

PART 2 OF THE DRC'S FORMAL INVESTIGATION REPORT

Report of the DRC Formal Inquiry Panel to the DRC's Formal Investigation

into the inequalities in physical health experienced by people with mental health problems and people with learning disabilities

July 2006

Disability
Rights
Commission



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Overview

- 1 The Disability Rights Commission (DRC)'s Formal Investigation has asked us to identify effective and feasible approaches to closing the gap of health inequalities highlighted by the Investigation.
- 2 Having received a great deal of written and oral evidence on the subject it is our clear view that:
 - It is not acceptable that people with learning disabilities and/or mental health problems tend to experience poorer physical health and die younger than other people.
 - It is also not acceptable that, in many instances, those people do not have full and proper access to the primary health care services they need to promote their health and well-being.
 - Those inequalities are not inevitable.
 - They have existed for far too long.
 - Those inequalities have been allowed to persist partly because people with learning disabilities and mental health problems all too often have reduced expectations of their physical health and of the services to support their physical health. That has been compounded by low expectations on the part of practitioners and policy makers.
 - Meeting the physical health needs of people with learning disabilities and mental health problems has, for too long, been given insufficient priority. This is true across the life course, and for women and men; albeit that the specific barriers people face differ by factors including age, ethnicity and gender.

- Urgent action needs to be taken to tackle those problems.
 - Many different people and organisations have a part to play. They need to act, now.
 - 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.
- 3 We have made detailed recommendations on who needs to do what.
- 4 Many of those bodies are ‘public authorities’ (including the Department of Health and the Welsh Assembly Government) and so are subject to the new Disability Equality Duty (DED) under the Disability Discrimination Act 2005 (DDA) which requires them, when carrying out their functions, to have due regard to the need to (among other things):
- promote equality of opportunity between disabled persons and other persons
 - eliminate discrimination that is unlawful under the Act
 - promote positive attitudes towards disabled persons
 - encourage participation by disabled persons in decision-making structures and processes; and
 - take steps to take account of disabled persons’ disabilities, even where that involves treating disabled persons more favourably than other persons.
- 5 Our recommendations clearly fall within the terms of the DED. Compliance with the Duty should lead to those recommendations being implemented by the relevant authorities.

- 6 The public authorities in question are also required to produce, by 4 December 2006, Disability Equality Schemes explaining how they are going to give effect to their Disability Equality Duty. We would expect those Schemes to show clearly that action has been taken to implement our recommendations and reduce health inequalities. Bodies such as the DRC and Healthcare Commission will have a clear role in checking that happens.
- 7 But it is important to remember that the specific suggestions for action which we make (such as the detailed practical suggestions for making primary care services more accessible) already fall within the ambit of the long standing duties to make 'reasonable adjustments' under the Disability Discrimination Act 1995 which does not just apply to public authorities. Accordingly, even bodies not specifically subject to the DED (such as General Practitioners (GPs) practices for example), should consider taking action. Indeed, they could and should have done so already and it is a great disappointment that they have not done so. This report should provide them with a reminder of their obligations and a pointer as to what they can and should now do. And the DRC can monitor progress and take appropriate action where there has been insufficient progress.
- 8 Our recommendations are entirely consistent with the thrust of current Government and Welsh Assembly Government policy including the themes of the English Health White Paper 'Our Health, Our Care, Our Say' and the Welsh Assembly Government's 10 year strategy for health and social care in Wales – 'Designed for Life' – published in May 2005.
- 9 Accordingly, what we are suggesting should be entirely achievable.

- 10 However, the current emphasis within those documents on inequalities arising from poverty and from geography (where people live) needs to be broadened to ensure that the physical health inequalities experienced by people with learning disabilities and mental health problems are properly prioritised as part of wider action to tackle health inequalities.
- 11 Thus, for example, people with mental health problems and learning disabilities are particularly affected by reduced life expectancy and premature death (with particularly alarming examples being reported to us involving members of Black and Minority Ethnic (BME) communities). Similarly, people with mental health problems are more likely to smoke such that targeting smoking cessation support on such people would have a particular benefit for meeting wider targets for reducing smoking generally. Achieving equality for people with learning disabilities and mental health problems must be a key and essential part of the overall process of tackling health inequalities.
- 12 Equally, care needs to be taken to ensure that all proposed changes to health services (for example, in England moves to increase patient ‘choice’ in relation, say, to choosing a GP) are implemented in a way which recognises the particular needs of people with learning disabilities and mental health problems. Those people must get the full benefit of those more general changes which should provide an ideal opportunity to tackle some key long-standing inequalities. It would be quite wrong if, for example, general moves to increase the opening hours of GP practices were to achieve priority over the implementation of basic ‘reasonable adjustments’ designed to secure equality for people with learning disabilities and mental health problems.

- 13 Similarly, at national level in England and Wales, targets, for instance to reduce premature deaths from cancer or chronic heart disease, should be broken down by disability (including mental health problems and learning disabilities) so that policy makers focus on whether these highly excluded groups are or are not benefiting over time from general positive trends in life expectancy.

David Wolfe

Chair of the Formal Inquiry Panel

July 2006

Preface – The Panel and our Inquiry Process

- 1 The members of the Inquiry Panel are listed at Appendix 1. We also received advice, information and support from the DRC staff members and external advisers listed at Appendix 2.
- 2 The DRC Formal Investigation asked us to identify effective and feasible approaches to closing the gap of health inequalities highlighted by the Investigation.
- 3 In response to our initial request for submissions from a wide range of organisations, we received written submissions from the organisations listed in Appendix 3.
- 4 We met with the people listed in Appendix 4.
- 5 We circulated a draft (one version for England and another for Wales) of our recommendations for comment and received responses to it from the people listed in Appendix 5.
- 6 Appendix 6 explains the abbreviations we have used.
- 7 We are most grateful to all of the people and organisations mentioned above.
- 8 Some of them represent people with learning disabilities or mental health problems. Most of the rest have a role in the provision of health services to those people. All of them have key and obvious relevant expertise.
- 9 Although we have given some consideration as to why there has been a lack of action to address the problems we have identified, our main focus has been on what needs to be done to tackle those problems.
- 10 We are aware that our full list of recommendations and action points may seem daunting. However, with the exception of the Department of Health and the Welsh Assembly Government

(which need to take action in relation to all our recommendations), other organisations are only implicated by some of our recommendations. So while the task to be completed remains challenging, we consider that it is achievable.

- 11 We have not prioritised our recommendations because we consider them all to be important. Nevertheless, we recognise that the DRC, in Part 1 of its formal investigation report, has provided some top priorities as well as endorsing our complete action plan. It should be noted that, as explained above, not all recommendations require action by all organisations (with the exception of the Department of Health and the Welsh Assembly Government which are widely implicated).
- 12 We have also not ‘costed’ our recommendations. That is partly because we have avoided giving detailed prescriptions of how things should be done given that the cost of implementing something often depends upon precisely how it is implemented. It is also because we want full and proper consideration to be given to all of our recommendations by the organisations to which they are directed, rather than have some of them prematurely dismissed as too expensive. That is particularly so given that many of them involve no more than a change of emphasis, a change of policy, a change of attitude or a change in culture; and probably not significant expenditure.
- 13 As explained further below, we were struck by the almost complete agreement among everyone who gave evidence to us on what needs to be done, at least in overall terms. And their willingness to take action. For example, the National Health Service (NHS) Employers said that:

“NHS Employers welcome these interim findings and proposed solutions and will seek to support their agreed implementation through providing expertise and support to employers and employees.”

And, when giving oral evidence, Dr John Chisholm from the British Medical Association (BMA) said that:

“I think there is a message here for GPs and practices, which is that for some client groups they have to try harder in order to deliver the same outcomes.”

- 14 As a result, we have not considered it necessary or appropriate to include within our report extensive references to, or summaries of, the evidence we have received. That material, including transcripts of the sessions in which the Panel heard evidence is available at www.drc-gb.org/healthinvestigation
- 15 We have, where it seemed appropriate and necessary, tried to take account of planned changes, say in organisational structures and responsibilities. However, in a fast changing social care and health system, our Report unavoidably reflects the position at a particular point in time.
- 16 We have tried to take account of national difference and so have separated out ‘Who needs to do what in England’ from ‘Who needs to do what in Wales’. We would encourage organisations to consider working across borders to learn from good practice in each others countries and to work together to implement recommendations where doing so will progress matters more quickly. This is, of course, particularly pertinent for those recommendations involving organisations with a remit covering both nations which require action in both nations.
- 17 We are pleased to report to the DRC’s Formal Investigation as follows:

Introduction

The problems

- 1 It is overwhelmingly acknowledged, and clear from the evidence we have received, that people with learning disabilities and/or mental health problems experience considerable inequalities in their physical health and in their access to and treatment from primary care services (including from professionals such as practice nurses, dieticians and GPs) to deal with their physical health problems as compared with the general population.
- 2 Within that overall picture, there are many variations. In particular, the inequalities experienced by people with learning disabilities are not the same as those experienced by people with mental health problems, although there is a considerable overlap between the experiences and the action needed to tackle them. Equally, different people with learning disabilities or different mental health problems will experience different inequalities in physical health; children or elderly people may experience particular or additional inequalities which require particular responses. Overall, the required solutions will vary and will need to be tailored to the particular group or situation in contemplation, in a way that our – inevitably generalised – Report has not sought to do in a comprehensive way.
- 3 ‘Diagnostic overshadowing’ (where symptoms of a physical health problem are wrongly diagnosed as being a symptom of learning disabilities or mental health problems) is an area of particular concern. So too is an undue focus on learning disabilities/mental health needs at the expense of physical health needs (eg in the provision of forensic psychiatric services).

- 4 People whose physical health needs are not under the care of a primary care specialist, such as people with mental health problems while they are mental health inpatients (during which time their physical health needs are the responsibility of a psychiatrist) are particularly affected by these inequalities.
- 5 The evidence before us also suggests that people living in residential care or those who are homeless also often experience a reduced level of access, despite their entitlement to full access to primary care services. Children and young people have particular needs. As do people with autistic spectrum disorders, those with multiple impairments, the families and carers of people with those difficulties, and people with those difficulties who live in rural areas. Members of Black and Minority Ethnic (BME) communities are particularly affected by these inequalities. In the time available to us, we have not been able to give sufficient attention to what is required to tackle the problems they face. Nevertheless, in its wider investigation, the DRC has considered a range of issues relating to the different journeys through primary care experienced by different groups.

Good practice needs to become general practice

- 6 Within that overall bleak picture, we have heard of many individual instances of good local practice. For example, some GP practices have taken creative and innovative positive steps to make their services more appropriate for, and accessible to, people with learning disabilities or mental health problems. And some Primary Care Trusts (PCTs) and Local Health Boards (LHBs) have set up imaginative schemes for improving access to primary care services, such as for people with learning disabilities and mental health problems who are homeless. The best of these have involved users in the design, planning and implementation of what they do. The good practice we have

heard about shows that action to address some of the problems we have identified can be taken where there is a will to do so.

- 7 It would be a start if the good practice became general practice. But too little overall or strategic action is being taken at all levels by the organisations with the power to bring that about.

Urgent action is needed

- 8 We have not found any in-principle objection to taking action. We are pleased to report that there seems to be a huge goodwill to do so. That is a good start.
- 9 But there is also a widespread recognition that actually doing something about the problems involved has generally been a low priority at all levels within the health service. We have explored why that is.

Existing policy commitments have not led to enough action being taken

- 10 One major problem is that the main drivers for change in the health system are targets and financial incentives which have not so far taken sufficient account of the physical health needs of people with learning disabilities and mental health problems. That has contributed significantly to the fact that little has been done to address those problems. For example, in Wales, the National Service Framework (NSF) for Mental Health includes a policy which specifically promotes the physical health needs of people with mental health problems. But that policy seems to have little priority in practice because it does not feature in the 'Service and Financial Framework (SAFF)' targets against which action by the health service is measured.

- 11 Even where there have been relevant and positive policy commitments at the highest level in relation to the physical health needs of people with learning disabilities and mental health problems, these have not been translated into changes ‘on the ground’. For example, in England the ‘Valuing People’ White Paper of March 2001 set out a ‘New Strategy for Learning Disability for the 21st Century’ with a foreword personally signed by the Prime Minister. It promised that all people with learning disabilities would be registered with a GP by June 2004, and that all people with learning disabilities would have a ‘Health Action Plan’ by June 2005. Those things have not happened.
- 12 In England, Valuing People also stated that ‘the Government has launched a comprehensive plan to tackle health inequalities and work is taking place across government to tackle the root causes’ and that ‘the Government will ensure that policies on health inequality make explicit reference to people with learning disabilities’.
- 13 In 2003 the Department of Health in England published ‘Tackling Health Inequalities: A Programme for Action’ which, in the light of the Valuing People commitment, might have been expected to detail clear action to address the health inequalities experienced by people with learning disabilities. It too had a foreword signed by the Prime Minister. But Valuing People, and issues around health inequalities for people with learning disabilities, were barely mentioned in the health inequalities document. The only reference made was that the Department of Health was the ‘responsible department’ for addressing health inequalities as identified in Valuing People, and that local authorities, PCTs, GPs and health facilitators were the ‘delivery mechanism’.

- 14 In fact, the ‘Programme for Action’ simply stated the current position, but it did not call for or suggest – let alone require – any action to tackle the problems involved. It seems that the problem may have been compounded, or indeed caused by, the fact that the targets (‘Public Service Agreement (PSA) targets’) which set the priorities for the work of the Department of Health take no account of the particular inequalities experienced by disabled people, and specifically those with learning disabilities and mental health problems.

More leadership is needed from the Department of Health and the Welsh Assembly Government

- 15 Although there are undoubtedly examples of very good practice within some local authorities, PCTs, LHBs and GPs’ practices, this has been through local initiative, is not widespread and is largely unconnected to any action by the Department of Health. We consider that there needs to be consistent and clear political leadership to see commitments implemented.
- 16 We believe that the fragmentation of decision-making responsibility and a lack of clarity in the mechanisms of control and influence within the health service (particularly in England) has slowed down action to tackle the inequalities we have identified. We fear that those problems will hinder action in the future. In particular, even where particular individuals or bodies have identified inequalities or been given a clear role to promote the particular needs of people with learning disabilities or mental health problems, they lack any real power to bring about change (in either Wales or England). They can do little more than lobby the people with the power to bring about change (such as those who set targets or negotiate contracts). And they have struggled in the past to get those people to act because the inequalities with which we are concerned seem to have been a low priority for those people.

- 17 Given that fundamental structural change is unlikely, it follows that much more concerted action is needed across the health service than has previously been present if the inequalities we identify are to be addressed.
- 18 In particular, given the shift (as explained to us by a senior representative from the Department of Health) from 'command and control' to influence through 'policy and incentives' it is all the more important that those new mechanisms are fully utilised to bring about the changes we describe.

A commitment to change is needed

- 19 What is clear, and universally agreed by the people who gave evidence to us (including representatives from the Department of Health and the Welsh Assembly Government), is that the physical health needs of people with learning disabilities and mental health problems must now be 'moved up the agenda' at all levels of the health services in England and Wales. Service users and groups that represent those people could demand more if made more aware of their entitlements. A clear lead is also needed from the top of, and throughout, the health service. That lead needs to be matched by a clear commitment to act from all organisations with an ability to bring about change.

Concerted action could bring about real change

- 20 It is clear to us that, if all such organisations were to use their power and influence to bring about change at the earliest opportunity, real progress could be made. All the organisations which gave evidence to us said they have a role in promoting action to address the inequalities with which we are concerned, and all told us that they were willing to do so. We welcome that. It provides real scope for optimism that things could change for the better for people with learning disabilities and mental health problems.

- 21 We are conscious that many factors are involved in the causation of inequality. Things like poverty, poor housing and unemployment, all of which can often be both caused and exacerbated by disability discrimination, can have a key effect on physical health and on physical health inequalities. But they are not directly within our remit, and we have not made recommendations in relation to them.
- 22 But, even putting aside those other causes of inequality and focusing on the direct provision of primary care services as we have done, the clear message coming from this Inquiry is that further action is needed by all organisations with a direct or indirect influence on the inequalities in question. That ranges from front-line providers, such as GPs, practice nurses, their staff and the primary care team, through to all levels within the Department of Health and the Welsh Assembly Government. It also includes regulators and inspection bodies, professional bodies, user groups, other Non-Governmental Organisations (NGOs) and indeed bodies such as the DRC (including in conjunction, in England, with the Department of Health through the DH/DRC Action Partnership Framework). All of them need to take action now, and in collaboration with each other as necessary, to address long-standing inequalities.

Our recommendations for action

- 23 Accordingly, we have brought together some key recommendations for change. The ideas behind the recommendations have come largely from the people and organisations who gave evidence to us. Many of the ideas have been around for a long time. For example, in its 'Treat Me Right' report in 2004, Mencap made some of the same recommendations in relation to the needs of people with learning disabilities. It is alarming that little or nothing has been done to put many of those recommendations into effect by the people and organisations with the power to do so.

That is why we have also identified who we think needs to do what to implement the recommendations in a series of 'action points'. We hope that focusing on who needs to do what and identifying the organisations and people with the power to bring about change, we can ensure that those organisations and people do what they can, and now, rather than leaving it to others, or for later.

- 24 Our recommendations are set out in more detail on the pages that follow. They seek to address:
- Actual health inequalities (such as lower life expectancy and reduced quality of life).
 - Some of the direct causes of health inequalities (such as the side effects of psychiatric medication).
 - Specific inequalities in access to primary care services (such as lack of access to a GP and a primary care team).
 - Improvements in the way primary care services are provided (such as through better information to patients, equitable treatment or improved staff training).

Key themes

- 25 There are a number of key themes running through both our recommendations and the action we consider needs to be taken to implement them. These are worth spelling out at the outset. They are set out below in no particular order.
- Action needs to be taken to challenge low expectations and lack of knowledge on the part of people with learning disabilities and mental health problems as to what they should rightly be able to expect in terms of physical health and what they are entitled to in the form of services to address their physical health. Users and user groups must be empowered to demand more from

the health service. Change must come from the 'bottom' as well as the 'top'.

- It is clear that perception and stigma are key barriers to access to services and key drivers of discrimination and inequality. They need to be addressed urgently, including by equality and awareness training of key staff from users and user groups themselves, amongst others.
- The lack of detailed research into the problems caused by discrimination in access to primary care services should not prevent or delay urgent action to address these problems. The Disability Discrimination Acts of 1995 and 2005 create specific rights for disabled people including the right to equality of access to health services and the right to equality of opportunities arising from those health services. Securing equality of opportunity will sometimes mean that people with mental health problems need a higher level of service, or a different service than those without. For example, they may sometimes need a longer appointment with their GP than the current fixed slot which is generally available under the GP contract. The DDA 1995 and the DDA 2005 should lead everyone, from the Secretary of State to the individual GP practices, to take positive action to eliminate discrimination, encourage participation by disabled people in decision-making structures and processes and to promote positive attitudes towards disabled people. Monitoring and evaluation of the initiatives which give effect to those obligations can then be used to improve services in the future and help fill the current gaps in knowledge as to what is most effective in addressing the health inequalities with which we are concerned.
- Our clear view is that people with learning disabilities or mental health problems should be enabled to receive

their primary care services in the same way as everyone else, whether by attending a GP practice or other facility through which, for example, advice from a dietician is made available (including facilities which provide primary care alongside secondary care through, for example, innovative links with Accident & Emergency (A&E) departments). Targeted outreach services or home visiting would still be necessary for some people in some situations, but should not be the norm. However, enabling people to receive their primary care by attending the GP surgery will require a range of practical changes including significant improvements in the way in which GP surgeries deal with people with learning disabilities and mental health problems. Flexible appointments, as mentioned above, are an example of such a change. Such changes are likely to be 'reasonable adjustments' and thus have been required under the DDA since 1999. Most involve little expense. With strategic leadership, they have the potential to bring about real improvements. Similar changes should take place at other health settings, such as walk-in centres. There is no excuse at all for the changes as set out above not to happen.

- People with learning disabilities and mental health problems (and their carers where appropriate and subject to the requirements for consent and the maintenance of confidentiality) need information about health related matters and services to be given to them in an accessible and relevant form of their preference, if it is to be effective. That may include staff explaining information in face to face contact with people who cannot read. It may include documents in Easy Read or audio form, or in languages other than English. Similarly, greater use of email, fax and other electronic means of

communication would make it easier for some people with learning disabilities or mental health problems to access health services including, for example, when it comes to booking appointments.

- Users and user groups can offer a very knowledgeable and enthusiastic resource and should be involved in policy-making as consultees and, wherever possible, should form part of the decision-making body. For example, in Mental Health or Learning Disability Trusts there should be an expectation that people with mental health problems or learning disabilities will be on the board. As mentioned above, action to tackle inequality is often at its most effective when people with learning disabilities or mental health problems are involved in the design, implementation and operation of any action undertaken. Users and user groups should also be at the heart of designing, developing and providing disability equality and awareness training, as above.

Following up our recommendations

- 26 Our recommendations and suggestions for action are set out on the following pages. If everyone were to act as we have suggested, and without delay, a lot could be achieved. We hope they will do so. The DRC should encourage them to do so. The DRC should also ensure that the work of this Inquiry is followed up in, say, one year to report on progress. That follow-up should include an evaluation of the extent to which our recommendations have formed part of the Disability Equality Schemes which Public Authorities are required to produce by 4 December 2006 as part of their obligations under the new Disability Equality Duty under the Disability Discrimination Act.

Wider impacts and benefits

- 27 Finally, although our Inquiry has been into health inequalities in relation to primary health care, we believe that people with learning disabilities and/or mental health problems also face similar inequalities in relation to other health services. Many of our recommendations (eg for accessibility improvements, user involvement and training) would seem equally applicable in that context (and, as above, they are consistent with general innovations being promoted in the latest Department of Health and Welsh Assembly Government policy documents).
- 28 We are also conscious that many of the changes we suggest around, for example, improved appointments systems, could equally benefit people beyond the groups with which we are directly concerned, including other disabled people (such as those with sensory impairments, mobility impairments or long term health conditions). This should make them easier to implement. But, equally, making them available to people with learning disabilities and mental health problems should not mean having to wait for them to be available to everyone. Action must be taken now to address the historic inequalities.
- 29 What follows are our suggestions to the overall DRC Formal Investigation as to recommendations and action points which it might wish to include in its final report.

Recommendation 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

In accordance with the DDA 1995 and the Disability Equality Duty under the DDA 2005, all organisations (including policy makers and related bodies, commissioners, regulators and professional bodies) with a role in, or influence over, the services (including primary care services) relating to the physical health of people with learning disabilities and/or mental health problems should:

- 1 Act to promote effective interventions to ‘close the gap’ of inequality in health outcomes (eg premature mortality) and access to health services, between people with mental health problems and/or learning disabilities and other citizens.
- 2 Promote the rights of people with learning disabilities and/or mental health problems to good physical health and services (including primary health care services) to promote access to good physical health.
- 3 Track changes and their effectiveness over time.
- 4 Ensure that their policies, including Disability Equality Schemes under the DDA 2005 where applicable, include action to address inequalities experienced by people with learning disabilities and/or mental health problems in physical health and access to health services, checks and treatments to address poor physical health.

- 5 Secure the basic rights of the people involved by taking positive steps and making reasonable adjustments without seeking to justify inaction by the lack of research into the effectiveness of the steps involved. Accordingly, (as the National Patient Safety Agency put it to us):

“where barriers or disadvantages are identified within Disability Equality Schemes, action [should] be taken to address them even where such positive steps are unproven and/or experimental, as this will push forward innovation in tackling barriers”.
- 6 Consult and involve users and user groups in decisions around those services and in the auditing and monitoring of the effectiveness of those services.
- 7 Ensure that they make available all relevant information in an accessible and relevant form as preferred by users and that steps are put in place to ensure that the key information has been properly understood by users.
- 8 Ensure that staff involved in delivering or making decisions about the provision of relevant services have received disability equality and awareness training including with input from users and user groups wherever possible.
- 9 Be aware of, and responsive to, the needs of family carers of people with learning disabilities and/or mental health problems.
- 10 Act to encourage, assist and, where appropriate, require (whether through commissioning or regulation as appropriate) others involved in the provision of primary care services to people with learning disabilities and/or mental health problems to do 1-9.

- 11 Use assessment and performance management frameworks to ensure that both organisations and individual staff give effect to the principles set out in this report. Thus, for example, in England the Core Standards used by the Healthcare Commission for assessing the performance of healthcare organisations include the following:

Core Standard C18:

Healthcare organisations enable all member of the population to access services equally and offer choice in access to services and treatment equitably.

And

Core Standard C7e:

Healthcare organisations ... challenge discrimination, promote equality and respect human rights.

Those could plainly form the foundation for requiring action to address the inequalities considered in this report.

Who needs to do what in England?

- 1.1 A strategic lead needs to be taken at the highest level within the Department of Health and (led by the Office for Disability Issues) across government to ensure action by the Department and all other relevant bodies urgently to address the historic low priority given to tackling the inequalities we have referred to.
- 1.2 Tackling the inequalities we describe should form part of the Department of Health's 'departmental objectives' at the highest level. The relevant PSA targets should be broken down so that tackling such inequalities becomes a practical priority.

- 1.3 The Department of Health, Strategic Health Authorities (SHAs), PCTs, Local Authorities, regulators and other relevant bodies, when carrying out equality impact assessments under their respective duties arising from the Disability Discrimination Act 2005, should incorporate the findings within their assessments, and within their Disability Equality and Race Equality Schemes. They should report on progress in their subsequent annual reports.
- 1.4 Directors of Public Health and Directors of Adult Social Services, in gaining understanding of the health needs of their whole community, should explicitly report on the health needs of people with mental health problems and/or learning disabilities in their local strategic assessment of need (introduced in 'Our Health, Our Care, Our Say' the January 2006 White Paper). This evidence should directly inform commissioning for the whole population; and the Healthcare Commission should monitor whether commissioning has been properly informed by evidence of inequalities experienced by these groups.
- 1.5 The Secretary of State for Health in England, when providing an overview of progress made in her policy sector, should report on progress in tackling health inequalities experienced by people with severe mental health problems and/or people with learning disabilities, including progress in 'closing the gaps' of inequality and in implementing the recommendations of this Inquiry, as part of the reporting duties placed on her by the specific duties regulations of the amended Disability Discrimination Act 1995.

- 1.6 The Department of Health should make full use of the mechanisms available to it to give effect to our recommendations, including through guidance, target setting, contract specification and the PCT ‘accountability framework’. A key action will be to include within the new contract for GPs (the new General Medical Services (nGMS) contract) requirements which give effect to our recommendations including, in particular:
- Recommendation 8 (below) which calls for GPs and other staff involved in providing primary health care to make reasonable adjustments to make their services more accessible.
 - Recommendation 9 (below) which calls for people with learning disabilities and/or mental health problems to be offered an annual health check.
 - Recommendation 11 (below) which calls for GPs and other staff involved providing services relating to primary health care to receive disability equality and awareness training from people with learning disabilities and/or mental health problems.
- 1.7 The Department of Health should draw up and publish a ‘timeline’ explaining the steps which it proposes to take to tackle these matters, and the timescale over which that will take place. It should monitor progress against that timeline and report on progress or the reasons for any lack of progress.

1.8 Based on her experience of handling complaints, the Parliamentary and Health Service Ombudsman suggests that

“ ... the Department of Health should take a more active role in pulling together existing guidance on improving public health which is currently quite dispersed, and making it more accessible to all sectors of the community, but particularly those with significant communication or capacity impairments”.

We agree.

1.9 As part of giving effect to the Disability Equality Duty (DED), the Department of Health should identify indicators of the physical health inequalities experienced by people with learning disabilities and mental health problems (including life expectancy), include those indicators within the relevant PSA target and monitor progress in tackling those inequalities by reference to those indicators.

1.10 Similarly, PCTs should include within their Disability Equality Schemes monitoring and reporting on the inequalities in question (guidance on monitoring can be found at www.drc-gb.org/healthinvestigation). If challenged under the DED, it would be for PCTs to explain the action they had taken to work towards equal outcomes and equal access and patient experience.

1.11 Action is also needed by all organisations with a role in promoting good practice, commissioning, regulating and providing services relating to the physical health of people with learning disabilities and/or mental health problems, and policy decisions relating to those services.

Who needs to do what in Wales?

- 1.12 A strategic lead needs to be taken at the highest level within the Welsh Assembly Government (WAG) to ensure action by the Health and Social Care Department, NHS Wales and all other relevant bodies and departments, urgently to address the historic low priority given to tackling the inequalities we have referred to.
- 1.13 Tackling the inequalities we describe should form part of the Welsh Assembly Government's objectives at the highest level.
- 1.14 'Designed for Life', the WAG's 10 year vision for Health, states that there is to be a Revised Health Inequalities Strategy to be published in 2009. The review of Health Inequalities and the resulting strategy should explicitly emphasise the health inequalities faced by disabled people and a commitment to tackle them, and needs to give weight to disability equality (in line with the Welsh Assembly Government's and NHS's obligations to comply with the Disability Equality Duty) in developing services.
- 1.15 Moreover, the Welsh Assembly Government should develop a single over-arching Health Inequalities Strategy, which comprehensively addresses health inequalities experienced by disabled people, including these groups of disabled people, (alongside all the other work the Assembly does to address health inequalities), so that this strategy and associated action plans can, as planned in 5.3 of 'Designed for Life', be reviewed in 2009.

- 1.16 The Assembly Government and NHS Wales, Local Health Boards (LHBs), Local Authorities, regulators and other relevant bodies, when carrying out equality impact assessments under their respective duties arising from the Disability Discrimination Act 2005, should incorporate the findings within their assessments, and within their Disability Equality and Race Equality Schemes. They should report on progress in their subsequent annual reports.
- 1.17 Public bodies responsible for health should ensure that the tools used to equality impact assess and supporting literature on the DED, draw attention to health inequalities experienced by disabled people, and particularly these groups of disabled people, so that these issues do not get overlooked by those carrying out assessments.
- 1.18 The report of the First Minister on progress made towards meeting the DED in relation to the health service in Wales, should include an account of progress in tackling health inequalities experienced by people with severe mental health problems and people with learning disabilities, including progress in implementing the recommendations of this Inquiry. (Explanatory note – at end of this recommendation)
- 1.19 As part of giving effect to the DED, the Welsh Assembly Government should identify indicators of the physical health inequalities experienced by people with learning disabilities and mental health problems (including life expectancy), include those indicators within existing targets or create new targets and monitor progress in tackling those inequalities by reference to those indicators.

- 1.20 Similarly, LHBs should include within their Disability Equality Schemes monitoring and reporting on the inequalities in question (guidance on monitoring can be found at www.drc-gb.org/healthinvestigation). If challenged under the DED it would be for LHBs to explain the action they had taken to work towards equal outcomes and equal access and patient experience.
- 1.21 The Assembly Government should ensure that all those responsible for the health of the population of Wales, should, in gaining an understanding of the health needs of the population, explicitly report on the health needs of people with learning disabilities and people with mental health problems. This evidence should directly inform commissioning for the whole population; and those responsible for inspection and regulation should monitor whether commissioning has been properly informed by evidence of inequalities experienced by these groups.
- 1.22 The Welsh Assembly Government should make full use of the legislative, executive and administrative mechanisms available to it to give effect to our recommendations, including through guidance, target setting, contract specification performance management and accountability through regional offices and LHBs. A key action will be to include within the new contract for GPs (the nGMS contract) requirements which give effect to our recommendations including, in particular:
- Recommendation 8 (see pg 81) which calls for GPs and other staff involved in providing primary health care to make reasonable adjustments to make their services more accessible.
 - Recommendation 9 (see pg 88) which calls for people with learning disabilities and/or mental health problems to be offered an annual health check.

- Recommendation 11 (see pg 104) which calls for GPs and other staff involved providing services relating to primary health care receive disability equality and awareness training from people with learning difficulties and/or mental health problems.
- 1.23 The Welsh Assembly Government should draw up and publish a ‘timeline’ explaining the steps which it proposes to take to tackle these matters, and the timescale over which that will take place. It should monitor progress against that timeline and report on progress or the reasons for any lack of progress.
- 1.24 Action is also needed by all organisations with a role in promoting good practice, commissioning, regulating, and providing services relating to the physical health of people with learning disabilities and/or mental health problems, and policy decisions relating to those services.
- 1.25 There should be strategic, clear and transparent pathways for turning a successful local health inequalities pilot project or local initiative into a national scheme. The steps involved, should be clarified and information and guidance readily available to user groups, voluntary sector organisations, primary health care providers, public health development workers, local authorities and others involved in small local projects. This should include guidance on what makes a successful or effective project, how to evaluate a project, how to share the good practice, and how to access policy makers and influence or reflect the current national policy priorities and interests. The National Leadership and Innovation Agency for Healthcare should spearhead this work in collaboration with the Office of the Chief Medical Officer (OCMO), National Public Health Service (NPHS), those already involved in projects funded by WAG/NHS, Wales Council for Voluntary Action (WCVA) and disability organisations.

Explanatory Note:

The Disability Discrimination (Public Authorities) (Statutory Duties) Regulations 2005, arising under the Disability Discrimination Act 1995 (as amended in 2005), place the duty to report on the National Assembly for Wales, but it is understood that the reporting duty will in fact rest with the First Minister. The First Minister is to report every three years, the first report to be published by 1 December 2008.

Recommendation 2:

The planning and commissioning of primary care services for people with learning disabilities and/or mental health problems need to take greater account of their physical health care needs

We consider that some significant barriers to making progress in local services are related to problems derived from features of the wider health care system, such as the effect of national priority and target setting on local decisions, issues of fragmentation, and confusion about roles. A clear shared understanding about the respective roles, and contribution of different parts of each country's healthcare system, including the Department of Health and the Welsh Assembly Government, is essential for delivering patient-led services and improving health. It is also vital to ensure that each part can make a contribution to the whole that makes a positive impact.

We have identified a number of areas in which action should be taken to benefit people working locally wherever they are, and to accelerate change across a range of functions and organisations. We have in mind national leadership, inspection and performance management, planning and commissioning services, evaluation and sharing the interventions that work. And underpinning much of this, the information and evidence base that everyone can draw on to set priorities, plan and make decisions, invest resources, steer service provision and judge success.

We touch on 'leadership' in various ways throughout this report. Here, we want to re-emphasise the need for visible leadership, particularly at the top, and a clear line of direction running consistently across the Department of Health and Welsh Assembly Government, translated into decision-making on the ground in order to tackle the inequalities we have been considering. Leadership can be strengthened in two key dimensions. First, ensuring the full participation of disabled people in top decision-making bodies. Second, a more focused public accountability framework, one which we believe the new Disability Equality Duty provides.

We have proposed above a number of action points concerned with national standards, improving commissioning, inspection and performance management in respect of particular recommendations.

Fundamental to all of this, we recognise how the current approaches to measuring health inequalities militate against making good progress in the areas of concern to this inquiry. In particular, current policies in both countries on addressing health inequalities tend to focus overwhelmingly on inequalities arising from poverty and geography (ie where people live). That must change to include the inequalities on which we are reporting.

We have repeatedly heard from witnesses how people with disabilities, including people with mental health problems and/or with learning disabilities and, to an extent, Black and Minority Ethnic people, remain largely invisible in national policy and priorities for health inequalities, as we noted earlier. This problem is compounded by the absence of indicators in the health inequalities baseline measures and in other national data collections.

In England

We note this issue is highlighted in ‘Tackling Health Inequalities: Status Report on the Programme for Action’ published in August 2005, three years after the original PSA target was set. We note that the Status Report explains that gaps in the available data make it impossible to report on the experience of groups such as disabled people, but, to our knowledge, no action is proposed to remedy this deficit. And in its evidence to us, the Department of Health did not offer any proposals for systematic action within the Programme of Action to tackle the known health inequalities experienced by disabled people, who, it seems, remain caught in a policy ‘Catch-22’ situation. In our view, this standstill is unacceptable. And when the Disability Equality Duty bites, this policy weakness will also be open to legal challenge.

The Department of Health has an obligation to turn this situation around, and should prioritise and lead action to establish the necessary evidence base for improving policy, delivery and evaluation (including through setting the framework for inspection and performance evaluation of providers). Of course, this is not for the Department of Health to carry through alone; the national inspection bodies, for example, are key partners in this. We therefore welcome work by Commission for Social Care Inspection (CSCI) and Healthcare Commission (HCC) that will help to make a difference, including the joint development review of mental health services, the extension of the census ‘Count Us In’ to people with learning disabilities, the proposed HCC review of residential provision for people with learning disabilities, and the HCC’s three year strategic plan on adults with learning disabilities. We also commend the development work by Strategic Health Authorities (SHAs), ‘Better Metrics’. All these programmes will contribute to building a more robust evidence base. However, the Department of Health is uniquely placed to influence decision-making and delivery by making this a priority within its own policy and analytical programmes, and to facilitate and keep up the momentum among partner agencies.

We have already made the point that our report is, unavoidably, written by reference to the structures and organisations which exist at the moment. What follows must be interpreted as applying to existing bodies and their successors.

- 2.1 The Chair of the Appointments Commission and the Chief Executive of the NHS should steer a joint action plan to significantly improve the participation of disabled people, including people with mental health problems and/or learning disabilities in leadership roles, as executive and non-executives on the boards of national and local health bodies. In the case of Mental Health (MH) and Learning Disability (LD) Trusts there should be a clear expectation of involvement of people with mental health problems and learning disabilities at Board level. They should also ensure that NHS leaders are supported and trained in their governance role, to take a strategic approach to promoting greater equality for disabled people across health services, including those with learning disabilities and/or mental health problems.
- 2.2 The Department of Health, National Patient Safety Agency (NPSA) and the Healthcare Commission should ensure that user involvement mechanisms – including Patient and Public Involvement (PPI) Forums, Patient Advice and Liaison Services (PALS) and patient surveys – are fully inclusive of the experiences and views of people with learning disabilities and/or mental health problems, and that their views act as an effective lever for change within health services.
- 2.3 The Department of Health should work with the Department for Communities and Local Government (DCLG) to prompt action by Local Authorities by making health outcomes a key target area in forthcoming Local Area Agreements.

- 2.4 The report of the Secretary of State on progress made towards meeting the Disability Equality Duty in relation to the NHS, should include an account of progress in tackling health inequalities experienced by people with severe mental health problems and people with learning disabilities, including progress in implementing the recommendations of this Inquiry.
- 2.5 PCTs should include the topic of health inequalities experienced by people with mental health problems and/or learning disabilities in their local strategic assessments of needs (introduced in 'Our Health, Our Care, Our Say', the January 2006 White Paper) and health equity audits. They should address the disability dimensions of inequity in the audit process, ensuring that disability is established as part of the patient profile, assessing how this profile will affect how services are provided and building this into their plans to commission services for their whole population.
- 2.6 Strategic Health Authorities (SHAs) should ensure that the physical health needs of people with mental health problems and/or learning disabilities are addressed by PCTs as part of their local review of need and local health equity audit, and that needs identified through this and other processes such as user consultation, are incorporated in their Local Delivery Plans and in commissioning frameworks.
- 2.7 SHAs should develop and implement a framework for performance management of the local health economy in complying with the Disability Equality Duty. This should build on, and link with, the existing framework developed by SHAs for the parallel Race Relations Act duties. It should track progress towards narrowing the gaps in health inequality over time.

- 2.8 Commissioners of all relevant services should ensure that, in planning and commissioning for national and local priority delivery areas, they are systematically looking to secure equity for disabled people in the services being commissioned including, where necessary, by requiring positive action to be taken by the service supplier. All contracts should include requirements on disability access and equality, so that providers – whether in the public, private or voluntary sectors – have to achieve the quality and access standards and progress towards equal outcomes required by the Disability Equality Duty. Performance against contracts should be transparent.
- 2.9 Local Authority Scrutiny Committees should periodically assess the extent to which health bodies in their area are taking appropriate steps to tackle the inequalities described in this report.
- 2.10 The Department of Health should prioritise action to establish a robust evidence base that will ensure the health and healthcare needs of disabled people including people, with mental health problems and/or learning disabilities, can be routinely considered in the planning, commissioning, monitoring and scrutiny of service delivery and health outcomes. This should be in partnership with relevant bodies including the HCC, CSCI, National Institute for Clinical Excellence (NICE), and the Health and Social Care Information Centre.
- 2.11 The Department of Health should commission the development of measures to be incorporated within the existing health inequalities local ‘basket of indicators’ developed by the London Health Observatory, to be used locally to monitor need and assess progress in relation to disability.

- 2.12 The regional network of Public Health Observatories should identify a national lead for disability equality, to help NHS organisations improve audit, planning, delivery and evaluation in tackling health inequalities experienced by disabled people and specifically people with mental health problems and/or learning disabilities.
- 2.13 The Centre for Public Health Excellence in NICE should develop guidance and tools in conjunction with the regional Public Health Observatories to assist PCTs and their partners in building disability into health equity audit and in doing impact assessments of all policies and procedures, as required under the DED.
- 2.14 Those organisations responsible for complaints procedures – all health and social care providers (GP Practices, NHS Trusts, care homes etc), PCTs, the Healthcare Commission, the Health Ombudsman – should work to improve the accessibility of the complaints procedure including by providing accessible information on how to complain and marketing it widely to people with learning disabilities and/or mental health problems.
- 2.15 The NPSA should consider extending its confidential inquiry into premature deaths of people with learning disabilities to people with mental health problems (including, in particular, the problems experienced by people from BME communities with mental health problems) or undertake a similar investigation into that matter if it is neither appropriate or possible to extend the existing one.
- 2.16 NICE should investigate the extent to which key interventions to increase physical activity are effective for people with learning disabilities and/or severe mental health problems.

- 2.17 NICE should undertake disability equality impact assessments of its guidance, considering the specific implications for disabled people of their guidelines, and include targeted interventions where needed, for instance encouraging clinicians to prioritise at risk groups and to avoid diagnostic overshadowing, in line with available evidence.
- 2.18 NICE should audit existing guidelines of most significance to inequalities faced by disabled people – eg diabetes, obesity, chronic heart disease – and revise them when feasible. Mental health or learning disability specific guidelines should include a focus on physical health, including clear guidance on best practice in prescribing psychiatric medication, ensuring no inappropriate prescribing for people with learning disabilities and enabling people with mental health problems to make choices that balance their physical and mental well being.
- 2.19 NICE should prioritise specific new work on effective access to primary care for disabled people including those with learning disabilities and/or mental health problems – including evaluating the implementation and impact of the recommendations in this report.

In Wales

The Panel have identified gaps in policy in the area of health inequalities, but there are clear opportunities for the Assembly to turn this around.

The Inquiry Panel found that in relation to Mental Health in Wales the National Service Framework (NSF) holds some weight, and much of the action undertaken at Local Health Board (LHB) level is linked to targets in the NSF.

- 2.20 It is recommended that the Welsh Assembly Government should ensure that the NSF for mental health better addresses the physical health inequalities faced by people with mental health conditions and provides a coherent strategy for improving physical health of people with mental health impairments, tying together issues such as health checks for people with 'Severe Mental Illness (SMI)', and the Health Gain Target for Mental Health.
- 2.21 However, the Inquiry Panel also recognised the weaknesses of the NSF as a vehicle in that it only covers adults of working age and that many have been critical of the lack of funding associated with some of the actions. The Welsh Assembly Government should therefore not only use the NSF to tackle health inequalities for people with mental health problems. Other national policies and strategies will also need to be reviewed and utilised more effectively, especially in relation to children and older people.

2.22 The ‘Guidance on Service Principles and Service Responses for Adults and Older people with Learning Disabilities’ appears to be a key document for learning disability in Wales. However, it appears to the Inquiry Panel to be less than forceful in relation to health; having been issued in part as ‘section 7’ guidance for local authorities. The principles in the document about tackling health inequalities are very positive, but lack an enforcement mechanism or rigorous action plan. With no NSF or Health Gain Target on learning disabilities there seems to be a vacuum at a strategic level.

- The Welsh Assembly Government (WAG) should develop a health gain target on Learning Disability by 2007. In developing this target, research should make use of the data collected by the new regular health check for learning disability.
- Existing pieces of health strategy for people with learning disabilities should be brought together and reviewed and a new strategic framework created to improve the health of people with learning disabilities in Wales (akin to an NSF on Learning Disability). Work on the physical health elements of Learning Disability Strategy, Services and Principles should be transferred into the new framework and an action plan developed to convert these positive ‘principles’ or aspirations, into achievable and measurable targets for bodies and organisations in Wales. The strategy should come under the health division of the WAG health and social care department and tie together all related work including: health checks and the proposed Health Gain Target. It should tie in with work of other Assembly departments.

2.23 The Inquiry Panel heard that much of learning disability policy sits in the social care side of the Health and Social Care Department of Assembly. The Panel were told that Learning Disability is seen as a social care issue. Given the history of institutionalisation and inappropriate hospitalisation of people with learning disabilities in the past, it is understandable that the health service stepped away from Learning Disability policy. However, it is necessary for the health service and health policy makers to understand and meet the needs of people with learning disabilities as citizens and users of the health service. It is essential that health policy departments and the health service engage with the issues in order to tackle health inequalities faced by people with learning disabilities. The Assembly's Learning Disability Implementation Advisory Group (LDIAG) could be the consultation mechanism for carrying forward the new strategic framework for improving the health of people with learning disabilities. However the Inquiry Panel heard that LDIAG currently has minimal civil servant links to the health service, sitting as it does within the social care side of the health and social care department. The Inquiry Panel recommends that either these links be established or a new mechanism be established for consultation and involvement in the proposed new national strategy. Whatever advisory group is used, accountability for delivery of this proposed new strategic framework should lie squarely with Welsh Assembly Government.

2.24 The Inquiry Panel was told that Health Social Care and Wellbeing (HSCWB) Strategies (that Local Authorities and LHBs are obliged to work on together) present an excellent opportunity for tackling health inequalities in Wales at a local level. The Inquiry Panel heard evidence that many Local Health Boards and Local Authorities had indeed addressed health inequalities for these groups, but also that some had not.

- 2.25 The Welsh Assembly Government should produce new guidance on Health, Social Care and Wellbeing Strategies making it mandatory for LHBs and Local Authorities to explicitly include the physical health needs of people with learning disabilities and/or mental health problems when undertaking health needs assessments and when writing their strategies.
- 2.26 The National Public Health Service work on developing toolkits for Local Health Boards and Local Authorities on how to undertake their local area Needs Assessment for People with Learning Disabilities should be accelerated and key disability organisations and health bodies consulted. The same work should be started in relation to toolkits on Needs Assessment for People with mental health impairments.
- 2.27 Further strategic development on action planning for these HSCWB strategies is needed urgently and is promised. This should include advice and guidance on action planning to reduce health inequalities for these groups; advice and guidance on effectiveness of solutions and projects (or where to get it), guidance on user involvement, and commissioning services. This action planning must incorporate rural proofing and an equalities impact assessment.
- 2.28 We recommend that there is robust review and monitoring of the Strategies and resulting action plans referred to immediately above. This should include monitoring to ensure that the Strategies are tackling health inequalities for people with mental health problems, people with learning disabilities and disabled people generally and that there is evidence of equalities impact assessment having been carried out and that service users from these groups have been appropriately involved.

- 2.29 Where activities are the responsibility of both Local Authorities and Local Health Boards and/or in partnership with others such as voluntary sector organisations, accountability and auditing structures should be clear and transparent.
- 2.30 There must be an early review of the success of the HSCWB strategies in achieving change and reducing health inequalities for these groups in 2008. This could be carried out as part of the development of the Revised Health Inequalities strategy (described in the NHS 10 year vision – ‘Designed for Life’).
- 2.31 Commissioners of all relevant services should ensure that, in planning and commissioning for national and local priority delivery areas, they are systematically looking to secure equity for disabled people, where necessary, by requiring positive action to be taken by the service supplier. All contracts should include requirements on disability access and equality, so that providers – whether in the public, private or voluntary sectors – have to achieve the quality and access standards and progress towards equal outcomes required by the Disability Equality Duty. Performance against contracts should be transparent.
- 2.32 The Chief Executive of NHS Wales and the Public Appointments Division of the Assembly Government should steer a joint action plan, in conjunction with the Office of the Commissioner of Public Appointments if necessary, to significantly improve the participation of disabled people including people with mental health problems and/or learning disabilities in leadership roles, as executive and non-executives on the boards of national and local health bodies. They should also ensure that NHS Wales leaders are supported and trained in their governance role, to take a strategic approach to promoting greater equality for disabled people across health services, including those with learning disabilities and/or mental health problems.

- 2.33 The Welsh Assembly Government, Inspectorates and Regulators of health and social care services in Wales should ensure that user involvement mechanisms – including Public and Patient involvement initiatives, Community Health Councils (CHC) and patient surveys – are fully inclusive of the experiences and views of people with learning disabilities and/or mental health problems, and that their views act as an effective lever for change within health services.
- 2.34 The Welsh Assembly Government and NHS Wales should prioritise action to establish a robust evidence base that will ensure the health and healthcare needs of disabled people including people with mental health problems and/or learning disabilities can be routinely considered in the planning, commissioning, monitoring and scrutiny of service delivery and health outcomes. This should be in partnership with relevant bodies including, for example, the National Public Health Service, Care Standards Inspectorate Wales, Healthcare Inspectorate Wales (HIW) and NICE (and where relevant the All Wales Medicine Strategy Group).
- 2.35 The Office of the Chief Medical Officer and National Public Health Service in Wales should systematically collect and analyse data on mortality and morbidity for those with learning disability and mental health problems (and disabled people generally) in order to measure and identify health inequalities and patterns of disadvantage. Similarly, more data on take up of particular services by these groups will be necessary. This will require better collection and use of existing data and some new data collection systems. (eg building on Welsh Health Survey).
- 2.36 The Welsh Assembly Government should commission the development of measures to be incorporated within the existing health inequalities indicators to be used locally to monitor need and assess progress in relation to disability.

- 2.37 If as stated the Wales Centre for Health is to establish a Public Health Observatory in Wales this should link to any progress made in England and should identify a national lead for disability equality, to help NHS organisations improve audit, planning, delivery and evaluation in tackling health inequalities experienced by disabled people and specifically people with mental health problems and/or learning disabilities.
- 2.38 All those responsible for driving the delivery of Race Equality in Health Service in Wales (including the Equality Policy Unit at the Assembly, NHS Centre for Equality and Human Rights, and the Selected Minorities Group) should ensure that the issue of health inequalities and the findings of this Inquiry are addressed by their programmes to deliver race equality in the NHS, as these relate to the experience of Black and Minority Ethnic (BME) people in accessing primary healthcare services. Action should be built in to the national and regional activity as an integral part of delivery programmes.
- 2.39 Those organisations responsible for complaints procedures – CHCs, LHBs, the Healthcare Inspectorate Wales, the Public Service Ombudsman for Wales and individual general practices – should work to improve the accessibility of the complaints procedure including by providing accessible information on how to complain and marketing it widely to people with learning disabilities and/or mental health problems.
- 2.40 The NPSA should consider extending its confidential inquiry into premature deaths of people with learning disabilities to people with mental health problems, including in particular the problems experienced by people from BME communities with mental health problems or undertake a similar investigation into that matter if it is neither appropriate nor possible to extend the existing one.

- 2.41 NICE or, where relevant, the All Wales Medicine Strategy Group should investigate the extent to which key interventions to increase physical activity are effective for people with learning disabilities and/or severe mental health problems.
- 2.42 NICE or, where relevant, the All Wales Medicine Strategy Group should undertake disability equality impact assessments of its guidance, considering the specific implications for disabled people of their guidelines, and include targeted interventions where needed, for instance encouraging clinicians to prioritise at risk groups and to avoid diagnostic overshadowing, in line with available evidence.
- 2.43 NICE or, where relevant, the All Wales Medicine Strategy Group should audit existing guidelines of most significance to inequalities faced by disabled people – eg diabetes, obesity, Coronary Heart Disease (CHD) – and revise them when feasible. Mental health or learning disability specific guidelines should include a focus on physical health, including clear guidance on best practice in prescribing psychiatric medication, ensuring no inappropriate prescribing for people with learning disabilities and enabling people with mental health problems to make choices that balance their physical and mental well being.
- 2.44 NICE or, where relevant, the All Wales Medicine Strategy Group should prioritise specific new work on effective access to primary care for disabled people including those with learning disabilities and mental health problems – including evaluating the implementation and impact of the recommendations in this report.

2.45 The Inquiry Panel heard that capacity building within the NHS and within the Disability movement will be necessary in order to address health inequalities in Wales. This includes:

- Addressing the ongoing and long standing shortages of speech and language therapists in Wales (including Welsh language medium) so that disabled people have means to communicate their health needs and participate in family and community life. The lack of provision has serious implications for disability equality but also for health inequalities.
- Addressing the shortage of dieticians in Wales so that support is available to assist those people with learning disabilities and/or mental health problems, particularly for those on medication which has side effects of weight gain.
- Improvement to mental health services in Wales, in recognition of the connection between physical and mental health and the impact of some treatments and settings on physical health. There should be increased availability of cognitive behaviour therapy, self management programmes, self help, social support and overall the development of mental health services tailored to the aspirations of the patient. The panel also heard that Wales needs a Suicide Prevention Strategy.
- Capacity building and resources for Disability Organisations to strengthen infrastructure so that the NHS can consult and involve disabled people in initiatives including training. This is especially pertinent given the new Disability Equality Duty on public bodies which emphasises involvement and the new demands this will place on disability organisations.

Recommendation 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

In order to bring about the urgent changes which we consider are needed to address historic inequalities and secure access to rights, change will need to come from 'below' as well as from 'above'.

People with learning disabilities and/or mental health problems often have lowered expectations in terms of their physical health and what the health service can and should do in relation to this. Empowering people with learning disabilities and/or mental health problems is key to bringing about change in their physical health and the health services they receive.

They need to know, for example:

- What they are entitled to from the primary care system.
- What questions to ask the receptionist, doctor or nurse.
- How to negotiate for 'access' requirements to be met and reasonable adjustments to services to be made.
- How to ask for health promotion information, health checks or medication options.
- How to make complaints; both who to complain to and where to get support and advocacy to complain.

- How to influence services through for example Patient and Public Involvement (PPI) forums, Community Health Councils (in Wales) or their equivalents in bodies such as Foundation Trusts (which do not at present have PPI forums).
- How to participate in training primary care staff and in decisions surrounding the provision of primary care services if they wish to do so.

That information should also, where appropriate, be shared with people assisting the disabled person to formulate or communicate their views (such as an advocate); and with people involved in providing them with care and other support (including family carers and others).

All of this should be done ‘bottom up’ and ‘top down’.

Firstly, user groups, particularly local user groups, need to be funded and supported to enable service users to support and inform each other.

Secondly, there needs to be wide dissemination of information on ‘Your Rights’ produced by people with learning disabilities and/or mental health problems themselves. That information should be written and presented in an accessible form so as to be relevant to the intended audience (this being an area in which it may well be necessary to tailor information differently for people with learning disabilities and people within mental health problems, and even to different groups of people within those larger groups). It should be provided in the users’ preferred format. It should be distributed through user groups and places attended by people with learning disabilities and/or mental health problems including GP surgeries, outreach centres, day centres, hospitals and prisons.

Similarly, people with learning disabilities and/or mental health problems who also have particular (perhaps chronic) physical health problems have a key role in managing their own physical health conditions, but often lack the knowledge and confidence to do so.

Accordingly, people with learning disabilities and/or mental health problems also need access to programmes geared to supporting them to manage particular physical health conditions such as diabetes or heart problems. The aim of the programmes should be to develop people's confidence and capacity to tackle the problems they face. The programmes should include the opportunity to take part in groups with other people with learning disabilities or a mental health problem or, if preferred, a group of people with the physical condition in question.

Advocates will have a key role in ensuring that people with learning disabilities or a mental health problem understand their rights and are able to demand their entitlements. People involved in providing services to them, such as health trainers, key workers, community psychiatric nurses and care co-ordinators, should also play an important part in empowering those people in the ways we describe above.

One very specific barrier which makes it harder for some people with learning disabilities to manage their physical health conditions is the use of brand names rather than generic names to describe medicines.

Particular account will need to be taken of the needs of disabled people for whom English is not their first language (or, in Wales, for whom neither English nor Welsh is their first language).

Who needs to do what in England?

- 3.1 The Department of Health should support a partnership of organisations of people with learning disabilities and/or mental health problems to develop (in discussion with the Royal Colleges and other similar bodies) a package of information and a programme of information sharing within its mainstream Patient and Public involvement programmes.
- 3.2 NHS Direct, Health Direct, Patient and Public Involvement Forums and mechanisms, PALS, the Healthcare Commission and the Health Ombudsman should all put the best available accessible information on 'Your Rights' in primary care, once produced, available on their websites and via advisors; and to publicise it so that it is routinely given to people at local level including through NHS Direct's Patient Information Bank for GP surgeries.
- 3.3 Voluntary sector and statutory mental health, learning disability and carer organisations should make the information available through their networks, websites and helplines to people with learning disabilities and/or mental health problems and their families.
- 3.4 The Department of Health should ensure that PCTs or their successors support local user groups to share the information and to support and empower people with learning disabilities and/or mental health problems to have raised expectations in terms of their physical health and the services to address their physical health.
- 3.5 The Department of Health should make general Expert Patient Programmes known and accessible to people with learning disabilities and/or mental health problems who wish to access general programmes; and track effectiveness with these groups.

- 3.6 The Department of Health should act, in consultation with user groups, to establish, develop and publicise similar programmes involving (and where possible led by) groups of people with learning disabilities and/or mental health problems.
- 3.7 Learning Disability teams should offer 'health passports' linked to an individual's Health Action Plan which supplement the information on the ordinary patient record and which is designed to empower the patient in accessing health services. Similarly, mental health teams should provide their clients with a copy of their care plan (a matter which the National Institute for Mental Health Excellence in England (NIMHE) should support and encourage). Through its system of assessment (including improvement reviews, patient surveys and national audit), the Healthcare Commission should also monitor the implementation of these measures we have described.
- 3.8 Voluntary sector or statutory organisations that have promoted 'crisis cards' should encourage service users, professionals and carers/advocates to record any key physical health needs (such as diabetes) on those cards and the action required to address them.
- 3.9 The Department of Health should ensure that, wherever information is to be provided to people with learning disabilities and/or mental health relating to a branded drug, the generic name is also used.
- 3.10 GPs and other health professionals should ensure that whenever information is to be provided to people with learning disabilities and/or mental health problems relating to a branded drug, the generic name is also used; and the Royal College of General Practitioners (RCGP) and the Royal College of Psychiatrists (RCPsych) should act to encourage them to do so.

- 3.11 The Parliamentary and Health Service Ombudsman should consider further action to make people with learning disabilities and/or mental health problems aware of the service she provides, including publications available in accessible formats which are aimed at empowering people to secure their rights.
- 3.12 The Department of Health and the Department for Constitutional Affairs (DCA) should commission a guide for primary care staff on the complex questions of whether and how to intervene when someone may not have capacity to consent to an investigation or treatment. The guide should be based on the principle that the first task is to assume capacity and ability to consent and to enable the person to understand and make choices, with support if needed, wherever possible.

Who needs to do what in Wales?

- 3.13 The Welsh Assembly Government should support a partnership of organisations of people with learning disabilities and/or mental health problems to develop (in discussion with the Royal Colleges and other similar bodies a package of information and a programme of information sharing within its mainstream Patient and Public involvement programmes.
- 3.14 CHCs, Patient and Public Involvement groups, the Public Services Ombudsman and Healthcare Inspectorate Wales should put the best available accessible information on 'Your Rights in Primary Care', once produced, on their websites and via advisers; and to publicise it through existing patient information networks and mailings so that it is routinely given to people at local level in GP surgeries.

- 3.15 Voluntary sector and statutory mental health, learning disability and carer organisations should make the information available through their networks, websites and helplines to people with learning disabilities and/or mental health problems and their families.
- 3.16 The Welsh Assembly Government should ensure that Local Health Boards, Local Authorities and CHCs support local user groups to share the information and to support and empower people with learning disabilities and/or mental health problems to have raised expectations in terms of their physical health and the services to address their physical health.
- 3.17 The Welsh Assembly Government should make general Expert Patient Programmes known and accessible to people with learning disabilities and/or mental health problems (and indeed other disabled people) and track effectiveness with these groups.
- 3.18 The Welsh Assembly Government should act, in consultation with user groups, to establish, develop and publicise Expert Patient Programmes or similar programmes involving (and where possible, led by) groups of people with learning disabilities and/or mental health problems.
- 3.19 The Care Programme Approach (CPA) should be fully implemented across Wales and include the assessment of physical health needs and access requirements for getting those needs met. Copies of the care of CPA care plans must be given to service users.

- 3.20 People with learning disabilities should have a multidisciplinary assessment in accordance with the unified assessment process to identify and plan for their health as well as social care needs as stated in the Assembly's guidance 'Services principles and services responses for adults and older people with learning disabilities'. Copies of the assessment must be given to service users.
- 3.21 The comprehensive introduction and use of health passports and health action plans (HAPs) should be explored in Wales and linked to the introduction of regular health checks to be offered to people with learning disabilities (see Recommendation 9) as part of assessment of their needs.
- 3.22 Voluntary and statutory sector mental health organisations that have promoted crisis cards should consider encouraging people to include details of key physical health issues on the cards (such as diabetes), to ensure that, at time of crisis, physical health needs are properly addressed.
- 3.23 The Welsh Assembly Government should ensure that, wherever information is to be provided to people with learning disabilities and/or mental health relating to a branded drug, the generic name is also used.
- 3.24 Welsh Assembly Government should see what more can be done through the licensing and contractual arrangements with pharmacists to ensure the provision of accessible information on dosage and side effects of medication to disabled people in Wales.
- 3.25 GPs and other health professionals should ensure that whenever information is to be provided to people with learning disabilities and/or mental health problems relating to a branded drug, the generic name is also used; and the RCGP and RCPsych should act to encourage them to do so.

3.26 The Welsh Assembly Government should lead discussion with NHS Wales, Royal Colleges and disability organisations in Wales to review current guidance on the complex question of whether and how to intervene when someone may not have the capacity to consent to an investigation or treatment. The need for further guidance on this matter should be addressed. Guidance should be based on the principle that the first task is to enable the person to understand and make choices wherever possible.

Recommendation 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

Although everyone has the right in theory to be registered with a GP, the reality is often very different for people with learning disabilities and/or (more particularly) mental health problems.

Mind, the mental health charity, has also reported to us that people with mental health problems sometimes comply with treatment they do not really want in order to stay with a particular GP practice which insists they receive that treatment.

People with learning disabilities and/or mental health problems appear to experience difficulties, particularly when it comes to registering with, or staying registered with, their GP of preference. Of course, GPs sometimes refuse to register prospective patients because they are genuinely 'full'. Or they may remove patients from their registers for perfectly legitimate reasons arising from a breakdown in the doctor – enrole patient relationship. However, there is considerable concern that such registration decisions in relation to people with learning disabilities and/or mental health problems at times impermissibly relate to their disability. Such refusals of registration or decisions to deregister can have considerable knock on effects for people with learning disabilities and/or mental health problems by making it more difficult for them to register with other GPs in their area. That is a particular problem for people living in rural areas, where alternative GP practices may be a long way from their homes and particularly difficult to get to by public transport. There is also a difficulty that if a person is de-registered on grounds of alleged aggressive behaviour in circumstances in which the alleged behaviour may relate to their disability and in which there is currently no mechanism to challenge the GP's decision or the basis on which it was taken.

For example, the Parliamentary and Health Service Ombudsman in England said to us that:

“ I have seen a number of complaints where people with mental health and/or learning difficulties have been left without GP services, often because the relationship between doctor and patient is perceived by the GP to have broken down. The reason for such breakdowns often offered by GP practices is that the patient has been ‘unreasonable’ or ‘too demanding’, and the interactions referred to as evidence of this might be either directly with GPs or with other practice staff. I believe that many of these situations could be avoided if there was greater discussion and understanding at the outset of patients’ needs. I see [other Panel recommendations] which relate to the training of frontline staff and the involvement of patients in the recording of their access needs as key factors in improvement”.

Although improved training (which we have recommended below) could indeed help deal with an underlying cause of the problem, we doubt that will be enough.

The current ‘good practice’ arrangement between the Department of Health/ Welsh Assembly Government and the BMA for GPs to give their reasons for ‘deregistering’ a patient is welcome. But more effective mechanisms are needed to address the problem for people with learning disabilities and/or mental health problems.

People with learning disabilities or mental health problems often also have a particular need for continuity of GP within the practice, something which booking arrangements should try to accommodate wherever possible.

Overall, general policies to improve ‘choice’ of GP will need to take account of the particular needs of people with learning disabilities and/or mental health problems in order to ensure that they get full and equal benefit from any enhanced entitlements.

Who needs to do what in England?

- 4.1 The Department of Health should act to ensure that, when GPs refuse to register a person with learning disabilities or mental health problems, or decide to ‘deregister’ such a person, they should give the person (or their carer where appropriate) their reasons for doing so in writing.
- 4.2 The Department of Health (following consultation with the BMA) should act to establish mechanisms for mediation of disputes arising from refusals to register or decisions to deregister in relation to people with learning disabilities and/or mental health problems.
- 4.3 The Department of Health (following consultation with the BMA) should establish a regime of independent appeals (for where mediation has proved unsuccessful) against refusals to register or decisions to deregister in relation to people with learning disabilities and/or mental health problems where it appears that the decisions in question may relate to the person’s disability.
- 4.4 The Department of Health should ensure that people with learning disabilities and/or mental health problems get full and equal benefit from any enhanced entitlements to improve ‘choice’.

- 4.5 PCTs should track over time the proportion of allocation requests that relate to people with learning disabilities and/or mental health problems, in order to ascertain whether these groups are more likely to be without a GP. If such inequalities are identified, PCTs should take action to tackle them. The Healthcare Commission should ensure the proper operation of that process.
- 4.6 Community Psychiatric Nurses and other members of community mental health teams should ensure that their clients are registered with GPs.
- 4.7 The Department of Health and PCTs need to ensure that people with learning disabilities or mental health problems leaving prison or hospital are registered with a GP.

Who needs to do what in Wales?

- 4.8 The Welsh Assembly Government should act to ensure that, when GPs refuse to register a person with learning disabilities and/or mental health problems, or decide to ‘deregister’ such a person, they should give the person (or their carer where appropriate) their reasons for doing so in writing.
- 4.9 The Welsh Assembly Government (following consultation with the BMA and disability organisations) should act to establish mechanisms for mediation of disputes arising from refusals to register or decisions to deregister in relation to people with learning disabilities and/or mental health problems.
- 4.10 The Welsh Assembly Government (following consultation with the BMA and disability organisations) should establish a regime of independent appeals (for where mediation has proved unsuccessful) against refusals to register or decisions to deregister in relation to people with learning disabilities and/or mental health problems where it appears that the decisions in question may relate to the person’s disability.

- 4.11 LHBs should track over time the proportion of allocation requests that relate to people with learning disabilities and/or mental health problems, in order to ascertain whether these groups are more likely to be without a GP. If such inequalities are identified, LHBs should take action to tackle them. Healthcare Inspectorate Wales should ensure the proper operation of that process.
- 4.12 Community Psychiatric Nurses and other members of community mental health teams should ensure that their clients are registered with GPs.
- 4.13 The Welsh Assembly Government and LHBs need to ensure that people with learning disabilities or mental health problems leaving prison or hospital are registered with a GP.

Recommendation 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

Psychiatrists and other mental health professions have a key role in observing and monitoring physical health issues, including those resulting from psychiatric medication side effects, and prescribing and administering treatment; and, together with pharmacists, providing medication information and options.

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They cannot, however, be expected to have the same level of expertise in general practice as GPs and other primary care specialists do. We are very concerned at evidence that inpatients can have their physical health needs poorly served and some leave hospital more physically unwell than when admitted, often over long periods.

We consider that action is needed to ensure that people with learning disabilities and/or mental health problems in learning disability or psychiatric hospital (including secure provision) have proper, regular access to a primary care service, including being registered with and able to see a GP or other primary care specialist. That may require them to be provided with an appropriate escort.

Such people should also have the right to the same 'outcomes' required in the new GP contract (the nGMS contract) as people living outside hospitals.

They also need access to the information and opportunities to support and encourage healthy living as described in our recommendation 10 below.

Urgent consideration needs to be given to preventing inappropriate prescribing of psychiatric medication including to people in residential, nursing and inpatient settings which has a major impact on physical health. Making reference to the physical effects of psychiatric medication Professor O'Brien, giving oral evidence on behalf of the Royal College of Psychiatrists, said:

“I’m afraid to say...we make people fat and give them health problems. We need to look at them very carefully, that is something we as a college are very worried about”.

For people with a learning disability who do not have a psychotic condition, there is no evidence that anti-psychotics have clinical benefit; rather they are used to control behaviour. This is not acceptable. For people with mental health problems, for whom anti-psychotic medication may have benefits, there should be a stronger process than currently of informing the individual of the potential benefits and risks – including physical health risks – so the person can decide on the ‘trade-off’ between relief of troubling psychiatric symptoms and physical risks. Regular medication reviews need to address physical risks and enable individuals to try different medications or other services, to find an approach that suits them.

Who needs to do what in England?

5.1 The Department of Health should ensure that PCTs commission primary care services which include regular health checks (see below) for people in inpatient care. These should be governed by the nGMS requirements for interventions and outcomes for specific conditions such as hypertension, diabetes etc – as well as for regular health checks for people with schizophrenia or bi-polar disorder. Health checks should be triggered at particular points – including admission to psychiatric hospital and CPA assessments. This may be particularly important for people who have under-used primary

care and are likely to have unmet health needs, including for instance people with undiagnosed heart conditions for whom certain medications may pose significant risks. Groups such as African-Caribbean men and homeless people are likely to be at particular risk.

- 5.2 The Department of Health, RCGP and RCPsych should discuss what needs to be done so that commissioners can require that consultants in psychiatry cease to have overall sole responsibility for the physical healthcare of inpatients. Instead this responsibility should be held by the primary health care professionals providing regular 'in-reach', with psychiatrists and psychiatric nurses having a complementary role in providing psychiatric treatment; and in monitoring and providing treatment for physical health problems. For patients who are cared for entirely in the community by a mental health team, and are not yet registered with a GP, it is the responsibility of the key worker to ensure that the patient becomes registered with a GP at the earliest opportunity.
- 5.3 The RCPsych and RCGP should work jointly (in discussion with the BMA) to agree respective professional responsibilities and to develop and implement the very helpful 2005 RCPsych guidelines for psychiatrists on physical health care. The RCPsych should include in the guidelines clear advice to psychiatrists on how to offer full information and options on type and dosage of psychiatric medication, so that people can make informed choices about how to maximise their physical – as well as psychological – well-being.

- 5.4 The National Patient Safety Agency should investigate and report on the problem of physical health deterioration experienced by some people during inpatient psychiatric treatment. In that context, we welcome the NPSA's approach to, and understanding of, patient 'safety' which embraces issues which impact gradually on patient health and not just things which occur relatively suddenly.
- 5.5 The Healthcare Commission, Commission for Social Care Inspection and Mental Health Act Commission should build in to their inspection criteria an assessment of the appropriateness of psychiatric prescribing in residential, nursing and inpatient settings.

Who needs to do what in Wales?

- 5.6 The Welsh Assembly Government should ensure that LHBs commission primary care services which include regular health checks (see below) for people in inpatient care. These should be governed by the nGMS requirements for interventions and outcomes for specific conditions such as hypertension, diabetes etc – as well as for regular health checks for people with schizophrenia or bi-polar disorder. Health checks should be triggered at particular points – including admission to psychiatric hospital and CPA assessments. This may be particularly important for people who have under-used primary care and are likely to have unmet health needs, including for instance people with undiagnosed heart conditions for whom certain medications may pose significant risks. Groups such as African-Caribbean men and homeless people are likely to be at particular risk.
- 5.7 The Welsh Assembly Government, RCGP and RCPsych should discuss what needs to be done so that commissioners can require that consultants in psychiatry cease to have overall sole responsibility for the physical healthcare of inpatients. Instead this responsibility should be held by the primary health care

professionals providing in-reach, with psychiatrists and psychiatric nurses having a complementary role in monitoring and providing treatment for physical health problems. For a patient who is cared for entirely in the community by a mental health team, and is not yet registered with a GP, it is the responsibility of the key worker to ensure that the patient becomes registered with a GP at the earliest opportunity.

- 5.8 The RCPsych and RCGP should work jointly (in discussion with the BMA) to agree respective professional responsibilities and to develop and implement the very helpful 2005 RCPsych guidelines for psychiatrists on physical health care. The RCPsych should include in the guidelines clear advice to psychiatrists on how to offer full information and options on type and dosage of psychiatric medication, so that people can make informed choices about how to maximise their physical – as well as psychological – well-being. CPA and RCGP and BMA to agree protocols so that when a psychiatrist prescribes psychiatric medication with known side effects, the persons GP is notified and arrangements agreed for addressing these issues.
- 5.9 The National Patient Safety Agency should investigate and report on the problem of physical health deterioration experienced by some people during inpatient psychiatric treatment. In that context, we welcome the NPSA's approach to, and understanding of, patient 'safety' which embrace issues which impact gradually on patient health and not just things which occur relatively suddenly.
- 5.10 The Healthcare Inspectorate Wales (HIW), Care Standards Inspectorate Wales (CSIW), Social Services Inspectorate Wales and Mental Health Act Commission should build in to their inspection criteria an assessment of the appropriateness of psychiatric prescribing in residential, nursing and inpatient settings.

Recommendation 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

Although people in situations such as those which we have identified in this recommendation have theoretical access to a GP, there can be many practical barriers to them having equal access to GP services. Those barriers need to be removed if such people are to exercise equal rights to other members of the community.

For example, people with learning disabilities in residential homes often find their access to the GP of their preference is constrained for the convenience of the residential home; or that homes are unwilling or unable to provide the staff, transport, or other practical support which residents require in order to attend GP appointments as they need them. In her oral evidence to us, Michele Chinnery from the Department of Health Learning Disability Task Force said:

“ ...some of the care homes are not very forthcoming with making sure their residents get health checks. I know residences where....doctors prescribe medication without seeing the patient. That’s something that happens”.

Similarly, the arrangements for providing community care to people in supported living arrangements often lack the flexibility to enable service users to be assisted in getting to GP appointments, particularly where GPs are unwilling to give appointments at a specified time (a matter considered in our next recommendation).

We are also particularly alarmed to hear of residents being asked to pay charges (sometimes called ‘retainer fees’) to a residential home provider or directly to a GP for GP or other primary care services which should be free. There seems to be confusion (including from the Department of Health) about what charges are being levied, by whom and for what, and whether particular practices are permissible. Such confusion creates a very real risk of people being charged when they should not be. Urgent action is required.

Finally, residential establishments and their staff can have a considerable influence on promoting physical health and well-being and they should be encouraged to do so.

It is also vital that the physical health needs of people with learning disabilities or mental health problems are properly considered if they are leaving an institution such as prison or a long stay hospital to identify and act on any problems and to ensure a proper transition to mainstream GP services.

What needs to be done in England?

- 6.1 The Healthcare Commission and CSCI (as appropriate) should ensure that those organisations, including PCTs and local authorities, which commission facilities of the kind described should ensure that their commissioning arrangements (including contracts) ensure that residents (or service users as appropriate) have full and proper access to the GP services they require.
- 6.2 The Department of Health should put in place standards for the inspection of registered homes and other residential facilities (including supported living schemes and registered hospitals under the Care Standards Act 2000), including through amendment of the Care Homes Regulations 2001 as necessary, which ensure that residents have full and proper access to the GP services they require.

- 6.3 The Commission for Social Care Inspection and the Healthcare Commission (HCC) should give guidance to their inspectors to ensure that residents have full and proper access to the GP services they require, including as part of the existing requirement of the regulatory standard, to ensure residents are able to register with the GP of their choice. They should also ensure that, when they inspect homes and other residential establishments occupied by people with learning disabilities and/or mental health difficulties, their inspection team (or other process of assessment and inspection) involves at least one person with such difficulties. And that, as part of the inspection, they provide accessible information about the inspection process to, and specifically consult with, residents with such difficulties. (We are aware that CSCI is currently considering a plan to include an ‘expert by experience’ on one in twenty inspection teams. That is a welcome first step. But our view remains that all teams should include such a person).
- 6.4 The Department of Health, PCTs, the RCGP and BMA should work together to ensure that GPs ensure that residents of residential homes and similar receive the equal access to GP services to which they are entitled under the GP contract including by ensuring that GPs work in partnership with residential care home managers around questions such as appointment times.
- 6.5 The Department of Health, PCTs and the bodies responsible for commissioning residential care should take the necessary steps to ensure that GPs do not charge, and residents are not asked to pay, charges (whether as ‘retainer fees’ or under some other label) for services which should be free under the ordinary GP contract. The RCGP and BMA should issue clear guidance to their members on the point. One way to do that would be to add to the requirements imposed by paragraph 53 of the General Medical Council (GMC)’s ‘Good Medical Practice’ (which requires a doctor to be honest and open in any financial

obligations with patients) a specific prohibition on charging the patient (directly or indirectly) for anything which the patient should be receiving free.

- 6.6 The Department of Health should work together with the BMA, RCGP and bodies responsible for commissioning residential care and primary health services to assess the unmet primary healthcare needs of those in residential settings. Studies should be undertaken to examine the best way to meet these health needs in a consistent way, including whether the Locally Enhanced Service which operates in some parts of Wales, where a GP together with a pharmacist provides ‘ward rounds’ to nursing and residential homes, should be adopted across England. And, in calculating the costs of offering such a service, consideration must be given to the impact on secondary services when health of residents deteriorates, as well as the implications of the DDA 2005 duty to promote equality.
- 6.7 The Department of Health, the bodies responsible for commissioning residential care and domiciliary care for those in ‘supported living’ and the bodies responsible for regulating such care should put in place mechanisms to monitor the physical health of residents and service users, to encourage attention to their physical health and well-being and promote their access to, and opportunities for, healthy eating, smoking cessation programmes and other aspects of a healthy lifestyle. This should be in line with current Department of Health guidelines on healthy living. For instance, it should generally be possible for residents of care homes, nursing homes or supported living schemes to eat five portions of fruit and vegetables a day and to get access to 10,000 steps of walking per day or equivalent amount of exercise.

- 6.8 Local Authorities and PCTs should adopt joint support strategies to promote better practice, training and health care in care homes, such as the model of joint Care Home Support Teams.
- 6.9 The Department of Health should ensure that those organisations, including PCTs and local authorities, which commission facilities of the kind described ensure that their commissioning arrangements (including contracts) ensure that staff undergo disability equality and awareness training in relation to learning disability and mental health.
- 6.10 Training courses (such as the National Vocational Qualification (NVQ)) for staff working in residential care and similar support should include training on physical health care and monitoring the physical health of people with learning disabilities and/or mental health problems.
- 6.11 The Department of Health and PCTs need to ensure that people with learning disabilities or mental health problems who are leaving prison or long stay hospitals receive a physical health check (as explained in our recommendation 8 below) and are registered with a GP.

What needs to be done in Wales?

- 6.12 Those organisations, including Trusts, LHBs and local authorities, which commission residential or nursing homes, 'supported living' arrangements, secure accommodation, long term hospital facilities, rehabilitation or any other residential facilities should ensure that their commissioning arrangements (including contracts) guarantee that residents/or service users have full and proper access to the GP services they require. This should be rigorously monitored by Healthcare Inspectorate Wales and Care Standards Inspectorate Wales and other regulators such as Social Services Inspectorate Wales if necessary.

- 6.13 Attention must be given to out of county or indeed country placements. The Welsh Assembly Government, LHBs and Local Authorities should ensure that children and adults who are provided with educational, health or social care placements out of county (or country) are registered with GPs and have access to primary care services in the area in which they are placed.
- 6.14 The Welsh Assembly Government should put in place, standards for the inspection of registered homes and other residential facilities which ensure that residents have full and proper access to the GP services they require. The Welsh Assembly Government should ensure that these standards are enforced and that progress is monitored and reviewed and failings addressed.
- 6.15 CSlW and HIW should give guidance to their inspectors to ensure that residents have full and proper access to the GP services they require including as part of the existing requirement of the regulatory standard to ensure residents are able to register with the GP of their choice. They should also ensure that, when they inspect homes and other residential establishments occupied by people with learning disabilities and/or mental health problems, their inspection team (or other process of assessment and inspection) includes at least one person with learning disabilities and/or mental health problems; and that, as part of the inspection, they provide accessible information about the inspection process to, and specifically consult with, residents.
- 6.16 The Welsh Assembly Government, LHBs, the RCGP and BMA should work together to ensure that GPs enable residents to receive the equal access to GP services to which they are entitled under the GP contract including by ensuring that GPs work in partnership with residential care home managers around questions such as appointment times.

- 6.17 The Welsh Assembly Government, LHBs and the bodies responsible for commissioning residential care should take the necessary steps to ensure that GPs do not charge, and residents are not asked to pay, charges (whether as ‘retainer fees’ or under some other label) for services which should be free under the ordinary GP contract. The RCGP and BMA should issue clear guidance to their members on the point. If necessary this should be underpinned by legislation.
- 6.18 The Welsh Assembly Government should work together with the BMA, RCGP and bodies responsible for commissioning residential care and primary health services to assess the unmet primary healthcare needs of those in residential settings. Studies should be undertaken to examine the best way to meet these health needs in a consistent way, including whether the Locally Enhanced Service which operates in some parts of Wales, where a GP together with a pharmacist provides ‘ward rounds’ to nursing and residential homes, should be adopted across Wales – and in calculating the costs of offering such a service, consideration must be given to the impact on secondary services when health of residents deteriorates, as well as the implications of the DDA 2005 duty to promote equality.
- 6.19 The Welsh Assembly Government, the bodies responsible for commissioning residential care and domiciliary care for those in ‘supported living’ and the bodies responsible for regulating such care should put in place mechanisms to monitor the physical health of residents and service users, to encourage attention to their physical health and well being and promote their access to, and opportunities for, healthy eating, smoking cessation programmes and other aspects of a healthy lifestyle, including access to leisure and sports facilities. This should be in line with current government guidelines on healthy living: for instance it should generally be possible for residents of care homes, nursing homes or supported living schemes to

choose to eat five portions of fruit & vegetables a day and to have access to 10,000 steps of walking per day or equivalent appropriate exercise.

- 6.20 Local Authorities and LHBs should adopt joint support strategies to promote better practice, training and health care in care homes (such as the model of joint Care Home Support Teams).
- 6.21 The Welsh Assembly Government should ensure that those organisations, including LHBs and local authorities, which commission facilities of the kind described should ensure that their commissioning arrangements (including contracts) ensure that front-line staff undergo disability equality and awareness training, and training on physical health care support and monitoring in relation to people with learning disabilities and people with mental health problems.
- 6.22 Training courses (such as the NVQ) for staff working in residential care and similar support should include training on physical health care and monitoring the physical health of people with learning disabilities and mental health problems.
- 6.23 The Welsh Assembly Government and LHBs need to ensure that people with learning disabilities or mental health problems who are leaving prison or long stay hospitals receive a physical health check (as explained in our recommendation 8 below) and are registered with a GP.

Recommendation 7:

Services and 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 experience exclusion on multiple grounds receive full and proper primary health care services

The evidence we have received shows that most people with learning disabilities and/or mental health problems can and should receive equal access to primary care services by attending their GP surgeries or other primary care facilities in the normal way, albeit with adjustments made to practical things such as the way in which they make bookings, and the appointments they receive. Those facilities may well be innovative in the way they deliver primary care. For example, it may also be appropriate to locate GP ‘drop in’ facilities at or near secondary care services including, in particular A&E departments, for those people including members of BME communities in particular, who (for whatever reason) find such services more accessible than ordinary GP facilities or who turn to them as their first port of call when ill. Our other recommendations seek to ensure that happens in practice.

However, in some situations (including for homeless people and those in the most rural areas who have learning difficulties or mental health problems), it may be more effective for primary care services to be provided in other ways including through ‘outreach’ services or new service configurations for instance involving voluntary sector providers. Such developments would be entirely consistent with wider trends in the health service.

For some other populations, such as African and Afro-Caribbean people with mental health problems, there is an under-use of primary care: these groups tend to be admitted directly to psychiatric hospital, sometimes via the police, and are more likely to be compulsorily detained and treated with high doses of psychiatric medication. They also, for physical health problems like diabetes, tend to seek treatment later, sometimes via A&E, and as a result get relatively little primary care attention. This has significant implications for their trust in and use of services and for their physical health and well being. A form of 'outreach' may be useful via community groups and organisations which have already gained the trust of the people with whom they have contact, in order to encourage black people to make greater use of primary care; and to support primary care teams in better serving BME service users including by improving their understanding of the needs of those service users. In addition, access to physical health care in hospital settings is especially significant for these groups (see recommendation 6). We welcome the review by the Commission for Racial Equality (CRE), Healthcare Commission and Mental Health Act Commission of mental health services' efforts to address the unequal treatment and care of patients because of their race following the publication of 'Count me in' (Dec 2005, England and Wales). We note also the CRE Wales approach to monitoring and progressing these issues. We urge the CRE in England and Wales to consider the physical health and well being of service users from Black and Minority Ethnic communities within their terms of reference. This should include both those people experiencing the coercive end of mental health services; and those who are simply under-diagnosed with problems like depression and not offered good holistic primary care for their physical and mental health needs.

What needs to happen in England?

- 7.1 The Department of Health should establish a robust and national system for people who do not have an address to register with a GP.
- 7.2 The Department of Health needs to ensure that PCTs and local authorities commission a comprehensive and accessible primary care health service (possibly through 'outreach' or partnerships) which enables homeless people and other excluded groups within their population without easy access to a GP practice for whom access cannot be arranged by registration, as above. Such services should be sensitive to the particular needs of this group and appropriately publicised within the homeless community. In addition outreach via trusted groups and organisations should be considered in order to encourage higher take-up of primary care by groups who under-use it, including black people with mental health conditions.
- 7.3 The National Steering Group for Delivering Race Equality should ensure that the issue of health inequalities and the findings of this Inquiry are addressed by the Programme, as these relate to the experience of Black and Minority Ethnic people in accessing primary healthcare services. Action should be built in to the national and regional activity led by Care Services Improvement Partnership (CSIP) as an integral part of its delivery programmes.
- 7.4 The CRE, Healthcare Commission and Mental Health Act Commission, in reviewing mental health services' efforts to address the unequal treatment and care of patients because of their race, should take account of the findings of this Inquiry and should monitor efforts to address physical as well as mental health by services including making use, as appropriate, of data from the National Mental Health and Ethnicity Census and the national mental health patient survey.

What needs to happen in Wales?

- 7.5 The Welsh Assembly Government should establish a robust and national system for people who do not have an address to register with a GP.
- 7.6 The Welsh Assembly Government needs to ensure that LHBs commission a comprehensive and accessible primary care health service (possibly through 'outreach' or partnerships) for homeless people and other groups in vulnerable situations within their population without easy access to a GP practice for whom access cannot be arranged by registration, as above. Such services should be sensitive to the particular needs of this group and appropriately publicised within the homeless community. In addition outreach via trusted groups and organisations should be considered in order to encourage higher take-up of primary care by groups who under-use it, including black people with mental health conditions.
- 7.7 All those responsible for driving the delivery of Race Equality in Health Service in Wales (including the Equality Policy Unit at the Assembly, NHS Centre for Equality and Human Rights, and the Selected Minorities Group and the CRE) should ensure that the issue of health inequalities and the findings of this Inquiry are addressed by the programmes to deliver race equality in the NHS, as these relate to the experience of black and minority ethnic people in accessing primary healthcare services. Action should be built in to the national and regional activity as an integral part of delivery programmes.

- 7.8 The recommendations in Homeless Link Cymru’s report to the Welsh Assembly Government on access to healthcare should be implemented. This inquiry panel particularly notes and supports their Recommendation 1, ‘To appoint a national Health and Homelessness Co-ordinator whose role will be to consult with stakeholders in the development of Health and Homelessness Guidance, to work with Local Health Boards in developing local Health and Homelessness Action Plans, to consider best practice models currently operating in Wales and elsewhere in the UK, and to develop a series of National Standards relating to local service provision, assessment and accountability, in consultation with an Assembly steering group’.
- 7.9 Welsh Assembly Government together with the Welsh Language Board and its successor organisation, should consider questions relating to barriers faced by people with learning difficulties and/or mental health problems whose first language is Welsh.

Recommendation 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

A range of practical problems all too often act as unintended barriers to people with learning disabilities and/or mental health problems in accessing GP services. ‘Reasonable adjustments’ (in the jargon of the DDA) should be made to remove these barriers in order to be able to deliver the same services in different ways that account for the needs of service users. Positive steps (in the form of additional service or a tailored service) are also likely to be necessary.

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We consider that, under the DDA 1995, GP practices and other providers of primary health care services need to have in place measures which make it easier for people with learning disabilities and/or mental health problems to make an appropriate appointment; also measures to ensure that those people are appropriately dealt with by all staff; and measures to ensure that those people have access to appropriate information in an accessible form of their preference.

Absence of research support for the effectiveness of these measures in changing health outcomes should not stand in the way of them being implemented. They are required to secure for people with learning disabilities and/or mental health problems equal access to, and outcomes from, primary care health services and physical health.

Examples of the sorts of changes we have in mind include the following

- GP practices and other providers of primary health care services should offer people with mental health conditions and/or learning disabilities, and other disabled people, the option of identifying and recording their own 'access requirements' on the electronic patient record, so that this 'pops up' to remind primary care staff of the person's requirements (such as for a longer appointment time, to be allowed to wait in a separate area, and so on). In the interim, the same thing could be done on existing records. This is a simple way of encouraging good practice under the Disability Discrimination Act and also has wider applicability, for instance to people whose first language is not English. Where relevant, the record could refer to any 'advanced directive' such as that given by a patient with a fluctuating condition (and thus fluctuating capacity) that another person should be able to give instructions on their behalf in specified circumstances. Staff should refer to and act on the information on individual requirements whenever there is contact with the person. Staff should welcome requests from individuals for reasonable adjustments. Practice staff should provide service users with clear information on how any information on their record will be used, the confidentiality to which it will be subject and their rights to see and where appropriate (eg on their own access requirements) amend the information.

- As the Parliamentary and Health Service Ombudsman in England put it to us:

“ I welcome the suggestion that people with mental health conditions and/or learning disabilities should be given the option of identifying and recording their own access requirements. I also think it would be helpful for practices to provide such patients with as high a level of continuity as possible in terms of their regular contact with practitioners; in some of the complaints I have considered, problems have arisen because of lack of continuity and failures in effective communication where care is shared by several practitioners”

We agree.

- GP practices should offer people with learning disabilities and/or mental health problems the option of different length appointment times (since some people will choose shorter, some longer appointments).
- GP practices should offer people with learning disabilities and/or mental health problems the option of having a first or last appointment, for instance so that a child with autism or adult with extreme anxiety can avoid having to wait, when waiting is difficult or impossible; the option of dropping in and making an appointment or waiting to be seen; there also needs to be flexibility about how appointments are made (eg to allow for the use of email or fax) for those people who find it difficult to make appointments by telephone.
- GP practices should offer people with learning disabilities accessible appointment cards (eg in large print or Easyread).

- GP practices should offer people with learning disabilities and/or mental health problems telephone or text reminders of appointments where wanted.
- GP practices should offer people with learning disabilities and/or mental health problems telephone appointments, for instance if someone finds travel impossible; or home visits; or choosing – where practical and reasonable – to see a particular GP.
- GPs, receptionists, practice nurses, dieticians and other front line staff should be given ongoing professional development on the DDA requirements generally, and the access needs of people with learning disabilities and/or mental health problems in particular, including (wherever possible) equality and awareness training from users and user groups.

We welcome the steps that have been taken in Wales to address some of these issues through the nGMS contract with GPs. In Wales from April 2006 there will be a Directed Enhanced Service which will give incentive to GPs to comply with disability access criteria, and as it will be part of the contract, Local Health Boards will monitor this. Although it may be argued that this doesn't take GPs beyond their legal obligations under the DDA 1995, it does represent progress and can (we believe must) be built on year on year to push accessibility of GP services forward so that services move beyond mere legal compliance. We recommend that similar arrangements be made in England.

Who needs to do what in England?

- 8.1 Each primary care practitioner needs specifically to consider implementing the suggestions above.
- 8.2 The Department of Health, the NHS Confederation and the BMA should prioritise implementation of the above suggestions through the nGMS contract. They should learn, as appropriate, from moves to give incentives to GPs in Wales to improve access to their services by disabled people.
- 8.3 PCTs should take steps to encourage primary care practitioners to make the adjustments in question, which are legally required, and audit them in doing so including through patient satisfaction surveys conducted among people with learning disabilities and/or mental health problems.
- 8.4 The Healthcare Commission should monitor and report on the implementation and effectiveness of this proposal, including through its oversight of PCTs.
- 8.5 The Association of Medical Secretaries, Practice Managers, Administrators and Receptionists (AMSPAR), the Practice Manager Network, the RCGP, the Royal College of Nursing (RCN), the BMA, NICE and the NPSA should collaborate with user groups to draw up guidance to encourage and support the implementation of the above recommendations. The guidance could include accessible versions of typical documents (such as patient information leaflets) which GP practices could then adapt to their local circumstances.
- 8.6 Connecting for Health (the national Information Technology (IT) strategy) and the Care Records Standards Board should actively encourage the practice of offering disabled people the opportunity to record their access requirements. They should ensure that software development facilitates this. They should actively promote and spread good practice.

- 8.7 The DRC should work with user groups to consider the desirability and potential development of an appropriate mechanism for GP practices which have adopted such practices to be identified to users as ‘disability friendly’.

Who needs to do what in Wales?

- 8.8 Each primary care practitioner needs specifically to consider implementing the suggestions above.
- 8.9 LHBs should audit these changes including through patient satisfaction surveys conducted among people with learning disabilities and/or mental health problems.
- 8.10 AMSPAR, the Practice Manager Network, the RCGP, the RCN, the BMA, NICE and the NPSA should collaborate with user groups to draw up guidance to encourage and support the implementation of the above recommendations. The guidance could include accessible versions of typical documents (such as patient information leaflets) which GP practices could then adapt to their local circumstances.
- 8.11 All bodies responsible for patient records systems, including Informing Healthcare (the national IT strategy for NHS Wales) and the soon to be established Welsh Information Standards Board, should work to ensure that disabled people have the opportunity to record their access requirements and that software development facilitates this across the NHS and in primary care in particular.

8.12 The Welsh Assembly Government and the GP contract negotiating team should gather information from Local Health Boards on the progress made by GPs in complying with the new Disability Access Criteria set out in the Directed Enhanced Service. Before the end of the contract year, they should report on this progress and investigate and report on any problems or failure to achieve desired outcomes. This must include a report to disability organisations (including members of RCGP's EQUIP – Disability Equality In Primary Care). The Welsh Assembly Government and GP contract negotiating team must consult with disability organisations on how to build on current criteria and ensure that next year's Directed Enhanced Service takes a firmer line and the criteria push GPs to do more to improve the accessibility of their services. This process should be repeated year on year.

8.13 There should be an equalities impact assessment and access audit of the Out of Hours Service to find out whether it is working and accessible for people with learning disability and/or mental health problems.

Recommendation 9:

People with learning disabilities and/or people with enduring mental health problems should be offered an annual 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

The Department of Health and Welsh Assembly Government have in the past committed themselves to introducing annual health checks for all people with learning disabilities.

It is not clear why this has not happened yet. It appears to have been because the requirement for GPs to undertake such checks was not included within the requirements of the GP contract (as it needed to be to make it happen given that the GP contract is the principal driver for such initiatives). That appears to be an example of the historic lack of priority given to the physical health needs of people with learning disabilities when it comes to actually securing change. And it is most regrettable because it had been assumed that the case for such checks had been accepted and they would be forthcoming.

Whatever the history, we consider that offering periodic physical health checks to people with learning disabilities should now be a priority. It should certainly not be held up by any claimed need for further research to be undertaken into matters such as the content or frequency of the checks. There is already sufficient research support for the principle of such a health check (see background evidence paper by A Nocon at www.drc-gb.org/healthinvestigation).

We welcome the Welsh Assembly Government's commitment to introduce such health checks for people with learning disabilities in Wales as a 'Directed Enhanced Service' in the GP contract from April 2006.

We welcome evidence that the incentives in the nGMS contract to offer health checks to people with bi-polar disorder or schizophrenia is resulting in high levels of compliance. Similar health checks should also be offered to other people with enduring mental health problems on the same basis. It will be important over time to track the follow-up activities from health checks and the health outcomes.

We are interested to note that in Wales there has been the introduction of a Directed Enhanced Service in the GP contract from April 2006 to encourage GPs to provide annual health reports called Practice Mental Illness (PMI) Reports. These are reports provided on the health of individuals with mental health problems who are in receipt of 'Enhanced' CPA, (ie those individuals who are assessed as having enhanced needs using the CPA). The existing health check for people with 'Severe Mental Illness' and this new PMI report each cover slightly different groups of people with mental health problems. We recommend that consideration be given as to whether they should both cover the widest group of people who require them. We would also recommend that England should learn from progress in Wales on this matter.

A check should be offered at the point of transition to adulthood.

The evidence to us suggests that, after that and for people who are already adults, checks should probably be offered on an annual basis.

A check should be offered at the point of admission to hospital (see above) or prison. And a check should also be offered to people leaving prison and other long stay institutions.

Physical health should be included in care plans and health checks triggered at the point of first assessment, where they are needed. The detailed content of the health check should be decided by reference to the currently-available research information. We expect it will include, among other things, ensuring that women and men get access to routine cancer screening. It may well be that it will be

appropriate, in many or all cases, for a primary care specialist other than a GP (for example a practice nurse) to undertake such health checks.

Particular attention will be needed to ensure that all people with learning disabilities and/or mental health problems are able to take advantage of a health check, including those who might experience difficulties accessing a GP (as noted above) such as those in residential care, in-patient mental provision or who are homeless.

Monitoring and evaluation of the scheme once in place can be used to refine the content and frequency of the health check.

Who needs to do what in England?

- 9.1 The Department of Health, in discussion with the NHS employers and the BMA, needs to include within the nGMS contract a requirement that periodic physical health checks be offered to all people with learning disabilities and/or enduring mental health problems as soon as possible.
- 9.2 The Department of Health and PCTs should ensure that such health checks are also available to people being admitted to or leaving prison and other long stay institutions.
- 9.3 NICE, the RCGP and RCN should advise on the content of the health check and support and facilitate its introduction.
- 9.4 NICE, the Commission for Social Care Inspection and the Healthcare Commission, as appropriate, should evaluate and monitor the implementation and effectiveness of the scheme once implemented with a view to reporting on how it can be improved in the future. This should include monitoring access to routine interventions for particular to ensure both that there is no discriminatory under-use of such interventions in relation to these excluded groups; and that where health need is particularly high, interventions are commensurate.

- 9.5 The Department of Health should require that physical health be included in care plans and health checks triggered at the point of first assessment, where they are needed.
- 9.6 NICE and the British National Formulary should provide guidance to GPs on the specific physical health monitoring required for people taking particular psychiatric medications, given known adverse effects such as weight gain and diabetes
- 9.7 PCTs should monitor at local level the use of routine interventions, as above, in order to rectify any under usage of evidence-based interventions for these groups. In some instances one would expect a greater use of physical tests or onward referral: for instance, where someone has any difficulty in communicating, greater suspicion should be exercised which might result in a swifter move to physical tests or onward referral.
- 9.8 The availability and utility of such checks should be promoted as part of the process of informing people with learning disabilities and/or mental health problems of their rights in accordance with our recommendation 3.
- 9.9 The Department of Health, RCGP and BMA should work with user groups to develop and then distribute to GPs a 'good practice' guide on how to go about including in patient records information about whether individuals have learning disabilities, for the purposes of offering those people health checks. (It appears that GPs are likely to already have good records of which of their patients have mental health problems.)

Who needs to do what in Wales?

Learning Disabilities:

- 9.10 In Wales, a regular health check for people with learning disabilities is to be introduced by April 2006 (using a Directed Enhanced Service). We hope to see this start without delay.
- 9.11 The evaluation of this Directed Enhanced Service should monitor take-up by gender, race, age and disability (ie multiple impairment), and housing and support arrangements so that the effectiveness of the checks for different groups can be ascertained and changes made if necessary to ensure the scheme is appropriate, accessible and effective to all with learning disabilities regardless of gender, race, age, disability or where people are living. We believe it should be reasonably straightforward to monitor take up by gender, race, age, and disability based on anonymised data, so this should begin immediately but that particular consideration and implementation work will be required in order to monitor by housing and support arrangements. We have recommended this is undertaken because of the barriers certain groups face in accessing healthcare associated with where they live or the level or type of support they receive (as identified in recommendations 5, 6 & 7).
- 9.12 The Welsh Assembly Government and the National Public Health Service should monitor data from LHBs to assess the numbers of GPs undertaking the health checks across Wales. They should work with existing bodies involved in the health check, including academics, LHBs, RCGP and BMA to encourage all Wales coverage.

- 9.13 The Welsh Assembly Government and National Public Health Service together with LHBs and all those involved in the health check should ensure that data gathered through health checks is effectively used to monitor health inequalities, health need and health gain for this group.
- 9.14 The availability and utility of such checks should be promoted as part of the process of informing people with learning difficulties of their rights in accordance with our Recommendation 3.
- 9.15 The Welsh Assembly Government, Local Authorities, RCGP and BMA and other bodies involved in the health check in Wales should work with user groups to develop and then distribute a 'good practice' guide for GPs on how to go about compiling a voluntary register of people with learning disabilities among their patients for the purposes of offering those people health checks.
- 9.16 Welsh Assembly Government should ensure that guidance on the availability of health checks and referral onto the register is produced for social services staff and others involved in care plans, and assessments if this is to be a mechanism for registering for the checks.
- 9.17 The Welsh Assembly Government and Local Health Boards should ensure that such health checks are also available to people being admitted to or leaving prison and other long stay institutions.

Mental Health

- 9.18 The Wales Assembly Government, mental health organisations, service user groups, BMA and NHS confederation and other relevant bodies such as the Local Health Boards and National Public Health Service should meet to discuss how the existing health check for people with ‘severe mental illness’ and the new PMI Report can be most effective in reducing health inequalities for people with mental health problems.
- 9.19 This group should consider whether both the health check and the annual health report should cover the widest group of people who will benefit from them eg both cover those with assessed social needs,(ie enhanced CPA) and those defined as having severe mental illness.
- 9.20 This group should ensure that detailed guidance is provided for GPs on the use of the information and the health check and the new PMI report, building on existing guidance as necessary. Guidance must include advice on who is entitled, how to use the information about patients, how to carry out the check, and how to undertake the PMI health report; and clear reasons as to why these things are so important and how to involve patients positively.
- 9.21 Mental health service user groups should be involved in this work, particularly regarding guidance on seeking consent from patients.
- 9.22 NHS Confederation, RCGP, RCPsych and BMA should work together with Mental Health service user groups and National Public Health Service to develop guidance for patients on the existing health check and record of information about patients with SMI.

- 9.23 Review and monitoring of the existing SMI health check and the new PMI Report should be undertaken by Local Health Boards in conjunction with National Public Health Service and Assembly Government to assess their impact. Review and monitoring should include equality monitoring to ascertain take up by different groups and those living in different settings (eg by at least gender, race, age, disability – ie multiple impairment, and housing and support arrangements).
- 9.24 The Welsh Assembly Government and National Public Health Service and existing bodies including LHBs and Local Authorities involved in the health check should ensure that data gathered through SMI health checks is effectively used to monitor health inequalities, health need and health gain for this group.
- 9.25 The Welsh Assembly Government should consider and act on the recommendations of research it commissioned (through WORD) by Prof J Richards, ‘The All Wales Study of the physical health of people with Mental Illness’.

For health checks generally

- 9.26 The Welsh Assembly Government and Local Health Boards should ensure that these health checks for people with learning disabilities and people with mental health problems are also available to people being admitted to or leaving prison and other long stay institutions.
- 9.27 The Welsh Assembly Government should require that physical health be included in care plans and health checks triggered at the point of first assessment, where they are needed.
- 9.28 NICE and the British National Formulary should provide guidance to GPs on the specific physical health monitoring required for people taking particular psychiatric medications, given known adverse effects such as weight gain and diabetes.

- 9.29 Informing Health Care, (Responsible for NHS Wales National IT strategy), BMA, RCGP and NHS Confederation should ensure that GPs have appropriate IT software and templates to support and prompt these health checks, engaging directly with software firms as necessary.
- 9.30 NICE (and where relevant the All Wales Medicine Strategy Group) the CSIW and HIW, as appropriate, should evaluate and monitor the implementation and effectiveness of health checks with a view to reporting on how the systems can be improved in the future. This should include monitoring access to routine interventions for particular conditions (eg use of stations, etc) to ensure both that there is no discriminatory under-use of such interventions in relation to these excluded groups; and that where health need is particularly high, interventions are commensurate.
- 9.31 LHBs should, through use of these checks and other measures, monitor at local level the use of routine interventions, in order to rectify any under-usage of evidence-based interventions for these groups. In some instances one would expect a greater use of physical tests or onward referral: for instance, where someone has any difficulty in communicating, greater suspicion should be exercised which might result in a swifter move to physical tests or onward referral.

Recommendation 10:

We recommend that 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

We are alarmed by the apparent lack of appropriate, accessible and targeted information and support to encourage and enable people with learning disabilities and/or mental health problems to improve their physical health, particularly where they are in residential settings such as residential care homes and hospitals. As a minimum, the support offered to people with learning disabilities and/or mental health problems should include:

- 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.
- Individual advice on health promotion and wellbeing from GPs and practice nurses.

- Information in an accessible form of their preference on all psychiatric and other medication which the GP is contemplating prescribing for them (by reference to generic as well as brand names) including an explanation of side effects, so that they can make fully informed choice about the medication they take, making their own decisions about balancing mental health and physical health needs.
- Opportunities for healthy eating and access to opportunities for exercise and healthy living when they are in residential setting such as residential care or hospitals.
- Access to local leisure services.
- Peer support.
- Support and information to enable participation in employment, education and other positive social roles (which in themselves tend to improve health).

We are particularly alarmed by evidence of people having experienced a marked deterioration in their physical health while in inpatient mental health provision. Our recommendation (above) that they get proper access to primary care services in relation to their physical health is only part of the picture.

Who needs to do what in England?

10.1 Community Mental Health Teams and Community Learning Disability Teams should provide a service to support people with learning disabilities and/or mental health problems to access facilities and opportunities which can improve their physical health.

- 10.2 The Department of Health should ensure that Smokefree NHS and tobacco control programmes are fully focused on the needs of people with severe mental health problems, drawing on evidence of ‘what works’ in supporting mental health service users to quit, and on user preferences.
- 10.3 NICE should develop guidelines for effective approaches to smoking cessation and weight management specifically for people with mental health problems: when smoking can be harder to quit (being used to self-medicate) and weight harder to lose (given psychiatric medication effects, discrimination in mainstream leisure, poor food in residential and hospital settings).
- 10.4 NICE should produce guidelines on effective approaches to psychiatric prescribing and weight management for people with learning disabilities.
- 10.5 The Department of Health should make ‘health trainer’ advice and support available to all people with learning disabilities or mental health problems.
- 10.6 NHS Direct/Health Direct should work with learning disability organisations to develop a full range of health information materials in EasyRead, downloadable from the web. That information should then form part of the information which is made available in accordance with our recommendation 3, as above.
- 10.7 The RCGP and RCPsych should encourage their members to ensure that they pay particular attention to providing people with learning disabilities and/or mental health problems with full information in an accessible form about the benefits and side effects of medication (including in relation to physical health effects), particularly psychiatric medication where prescribed to people with mental health problems, in order to enable patients to exercise a properly informed choice about their treatment options.

- 10.8 PCTs and local authorities commissioning residential care services should ensure that those facilities offer dietary and other regimes which encourage healthy eating and living. This should be in line with current DH guidelines, for instance residents should generally be able to eat 5 portions of fruit and vegetables per day and to achieve 10,000 steps of exercise or equivalent if they wish to. Commissioners of domiciliary care and other workers supporting people in their own homes should ensure that those workers facilitate options around healthy eating and living wherever possible.
- 10.9 The Commission for Social Care Inspection and the Healthcare Commission should ensure that establishments are acting to promote healthy eating and living and offering options for healthy eating and living. The aim should be to ensure that effective approaches to exercise (often in very restricted environments) and food (often not nutritious) are offered to residents/patients, as well as relevant and supportive approaches to quitting smoking.
- 10.10 Although not directly within the ambit of our Inquiry, the evidence to us also suggests that:
- The Government should encourage food manufacturers to label foods and provide information on content/nutrition with pictures or other easy to understand communication.
 - Local authorities should ensure that leisure and sports services are fully accessible to, and promoted to, people with learning disabilities and/or mental health problems, in line with DDA requirements.
 - NHS Direct/Health Direct should undertake access audit and 'mystery shopping' to ensure people with learning disabilities and/or mental health problems can use the services effectively.

Who needs to do what in Wales?

- 10.11 Local Authorities and Local Health Boards should provide/commission services to support people with learning difficulties or mental health problems to access facilities and opportunities which can improve their physical health.
- 10.12 The Welsh Assembly Government (through the Office of the Chief Medical Officer) should ensure that smoke free and tobacco control programmes are fully focused on the needs of people with severe mental health problems, drawing on evidence of ‘what works’ in supporting mental health service users to quit, and on user preferences.
- 10.13 NICE (and where relevant the All Wales Medicine Strategy Group) should develop guidelines for effective approaches to smoking cessation and weight management specifically for people with mental health problems: when smoking can be harder to quit (being used to self-medicate) and weight harder to lose (given psychiatric medication effects, discrimination in mainstream leisure, poor food in residential and hospital settings).
- 10.14 NICE (and where relevant the All Wales Medicine Strategy Group) should produce guidelines on effective approaches to psychiatric prescribing and weight management for people with learning difficulties.
- 10.15 The Welsh Assembly Government should consider the proposals in England about ‘health trainers’ providing advice and support, and consider whether similar schemes in Wales should be made available to all people with learning disabilities or mental health problems.

- 10.16 Those responsible for health promotion information (Office of the Chief Medical Officer, National Public Health Service and NHS Direct Wales) should work with learning disability organisations to develop a full range of health information materials in Easyread, downloadable from web. That information should then form part of the information which is made available in accordance with our Recommendation 3, above.
- 10.17 The RCGP and RCPsych should encourage their members to ensure that they pay particular attention to providing people with learning disabilities and/or mental health problems with full information in an accessible form about the benefits and side effects of medication (including in relation to physical health effects), particularly psychiatric medication where prescribed to people with mental health problems in order to enable patients to exercise a properly informed choice about their treatment options.
- 10.18 LHBs and local authorities commissioning residential care services should ensure that those facilities offer dietary and other regimes which encourage healthy eating and living. This should be in line with current government guidelines, for instance residents should generally be able to choose to eat 5 portions of fruit and vegetables a day and achieve 10,000 steps of exercise or equivalent exercise. Commissioners of domiciliary care and other workers supporting people in their own homes should ensure that those workers facilitate options around healthy eating and living wherever possible.

10.19 Care Standards Inspectorate Wales, Healthcare Inspectorate Wales and the Healthcare Commission should ensure that establishments are acting to promote healthy eating and living and offering options for healthy eating and living. The aim should be to ensure that effective and appropriate approaches to exercise and food are offered to residents/patients, as well as relevant and supportive approaches to quitting smoking.

10.20 Although not directly within the ambit of our Inquiry, the evidence to us also suggests that:

- The Welsh Assembly Government in conjunction with Westminster and Food Standards Agency Wales should encourage food manufacturers to label foods and provide information on content/nutrition with pictures or other easy to understand communication.
- Local authorities should ensure that leisure and sports services are fully accessible to, and promoted to, people with learning disabilities and/or mental health problems, in line with DDA requirements.
- CHCs should undertake access audit and 'mystery shopping' to ensure people with learning disabilities and/or mental health problems can use the services effectively.

Recommendation 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 health care staff

We have mentioned the need for disability equality and awareness training at various points in our recommendations and ‘actions’ above. However, we see training and the issues surrounding it as being so important as to justify a freestanding recommendation in their own right.

Firstly, disability equality and awareness training is a key way to challenge stigma and prejudice and improve the way in which front line staff deal with people with learning disabilities and/or mental health problems.

Secondly, much of what we say should be done can happen through simple changes of attitude and practice and without great investment of resources. Disability equality and awareness training would make those changes more likely, as long as evidence based approaches are used and the training is mental health and learning disability focused. We note that historically generic disability equality and awareness training has tended to be very weak on mental health and learning disability issues. Similarly, the lack of priority given by policy makers and decision makers when it comes to committing to action to address these inequalities arises – we believe – from a lack of awareness of the issues involved and not from any in principle resistance. Again, this training may help to secure change.

Accordingly, the training we have in mind is training for everyone dealing with the physical health of people with learning disabilities and/or mental health problems, including those involved in making decisions about, or actually providing, services (including physical health services) to those people.

Such training should be part of initial professional training and (particularly for those who are already qualified) part of their ongoing Continuing Professional Development (CPD).

Wherever possible, the training should be designed in conjunction with, and delivered in part (at least) by, people who themselves have learning disabilities and/or a mental health problem.

To make that possible, it will be necessary, at least in some places, for user groups to be developed and supported, in some cases financially. We see that as a vital, effective and efficient investment in addressing the inequalities we have assessed.

The training we have described should include training to address 'diagnostic overshadowing'. In particular, we believe that the knowledge, attitudes and skills possessed by clinicians should include:

- The relationship that exists between physical health conditions and mental health conditions.
- That diagnostic overshadowing is a significant problem in consultations with people with learning disability and/or with mental health conditions. These conditions are likely to have associated physical health conditions, and the consultation process must therefore give due weight to ensuring that those physical health conditions are enquired and managed appropriately, in their own right, and not seen to be a manifestation of the mental and/or learning disability problem which is a particular issue for members of some Black and Minority Ethnic (BME) communities. (It seems that the reverse is also true for members of some BME communities where mental health problems may

appear to professionals to be physical health problems, thus reinforcing the need for diagnosis to involve a holistic approach that recognises both physical and mental health needs).

The training should aim to raise awareness of the need to see each aspect of the needs of a person with learning disabilities or a mental health problem in the context of their wider needs and not to consider the provision of particular services in isolation from other potential service needs. Most of those giving oral evidence to us acknowledged that diagnostic overshadowing is a common trait. Professor O'Brien from the Royal College of Psychiatrists said:

“ It is the case that doctors far too readily – and I mean all doctors – far too readily see people with disabilities and mental health problems and miss important basic health problems such as tooth ache, the in-growing toenail, ulcer or worse. That is a big problem”.

A key element of the training we have in mind is training to ensure that, when dealing with someone who has a communications impairment – for instance, someone with learning disabilities who has limited language – a GP should have a greater degree of suspicion about physical ill health than he or she might in relation to someone who could clearly express their pain or concern. The clinician should take note of the views of family members/care staff if they have noticed changes in behaviour or mood. The increased suspicion might mean moving more readily to objective physical tests or to onward referral; taking longer to clarify exactly what the problem may be; providing closer supervision; or involving an advocate or interpreter to help clarify the person's experience. These would be considered positive actions to promote equality of disabled people under legislation – and could on occasion be life saving. Good practice in this regard should be built into the proposed RCGP/RCN resource for primary care professionals and into training.

The benefits of training should be complemented by the inclusion within the performance management frameworks for individual staff of a requirement to demonstrate an adherence to the principles embodied in this report.

Who needs to do what in England?

- 11.1 Those organisations responsible for the specification, design and delivery of 'appraisal' to GPs should ensure that GPs receive regular and appropriate disability equality and awareness training in relation to the needs of people with learning disabilities and/or mental health problems.
- 11.2 The Department of Health, NHS Employers and BMA should ensure that the nGMS contract requires training, as explained below. Likewise, PCTs should ensure that GPs in their area put it into effect including by supporting them in organising regular practice-based or area-wide training events.
- 11.3 The organisations responsible for undergraduate medical training (including the GMC) need to ensure that courses include a compulsory element of disability equality and awareness training including in relation to learning disability and mental health which is designed and delivered by people with learning disabilities and mental health problems.
- 11.4 The Post Graduate Medical Education Training Board (PMETB) should ensure that undergraduate training is reinforced through further more focused and substantial training, as part of the post graduate training of doctors involved in relevant practice areas including general practice.

- 11.5 The Nursing and Midwifery Council and Nursing Council of Deans should ensure that undergraduate and postgraduate nursing training includes training on disability equality/access in relation to mental health and learning disability, provided by people with learning disabilities and/or people with mental health problems.
- 11.6 The RCGP, RCN, NHS Employers and DRC should work with user groups to develop and deliver disability equality and awareness training programmes and materials for GP practice staff and others involved in decisions relating to, and the provision of services to, people with learning disabilities and/or mental health problems. The training should be evidence based and pay particular attention to the needs of people with learning disabilities or mental health problems including in particular giving guidance on dealing with ‘capacity’ questions and on issues around confidentiality, particularly for a disabled person who is supported by a carer, an advocate, a key worker, or similar person.
- 11.7 All bodies (including therefore PCTs and GPs) employing staff providing services to people with mental health problems or learning disabilities should ensure that those staff receive appropriate disability equality awareness training (as part of their continuous professional development) in relation to the needs of people with learning disability and/or mental health problems, including from those people themselves.
- 11.8 Local groups representing people with learning disabilities or mental health difficulties (such as Learning Disability Partnership Boards) should, in conjunction with each other, develop their capacity to provide equality and awareness training to GP practices and others involved in the provision of physical health care services in their area, and provide such training.

- 11.9 PCTs should provide financial and other support to enable that to happen. The Department of Health should ensure that they do.
- 11.10 The Department of Health should work with the BMA and AMSPAR to consider requiring that, over time, everyone working as a receptionist in a GP practice or other primary health care setting should demonstrate specified competencies or hold an appropriate qualification which includes a substantial disability equality and awareness training element, explicitly including learning disability and mental health.

Who needs to do what in Wales?

- 11.11 The organisations responsible for undergraduate medical training (including the GMC) need to ensure that courses include a compulsory element of disability equality and awareness training including in relation to learning disability and mental health which is designed and delivered by people with learning disabilities and people with mental health problems.
- 11.12 The Post Graduate Medical Education Training Board (PMETB) should ensure that undergraduate training is reinforced through further more focused and substantial training, as part of the post-graduate training of doctors involved in relevant practice areas including general practice.
- 11.13 The Nursing and Midwifery Council and Nursing Council of Deans should ensure that undergraduate and postgraduate nursing training includes training on disability equality/access in relation to mental health and learning disability, provided by people with learning disabilities and people with mental health problems.

- 11.14 All bodies (including therefore LHBs and GPs) employing staff providing or commissioning services to people with mental health problems or learning disabilities should ensure that those staff receive appropriate disability equality and awareness training (as part of their continuous professional development) in relation to the needs of people with learning disability or mental health problem, including from those people themselves.
- 11.15 The Welsh Assembly Government, NHS Employers and BMA should ensure that the nGMS contract requires that to happen. Likewise, LHBs should ensure that GPs in their area put it into effect including by supporting them in organising regular practice-based or area-wide training events.
- 11.16 The Inquiry Panel notes the progress made in Wales by RCGP in partnership with disability organisations to develop a model of disability equality and awareness training and on going service development for GP practices (named 'Equip' – Disability Equality in Primary Care). The Welsh Assembly Government and Local Health Boards should provide support and appropriate resources to ensure the project is successfully piloted and a sustainable ongoing programme developed.
- 11.17 The RCGP's Equip Project should make appropriate use of training materials and resources developed in England and Wales following this formal investigation. The content of Equip training and ongoing service development should incorporate the findings of this formal investigation.

- 11.18 Local groups representing people with learning difficulties or mental health difficulties should, in conjunction with each other and with other disability organisations, develop their capacity to provide awareness training to GP practices and others involved in the provision of physical health care services in their area; and provide such training. We are pleased that these issues have been considered as part of the 'Equip' initiative in Wales.
- 11.19 LHBs should provide financial and other support to enable that to happen. The Assembly should ensure that they do.
- 11.20 Those organisations responsible for the specification, design and delivery of 'appraisal' to GPs should ensure that GPs receive regular and appropriate disability awareness training in relation to the needs of people with learning difficulties and people with mental health problems.
- 11.21 The Welsh Assembly Government should work with the BMA and AMSPAR to consider requiring that, over time everyone working as a GP receptionist or other primary healthcare setting should demonstrate specified competencies or hold an appropriate qualification which includes a substantial disability equality and awareness training element, explicitly including learning disability and mental health.

Appendix 1

The Panel

Dr David Wolfe – Chair

Barrister at Matrix. 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 the 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 Disabilities Action Group, with personal experience of learning disability.

Professor Zenobia Nadirshaw

Head of Clinical Psychology Service in the Kensington & 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 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.

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 2

Advisers and Assistants to the Panel

Jonathan Holbrook

DRC Head of Strategic Enforcement Team

Dr Andrew Nocon

DRC Senior Research Officer

Joanna Owen

DRC Legal Officer

Laura Jerram

DRC Practice Development Officer

David Groves

DRC Policy Officer (Health)

Glynis O'Halloran

Administrator

Racheal Ujanga

Administrator

Elisabeth Al-Khalifa

DRC's adviser on health

Prof. Eric Emerson

University of Lancaster

Dr Alan Cohen

Sainsbury Centre for Mental Health

Dr Huw Lloyd

Royal College of General Practitioners Mental Health Task Group

Appendix 3

Organisations Providing Written Evidence

England

Association of Medical Secretaries, Practice Managers,
Administrators and Receptionists (AMSPAR)

Commission for Social Care Inspection

Coventry PCT

Equality & Human Rights, Department of Health

General Medical Council

Health Service Ombudsman

Healthcare Commission

Mencap

Mind

National Patient Safety Agency

NHS Direct

Prison Health, Department of Health

Rethink

Royal College of General Practitioners

Royal College of Nursing

Royal College of Paediatrics & Child Health

Social Exclusion Unit, Office of the Deputy Prime Minister

Turning Point

Valuing People Support Team

Wales

All Wales People First

Auditor General

Chief Medical Officer for Wales

Children's Commissioner for Wales

Depression Alliance Cymru

Learning Disability Wales (formerly Standing Conference of Voluntary Organisations)/Mencap

Mind Cymru

National Public Health Service

NHS Centre for Equality & Human Rights

Ombudsman – Wales

Welsh Assembly Government

Welsh Local Government Association

Appendix 4

Organisations which gave oral evidence to the Panel

England

Access, Policy Development & Capacity Planning, Department of Health

British Medical Association

Commission for Social Care Inspection

Equalities

Health Inequalities, Department of Health

Healthcare Commission

Learning Disability Task Force

Mencap

Mind

Mindlink

National Institute for Health & Clinical Excellence

National Institute for Mental Health for England

NHS Employers

People First

Primary Care, Department of Health

Rethink

Royal College of General Practitioners

Royal College of Psychiatrists

Valuing People Support Team

Wales

All Wales People First

Learning Disability Wales
(formerly Standing Conference of Voluntary Organisations)

Mencap Cymru

Depression Alliance Cymru

Mind Cymru

National Public Health Service in Wales

Wales Local Government Association

Welsh Assembly Government

Members of the Panel also met with the following

Breaking the Circles of Fear, SCMH

Department of Health Director for Delivery

Department of Health National Director for Mental Health

Department of Health GP Contract Lead

NHS Appointments Commission

NHS Direct

Turning Point

Professor Malcolm Lader

Appendix 5

Organisations which commented on a consultation draft of our emerging recommendations

England

British Medical Association

Commission for Social Care Inspection

Care Services Improvement Partnership

Expert Patients Programme

General Medical Council

Healthcare Commission

Mencap

Mind

National Patients Safety Agency

NHS Direct

NHS Employers

Parliamentary and Health Service Ombudsman

Royal College of General Practitioners

Royal College of Paediatrics & Child Health

Social Exclusion Unit

Wales

Depression Alliance Cymru

Mind Cymru

National Public Health Service for Wales

Welsh Assembly Government

Appendix 6

Acronyms we have used

A&E	Accident and Emergency
AMSPAR	The Association of Medical Secretaries, Practice Managers, Administrators and Receptionists
BMA	British Medical Association
BME	Black and Minority Ethnic
CHC	Community Health Council
CHD	Coronary Heart Disease
CPA	Care Programme Approach
CPD	Continuing Professional Development
CRE	Commission for Racial Equality
CSCI	Commission for Social Care Inspection
CSIP	Care Services Improvement Partnership
CSIW	Care Standards Inspectorate Wales
DCA	Department for Constitutional Affairs
DCLG	Department for Communities and Local Government
DDA	Disability Discrimination Act
DED	Disability Equality Duty
DH	Department of Health
DRC	Disability Rights Commission
GMC	General Medical Council
GP	General Practitioner

HAP	Health Action Plans
HCC	Healthcare Commission
HIW	Healthcare Inspectorate Wales
HSCWB	Health Social Care and Well Being
IT	Information Technology
LD	Learning Disability
LDIAG	Learning Disability Implementation Advisory Group
LHB	Local Health Board
MH	Mental Health
nGMS	new General Medical Services
NGO	Non-Governmental Organisation
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NIMHE	National Institute for Mental Health in England
NPHS	National Public Health Service
NPSA	National Patient Safety Agency
NSF	National Service Framework
NVQ	National Vocational Qualification
OCMO	Office of the Chief Medical Officer
PALS	Patient Advice and Liaison Services
PCT	Primary Care Trust
PMETB	Post Graduate Medical Education Training Board
PMI	Practice Mental Illness

PPI	Patient and Public Involvement
PSA	Public Service Agreement
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCPsych	Royal College of Psychiatrists
SAFF	Service and Financial Framework
SHA	Strategic Health Authority
SMI	Severe Mental Illness
WAG	Welsh Assembly Government
WCVA	Wales Council for Voluntary Action

