

The evidence we gathered during our investigation was similar to that generated more widely through monitoring children's initiatives. With specific reference to primary care, the following points are particularly noteworthy:

- The most satisfied families stressed the value of the primary care practice knowing the whole family and being able to address a wider range of problems relating to parents', as well as the disabled child's, health needs. Parents who were least satisfied were usually parents of children or young people with the most complex multiple impairments.
- Some parents felt that the difficulties experienced by families with children with autistic spectrum disorders or other behavioural difficulties were insufficiently understood, particularly in relation to the need for home visits and waiting arrangements.
- Some practices offered additional services to families with disabled children, such as prescription collection and delivery services.
- A growing number of disabled children now have individual health plans and these were seen as particularly helpful in bridging communication between primary and secondary health services and encouraging parents, children and young people to fully understand health needs and any treatments or interventions.
- A special and recurrent area of concern was the management of any specific healthcare needs at transition to adult life.



## Older people

A focus group made up of experts in older people's issues gave evidence to the investigation of instances where older people were effectively barred from taking steps to improve their physical health. It was reported that access to fresh fruit was often non-existent in some residential units. In one home for older people, staff restricted fresh fruit to residents with diabetes only. Poverty was a barrier for people living in the community – many older people could not afford to go to weightwatchers or join a gym.

One study found that 20% of people living in institutions were either malnourished or at risk of malnourishment,<sup>59</sup> and around 60% of people in hospital experienced malnutrition.<sup>60</sup> There is often inadequate attention to their nutritional needs, including food being given to someone and then removed untouched, when the individual is not able to reach or eat the food unaided.<sup>61</sup> This is likely to affect older people with learning disabilities and/or mental health problems more seriously than others given their additional communication barriers.

Aspects of service access were also problematic. The investigation's expert older people's group reported that sometimes staff allocated treatment to older people according to their economic contribution. For example, physiotherapy was not considered a priority for people who were not in paid work. Ageism sometimes operated in breast screening not being routinely offered to women over 70. Failure to make adjustments for co-existing sensory and physical impairments, common in old age, was a problem. For instance, people who were unable to manage blister packs of tablets or to read medication information in small print were not offered alternatives. People with dementia needed systems to support them to take medication.

For people with learning disabilities and/or mental health problems reaching the end of life, hospice and other palliative care were not generally geared to their needs. One adverse effect of psychiatric medication in this age group included falls.

Older people often had low expectations and therefore did not assert their rights as much as younger people.

Physical symptoms could be inappropriately attributed not only to an established learning disability and/or mental health problem but also to age:

‘Some doctors don’t take notice of physical pain once they know you have a mental one. They put everything down to depression, age, change of life, and weight and don’t listen.’<sup>62</sup>

Equally, mental health issues could be missed, with all the focus being on physical health. A holistic approach to the individual was important.

### **People from black and minority ethnic (BME) communities**

Focus groups facilitated by disabled people from BME communities and our BME experts forum confirmed that experiences of primary care were mixed but that people with learning disabilities and/or mental health problems from BME communities face complex barriers. These range from the practical – eg lack of health information available in community languages where people can access it (places of worship, community centres, refugee centres) to the attitudinal.

Some concerns were common across ethnic groups. For instance, the lack of accessible information; and physical health problems sometimes being viewed by primary care staff as symptoms of a learning disability or mental health condition. There was also a theme of mistrust of services that seemed to inform how some people from BME communities experienced health services.

In one focus group, fear of going back into a long stay hospital was cited as a reason for not seeking help from primary care. We were also told how some refugees and asylum seekers feared seeking support from statutory services.

The Healthcare Commission Census 'Count Me In' (2005) found that, in England, people who are black (including Caribbean, African and others) or of white/black mixed ethnicity, were at least three times more likely than the average to be admitted to psychiatric hospital.<sup>63</sup> Black people are also eight times more likely (and in the North West 25 times more likely) than the overall population to be in high security psychiatric hospitals.

Black people with mental health problems are more likely than others to bypass primary care, and to be admitted straight to psychiatric hospital.

Given these pathways through services, the physical health needs of black people with mental health problems are likely to be under-addressed in primary care. This can be exacerbated by high doses of psychiatric medication which can impact on physical health.

Asian people and people from other minority ethnic communities also raised issues about losing trust, for instance when they did not feel listened to or communication was not effective. One person we spoke to was seen as non-compliant with treatment because he was fasting at Ramadan. People may feel they have to leave their spiritual or other beliefs behind when consulting health professionals, which can impact on decisions about treatment. They may not be, or feel, understood.

The Sainsbury Centre for Mental Health's 'Breaking the Circles of Fear' project argues, in relation to people from African Caribbean communities, that service users are afraid that services will harm them.<sup>64</sup> This means they seek help late. Staff meanwhile are afraid to discuss issues of race and culture openly – and are also disproportionately fearful of potential violence from black mental health service users. When this fear influences risk assessments and decisions on treatment, responses are likely to be dominated by a heavy reliance on medication and restriction. Service users then become even more reluctant to seek help, which increases the likelihood of personal crisis. This leads to more disturbed behaviour, thereby amplifying staff fears and generating yet more coercive responses, in an endless vicious circle.

It seemed to us that circles of fear were operating between some service users from BME communities and the primary care services that they used – or did not use.

It is likely that such fears and the tendency to delay seeking help for mental health problems also means that physical health problems are missed or spotted late. It is impossible to quantify this from primary care data because ethnic monitoring statistics are patchy and unreliable. One of the reasons for unreliable statistics is that some healthcare staff ‘guess’ or leave blank the answer to ethnic monitoring questions because they are embarrassed to address the subject.

Most people with learning disabilities and/or mental health problems from BME communities are not subject to coercive services. They may rather be underserved: for instance, young Asian women may have suicide risk and depression which is not recognised.

Disabled people from many BME communities are at particularly high risk of living in poverty, which exacerbates health problems. In some communities including refugees, families are particularly likely to be managing without adequate information, support or income. These situations can make it hard for families and communities to support their disabled family member.

**‘I lost trust... I wouldn’t go to my GP first. I would seek other options before I go to a GP.’**

(Dominic Walker, featured on the DRC formal investigation DVD)

Those we consulted thought health services should respond better to the needs and beliefs of their 'market' – rather as a supermarket would change its products, or a school cater for all its potential pupils – depending on the different beliefs and priorities and the religious and ethnic make-up of an area.

### **People with multiple impairments and challenges**

We held a seminar in conjunction with the Judith Trust focusing on the needs of people who have both mental health problems and learning disabilities. This highlighted the importance of access. For example, making appointments systems straightforward, training receptionists and other staff to communicate effectively and putting correspondence into accessible formats. Currently, often only one set of needs is met at a time – for instance, mental health services could cater for mental health but not learning disability needs. People with autistic spectrum disorders also sometimes slip between mental health and learning disability services.

The issues faced by people with mental health problems and physical impairments are highlighted in a 2004 study by Jenny Morris.<sup>65</sup> Services were often not flexible enough to cater for people who did not fit neatly under either the mental health or physical impairment label. Specific problems included negative interactions between medications for physical and mental ill health. Negotiation on these interactions were interpreted as non-compliance with psychiatric treatment. There were also difficulties of physical access in mental health services and lack of mental health awareness in services catering for physical impairment.

People who have a sensory impairment as well as a learning disability and/or mental health problem face additional access barriers.

The Royal National Institute for the Blind (RNIB) has researched the needs of people with learning disabilities and visual impairment and highlighted the barriers to getting eyesight tested. It is common for people to struggle without the glasses they need. This may mean that even if they are able to read, they may be unable to read small print information about their treatment provided by a GP surgery. This suggests that regular health checks should cover sight and hearing, and that health information should be provided in a range of formats and print sizes. Similarly we heard about people with mental health problems who, because of a hearing impairment, had not understood the treatment being proposed, or even their rights under the Mental Health Act. Sign language users often found it difficult to access information on mental or physical health.

For some people with learning disabilities and/or mental health problems, physical health is adversely affected by use of alcohol or street drugs. 'Dual diagnosis' services and expertise in relation to people with both mental health and substance abuse problems have grown over recent years. Addiction issues need to be integrated into health checks and programmes.

People with this range of experiences would all benefit from improvements suggested in this report for personalised service, reasonable adjustments, staff training and strengthened commissioning to target unmet need.

## Family carers of adults with learning disabilities and/or mental health problems

The health and well-being of many people with learning disabilities and/or mental health problems will depend upon their relationships with members of their family or the local community. Many families provide a range of practical and emotional supports to adults in supported living or residential care. A growing number of people with learning disabilities and/or mental health problems are also family carers in their own right, whether as parents, partners or siblings.

A number of family carers (including members of the National Family Carers' Network) shared their views with the investigation:

- Most families were satisfied with their local services. However, some reported problems in registering with a GP because of the perceived 'complexity' and likely level of demand of their adult child. Families were less satisfied with access to the wider range of primary care services, for example advice on diet, exercise and general well-being. Some were unhappy at problems in accessing health screening and promotion programmes.
- There was universal support for the concept of regular health checks. Those families whose relatives had them felt they encouraged a much more holistic and proactive approach to healthcare. Families also felt that they were better informed about their relatives' health needs and how they could support them.



Family carers' concerns primarily related to what they perceived as frequent misunderstandings of their roles in relation to adult relatives with a learning disability. They noted that they provided significant levels of personal (and sometimes financial) support and were often the key players in ensuring that their relatives accessed appropriate healthcare. They wanted maximum autonomy for their relatives but were concerned when unclear understanding about confidentiality and consent inhibited them from providing the best possible support. An emerging (and often neglected) issue in our evidence was the role of people with learning disabilities and/or mental health problems themselves as family carers and their access to appropriate support in that role.



# Conclusion, recommendations and action

The evidence collected for this formal investigation makes a compelling case for targeted, concerted action and leadership to reduce the marked health inequalities experienced by people with learning disabilities and/or mental health problems.

The detailed findings provide strong indicators of priorities for action at the different stages of the 'journey' through primary care.

Action is needed to ensure people can register with a GP in the first place and access services in practice. Regular health checks would help address high levels of unmet health need. For instance, this investigation has highlighted high unmet need in people with learning disabilities; and particular risks of heart disease, stroke, diabetes and chronic obstructive pulmonary disorder experienced by people with depression. Physical health checks should be made available in line with evidence of need.

However, the focus of initiatives so far – on access and health checks – is only one part of what is required. The evidence also strongly indicates a need for:

- **Equitable treatment and interventions once people have accessed the service or received the health check.**
- **Improved staff training explicitly to reduce the risk of ‘diagnostic overshadowing’ and unequal treatment. Clinicians need to be encouraged to have a greater level of suspicion about physical ill health in someone with a mental health problem, learning disability or communications impairment.**
- **Improved prescribing, monitoring, information and choice in relation to psychiatric medication. For people with learning disabilities, use of anti-psychotic medication for people with no psychosis to control behaviour, is inappropriate. For all service users information on risks and benefits needs improvement, so people can make a balanced decision that takes account of potential physical adverse effects.**
- **Effectively targeted health promotion, given highly challenging smoking and obesity rates and low staff expectations about whether people will take action to improve their health (despite evidence that health promotion interventions can work).**
- **The direct involvement of disabled people in influencing and leading service improvements.**

Whereas people with learning disabilities and/or mental health problems tended to identify service difficulties in terms of access barriers or ‘diagnostic overshadowing’, primary care practitioners were more likely to view the difficulties as intrinsic to the individual and their impairment. A cultural shift is needed, to embed the principle that services need to be adjusted to suit individual requirements and to raise expectations for improved health outcomes.

There are a number of very positive examples to build on, where individual practitioners, GP practices, PCTs or Local Health Boards (LHBs) have taken action to improve access, enhance integration between primary and secondary services and build service users’ views directly into training. Commissioning voluntary sector activities relating to physical health can also be helpful. For example, those run by Mind groups in Thame and Maldon on healthy eating, and in Coventry, Redcar and Cleveland, Harrow and Newham on physical activity. However, at a systems level we found little or no use of data on the physical health experiences of people with learning disabilities and/or mental health problems to inform commissioning; little evidence of expertise in these areas amongst commissioners; and no tracking of these health inequalities as part of health inequalities initiatives. There was also a lack of systematic assessment of the impact on disabled people of new service developments.

We convened the Inquiry Panel to propose recommendations that would most practically and effectively redress the inequalities we identified, in the newly configured health services in England and Wales. The Panel’s full findings form Part 2 of this report and are available on the accompanying CD-ROM.

The Inquiry Panel concluded that:

- The inequalities in health and service access documented in this report are not inevitable.
- They have existed for far too long.
- They have been allowed to persist partly because of low expectations: on the part of people with learning disabilities and/or mental health problems themselves and also on the part of practitioners and policy makers.
- Urgent action is needed and many different people and organisations have a part to play.
- A clear lead needs to come from the highest level within the Department of Health and the Welsh Assembly Government in taking action and ensuring that others take action.

The Inquiry Panel found that fragmentation of decision making had slowed down action and that service users were left in a policy ‘Catch 22’ situation by a failure to drive change through the health system. They noted their great disappointment that primary care had not taken action to improve access by making ‘reasonable adjustments’ for these groups of disabled people, as required under the Disability Discrimination Act since 1999.

The Panel also found a huge reservoir of goodwill amongst organisations key to delivery. There was near-total agreement on what needed to be done and a positive commitment to act, together.

The DRC supports the Panel's conclusions and imperatives for action, which are summarised at Appendix 2; their full framework for action is in Part 2 of this report and available on the CD-ROM which accompanies it. The DRC's recommendations, drawn from both the research evidence and the Inquiry Panel's conclusions, are listed under the body or sector with responsibility for implementing them.

### Recommendations and action points

1 **Governments in England and Wales** should make closing these gaps of health inequality part of their departmental objectives, at the highest level, and lead improvements in:

**Primary care access and health checks.** They should:

- Strengthen guidance for commissioners to ensure services effectively meet the health needs of the whole population.
- Include incentives in the GP contract for evidence-based regular health checks for people with learning disabilities and/or enduring mental health problems, in line with evidence of need. Their outcomes should be audited in terms of quality and subsequent treatment.
- Ensure screening programmes are targeted in line with evidence and are fully inclusive of people with learning disabilities and/or mental health problems.
- The national bowel cancer screening programmes in England and Wales should ensure eligible people with schizophrenia are offered screening on an equitable basis and should in future consider prioritising them as a high risk group.

- Take action where access to primary care is a problem for particular populations – ensuring there is a robust national system for people without a permanent address to register with a GP and that charges in residential settings for receiving GP services are not passed on to residents.

**Equitable treatment.** They should:

- Spearhead (with partners) medical and nursing training that explicitly tackles ‘diagnostic overshadowing’ and unequal treatment, at undergraduate, postgraduate and continuing professional development levels. They should incentivise training through the GP appraisal system.
- Consider requiring receptionists to hold specific competencies, working with the Association of Medical Secretaries, Practice Managers Administrators and Receptionists (AMSPAR) and the British Medical Association (BMA).

**Positive health.** They should:

- Centrally target these very high risk groups in national health inequalities programmes.
- Require that each country’s Care Programmes Approach and unified assessment should include access to primary care, achieved to Quality and Outcome Framework standards; and access to health promotion and health checks.

**Expectations.** They should:

- Improve the participation of people with learning disabilities and/or mental health problems as leaders in health service organisations.
- Support a partnership of people with learning disabilities and/or mental health problems to spread knowledge on rights. This should include a package of information on how to negotiate for improved services and questions to ask in primary care, which can be easily downloaded and provided to service users when needed.

**Performance management.** They should:

- Set standards and use inspection, scrutiny and performance management frameworks to verify that organisations are meeting standards and using the DED positively to promote disability equality in relation to mainstream health priorities.
- Ensure these groups get full and equal benefit from any new developments, by subjecting proposals to Disability Equality Impact Assessments.
- Produce a timeline explaining proposed actions by the Department of Health and Welsh Assembly Government.



Progress should be tracked by breaking down Public Service Agreement (PSA) targets in England and Health Gain Targets in Wales (like early death from CHD and cancer) by broad impairment group – so we know who is dying young from CHD or cancer, over time. The Secretary of State for Health in England and the First Minister in Wales should report on progress in tackling health inequalities as part of their Secretary of State Duty under the DED.

**2 Commissioners of services** (practice-based commissioners, Primary Care Trusts, Local Health Boards and local authorities) should analyse the physical health needs, experiences and views of people with learning disabilities and/or mental health problems as part of their local strategic assessments of needs (in England) and health needs assessments in ‘health, social care and well-being’ strategies (in Wales); and use this data directly to commission services to close gaps of inequality. They should:

- Identify groups who may need outreach or new service models to ensure they get primary care, to at least the same standard required for everyone (for instance, people in residential and hospital provision receiving primary care to Quality and Outcomes Framework standards).
- Ensure the views of people with learning disabilities and/or mental health problems are used to drive actual improvements in service, through public and patient involvement. They should also ensure service users are welcomed and supported to participate in patient and public involvement initiatives including patient forums, expert patient programmes, Community Health Councils (in Wales) and patient surveys. This may require targeted focus groups and production of accessible materials.

- Commission new service models and evidence-based collaboration, between primary care and voluntary sector or specialist services such as Community Mental Health Teams (CMHTs)/ Community Learning Disability Teams (CLDTs) and residential services, to improve access and day-to-day support on physical health by those in touch with service users.
- Ensure healthy living support is targeted at people with learning disabilities and/or mental health problems and their families and that they can be involved in designing their individual health promotion programmes.
- Build robust disability access and quality standards into all contracts with providers, in the public, private and voluntary sectors. Healthy living standards should be included in contracts: for instance, it should be possible for users of residential or hospital services to eat the recommended five portions of fruit and vegetables per day and take the recommended levels of exercise.
- Track GP allocation requests to spot any potential discrimination on grounds of disability or race.

This will require strengthening capacity and expertise in mental health and learning disability. Progress should be tracked by monitoring trends in morbidity, survival rates, diagnosis, condition management and patient experience. Guidance is available at [www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation)

**3 Primary care providers** should improve equity of access and treatment. They should:

- Offer people with learning disabilities and/or mental health problems the option of recording their access needs so they appear on patient records and can be easily identified and met. The primary care provider should offer a range of personalised adjustments including different appointment lengths, first or last appointments, text or telephone appointment reminders, accessible appointment cards, telephone consultations and specific waiting arrangements.
- Offer regular evidence-based health checks and close monitoring of the physical effects of any psychiatric medication to people with learning disabilities and/or enduring mental health problems.
- Take extra care to ensure these groups receive the health promotion, screening and physical treatment they require, as well as information and choice in relation to physical effects of psychiatric medication.
- Make direct contact with local disability groups and involve them in advising on improvements, for instance through delivering training to the whole primary care team so that everyone from receptionists, to practice managers and GPs engage in improving systems.
- Give anyone removed from a GP's list or refused access to a list written reasons why, in line with existing guidance.

Progress can be tracked by including people with learning disabilities and/or mental health problems and their organisations in patient and public involvement initiatives and surveys.

4 **Specialist mental health and learning disability providers** should support people with learning disabilities and/or mental health problems in accessing primary care and taking care of their physical health. They should:

- Ensure through care plans and health action plans that service users can access primary care to Quality and Outcome Framework standards and give service users copies of their plans.
- Prevent inappropriate prescribing of psychiatric medication and inform people of benefits and risks.
- Positively promote healthy living, including through options for diet and exercise, in their own services and raise expectations of good health including by access to expert patient programmes, so people can take charge of their own health.

5 **Performance management, inspection and scrutiny bodies** should require action by commissioners and providers to close gaps of inequality. They should:

- Support Boards in their governance role, to take a strategic approach to disability equality.
- Ensure capacity and expertise in learning disability and mental health are established for effective commissioning.
- Strengthen, scrutinise and inspect commissioning, including on how local assessment of the needs of people with learning disabilities and/or mental health problems is used actively to commission effective service models and to drive up quality and access.

- Inspect services against standards for primary care access and healthy living, with user involvement in inspection.
- Assess progress in closing gaps of inequality.

## 6 Professional bodies, standard setting and good practice organisations should:

- Improve the evidence base, guidelines and indicators to support commissioners and providers to ‘close gaps’. The Royal Colleges, British Medical Association, National Institute for Clinical Excellence (NICE), National Primary Care Development Team, Public Health Observatories, Care Services Improvement Partnership (CSIP), National Patient Safety Agency (NPSA), National Public Health Service (Wales), Wales Centre for Health and other relevant good practice organisations have key roles. Public Health Observatories should appoint a national lead for disability equality.
- Integrate the needs of people with learning disabilities and/or mental health problems into relevant clinical guidelines, standards and good practice guides, for instance on CHD, diabetes, obesity and smoking.
- Develop specific guidelines where needed. For instance NICE could provide guidance to primary care on the content of regular health checks and (with the British National Formulary) on the physical health monitoring required for people taking specific psychiatric medication. The Association of Medical Secretaries, Practice Managers, Administrators and Receptionists (AMSPAR), the Practice Managers’ Network and others could draw up guidance with user groups to support implementation of reasonable adjustments in primary care.
- Actively promote good practice through primary care and other relevant networks.

In taking forward the recommendations it will be important to address the needs of different populations including people from different minority ethnic communities and age bands in order to work to close gaps of inequality by race, age, gender, sexual orientation and other factors in line with current and planned legislation. Our overall recommendations to strengthen strategic needs assessment and commissioning for the whole population and to personalise services are complemented by some more specific proposals for different populations which are set out below.

#### For children and young people:

- The National Service Framework for Children, Young People and Maternity Services establishes clear standards for promoting the health and well-being of children and young people. Children's services should take account of this framework and ensure that they deliver access to the full range of health and social care for disabled children and their families, with all children with learning disabilities and/or mental health problems having an individual healthcare/health action plan, that includes health promotion and physical and emotional well-being.
- PCTs and LHBs should have regard to the needs of children and young people with learning disabilities and/or mental health problems within their commissioning arrangements and delivery plans, linking with the Children and Young People's plans and the development of Children's Trusts.
- Primary care providers should promote active participation by young people in identifying and meeting their own health needs (with special reference to the development of expert patient and other participation programmes designed for children and young people).

- Child and adult health services should jointly manage the transfer to adult services for young people with long term health needs through proactive planning.

#### For older people:

- PCTs, LHBs and other commissioners should start to quantify and plan for the implications of an ageing learning disabled population.
- PCTs and LHBs, in tracking access to services and treatments, should also monitor by age, in order to rectify any ageism in availability of key health checks, promotion or treatments.
- Standards for residential and nursing care, including safe prescribing, access to primary care and healthy living are particularly important for older people and should be inspected by inspection bodies.
- Training of health professionals should encourage attention to both mental and physical health in older people.

#### For people from BME communities:

- Services should encourage champions to lead improvement and implementation of existing policies, including ethnic monitoring and race equality impact assessments.
- PCTs and LHBs should consider combining ethnic, gender and disability monitoring with patient surveys and community discussions in order to provide stronger local profiles. This should help commissioners switch resources to groups with the highest needs, improve early intervention and meet requirements under the Disability, Race and Gender Equality Duties.

- Commissioners should consider outreach to communities who under-use primary care, potentially through new service configurations whereby BME organisations provide primary care or work in partnership with primary care providers, to improve the service responsiveness to different communities.
- The Department of Health and Welsh Assembly Government should report on PSA targets and Health Gain Targets respectively, by ethnicity as well as by broad impairment group, to enable progress to be tracked nationally.

#### For people with multiple impairments and challenges:

- Local strategic assessments of needs should report multiple needs to inform service commissioning, including the growing numbers of people with complex multiple conditions.
- Practices and health centres should make reasonable adjustments to improve access for the full range of physical, mental and sensory impairments and learning disabilities.
- Health checks should include attention to eyesight and hearing.
- Training providers should build in to training at different levels and career stages the requirements of people with multiple impairments and needs.



### For family carers:

- PCTs and Local Health Boards (LHBs) should ensure that data collection and strategic commissioning identify the specific health needs of family carers and support them in their role.
- PCTs and LHBs should work proactively with local authorities and organisations of family carers and service users to agree arrangements for information exchange and support for family carers (including family carers with a learning disability or mental health problem) in accessing the full range of primary care in their area. In England this can be facilitated by Learning Disability Partnership Boards.
- Local authority and national carers' strategies should be proactive in addressing the health needs of people with learning disabilities and/or mental health problems who also have a family carer role and ensure they have access to the full range of health promotion and screening services.
- Annual health checks and health action plans should ensure that all concerned (including family carers as covered by guidance on consent under the Mental Capacity Act) have the best possible information on their relatives' health status.
- Transitions between primary, secondary and tertiary care should be planned and well managed (with particular reference to discharge from hospital).

## Moving forward

Many of the recommendations in this report cost little or nothing and some very simple steps could be taken immediately by practices and health centres. For example, making the appointments system more accessible, making sure someone with a learning disability understands what they have to do with their treatment, or guarding against assuming someone with a mental health problem's physical symptoms are 'all in the mind' – can make a real difference.

The whole primary care team has a significant part to play – receptionists, practice nurses, GPs and other practitioners. Advice and support are available. Talking with people who have learning disabilities and/or mental health problems and involving them in training or audit can bring real results.

This report also proposes strengthened commissioning, to meet the most significant health needs of these excluded groups, in line with the 'Valuing People' and 'Choosing Health' White Papers in England and 'Designed for Life' in Wales. It proposes strengthened performance management and inspection to drive change through the system. It identifies clear roles for standard setting and good practice organisations and for disabled people themselves. By implementing these recommendations, there is a real prospect of targeting resources on those with the highest need. This would help meet each government's targets to reduce health inequalities, premature death from CHD and cancer, smoking rates and the unnecessary costs of high health service demand amongst 'at-risk' groups who currently miss out on effective early intervention.

Implementation is a matter of social justice, of raised expectations and of simple effectiveness in targeting resources on greatest need.

In the newly configured NHS, change will only be driven by such a concerted approach.

# Appendix 1

## Terms of reference

- 1 To collate, assess and publish existing evidence on the nature, extent and causes of inequalities in physical health outcomes and in the access to, and quality of, primary healthcare services experienced by people with learning disabilities and people with mental health problems regardless of age.
- 2 To identify the principal barriers for people with learning disabilities and people with mental health problems to accessing primary healthcare services, including physical health promotion, and assessment and treatment in primary care.
- 3 To investigate what steps have been taken by primary care trusts, local health boards, strategic health authorities and healthcare practitioners to comply with Part 3 of the DDA, with particular regard to the needs of people with learning disabilities and people with mental health problems. In addition, to investigate what steps have been taken to meet relevant policy targets set out in Valuing People, GP contract requirements, and the Mental Health National Service Framework.
- 4 To identify measures which successfully facilitate access to quality primary healthcare services for people with learning disabilities and people with mental health problems, and to consider what other measures would be likely to improve such access.
- 5 To investigate the effectiveness and adequacy of steps taken by primary healthcare service providers and by government departments to reduce inequalities in health outcomes for people with learning disabilities and people with mental health problems, and to recommend further action where appropriate.

# Appendix 2

## Principal conclusions of the Inquiry Panel

The Panel recommended the following to the DRC:

- 1 All professionals and organisations with a role in the provision of primary care health services to people with learning disabilities and/or mental health problems must act now to tackle the inequalities in physical health and primary health care services they experience.
- 2 The planning and commissioning of primary care services and services for people with learning disabilities and/or mental health problems need to take greater account of their physical health-care needs.
- 3 Urgent and positive action is needed to ensure that people with learning disabilities and/or mental health problems and their carers (and other support workers) where relevant know their rights in relation to physical health and the services to support this, and are able to take part or receive appropriate help in programmes geared to supporting them in managing their physical health conditions.
- 4 People with learning disabilities and/or mental health problems have a right to be registered with a GP and this needs to be made a reality.
- 5 Everyone with learning disabilities and/or mental health problems under the active care of a psychiatrist should also have their physical health monitored by regular review from primary health care services including a GP or other primary care practitioner.

- 6 People with learning disabilities and/or mental health problems living in residential or nursing homes, in 'supported living' arrangements, in prisons or in secure accommodation for young people should have equal access to a GP and access to options for healthy living.
- 7 Services and specific equality schemes need to be put in place to ensure that people with learning disabilities and/or mental health problems who do not have easy access to a GP or who experience exclusion on multiple grounds receive full and proper primary health care services.
- 8 GP practices and primary care centres need to make 'reasonable adjustments' to make it easier for people with learning disabilities and/or mental health problems to get proper access to the services offered by the practice.
- 9 People with learning disabilities and/or enduring mental health problems should be offered an annual health check on their physical health by a primary care specialist and access to health interventions that fit the level of their health needs, regardless of age.
- 10 People with learning disabilities and/or mental health problems should be offered accessible and appropriate support to encourage healthy living and overcome any physical health disadvantages which come with their condition or treatments administered for the condition including information, advice and support, in an accessible, relevant and targeted form, on how to quit smoking, on good diet, on sexual health, on alcohol, on street drugs and on physical exercise.
- 11 There should be a comprehensive programme of evidence-based training and information resources (the design and at least some of the delivery of which involves users and user groups) for primary healthcare staff.



# Appendix 3

## List of research reports for this investigation

All are available on the DRC website  
[www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation)

### Background evidence

Graham H (2004) Socioeconomic inequalities in health in the UK: evidence on patterns and determinants.

Nocon A (2006) Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities and/or mental health problems.

### Consultations

DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

DRC (2006) Results of questionnaires on policy and practice.

### Analysis of clinical data (mental health problems)

Hippisley-Cox J and Pringle M (2005) Health inequalities experienced by people with schizophrenia and manic depression: analysis of general practice data in England and Wales.

Hippisley-Cox J, Coupland C, Langford G, Parker C and Vinogradova Y (2006) Management of chronic obstructive airways disease in patients with serious mental health problems.

Hippisley-Cox J, Parker C, Coupland C and Vinogradova Y (2006) Use of statins in coronary heart disease patients with and without mental health problems.



Hippisley-Cox J, Vinogradova Y, Coupland C, Langford G and Parker C (2006) A comparison of survival rates for people with mental health problems and the remaining population with specific conditions.

Hippisley-Cox J, Vinogradova Y, Coupland C and Parker C (2006) Risk of malignancy in patients with mental health problems.

Hippisley-Cox J, Pringle M, Parker C, Vinogradova Y and Coupland C (2006) Health inequalities experienced by people with schizophrenia and bipolar disorder: analyses of general practice data in England and Wales. Executive summary.

Parker C, Hippisley-Cox J, Vinogradova Y and Coupland C (2006) Outcomes following postmenopausal bleeding or rectal bleeding in patients with serious mental health problems.

### Area Studies

Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or mental health problems. Area Studies report.

Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report. Executive summary.

### Wales-specific study (learning disabilities)

Kerr M, Felce D and Felce J (2005) Equal treatment: closing the gap. Final report from the Welsh Centre for Learning Disabilities.

Kerr M, Felce D and Felce J (2005) Equal treatment: closing the gap. Final report from the Welsh Centre for Learning Disabilities. Executive summary.

## Effectiveness reviews

Alborz A, Kalambouka A, McNally R and Parkinson G (2006) A Literature review on the effectiveness of interventions to improve the physical health of people with learning disabilities.

Alborz A, Kalambouka A, McNally R and Parkinson G (2006) A Literature review on the effectiveness of interventions to improve the physical health of people with learning disabilities. Executive summary.

Samele C, Hoadley A and Seymour L (2006) A systematic review of the effectiveness of interventions to improve the physical health of people with severe mental health problems.

Samele C, Hoadley A and Seymour L (2006) A systematic review of the effectiveness of interventions to improve the physical health of people with severe mental health problems. Executive summary.

# Appendix 4

## Members of the formal investigation Inquiry Panel

### Dr David Wolfe – Chair

Barrister at Matrix Chambers. Specialist in disability, health and public law.

### Dr David Bailey

GP, Deputy Chair of BMA (British Medical Association) in Wales.

### Professor David Haslam

GP, President Elect of RCGP (Royal College of General Practitioners); National Clinical Adviser to Healthcare Commission, and member of Post Graduate Medical Education Training Board.

### Andrew Lee

Director of People First and member of DRC's Learning Disability Action Group, with personal experience of learning disability.

### Rachel Monk

Member of and representing DRC's Learning Disability Action Group, with personal experience of learning disability.

### Professor Zenobia Nadirshaw

Head of Clinical Psychology Service in the Kensington and Chelsea PCT with expertise in developing services for people from black and minority ethnic communities.

### Dr Rachel Perkins

Director of Quality Assurance at South West London and St George's NHS Mental Health Trust, user of mental health services, Consultant Clinical Psychologist and member of DRC's Mental Health Action Group.

### Cliff Prior

Chief Executive of Rethink; member of the National Leadership Network for Health and Social Care and member of the Mental Health Task Force.

### Dr Philippa Russell

DRC Commissioner, special adviser on disability policy at the National Children's Bureau, special adviser on disability to the SEN and Disability Division DfES and the parent of an adult son with learning disabilities.

113

### Liz Sayce

DRC Director of Policy and Communications.

### Andrew Watkiss

Chair of Harrow Mind, user of mental health services and member of DRC's Mental Health Action Group.

### Dafydd Wigley

Honorary President of Plaid Cymru; joint president of Mencap Cymru and former Vice Chair of the All Party Disablement Group at the House of Commons.

### Jo Williams and David Congdon

Chief Executive and Director of Campaigns and Policy at Mencap.

### Lynn Young

Royal College of Nursing Community Health Adviser.

## ◀ Appendix 5

### Table of responsibilities for action

The formal investigation Inquiry Panel put forward a detailed framework of action points to facilitate the implementation of its recommendations. That framework is set out in Part 2 of this report (and is available on the CD-ROM which accompanies it). The following tables, which refer to the numbered action points proposed by the Inquiry Panel, give an overview of the principal responsibilities for delivering the changes called for in this report.

## 1. Government, performance management, standard setting and inspection bodies

## 2. Providers and commissioners of primary care services

	Department of Health	Welsh Assembly Government	Directors of Public Health /Public Health Observatories/ National Public Health Service	Healthcare Commission	Healthcare Inspectorate Wales	Management and good practice organisations *	CSCI / CSTW	NICE (and All Wales Medicine Strategy Group)	Professional and practitioner organisations **	BMA	GPs and primary care practitioners	Primary Care Trusts	Strategic Health Authorities	Local Health Boards	Local Authorities	NHS	Specialist providers of mental health and learning disability services	Voluntary sector and disabled people's organisations
Action Points from the Inquiry Panel's report										Action Points from the Inquiry Panel's report								
Recommendation 1 Tackling Inequalities	1.1-1.3, 1.5-1.9	1.12-1.16, 1.18, 1.19, 1.21-1.23	1.4, 1.25	1.4	1.21	1.25						1.3, 1.10	1.3	1.16, 1.20	1.3, 1.4, 1.16	1.16		1.25
Recommendation 2 Planning and Commissioning	2.2-2.4, 2.10, 2.11	2.20-2.23, 2.25, 2.32-2.34, 2.36	2.12, 2.26, 2.34, 2.35, 2.37	2.2, 2.10, 2.14	2.33, 2.34, 2.39	2.2, 2.15, 2.40	2.10, 2.34	2.10, 2.13, 2.16-2.19, 2.34, 2.41-2.44			2.14, 2.39	2.5, 2.14	2.6, 2.7	2.24-2.31, 2.39	2.9, 2.24-2.31	2.1, 2.14, 2.32, 2.34, 2.38		
Recommendation 3 Enabling Users	3.1, 3.4, 3.5, 3.6, 3.9, 3.12	3.13, 3.16-3.18, 3.23, 3.24, 3.26		3.2, 3.7	3.14				3.1, 3.10, 3.13, 3.25		3.10, 3.25	3.4		3.16	3.16	3.2	3.3, 3.7, 3.8, 3.15, 3.19, 3.20, 3.22	3.1, 3.3, 3.4, 3.6, 3.8, 3.13, 3.15, 3.16, 3.18, 3.22, 3.26
Recommendation 4 Registration with a GP	4.1-4.4, 4.7	4.8-4.10, 4.13		4.5	4.11					4.2, 4.3, 4.9, 4.10	4.1, 4.6, 4.8, 4.12	4.5, 4.7		4.11, 4.13			4.6, 4.12	
Recommendation 5 Access to Primary Care	5.1, 5.2	5.6, 5.7		5.5	5.10	5.4, 5.9	5.5, 5.10		5.2, 5.3, 5.7, 5.8	5.3, 5.8		5.1		5.6				
Recommendation 6 Residential Institutions	6.2, 6.4-6.7, 6.9, 6.1	6.13, 6.14, 6.16-6.19, 6.21, 6.23		6.1, 6.3	6.12, 6.15		6.1, 6.3, 6.12, 6.15		6.4-6.6, 6.16-6.18	6.4-6.6, 6.16-6.18		6.1, 6.4, 6.5, 6.8, 6.9, 6.11		6.12, 6.13, 6.16-6.21, 6.23	6.1, 6.8, 6.9, 6.12, 6.13, 6.16-6.21	6.12		
Recommendation 7 Excluded Groups	7.1-7.3	7.5-7.9				7.3						7.2		7.6	7.2	7.3, 7.7		
Recommendation 8 Reasonable Adjustments	8.2	8.12		8.4		8.2, 8.5, 8.10		8.5, 8.10	8.5, 8.10	8.2, 8.5, 8.10, 8.12	8.1, 8.8	8.3		8.9, 8.12		8.6, 8.11		8.5, 8.7, 8.10, 8.12
Recommendation 9 Health Checks	9.1, 9.2, 9.5, 9.9	9.11-9.21, 9.23-9.27	9.12, 9.13, 9.18-9.24	9.4	9.30	9.1, 9.18-9.22, 9.29	9.4, 9.30	9.3, 9.4, 9.6, 9.28, 9.30	9.3, 9.9, 9.12, 9.15, 9.22, 9.29	9.1, 9.9, 9.12, 9.15, 9.18-9.22, 9.29		9.2, 9.7		9.11-9.13, 9.17, 9.18, 9.23, 9.24, 9.26, 9.31	9.15, 9.24	9.29		9.9, 9.14, 9.15, 9.18, 9.21, 9.22
Recommendation 10 Healthy Living	10.2, 10.5, 10.16	10.12, 10.15, 10.20	10.16	10.9, 10.19	10.19		10.9, 10.19	10.3, 10.4, 10.13, 10.14	10.7, 10.17			10.8	10.16	10.11, 10.18	10.8, 10.10, 10.11, 10.18, 10.20	10.6, 10.10, 10.16	10.1	10.6, 10.16
Recommendation 11 Training	11.2, 11.9, 11.10	11.15, 11.16, 11.19, 11.21				11.2, 11.6, 11.15			11.6, 11.10, 11.17, 11.20, 11.21	11.2, 11.10, 11.15, 11.20, 11.21	11.7, 11.14	11.2, 11.7, 11.9		11.14-11.16, 11.19			11.8	11.3, 11.5, 11.7, 11.8, 11.11, 11.13, 11.14, 11.18

\* These organisations include NPDT, NPSA, CSIP, NLIAH, NHS Alliance, NHS Confederation and NHS Employers

\*\* These organisations include the Royal Colleges and AMSPAR

## Notes and references

<sup>1</sup> This finding, and the analysis on which it is based, is currently being peer-reviewed, prior to publication in a medical journal.

<sup>2</sup> Lindsay P and Burgess D (2006) Care of patients with intellectual or learning disability in primary care. *British Journal of General Practice*, 56, 523: 84–86.

<sup>3</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>4</sup> Nocon A (2006) Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities and/or mental health problems.

<sup>5</sup> Hippisley-Cox J and Pringle M (2005) Health inequalities experienced by people with schizophrenia and manic depression: analysis of general practice data in England and Wales.

<sup>6</sup> Hippisley-Cox J, Vinogradova Y, Coupland C and Parker C (2006) Risk of malignancy in patients with mental health problems.

<sup>7</sup> Hippisley-Cox J, Vinogradova Y, Coupland C, Langford G and Parker C (2006) A comparison of survival rates for people with mental health problems and the remaining population with specific conditions.

<sup>8</sup> Hippisley-Cox J, Vinogradova Y, Coupland C, Langford G and Parker C (2006) A comparison of survival rates for people with mental health problems and the remaining population with specific conditions.

<sup>9</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>10</sup> Nocon A (2006) Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities and/or mental health problems.

- <sup>11</sup> Emerson E and Hatton C (in press) The contribution of socio-economic position to the health status of children and adolescents with intellectual disabilities in Britain. *American Journal on Mental Retardation*.
- <sup>12</sup> Graham H (2004) Socioeconomic inequalities in health in the UK: Evidence on patterns and determinants.
- <sup>13</sup> Hippisley-Cox J, Vinogradova Y, Coupland C, Langford G and Parker C (2006) A comparison of survival rates for people with mental health problems and the remaining population with specific conditions.
- <sup>14</sup> Nocon A (2006) Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities and/or mental health problems.
- <sup>15</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.
- <sup>16</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.
- <sup>17</sup> Hippisley-Cox J, Parker C, Coupland C and Vinogradova Y (2006) Use of statins in coronary heart disease patients with and without mental health problems.
- <sup>18</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.
- <sup>19</sup> Hippisley-Cox J and Pringle M (2005) Health inequalities experienced by people with schizophrenia and manic depression: analysis of general practice data in England and Wales.
- <sup>20</sup> Kerr M, Felce D and Felce J (2005) Equal treatment: closing the gap. Final report from the Welsh Centre for Learning Disabilities.



<sup>21</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>22</sup> Samele C, Hoadley A and Seymour L (2006) A systematic review of the effectiveness of interventions to improve the physical health of people with severe mental health problems.

<sup>23</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>24</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>25</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>26</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>27</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>28</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>29</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>30</sup> Hewstone M (2006) Intergroup contact: panacea for prejudice? *The Psychologist*, 16, 7: 352–355.

<sup>31</sup> Welthagen E, Talbot S, Harrison O and Phelan M (2004) Providing a primary care service for psychiatric inpatients. *Psychiatric Bulletin*, 28: 167–170.

<sup>32</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>33</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>34</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>35</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>36</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>37</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>38</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>39</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>40</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>41</sup> Hippisley-Cox J and Pringle M (2005) Health inequalities experienced by people with schizophrenia and manic depression: analysis of general practice data in England and Wales.

<sup>42</sup> Kerr M, Felce D and Felce J (2005) Equal treatment: closing the gap. Final report from the Welsh Centre for Learning Disabilities.

<sup>43</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.

<sup>44</sup> Alborz A, Kalambouka A, McNally R and Parkinson G (2006) A literature review on the effectiveness of interventions to improve the physical health of people with learning disabilities.

<sup>45</sup> Samele C, Hoadley A and Seymour L (2006) A systematic review of the effectiveness of interventions to improve the physical health of people with severe mental health problems.

<sup>46</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>47</sup> Hippisley-Cox J, Coupland C, Langford G, Parker C and Vinogradova Y (2006) Management of chronic obstructive airways disease in patients with serious mental health problems.

<sup>48</sup> Hippisley-Cox J and Pringle M (2005) Health inequalities experienced by people with schizophrenia and manic depression: analysis of general practice data in England and Wales.

- <sup>49</sup> Hippisley-Cox J and Pringle M (2005) Health inequalities experienced by people with schizophrenia and manic depression: analysis of general practice data in England and Wales.
- <sup>50</sup> Samele C, Seymour L, Morris B, Central England People First, Cohen A and Emerson E (2006) A formal investigation into health inequalities experienced by people with learning difficulties and/or people with mental health problems. Area Studies report.
- <sup>51</sup> Parker C, Hippisley-Cox J, Vinogradova Y and Coupland C (2006) Outcomes following postmenopausal bleeding or rectal bleeding in patients with serious mental health problems.
- <sup>52</sup> Hippisley-Cox J, Coupland C, Langford G, Parker C and Vinogradova Y (2006) Management of chronic obstructive airways disease in patients with serious mental health problems.
- <sup>53</sup> Hippisley-Cox J and Pringle M (2005) Health inequalities experienced by people with schizophrenia and manic depression: analysis of general practice data in England and Wales.
- <sup>54</sup> Hippisley-Cox J, Parker C, Coupland C and Vinogradova Y (2006) Use of statins in coronary heart disease patients with and without mental health problems.
- <sup>55</sup> Green H, McGinnity A, Meltzer H, Ford T and Goodman R (2005) Mental health of children and young people in Great Britain, 2004. Basingstoke: Palgrave Macmillan.
- <sup>56</sup> Emerson E and Hatton C (2004) Estimating the current need/demand for supports for people with learning disabilities in England. Institute for Health Research, Lancaster University.
- <sup>57</sup> Emerson E (2003) Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 47, 1: 51-58.
- <sup>58</sup> Emerson E (private communication).
- <sup>59</sup> Stratton RJ, Thompson RL, Margetts BM, Stroud M, Jackson AA and Elia M (2002) Healthcare utilisation according to malnutrition

risk in the elderly: an analysis of data from the National Diet and Nutrition Survey of people aged 65 and over. Proceedings of the Nutrition Society: 20A.

<sup>60</sup> Malnutrition Advisory Group (2003) The 'MUST' Report: Nutritional Screening for Adults – A multidisciplinary responsibility. London: British Association for Parenteral and Enteral Nutrition.

<sup>61</sup> Healthcare Commission, Commission for Social Care Inspection and Audit Commission (2006) Living Well in Later Life. London: Commission for Healthcare Audit and Inspection.

<sup>62</sup> DRC (2006) Results from questionnaires for people with learning disabilities and/or mental health problems, and for primary care practitioners.

<sup>63</sup> Healthcare Commission (2005) Count Me In. Results of a national census of inpatients in mental health hospitals and facilities in England and Wales. London: Commission for Healthcare Audit and Inspection.

<sup>64</sup> Keating F, Robertson D, McCulloch A and Francis E (2002) Breaking the Circles of Fear. London: Sainsbury Centre for Mental Health.

<sup>65</sup> Morris J (2004) 'One Town for my Body, Another for my Mind'. Services for People with Physical Impairments and Mental Health Support Needs. York: Joseph Rowntree Foundation / York Publishing Services.

## **Equal Treatment investigation publications**

The publications below are available electronically at [www.drc-gb.org/healthinvestigation](http://www.drc-gb.org/healthinvestigation) Those marked with an asterisk are also available in hard copy and can be ordered from the **DRC Helpline 08457 622 633, textphone 08457 622 644**

**Equal treatment investigation report – Part 1\***

**Equal Treatment investigation report – Part 2 (Inquiry Panel)**

**Wales report\***

**Summary for health commissioners (England only)\***

**Summary for practitioners\***

**Summary for disabled people\***

**Easy Read report\***

**Evidence from the literature review**

**Health inequalities monitoring tool**

**Investigation research reports**




An Equal Treatment investigation DVD has also been produced, which will be particularly useful for primary care practitioners and for trainers. Limited copies are available and can be ordered from the DRC Helpline.

You can contact the DRC Helpline by voice, text, fax, post or by email via the website. You can speak to an operator at any time between 08:00 and 20:00, Monday to Friday.

If you require this publication in an alternative format and/or language please contact the Helpline to discuss your needs. It is also available on the DRC website: [www.drc-gb.org](http://www.drc-gb.org)

You can email the DRC Helpline from our website:  
[www.drc-gb.org](http://www.drc-gb.org)

**HEALTH2**

-  **DRC Helpline** 08457 622 633
-  **Telephone** 08457 622 644
- Fax** 08457 778 878
- Website** [www.drc-gb.org](http://www.drc-gb.org)
  
-  **Post** DRC Helpline FREEPOST  
MID 02164  
Stratford upon Avon  
CV37 9BR



INVESTOR IN PEOPLE

