

# Equal Treatment: Closing the Gap - One Year On

## Report of the Reconvened Formal Inquiry Panel of the DRC's Formal Investigation

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

September 2007



**Equal Treatment: Closing the Gap**

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# Preface

Last year we said that urgent action was required by everyone concerned with the physical health of people with learning disabilities and/or mental health problems to tackle the huge inequalities they experience in their physical healthcare.

We said that if everyone acted together, and soon, real progress could be made. We made specific recommendations as to who needed to do what.

A year on, we have looked at progress in response to our recommendations and the Disability Rights Commission's Formal Investigation in general. Further information has also emerged confirming the problems we identified.

We are pleased to report that some organisations (including, for example, the British Medical Association, Royal College of General Practitioners and Welsh Assembly Government) have taken our recommendations very seriously and taken firm and positive action. That is most welcome.

Others have made a start, but still have a long way to go. We are particularly concerned that the Department of Health is only just beginning to show the high-level commitment and leadership that we said was necessary if real change was to come about in England. The first steps have been made. However, we are most concerned that physical health checks for people with learning disabilities have still not come forward and most frustrated that there is resistance to collecting the national data on health inequalities that we believe to be essential to any programme to tackle those inequalities.

In a health service that relies increasingly on action by local bodies and in which the Department of Health provides a policy and oversight role, it is all the more important that the Department uses its influence to the fullest.

That is particularly so given that many of the organisations to whom we directed recommendations appear to have taken no notice of them at all. For them, the physical health needs of people with learning disabilities seem still to be a low priority or not an issue of active consideration at all. It is, for example, woeful that only two out of 10 Strategic Health Authorities have Disability Equality Schemes that even come close to what is required. This is completely unacceptable. Failing SHAs must be urged into action, either by the Department of Health or through Equality and Human Rights Commission (EHRC) legal

enforcement. The term 'institutional discrimination' does not seem too strong to describe what is happening in some quarters.

In this follow-up report, we have updated our key recommendations for action. Given that the DRC's role and powers is about to be assumed by the new commission, we have also made recommendations for how the EHRC could pursue delivery. We strongly urge every relevant organisation to act on those recommendations. If they do not, a real opportunity will be missed. That will mean the difference between life and death for some people with learning disabilities and/or mental health problems.

Finally, can I thank all members of the Panel for their invaluable contribution to this work. The strength of our recommendations is undoubtedly all the greater because of the breadth of expertise represented. And can I also, on behalf of the Panel, thank all members of the DRC staff, and others, who have worked so hard over the last couple of years on this project, including on this update report.

David Wolfe  
Chair of the Formal Inquiry Panel  
September 2007

# Executive Summary

The Disability Rights Commission (DRC) Formal Investigation (FI), '**Equal Treatment: Closing the Gap**', found that people with learning disabilities and people with mental health problems are much more likely than other people to face significant health risks and experience major physical health problems. The FI also found that both groups are likely to die younger than other people.

Despite this pattern of early death – and experience of potentially avoidable ill health – these groups are less likely to get some standard, evidence-based checks and treatments (such as health screening or statin treatment for heart disease) and face huge access and attitude barriers in using health services.

Since the publication of the FI report in September 2006, further evidence has also emerged regarding serious problems with health care for people with learning disabilities. An example is the Healthcare Commission and Commission for Social Care Inspection (CSCI) report into services for people with learning disabilities in Cornwall Partnership NHS Trust, which catalogued numerous failings including a lack of treatment plans, a range of physical and emotional abuses and systemic failure to change underlying problems in the culture, policies and practice that enabled abuse and poor practice to flourish.

Earlier this year Mencap also published 'Death by Indifference' – a report on the death of people with learning disabilities in NHS care, which has subsequently prompted the government to set up an independent inquiry. Several of the cases in the Mencap report reflected the problems of 'diagnostic overshadowing'<sup>1</sup> and failures to record people's impairment related and access needs on their patient records, both of which were highlighted in the Investigation. Both reports highlight a lack of adequate performance management – both by Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs).

Our assessment of progress since September 2006 has identified some examples of positive action – for instance action to improve professional learning by the British Medical Association (BMA), General Medical Council (GMC) and Equip Cymru aimed at reducing diagnostic overshadowing and poor access. There have also been improvements to the GP contract in Wales and, very recently, the Wales Health Minister proposed a 'Task and Finish Group' on

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<sup>1</sup> Diagnostic overshadowing refers to the tendency of health and social care professionals and others to interpret the reporting of symptoms, and symptoms themselves, to a learning disability or mental health problem.

improving access to primary healthcare for people living in residential and institutional settings, in response to our investigation.

However, we also identified major weaknesses in implementing recommendations

It is clear to us that not enough strategic change or prioritisation has yet taken place for us to be confident that the stark inequalities the original DRC Investigation highlighted will be significantly reduced in the foreseeable future. This is extremely disappointing. We cannot over-emphasise the need for greater urgency. Accusations of institutional discrimination are not unfounded given the level of inaction to tackle the significant health inequalities evidenced. For many people with learning difficulties and mental health problems this is quite literally a matter of life and death.

- Only two SHAs were found to have adequate Disability Equality Schemes (DESSs), despite this having been a legal requirement since December 2006. SHAs should be showing leadership in this area but are actually behind PCTs' performance – which itself is very patchy.
- On health checks there has been some positive progress in Wales but no action in England due to negotiations over GP contracts breaking down.
- It is very disappointing that despite Disability Discrimination Act (DDA) requirements having been in force since 1999, there has been only limited progress in enabling people to record access needs or even to get basic access needs met (for example, diagnosis and treatments being communicated in ways people can understand). It is welcome however, that in Wales disability access has been incentivised in the GP contract, although there is little information yet as to the impact this has had or whether it will continue.
- There has been some progress on tackling diagnostic overshadowing and negative attitudes and we particularly welcome the support the Royal College of General Practitioners (RCGP) has given in promoting and disseminating the Disability Equality learning packs produced as a result of the original FI. More needs to be done, however, as some parts of the country have not taken these up. We also welcome progress by the Royal College of Psychiatrists (RCPsych) on including disability equality modules in Continuing Professional Development training but this needs to be

extended to people already working in the profession and also needs to become an integral part of the appraisal system.

- There has been a disappointing response to our recommendations on bowel cancer screening. The DRC's research found people with schizophrenia twice as likely to experience bowel cancer. The Department of Health (DH) has stated that more research is needed – but that should not stop action to ensure people who may be at high risk are included in screening where eligible. There has not been any action at all on screening for people with learning disabilities.
- It is deeply disappointing that the DH has rejected the recommendation to monitor Public Service Agreement (PSA) targets by broad impairment group so we know exactly who is dying young from the major killer diseases. With that monitoring, PCTs could take targeted action on health inequalities and nationally we could monitor progress. Without it this will remain a hidden issue, not measured and so not tackled. Further progress is also still needed on this in Wales and it is hoped that the Welsh Assembly Government (WAG) will use the new Public Health Strategy on health inequalities to work strategically on this issue.
- The DH has at least acknowledged that such monitoring data would be useful in guiding healthcare providers and in identifying/meeting needs - but it believes this should be done at local level. In that case, the Department must take the lead (through duties and guidance) to ensure this is done effectively locally and in a manner accessible at national level (e.g. by requiring standardised data collection).
- Finally, real change requires leadership. We know that some individuals in the DH have prioritized the health needs of people with the poorest health and highest risks – but there has been an absence of strategic action at the highest level. Busy health service commissioners and providers have therefore not placed priority upon it. This is wholly unacceptable when we are talking about the very people the NHS is there for above all – those with the poorest health and the greatest health risks. In Wales we are pleased that the WAG commitments made to date are being overseen by the WAG Department of Health and Social Services Equality group. There is, however, still a lack of coordination between the organisations and groups working on this agenda across Wales. Again, the new Public Health Strategy on health inequalities should be an opportunity to provide

leadership and coordination so that everyone is informed and working together maximising their efforts.

Our key recommendations on tackling these issues are that:

- Much greater urgency across the health sector – particularly from SHAs - needs to be given to DESs and associated Action Plans, and embedding our recommendations within them. We expect that legal enforcement action will result from any further inaction.
- The DH provide national leadership and hold SHAs to account to ensure the development of DESs that are effective at tackling evidenced health inequalities.
- The DH clearly lead delivery of our recommendations on monitoring data, demonstrating how it will use its national role to ensure the benefit of breaking down PSA targets by impairment is understood and acted upon at local levels.
- The WAG take the opportunity to use the Public Health Strategy currently being developed to tackle the health inequalities we have identified, to set high-level targets and to tackle the long-standing issue of breaking down health data by impairment group to ensure inequalities are tracked.
- The DH gives a stronger steer on what kind of minimum outcomes are expected in the 'Commissioning Framework for Health and Wellbeing' with regard to local action on reducing health, if the proposals are to be effective and to meet equality duty requirements.
- The DH reminds PCTs and their contractors (including GPs) of their DDA duties to ensure they can meet all users' needs, including the need to make reasonable adjustments and the Disability Equality Duty (DED) requirement to be proactive in tackling known barriers to healthcare services, such as those we highlighted in September 2006.
- The DH, BMA and RCGP restart negotiations on the GP contract as soon as possible and come to a firm agreement to ensure that our recommendation on access to annual health checks is implemented.
- PCTs make greater use of Enhanced Services Agreements to deliver health checks for people with learning disabilities.



- The WAG and the BMA in Wales ensure that the Directed Enhanced Service learning disability health check is established on a five-year rolling programme.
- The RCPsych, RCGP, Royal College of Nursing (RCN) and Association of Medical Secretaries, Practice Managers, Administrators and Receptionists (AMSPAR) should increase their efforts to ensure that disability equality training is delivered across the health profession.
- With regard to the online training module being developed by RCPsych and RCGP, the colleges should take appropriate steps to maximize the number of members enrolling for this module – making it a formal requirement if necessary - and consider extending mandatory courses to existing professionals as well as those entering professions.
- The Healthcare Commission and Health Inspectorate Wales should prioritise monitoring compliance with DDA and DED requirements in inspections.
- We recommend that the new Equality and Human Rights Commission (EHRC) continues and improves upon the joint working established between the DRC and the Healthcare Commission on the DED.

# Introduction and Background

The DRC originally undertook a Formal Investigation into health inequalities in the light of significant international research evidence showing that people with learning disabilities and/or mental health problems are more likely than other people to die young and to live with physical health problems, many of which are potentially preventable. The DRC wanted to understand this experience in England and Wales with a view to making recommendations on changes to primary care policy and practice that would help 'close the gap' in physical health inequalities.

The DRC Investigation revealed an inadequate response from the health services and governments in England and Wales to the major physical health inequalities experienced by some of the most socially excluded members of society: people with learning disabilities and/or mental health problems. This includes the 1 million people with learning disabilities, 200,000 people with schizophrenia or bipolar disorder and 6 million people with depression.

The Investigation found that people with learning disabilities and people with mental health problems are much more likely than other people to have significant health risks and major health problems. For people with learning disabilities these include obesity and respiratory disease; for people with mental health problems it includes obesity, smoking, heart disease, hypertension, respiratory disease, diabetes and stroke.

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

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

Despite this pattern of early death – and experience of potentially avoidable ill health – these groups are less likely to get some standard, evidence-based checks and treatments (such as health screening and statin treatment for heart disease) and face huge access and attitude barriers in using health services.

As part of the Investigation the DRC asked an Inquiry Panel of experts, chaired by barrister David Wolfe, to review the evidence, consult with stakeholders and

identify effective and feasible approaches for tackling the gap of health inequalities highlighted by the FI.<sup>2</sup>

Following publication of the findings and recommendations of its Investigation in 'Equal Treatment: Closing the Gap' in September 2006, the Inquiry Panel recommended that it should follow up its initial work after a year or so to report on progress. Also, that such follow-up should include an evaluation of the extent to which our recommendations have formed part of the DESs that Public Authorities were required to produce by 4 December 2006 (as part of their obligations under the new DED under the Disability Discrimination Act 2005). So the DRC reconvened the Inquiry Panel in July 2007 to review progress and to take further evidence from key organisations. This report summarises the Panel's findings.

In the past year, a lot has been done by some organisations in response to our recommendations, but not much has been done by others. A year has not been long enough to see the task completed but it has nevertheless been useful to reconvene after a year to ascertain action or inaction, give praise where it is due, and to apply pressure where action is now even more urgently required in order to ensure completion of the tasks we set.

The timing of our review is particularly important because the DRC closes at the end of September 2007, to be replaced by the new EHRC. We hope that this report will assist the new Commission to carry forward work in this priority area.

This report details our views on progress to date on implementation of recommendations and on priorities for ongoing action. The report aims to give the health sectors in England and Wales a clear steer on key priorities still to be addressed in order to tackle the significant inequalities evidenced by the DRC Formal Investigation.

The first part of the report gives an overview of the position one year on, summarises the main achievements to date and the key overall priorities for future action.

The second part of the report considers the priority actions arising from each of the 11 main recommendations from our original report. Under each recommendation we have identified specific actions for named organisations in the following categories:

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<sup>2</sup> Copies of the original FI reports from the DRC are available in an archive section of the Equality and Human Rights Commission website.

1. National Government bodies – Welsh Assembly Government and the Department of Health
2. Strategic Health Authorities and Primary Care Trusts in England and Local Health Boards & Local Authorities in Wales
3. Intermediary, standard setting and inspection bodies, and key NHS organisations including the National Institute for Clinical Excellence (NICE), Inspectorates, Patient Forums and Health Scrutiny Committees, National Public Health Service (NPHS), NHS Wales Centre for Equality and Human Rights, and the DRC's successor – the EHRC.
4. Professional bodies and colleges including the RCGP, RCPsych, BMA and AMSPAR.

We also hope disability organisations, service user organisations, and other voluntary sector organisations will continue to apply pressure to statutory bodies to implement the recommendations relevant to their members/users.

Our original report contained 11 main recommendations, each of which was broken down into more detailed recommendations. We have not commented on all of the detailed recommendations here, although many remain to be implemented.

Our main focus is on those recommendations which require urgent action. We identify which organisation needs to do what (including the EHRC) in order to ensure the recommendations are fully implemented.

# Overview

Since the publication of the FI report in 2006, further evidence has emerged regarding serious problems with health care for people with learning disabilities. For example the report published by the Healthcare Commission and CSCI into the provision of services for people with learning disabilities in Cornwall Partnership NHS Trust catalogued numerous failings, including a lack of treatment plans, a range of physical and emotional abuses and systemic failure to change underlying problems in the culture, policies and practice that enabled abuse and poor practice to flourish.

Earlier this year Mencap also published their 'Death by Indifference' report on the death of people with learning disabilities in NHS care, which has subsequently prompted the government to set up an independent inquiry. Several of the cases in the Mencap report reflected the problems of diagnostic overshadowing and failure to record people's impairment related and access needs on their patient records, both of which were highlighted in our FI.

Both reports highlight a lack of adequate performance management – by PCTs and SHAs. We are pleased to note that the Terms of Reference for the independent inquiry into healthcare for people with learning disabilities led by Sir Jonathan Michael specifically includes taking account of evidence and findings from the DRC's FI. The inquiry represents a significant further opportunity to make recommendations that impact on the issues we have identified, both in the original FI and in this follow-up report. We are pleased therefore that Sir Jonathan Michael and his team have been in dialogue with the DRC and very much hope that dialogue continues with the EHRC. We have made some specific recommendations on issues we would like to see addressed by the inquiry in this report.

## **Warm words need to be translated into action**

In our original report we said 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; nor that, in many instances, these groups do not have full and proper access to the primary health care services they need to promote their health and well-being. We concluded that:

“Those inequalities are not inevitable. They have existed for far too long. 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.”

No-one disagreed with that.

We also said that if all the relevant organisations were to use their power and influence to bring about change at the earliest opportunity, real progress could be made.

This has not yet happened. The very many expressions of support for, and agreement with, our recommendations have not so far been backed-up with sufficient action.

Many organisations have made progress to implement our recommendations, some of them a lot of progress.

For example, much has been done to tackle practice issues through professional learning and development. There is also a growing awareness of the health inequalities experienced by disabled people. That has generated a considerable amount of goodwill among some of the key professional organisations, such as the RCGP the BMA and Equip Cymru. All of that is to be greatly welcomed.

We very much welcome the detailed response to the FI from the Department of Health, which expressed agreement with most of our recommendations.

We also welcome the setting up of a high-level 'Delivery Group' within the Department, to oversee implementation of its Action Plan. It is vital that the DH continues the Delivery Group after the DRC's closure with membership from the EHRC, to ensure the actions it has committed to are implemented and that dialogue is continued. This would be both with the EHRC and with stakeholders progressing specific recommendations.

We were disappointed, however, with the lack of very specific commitments attached to clear timelines in the Department's action plan.

In Wales, we welcome Ministerial support for the implementation of the recommendations of the FI and the inclusion of specific action commitments, within an equalities action plan, overseen by the Chief Executive of NHS Wales and senior directors.

But, having now considered in detail the evidence on progress to date there can be no doubt that there is still a major challenge ahead. We have been disappointed to note a considerable degree of complacency and lack of

commitment in some parts of the health sector to tackle the inequalities in question. It seems to us that some parts of the health sector – particularly the SHAs in England – are simply not taking the issues seriously, and it is also particularly disappointing to find that there is still a widespread failure to meet even the most basic access needs more than ten years after the introduction of the DDA. There is no shortage of practical guidance on the DDA, so it is hard to identify any excuse at all for this state of affairs.

It is also clear to us that not enough strategic change or prioritisation has yet taken place for us to be confident that the stark inequalities found in the original DRC Investigation will start to be significantly reduced in the foreseeable future. This is extremely disappointing and we cannot over-emphasise the need for greater urgency. For many people with learning difficulties and mental health problems this is quite literally a matter of life and death.

In many areas, such as health checks in England, provision of accessible information, prescribing practices and leadership in public bodies at a local level, there remains a clear need for those at the top to translate words expressing agreement or goodwill into specific and concrete actions:

“.... there are a lot of warm words from the organisations; the Department of Health saying: ‘We agree, we agree, we agree.’ Then the next sentence is missing”. (David Wolfe, FI Inquiry Panel Chair)

A particular problem, with widespread consequences, has been a lack of leadership by the Department of Health. We believe that this has legitimised lack of action by others.

**A clear lead needs to come from the highest levels within the Department of Health and the Welsh Assembly Government taking action and ensuring that others take action**

Tackling health inequalities requires several things:

- disability equality must become part of everyday thinking and practice among health professionals;
- organisational structures must allow good practice to flourish and quickly root out bad practice;
- strong and clear strategic leadership is needed to make sure that all parts of the health sector are clear about what it is they are expected to deliver, and to make sure that they do.

The first is dependent on the second and both are, in turn, dependent on the third. We have found that leadership is the weakest link in the chain instead of being the strongest.

In England, the Department of Health has repeatedly said that it expects Primary Care Trusts to act in relation to health inequalities and that it is the job of Strategic Health Authorities to oversee them in doing so. It is very clear however that, so far, the SHAs have almost universally failed to take on board the implications of the DRC's Formal Investigation and implement our recommendations.

It is difficult to see how this can be turned around without stronger Department of Health leadership. In our original report we said that:

“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) have slowed down action to tackle the inequalities we have identified. We fear that those problems will hinder action in the future.”

But that is exactly what seems to have happened. The organisational shift from ‘command and control’ by the Department to influence through ‘policy and incentives’ is not working.

The shift away from centralised ‘command and control’ by the Department of Health should not signal any lessening in the strategic importance of the Department’s leadership role. Without this, there is a strong risk of creating the conditions for allowing systemic discrimination to persist by default. In our view the DH has still failed to grasp the significance of disability equality to mainstream public health objectives, as evidenced, in particular, by their unwillingness to require breakdowns of PSA targets by impairment group.

The deficit in life expectancy for people with learning difficulties and mental health problems is just as great as any of the geographical variations that are currently driving national policy. Indeed, to give just one example highlighted in the original FI report, there are more obese people with learning disabilities and/or mental health problems than there are obese people in Birmingham and Coventry combined. To tackle the problem of obesity among people with learning disabilities and/or serious mental health problems would thus have a greater impact than to do so across these two cities. A national programme to tackle health inequalities in England would not ignore whole cities like



Birmingham or Coventry and yet people with learning disabilities and/or mental health problems have, to date, been ignored in national health inequalities programmes.

So, specifically targeting health inequalities for these groups offers the opportunity for a win/win outcome as reducing the inequalities they experience would undoubtedly make a major contribution to achieving overall PSA targets.

Similarly, while we are encouraged to note that tackling health inequalities for people with learning disabilities and mental health problems has been highlighted in the WAG statutory guidance on Health, Social Care and Wellbeing Strategies, it is too early to tell whether this has been grasped by Local Health Boards (LHBs) and Local Authorities, or whether this will result in real changes to local service delivery. In Wales as in England we believe much more needs to be done to secure leadership and commitment at a local level.

We consider that both the DH and WAG need to do more to develop coherent national strategies on tackling the health inequalities disabled people experience, so that work is well coordinated. The proposed Public Health Strategy on health inequalities in Wales represents an enormous opportunity for the Assembly Government to address this.

Breaking down PSA targets by impairment group would be a major lever for concerted work on health inequalities in England and signal to the sector that it is a national priority. There is also a need for more impairment-specific targeted action within existing and national programmes like Spearhead in England and Health Gain Targets in Wales.

We also believe that the DH needs to give a stronger steer on what kind of minimum outcomes are expected by PCTs within the new Commissioning Framework to ensure local action on reducing health inequalities for disabled people.

We note that the Minister for Disabled People and the Office for Disability Issues (ODI) in England have discussed raising awareness of the FI amongst the Life Chances Ministerial Group. We hope that this report will provide the ODI with an opportunity to raise the profile of health inequalities with ministers will be acted on.

### **Holding the health sector to account**

The Healthcare Commission and the Health Inspectorate Wales will also have a crucial role in following up on the recommendations from the FI and holding the

health sector to account after DRC has closed down. So too will the Equality and Human Rights Commission (EHRC), as the DRC's successor.

We strongly urge the new Commission to formally commit, at the earliest opportunity, to take action on following up on recommendations that remain undelivered, linked to the Equalities Review and broader equalities concerns. Action by the EHRC should also include scrutiny of Single Equality Schemes and partnership work with the Healthcare Commission, Healthcare Inspectorate Wales (HIW) and the NHS Wales Centre for Equality and Human Rights.

Those responsible for inspection in both countries should take a stronger role in monitoring policy and practice to assess progress on embedding the recommendations. It is very important that monitoring DED compliance is prioritized in all annual and themed inspections where appropriate. We are pleased for example that the DRC investigation recommendations have informed the current HIW review of learning disability services.

### **Urgent action is needed on delivering access to health checks**

In our original report we emphasised the critical importance of access to regular health checks, which are particularly important for people who have under-used primary care and are likely to have unmet health needs.

In Wales we are pleased to note that regular health checks for people with learning disabilities have been introduced through the General Medical Services (i.e. GP) contract for 2006-2007; and that GPs in Wales have also been incentivised to write an Annual Health Report for individuals with mental health problems who are assessed as receiving 'Enhanced' support under the 'Care Programme Approach'.

We are very disappointed however at the lack of progress on delivering regular health checks in England. Contract negotiations between the DH and BMA need to be resolved to ensure health checks are incorporated into the GP contract as a matter of urgency. In addition, greater use could be made of Local Enhanced Services agreements to deliver access to health checks. It is clear from developments in Wales that this route can facilitate progress on this crucial recommendation even in the absence of a definitive conclusion to the GP contract negotiations so we strongly urge PCTs in England to make greater use of this option.

## **Prioritising disability equality training and education**

We have found that there is high degree of goodwill among professionals. We particularly welcome support and the progress to date from BMA, RCGP and Equip Cymru in particular.

However, priority still needs to be given to embedding disability equality learning and the lessons from the FI into professional development programmes run or commissioned by professional and training bodies, particularly the medical colleges. While RCGP and Equip Cymru and NHS Wales Centre for Equality and Human Rights have been very supportive on this issue, more specific commitments are required from other colleges/bodies such as the AMSPAR, RCPsych and RCN to incorporate disability equality competencies into training and appraisal programmes. The DH and WAG also need to prioritise supporting relevant bodies to deliver a national training programme.

## **Using the Disability Equality Duty as a tool for tackling health inequalities**

We remain of the view that the DED and the DESs which should flow from it, are crucial when it comes to understanding health inequalities and developing action plans.

So we are particularly disappointed at lack of progress to bring forward satisfactory DESs in most areas, particularly SHAs in England. In Wales, even though all LHBs say they intend to update their DED Action Plans in the light of our recommendations, most have not yet done so. LHBs, SHAs and PCTs must prioritise this work. And inspection bodies and the EHRC must monitor (lack of) progress and take enforcement action where necessary.

We believe that including embedding our recommendations in DESs would help to tackle health inequalities and ensure services are able to meet the needs of all groups of people. There are also long-term cost benefits available from supporting people to better manage health conditions and ensuring early (and lower-level) interventions are feasible, rather than leaving things until resource-intensive crisis treatment is needed.

**Much greater urgency needs to be given to embedding recommendations from the FI into Disability Equality Schemes and Action Plans within the health sector.**

# Recommendations

**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.**

## 1. Government: the WAG and the DH

Neither the DH nor the WAG has yet developed coherent national strategies on tackling the health inequalities we identified. There have been significant failures to tackle the health\_inequalities experienced by people with mental health problems and learning disabilities.

The DH should hold SHAs to account for their work, but it has failed to ensure they even meet a legal obligation to have DESs. David Nicholson, the NHS Chief Executive, recently asked SHAs how they were meeting this requirement. We hope this generates SHA action – and DH follow-up as required.

**The DH must provide national leadership and hold SHAs to account to ensure the development of DESs that are effective at tackling evidenced health inequalities.**

Breaking down PSA targets by impairment group would also be a major lever for concerted work on health inequalities and signal national prioritisation. The DH has made clear that it does not consider this to be its role, believing it is something which should be done at local level. The Department does acknowledge that breakdown of statistics would be useful in guiding healthcare providers and in identifying/meeting needs. The DH must take the lead (through duties and guidance) to ensure this is done effectively locally and in a manner that is accessible at national level (e.g. by requiring standardised data collection).

**The DH must clearly lead delivery of this recommendation, demonstrating how it will use its national role to ensure the benefit of breaking down PSA targets by disability is understood and acted upon at local levels.**

More positively, we welcome the establishment of a high level Department of Health Delivery Group to progress specific DRC recommendations. It is vital that dialogue continues between the Department and the new EHRC, to help ensure progress on delivery.

We also thank the ODI for considering supporting the Minister for Disabled People to raise awareness of the FI amongst the Life Chances Ministerial Group.

**The suggestion that the outcome of our review/this report will provide the ODI an opportunity to revisit this issue with Ministers should be acted on.**

In Wales, we welcome the WAG commitment to consider how Health Gain Targets can effectively tackle health inequalities by April 2008. The Equality and Human Rights Commission Wales (EHRC Wales) should hold the WAG to account on this.

The Public Health Strategy currently being developed to tackle health inequalities represents a vital opportunity for WAG to set high level targets on the health inequalities we have identified and to tackle the long-standing issue of breaking down health data by impairment group to ensure inequalities are tracked.

The WAG must grasp the opportunity presented by the new Public Health Strategy.

## 2. SHAs and PCTs in England and LHBs and LAs in Wales

We are very concerned at the failure of SHAs and PCTs to meet requirements to have DESs and associated Action Plans (due in December 2006). We hoped DESs would action our findings. It is unacceptable that some SHAs still do not have a DES.

There are 10 SHAs. In September 2007, only seven had DESs and only two were considered 'adequate' by the DRC. Of those, the North East SHA was notable in that it strongly focused on user-involvement and delivered a Scheme which the DRC viewed most likely to be effective. South West SHA have also produced a scheme that, while more limited in scope, does contain some specific actions on tackling inequalities highlighted in the FI.

Neither of these SHA schemes addresses all the health inequalities identified in the FI. However, the action by these two SHAs demonstrates that the task is possible and highlights the failings of other SHAs.

This widespread SHA failure is extremely disappointing, especially as SHAs are responsible for supervising PCTs tackling health inequalities. This should include ensuring PCT DESs are in place. But SHAs are failing to meet their own obligations.

In Wales, all LHBs and NHS Trusts report having Schemes<sup>3</sup>. All LHBs committed to updating DES Action Plans in light of our recommendations as part of the annual review process. We note that just 23% have done this to date.

**Much greater urgency across the health sector needs to be given to Disability Equality Schemes, associated Action Plans and embedding our recommendations within them. We expect legal enforcement action to result from further inaction.**

3. Intermediary, standard setters, inspectorates and key NHS organisations: NICE, Inspectorates, CHCs, National Public Health Service, NHS Wales Centre for Equality and Human Rights.

A further inquiry into healthcare for people with learning disabilities is currently being led by Sir Jonathan Michael, as a result of Mencap's 'Death by Indifference' report into institutional discrimination in the NHS causing avoidable deaths of people with learning disabilities. We were pleased that the DRC's Investigation formed part of the Terms of Reference of this inquiry and that DRC staff have had discussions with Sir Michael. We would like the inquiry to consider in detail the evidence and findings from the DRC Formal Inquiry and to endorse relevant recommendations from the investigation. Issues of particular relevance to new Inquiry include the problem of 'diagnostic overshadowing'; access to information and advocacy for patients and their families; and understanding and application of the DDA, its duties and the nature of reasonable adjustments for people with learning disabilities and other groups.

We welcome the joint work agreement established between the DRC and Healthcare Commission. We hope that the EHRC will renew a similar partnership from October 2007 and that this delivers action focused on our

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<sup>3</sup> In a survey by the NHS Wales Centre for Equality and Human Rights for the DRC which examined the extent of progress these bodies have made in utilising our findings in Schemes.

recommendations. We welcome the Healthcare Commission including new questions with more focus on disability in next year's assessment.

**The EHRC should support inspectorates in monitoring equality schemes and play an active role in enforcement measures - including legal enforcement action where required. We wholly recommend this route now against failing SHAs. Future joint work could be progressed by the EHRC in partnership with inspectorates in a similar way to the current DRC/Healthcare Commission framework.**

We also welcome the NHS Wales Centre for Equality and Human Rights commitment to mainstream the Investigation's findings into its work and to embed recommendations and the DED within NHS bodies.

It is important for regulators to prioritise monitoring DED compliance in inspections, including through existing standards.

The DRC DED scrutiny exercise highlighted user-involvement as a common weakness in nearly all SHA schemes. It was also a notable weakness in the DH Single Equality Scheme. Even where limited user consultation had taken place, little evidence existed of how users' views had informed Action Plans. We hope current inspectorates in England and Wales will be emphasising this as an important role of the future single inspectorate.

**Much greater urgency needs to be given to ensuring health bodies have DESs and associated Action Plans with our recommendations embedded into them. Inspectorates should also take a stronger role in monitoring user involvement. The CSIP must also do more to promote and disseminate good practice.**

#### 4. Professional bodies and colleges – RCGP, RCPsych, BMA and AMSPAR

Two recent reports from the BMA on disability equality sent to all primary care organisations across the UK represent an excellent example of leadership. It is too early to know impact yet. But we welcome this initial progress and the clear statement from the BMA that it believes: "Improving disability equality within the medical profession, and among other healthcare staff, is vital for developing a health service which is inclusive and responsive to the needs of disabled patients."

The RCPsych has suggested it will take two years for it and the RCGP to implement a joint equality agreement. Joint work is welcome but must not delay action by both colleges in the interim.

In Wales, statutory guidance for Health, Social Care and Wellbeing Strategies already requires area needs assessments to address the physical health needs of disabled people specifically.

We are very pleased that the Association of Directors of Adult Social Services (ADASS) strongly agrees that Directors of Adult Social Services and of Public Health, in gaining an understanding of the needs of their whole communities, should explicitly report on the full needs of people with mental health problems and/or learning disabilities and that this evidence should directly inform commissioning for the whole population in England. We hope that the DH recognises the agreement on this issue and the progress in Wales.

**We agree with the ADASS that this must clearly come within the Joint Strategic Needs Assessment (JSNA), as set out in the proposed Commissioning Framework for Health and Wellbeing. We agree this should be monitored by inspectorates.**

**Recommendation 2: The planning and commissioning of services for people with learning disabilities and/or mental health problems needs to take greater account of their physical health care needs.**

1. Government: the WAG and the DH

The DH believes that the most important concern is to get PCTs to take this issue seriously. The DH hopes that improvements in access to primary care will result from the GP patient survey results (and resulting Darzi review), which the DH believes will offer opportunities for reform and delivery of more accessible services; and the new commissioning framework which will help clarify the role of PCTs and ensure they plan services better.

We share this hope but believe that the DH must lead this process effectively and acknowledge our recommendations in its approach.

We welcome the thrust of the DH's proposed 'Commissioning Framework for Health and Wellbeing', which has a focus on ascertaining local needs and planning to meet them in future.



**However, the DH must give a stronger steer on what kind of minimum outcomes are expected with regard to local action on reducing health inequalities when it delivers the full commissioning framework if the proposals are to be effective and meet equality duty requirements.**

The DH has suggested some specific aspects of the framework on which they intend to hold PCTs to account.

**We give this a cautious welcome and hope leadership and accountability are clearly delivered.** We expect to see an approach strong enough not to be undermined by local pressures.

In Wales we welcome the WAG including in statutory guidance on the next round of Health, Social Care and Wellbeing Strategies a requirement on LHBs/local authorities to include the physical health of some disabled people in needs assessments and for strategies to address health inequalities.

**The EHRC Wales and the WAG should review implementation of the HSCWB Strategy guidance from an equalities perspective.**

The EHRC Wales should hold WAG to account on its commitment to issue guidance on commissioning and on care planning to ensure both address physical health needs of people with learning disabilities and/or mental health problems by April 2008.

## 2. SHAs and PCTs in England and LHBs and LAs in Wales

We recommend PCTs and LHBs and LAs in Wales use evidence of good practice on effective actions/health interventions for disabled people when planning and commissioning services.

**We also recommend PCTs make greater use of Enhanced Services Agreements to deliver health checks for people with learning disabilities.**

PCTs and LHBs, in partnership with local authorities, should use the opportunity that new commissioning and HSCWB proposals offer and ensure local services are planned and commissioned which meet the needs of people with mental health problems and/or learning disabilities.

In Wales, LHBs and LAs should support and promote delivery of the learning disability health checks and Annual Health Reports.

LHBs should engage with the National Public Health Service for Wales' report on mental health/public health issues published in September 2007.

### 3. Intermediary, standard setters, inspectorates and key NHS organisations

We welcome NICE's assurance that it will: "Make significant changes at each stage of the guidance development process to ensure that: disability equality impact assessment is an integral part of the scoping of each item of guidance; [NICE is] as effective as possible in involving relevant organisations of and representing disabled people as stakeholders and consultees; and independent advisory bodies which develop guidance recommendations are mindful of [NICE] responsibilities in this area and take proper account in their decision-making of implications for disabled people and the potential for making a positive impact on equality." We are pleased this will apply to all guidance.

In Wales, intermediary bodies, including the National Public Health Service and the NHS Centre for Equality and Human Rights should support LHBs and LAs to develop effective HSCWB needs assessments and strategies, by providing international, national and local data on health inequalities and advice on 'what works' to tackle health inequalities at a local level.

### 4. Professional bodies and colleges

Professional groups in England and Wales should ensure members are aware of opportunities they and their patients have to influence local commissioning and to contribute to addressing health inequalities more effectively addressed locally.

We welcome the RCPsych's recognition that it should do more to raise awareness among its members of the need to continually refresh their knowledge of the means to meet disabled people's holistic needs.

**Proactively seeking to ensure commissioners assist this process would be welcome**, through the DH and the new Framework in particular but also through discussions with the DH/SHAs/PCTs on providing guidance for local commissioners.

We also hope that the RCPsych and the DH are discussing the RCPsych's suggestion that psychotherapy be fitted within Service and Financial Framework (SAFF) targets to better ensure local delivery of services in an outcomes

approach, possibly within the minimum outcomes approach of the new Commissioning Framework.

**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 in or receive appropriate help in programmes geared to supporting them in managing their physical health conditions.**

#### 1. Government: the WAG and the DH

Government seems to have made little progress on this recommendation. We welcome opportunities that the development of Local Involvement Networks (LINKs) offer in England to address it further.

**The DH must ensure LINKs can effectively engage and involve all disabled people and ensure their views are addressed.** This can be done in the DH good practice guidance, to be published in 2007. **We recommend that national organisations of people with mental health problems and/or learning disabilities are involved in developing this guidance.** We welcome the new Director responsible for public and patient involvement and hope this will be an area of their remit that is pursued vigorously.

The DH needs to do more to better support disabled people through disseminating information about rights to health services.

#### 2. SHAs and PCTs in England and LHBs and LAs in Wales

Involvement and empowerment continue to be challenging areas for all bodies responsible for health. Whilst we have evidence of good practice in some areas, empowerment of these groups needs to be more effectively resourced.

SHAs and PCTs should use LINKs and new commissioning processes effectively, fully engaging local disabled people and delivering services accessible to all.

#### 3. Intermediary, standard setters, inspectorates and key NHS organisations

We welcome the involvement of people with learning disabilities in inspections by the Healthcare Inspectorate Wales. We ask that HIW ensure learning from

this involvement work is recorded and disseminated particularly to disability groups, other inspectorates, Patient Forums and Health Scrutiny Committees and the NHS Centre for Equality and Human Rights.

We welcome the CSCI achievement of including 'Experts by Experience' in 5 per cent of its inspections of services for people with learning disabilities and its plans to build on this further next year.

However, we are disappointed that 'logistical and resource constraints' have led the CSCI to conclude it is not possible to include Experts by Experience in *all* inspections of learning disability services. We hope the CSCI will continue to build on their progress and will aim to improve the percentage annually.

**We believe that the Healthcare Commission has a key role in ensuring action on disseminating information about disabled people's rights in health services** – and in acting on service failures resulting in disabled people being over-represented in complaints processes.

The Healthcare Commission should also assess LINKs' connectivity with local disabled people/organisations and specifically how people with evidenced needs/inequalities are engaged locally, have their views actioned and health outcomes realised.

#### 4. Professional bodies and colleges

We welcome the programme of work established by the RCPsych and RCGP on shared education/training activities which will look at issues including the recommendation that generic drug names are used alongside branding in medication provision. If delivered this could support people to manage their own health better. However, we would welcome a stronger timetable on delivery. It is also welcome that RCPsych is working with the RCGP Clinical Innovation Research Centre to develop an auditing tool. This also requires an explicit timetable.

Further action from professional colleges is also needed to provide information about disabled people's rights when using services.

The RCPsych believe that, in ensuring users get access to physical primary healthcare services, the challenge is the difference between national agreement on what should happen and local influences/availability of services. DH leadership is essential in ensuring national priorities are truly reflected in local delivery.

**We recommend that the RCPsych fully engages with the development of the Expert Patient Programmes in England and Wales for people with mental health problems.**

**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.**

1. Government: the WAG and the DH

There has been no progress in developing an independent system for mediation and appeal in relation to disability-related disputes on patient registration.

**The DH must ensure PCTs are aware of their responsibilities to ensure this occurs.**

We ask that the welcome WAG Task and Finish Group on access to primary care in residential and institutional settings considers this recommendation as it also applies to people in these settings.

**We recommend the WAG, in consultation with the BMA and disability organisations, establishes a mechanism for mediation of disputes** arising from refusals to register people with a GP (or de-registrations). Independent appeals should be established for use when mediation is unsuccessful and where decisions are impairment-based.

We also suggest the WAG, local authorities and NHS Wales establish systems to support registration with GPs, particularly when people move between services or into communities from hospitals, secure settings, residential and/or rehabilitation services.

2. SHAs and PCTs in England and LHBs and LAs in Wales

We are pleased that in Wales, the NHS Centre for Equality and Human Rights is calling on LHBs to equality monitor GP registration processes, to identify whether trends exist and if certain groups are more likely to lack a GP. This is following evidence that people with mental health problems and/or learning disabilities are far less likely than other patients to be registered. PCTs in England should follow suit.

**LHBs and PCTs should incorporate equality monitoring data on GP (de)registration** in their DESs and use this data to identify inequalities, and resolve any localised problems.

PCTs, LHBs and Local Authorities should work in partnership when undertaking JSNAs/HSCWB strategies to ensure the needs of unregistered people are considered (and to ensure registration) in future planning/commissioning services. This will require local commissioning arrangements being based on robust impairment-specific data regarding numbers and needs of the local populace.

3. Intermediary, standard setters, inspectorates and key NHS organisations

**No new recommendations.**

4. Professional bodies and colleges

The BMA is now informing members that they cannot charge for any service that should be provided within the NHS contract. The fact that BMA members are seeking guidance on this issue and that there is evidence of 'retainer fees' being charged suggests further action is required.

**The BMA should work with partners, including the DH and WAG, to ensure everyone can access services equally.**

**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.**

1. Government: the WAG and the DH

We hope that the DH review of the Comprehensive Performance Assessment (CPA) will show that specialist services are not considered appropriate providers of physical healthcare. The CPA could act as a useful 'signpost' to other health services where necessary and could also share the skills developed in working with people with mental health problems.

**The CPA review should conclude that it forms part of a holistic approach to service design**, ending compartmentalisation of mental health service users and instead genuinely putting users' needs at the heart of provision.

The review could demonstrate this by the CPA being used to support people with mental health problems to access physical healthcare services. The CPA could form an effective conduit, empowering users to access other services.

In Wales the Annual Health Report (for those on enhanced CPA), introduced into the GP contract in 2006-07, has aimed to improve communication between patients, psychiatrists, CPA coordinators and GPs about physical health issues. We welcome this effort.

We also welcome the WAG commitment to a follow-up review of the Annual Health Report, to analyse its efficacy.

We recommend that, as part of the review, the WAG considers how the Report can be used to clarify working roles/relationships in between reporting periods to empower people with mental health problems and address the physical health needs identified. User and professional groups should also be involved.

We believe that WAG efforts on the CPA should be informed by the England review and that, in consultation with RCGP, RCPsych and the BMA, WAG should ensure people under the care of a psychiatrist have their physical health monitored by regular review.

## 2. SHAs and PCTs in England and LHBs and LAs in Wales

PCTs and LHBs should ensure (in partnership with the Healthcare Commission) that health checks incentivised for local GPs for people with mental health problems are effective at delivering positive health outcomes for identified needs.

## 3. Intermediary, standard setters, inspectorates and key NHS organisations

The CSCI inspects care homes against the Care Standards Act, including section 23, standard 8: "The registered person [e.g. care home owner] promotes and maintains service users' health and ensures access to health care services to meet assessed needs." This is currently a key standard. **We recommend it retain high priority status in the review of standards** and in the merger of England's inspectorates.

All inspectorates should consider the findings of the Healthcare Commission national audit and HIW inspection of NHS learning disability services in relation to their roles.

We hope the Independent Inquiry into healthcare for people with learning disabilities currently being led by Sir Jonathan Michael will also consider our recommendations in producing findings and will make clear the role of inspectorates in ensuring residents of health and care homes have their health needs met. Inspectorates must act on the findings.

#### 4. Professional bodies and colleges

We welcome the RCPsych issuing new clinical guidelines for psychiatrists on mental and physical health.

**We are keen for the college to develop the means to ensure the guidance is used** and we fully agree with the RCPsych that psychiatrists should not be responsible for physical healthcare.

We believe it is also essential that the college ensures service-users are provided with fully accessible information on all aspects of treatment/options; this is not being done despite forming part of the training and continuing development of psychiatrists.

We welcome the RCPsych suggested timeframe of within the next 18 months to provide further action on this recommendation and hope this is achievable. We also believe it should not just be for people entering the profession, but be extended to those already qualified.

**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.**

##### 1. Government: the WAG and the DH

We are delighted that the Minister for Health in Wales will establish a Task and Finish Group on access to primary care for people in residential/institutional settings and feel this is wholly appropriate. The DRC has provided a scoping paper to support this to the Welsh Assembly. We urge the WAG to involve and report to the EHRC.



We welcome the commitment to ensure the WAG Quality of Food Strategy addresses food in residential and institutional settings.

In England, the DH must use the opportunity of reviewing National Minimum Standards to prioritise more highly in inspection regimes the provision of medication, a good diet and access to healthy living. This should be a priority for the merged health and social care inspectorate in England.

## 2. SHAs and PCTs in England and LHBs and LAs in Wales

**PCTs and local authorities in England must use the new Commissioning Framework to ensure local commissioning and planning tackles poor diet and/or medication provision. Rewarding good providers with contracts and using purchasing power to drive up standards could deliver this recommendation.**

WAG, LHBs, LAs and Healthcare Trusts commissioning residential or secure services, or placing people in them, should require access to appropriate exercise and diet for residents.

PCTs must also ensure prisoners can access quality health care services to equal standards as recommended by the RCN.

## 3. Intermediary, standard setters, inspectorates and key NHS organisations

We welcome the CSCI agreement to continue considering the relationship between commissioning arrangements and quality of outcomes for service users. We believe the regulatory framework could have ensured further action on our recommendations. We would welcome CSCI consideration of how our recommendations are relevant to standards 7-11 on health and personal care and standards 12-15 on daily life and social activities.

**The Inspectorates should urge the DH to embed recommendations into the regulatory framework** through the review of National Minimum Standards. **We recommend the EHRC considers its role in ensuring that access to GPs and to healthy living are prioritised by Government and inspectorates,** through influencing the process to develop a single inspectorate for health and social care services.

People with mental health problems and/or learning disabilities are over-represented in the criminal justice system and particularly in prisons, which have not long fallen under PCT responsibility. These groups have particular healthcare needs that need to be taken into account in local commissioning.

To help ensure that this happens, the EHRC and inspectorates should work together regarding access to healthcare for prisoners/people in police custody.

EHRC Wales should support the WAG Task and Finish Group looking at improving access to primary healthcare for people living in residential and institutional settings, and evaluate the outcomes.

EHRC Wales should also influence and evaluate the efficacy of the new WAG Quality of Food Strategy aimed at addressing provision of food in all statutory and publicly funded institutions and services.

#### 4. Professional bodies and colleges

**We recommend that ‘The Mind: A Users Guide’, published by RCPsych and Transworld Publications, be printed in Easyread and other accessible formats.**

**Recommendation 7: Services need to be put in place to ensure that people without easy access to a GP, such as homeless people or those in the most rural areas, receive full and proper primary health care services.**

#### 1. Government: the WAG and the DH

We welcome agreement from the DH to issue further advice to PCTs/practices on registration of patients without a permanent address.

We hope that the DH’s ‘Connecting for Health’ plans for people to be able to enter access requirements – initially through Summary Care Records and then HealthSpace – will be delivered. We welcome efforts to ensure the process is accessible to all, e.g. through partnership work with Mencap to deliver Easyread access to Summary Care Records. Connecting for Health expects HealthSpace to be implemented by 2009. This will be 10 years since the DDA requirement for people’s access needs to be met by health services came into force. Without adequate processes people’s access requirements will remain unmet.

**We recommend stringent plans are developed to ensure HealthSpace will be effectively implemented and used** by appropriate health service professionals – from GP’s receptionists right through the system.

We thank the Department for Communities and Local Government (DCLG) for highlighting to us the Local Government White Paper and how implementation would affect key policy areas including Local Area Agreements targets and their inclusion of health outcomes. The White Paper committed the Government to creating a single set of about 200 national indicators. We welcome DCLG notification that measures covering social care, public health, health protection, disease prevention and mental health are likely to be covered. We look forward to seeing the final indicators when announced at the same time as the Comprehensive Spending Review.

**We recommend DCLG (and other departments) review the indicators to ensure our recommendations have been acknowledged and the most effective indicators developed.**

EHRC Wales should influence the WAG to ensure there is increased equality monitoring, including breaking down of health data in primary care and health services overall by disability. This would ensure it is clear which people die sooner from particular health conditions and who receives health promotion interventions. It would also deliver more effective means to identify patterns of health inequality.

## 2. SHAs and PCTs in England and LHBs and LAs in Wales

It is vital that PCTs adhere to new DH guidance on registering patients who do not have a permanent address.

SHAs, in partnership with inspectorates, should ensure good practice by PCTs is rolled out.

EHRC Wales should influence commissioners to develop targeted outreach programmes for groups under-represented in take-up of primary care, or lacking easy access to it.

## 3. Intermediary, standard setters, inspectorates and key NHS organisations

We welcome the DH Delivering Race Equality team’s comment that it is “mindful of the key issues raised by the DRC report” and that it will consider these as it

implements its programme. We hope this will lead to concrete action to deliver results for people from black and minority ethnic communities with mental health problems and/or learning disabilities, as highlighted by the Investigation.

EHRC Wales should engage with Wales NHS Centre for Equality and Human Rights on its Patient Equality Monitoring Project and how best to gather and effectively track data regarding health inequalities.

#### 4. Professional bodies and colleges

We welcome the work in progress with the DH's 'Connecting for Health', the RCPsych and Rethink on Care Records, accessibility and confidentiality. Services should be able to share information to ensure needs are met flexibly whilst respecting users' privacy.

**Recommendation 8: GP practices 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.**

##### 1. Government: the WAG and the DH

We are disappointed that not enough has been delivered in this area. Health services have failed to recognise legal obligations to meet the requirements of the DDA since 1999.

The DH should remind PCTs and their contractors (including GPs) of their DDA duties to ensure they can meet all users' needs including the duty to make reasonable adjustments and the DED requirement to be proactive in tackling known barriers to healthcare services, such as those highlighted in the DRC's Investigation report in September 2006.

The DH should also lead development of protocols for the provision of accessible advice and information on medication.

Insufficient progress has been made on ensuring that disabled people have the option of recording their access needs with primary care services by, for example, making changes to the New Patient Registration Template in England. We hope Healthspace will belatedly improve the situation from 2009.

We hope EHRC Wales will support the WAG and the BMA in work to progress the Disability Access Criteria Directed Enhanced Service, which was first introduced into GP contracts in 2006-07.

## 2. SHAs and PCTs in England and LHBs and LAs in Wales

### **No new recommendations.**

## 3. Intermediary, standard setters, inspectorates and key NHS organisations

We recommend that inspectorates prioritise monitoring compliance with DDA requirements in inspections. We welcome ongoing work between the DRC and Healthcare Commission in this respect.

**We recommend that the EHRC continue and improve on the joint working established between the DRC and the Healthcare Commission on the DED.**

## 4. Professional bodies and colleges

Professional bodies, including RCGP, should take a proactive role in supporting/progressing access recommendations, perhaps in conjunction with disseminating the Disability Equality and Etiquette Learning (DEEL) framework (cf rec 11.4) which gives practical examples on access requirements.

EHRC Wales should support Equip Cymru's production of a standard letter for GPs to use to obtain patient access requirements and development of a self audit tool for GP practices. EHRC should also work with the Department of Health to ensure that similar steps are taken on recording patients' access needs in England.

EHRC should also consider working with the RCGP to encourage GP practices to support patients to record access requirements prominently on existing patient records and the Electronic Patient Record, so that medical/reception staff understand how to improve services to meet needs.

PCTs and LHBs also need to take a firm hand in ensuring that primary care services that they commission are fully DDA compliant with regard to access needs.

**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.**

1. Government: the WAG and the DH

We are very disappointed that negotiations on the GP contract have broken down between the DH, the BMA and NHS Employers and that this is leading to a lack of progress on some of our recommendations.

The DH has committed (since Valuing People) to providing regular health checks for people with learning disabilities. The BMA General Practitioners Committee is supportive of delivering annual health checks. Checks for people with mental health problems are already incentivised.

**We urge all partners to restart negotiations and to deliver this recommendation as soon as possible.**

Producing a draft communications strategy for promoting delivery of health checks was one of the first actions taken by the DH Delivery Group. We welcome this strategy and its general direction. The message from the National Clinical Director for Primary Care and the National Director for Learning Disabilities emphasising the crucial importance of health checks in tackling known health inequalities is strong.

However, we believe dissemination routes need strengthening through a proactive strategy to encourage implementation.

We hope the WAG and the BMA in Wales successfully negotiate the Directed Enhanced Service learning disability health check and the annual report for mental health for 2007-08 and establish these on a five-year rolling programme.

We hope EHRC Wales will actively engage with the WAG to evaluate the Annual Health Review for people with mental health problems to ensure appropriate targeting and delivery of positive health outcomes.

EHRC Wales should also monitor the joint NPHS and Welsh Centre for Learning Disabilities project to develop a database to measure progress in health outcomes for people with learning disabilities receiving new health checks.

## 2. SHAs and PCTs in England and LHBs and LAs in Wales

The DH is committed to delivering checks and other stakeholders are supportive. It is also good practice, an effective means to deliver results and cost-effective in the long-term.

**PCTs should deliver health checks for people with learning disabilities, possibly through Enhanced Services Agreements.**

**SHAs, in promoting measures to tackle health inequalities, should supervise delivery of health checks to target groups and ensure the most effective checks are delivered.**

## 3. Intermediary, standard setters, inspectorates and key NHS organisations

**The Healthcare Commission should ensure that all health checks are effective** at meeting identified health needs and producing positive health outcomes.

## 4. Professional bodies and colleges

**Professional organisations, including the BMA and RCGP must prioritise health checks for people with learning disabilities and work with the DH to ensure they are implemented.** This involves restarting negotiations on the GP Contract and reaching firm agreement on health checks as soon as possible.

**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 are caused by or associated with their condition, or treatments administered for the condition.**

### 1. Government: the WAG and the DH

NICE has stressed that, although it manages processes for nominating topics for guidance, the DH is ultimately responsible for selection.

**The DH must prioritise specific NICE work on effective access to and outcomes from health services for people with learning disabilities and/or**

**mental health problems.** This could include weight management for people with mental health problems.

The DH response to the FI was not strong on cancer screening, suggesting additional research into bowel cancer was required but with no date or organisation to undertake it and failing as yet to prioritise people more likely to experience bowel cancer in existing programmes. The DH should develop clear guidance for PCTs on actions to take on screening. We also hope the bowel screening advisory committee will progress this recommendation at the earliest opportunity.

EHRC Wales should work with the WAG and the Office of the Chief Medical Officer to also ensure health promotion programmes are accessible and well-targeted.

## 2. SHAs and PCTs in England and LHBs and LAs in Wales

We are disappointed by the current DH position regarding plans for the JSNA of the Commissioning Framework. This position is different to the one stated by the Director of Commissioning when he appeared as a witness to our Panel. We are aware that the DRC is still working with the DH to try and ensure the JSNA includes a minimum dataset and outcomes approach that progresses our recommendations. We would strongly welcome this approach. Using existing evidence, advice from the DRC on datasets and effectively engaging with people experiencing health inequalities will provide a baseline and indices of improvements and health trends. A failure by the DH to support PCTs and local authorities to effectively prioritise and measure would be dangerously complacent, resulting in health inequalities persisting.

Data collection must be standardised in order for PCTs, SHAs, the Healthcare Commission, the DH and other health observers to monitor effectively. We believe that without effective monitoring of the right data it will be very difficult to highlight national progress at tackling health inequalities.

## 3. Intermediary, standard setters, inspectorates and key NHS organisations

We thank the CSCI for raising concerns regarding provision of medication and adequate nutrition in care homes. We would like to see further action given the wider impact of failing to meet the key standards on maintaining health and on nutrition.



**We hope the CSCI will emphasise the need for these key standards to be strengthened in the review of minimum standards and to be effectively monitored by the single health and social care inspectorate.**

EHRC Wales should consider engaging with the Community Learning Disability Nurses conference in November 2007, which will showcase a successful project providing information in accessible formats to promote screening take-up.

#### 4. Professional bodies and colleges

We welcome NHS Direct reorganising its stakeholder group to include higher representation of disability organisations. We hope ongoing representation on this group and the requirement for more training of staff and development of more accessible existing material will deliver improvements for people with mental health problems and/or learning disabilities using this service.

We note the RCPsych's suggestion that guidance on medication, branding and side effects would still be helpful and that colleges need to work together to resolve this issue.

**We recommend concrete action is identified and an appropriate timeframe for delivery is developed.**

We welcome the NICE response but regret it did not include specific information on how it will be addressing our recommendations (though referencing the Investigation report in its Equality Scheme).

NICE must act in accordance with its Single Equality Scheme and ensure disabled people are involved when planning, developing and disseminating/implementing guidance. NICE must also ensure guidance is provided in appropriate accessible formats, including Easyread.

EHRC should also encourage RCGP and RCPsych to closely monitor side-effects of psychiatric medication; to provide more information for users on the benefits and side effects of such medication; and to provide information on the full range of treatment options available.

**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.**

1. Government: the WAG and the DH

We welcome the BMA suggestion that the DH and primary care organisations promote the DEEL framework (see rec 11.4) more widely and hope the DH take up this invitation.

We welcome the WAG's support for training and their engagement of the third sector and funding of learning packages.

**We hope the DH will follow up the agreement to consider the Welsh approach in England, targeted at PCT level.**

We suggest the DH more actively considers addressing 'diagnostic overshadowing' through the professional appraisal system to ensure, in particular, changes in GP practice.

2. SHAs and PCTs in England and LHBs and LAs in Wales

**We recommend LHBs continue to engage in Equip Training** and sustain the making of protected training time available.

3. Intermediary, standard setters, inspectorates and key NHS organisations

**Relevant inspectorates should monitor numbers of staff trained in awareness and ensure appropriate and effective training is in staff development programmes.**

4. Professional bodies and colleges

The DH, NHS Employers, Skills for Health, Skills for Care, BMA, GMC, RCN, AMSPAR, BDA, MIND, People First, Leonard Cheshire, RNID and the Disability Partnership have all actively supported the DRC in developing and disseminating FI learning packs and the DEEL framework. The RCGP have sent learning packs to 3000 GP trainers. We thank all organisations for engaging in developing this useful tool for frontline staff. We would welcome any attempts to

review the efficacy of this tool and further efforts to promote disability equality and awareness.

We understand the material receives positive feedback and is an attractive package for trainers wishing to introduce the concept of tackling health inequalities. It introduces core messages from the Investigation and disability equality issues in an easily understood but comprehensive manner.

The training packs have as yet only been adopted by about a third of English RCGP Deaneries and take their place amongst other local training priorities. Notably, the Deaneries that have not ordered packs include all those in southern England.

Training and education will not achieve sufficient depth without sustained monitoring and follow-up by professional bodies/colleges, which we hope to see these organisations develop and progress.

RCPsych and RCGP are developing an online training module and shared competencies in the training of junior doctors which are also welcome steps.

**We request the colleges** take appropriate steps to maximize the number of members enrolling for this module – making it a formal requirement if necessary - and welcome the commitment given by the RCPsych in this respect. **We also suggest the colleges consider extending mandatory courses to existing professionals** as well as those entering professions.

We also welcome the GMC co-production of a disability equality supplement to 'Good Medical Practice', the main code of practice for medical staff. Any means to review efficacy of this approach at highlighting access/equality needs would also be welcomed.

We also hope discussions between Wales NHS Centre for Equality and Human Rights and the Postgraduate Deanery continue to develop an equality awareness programme for senior medical staff.

## **Appendix 1: Inquiry Panel members**

### **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.

### **David Congdon**

Chief Executive and Director of Campaigns and Policy at Mencap.

### **Professor David Haslam CBE**

GP, President 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 the Disability Committee of the EHRC, 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.

### **Ann Norman**

Professional Nurse Adviser: Learning Disabilities/ Prison Nursing at the Royal College of Nursing.

### **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.

### **Paul Jenkins**

Chief Executive of Rethink

**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 Department for Children, Schools and Families, head of the standing commission of carers, and the parent of an adult son with learning disabilities.

**Liz Sayce**

Chief Executive of Radar and member of the Disability Committee of the EHRC.

**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.

Note that there have been two changes to the panel membership since the original Inquiry in 2006: Paul Jenkins has replaced Cliff Prior as the new Chief Executive at Rethink and Ann Norman has replaced Lynn Young as the Royal College of Nursing representative.

## **Appendix 2: Organisations which provided written and oral evidence<sup>4</sup>**

Association of Directors of Adult Social Services (ADASS)

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

British Medical Association (BMA)

Commission for Social Care Inspection (CSCI)

Department for Communities and Local Government (DCLG)

Department of Health (DH)

Directors of Public Health

Healthcare Commission

Mental Health Act Commission

NHS Centre for Equality and Human Rights

NHS Connecting For Health

National Institute for Clinical Excellence (NICE)

National Leadership and Innovation Agency for Healthcare

National Steering Group for Delivering Race Equality

Office of the Deputy Prime Minister

Office of Disability Issues (ODI)

Royal College of General Practitioners (RCGP)

Royal College of Psychiatrists (RCPsych)

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<sup>4</sup> There are many acronyms in this document and we give those that we have used in the report for organisations that submitted evidence above.