



Our ref: RG/PAW
Date: 16th April 2008

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Dear Lord Darzi,

National Director Breakfast Meeting about the 'Darzi Review'

You will know that National Director's were asked to host a breakfast discussion meeting to help ensure effective input, from their particular area of interest, to your review of the NHS. I held such a meeting on April 15th. This letter summarises the headline conclusions of that meeting. Your officials were also present and will have further detail to input to the review process.

This letter contains the views of a multi-stakeholder group – including people with learning disabilities, family carers, NHS clinicians, NHS managers, local authority commissioners and the voluntary sector. This letter summarises their views and conclusions – though I wish to say that I fully endorse and agree with them.

Context

One of the reasons I am writing to you in this form is that **there was a substantial level of disquiet amongst participants that the way in which the review process has been undertaken has failed to engage the**

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learning disability sector and thus consider actions that would address the NHS's historic failure to deliver high quality healthcare to learning disabled adults. On behalf of those participants (and many people across the country who have expressed similar concerns to me) this letter therefore asks you to take a personal interest to help ensure that those failings are addressed at this advanced stage of the review.

The NHS's failure in relation to adults with learning disabilities is well documented. This includes:

- The Disability Rights Commission's Formal Investigation into Health Inequalities in Primary Care – published last year and which the DH is now responding to
- Mencap's 'Death by Indifference' report focusing on deaths by neglect of people with learning disabilities in general hospitals, which led to the Secretary of State establishing an Independent Inquiry into the healthcare of people with learning disabilities. This is due to report around June
- The Healthcare Commission's investigations into abuse in specialist learning disability services in Cornwall and in Merton and Sutton
- The ensuing Healthcare Commission audit of specialist learning disability services – which found similar commissioning and delivery failures across most of England

Participants at the breakfast discussion were thus disappointed that, despite this clear evidence, the framework for the review process made no explicit reference to people with learning disabilities and their health. Several SHA learning disability leads reported being told by their SHA 'Darzi lead' that learning disabilities was not to be considered in the review process. In most regions local learning disability stakeholders reported that, when they tried to engage with the process, they were unable to find a way in. Speaking personally, I have raised these concerns over several months but not succeeded in getting any movement in the design of the process.

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The result has been that SHAs and others involved in its delivery have not considered this excluded section of society. With the exception of the South West SHA, no SHA process or resultant report gave specific consideration to the health of people with learning disabilities. (Eastern SHA has now acknowledged that failure and started a learning disability workstream). Three of the nine draft SHA reports do not even mention people with learning disabilities. Four only mention it is passing and/or in relation to their mental health needs. None even begin to address the range and depth of actions recommended as being necessary in the four reports listed above. One specific recommendation from the breakfast meeting is that **your Review Team should immediately meet with the Independent Inquiry Team** to discuss how their likely recommendations can be built into the Darzi Review conclusions.

The participants at the breakfast discussion said that after drawing all this to your attention, they did not want to continue to make these points in a negative way. Instead they want the DH to admit the failures to date in the Review process and take action to ensure that the process from now on engages the learning disability sector and - more importantly – ensures that action to address the historic NHS failures is incorporated into the recommendations and actions.

Key conclusions from the Breakfast Meeting

1. This may sound paradoxical given the preceding paragraphs, but people said it is time to stop asking them what should be done to address NHS shortcomings in the health of people with learning disabilities. The DH and NHS has been told this on several occasions in recent years and the answers are clear and always the same. Good practice exists in a minority of place and the Valuing People delivery support programme is trying to promote this being taken up by PCTs and NHS Trusts. **It is time to stop asking what to do and get on and do it.**

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2. Central to this is the need for a **cogent performance framework** that addresses the health of adults with learning disabilities. Participants were clear that, whilst this might not be the current prevailing wisdom, **the DH needs to tell the NHS what it has to do to improve the health of people with learning disabilities.** The current approach of producing good practice advice and encouraging the NHS to follow it is clearly not working. It is being ignored.
3. An underpinning problem is that **the DH's approach to health inequalities is flawed.** It focuses on geographically based socio-economic indicators and thus completely misses out targeted action in relation to excluded groups such as adults and children with a learning disability. This needs to change.
4. An important way to address these problems is to **ensure that the NHS makes itself accountable to people with learning disabilities and their families.** This could be in a range of ways, including PCTs properly engaging in and reporting to Learning Disability Partnership Boards and LINks ensuring that they fully engage with and represent adults with learning disabilities.
5. Leadership is felt to be a key element. Following the Cornwall abuse report, David Nicholson wrote to all SHAs and PCTs stating they should ensure they have sufficient capacity and expertise in learning disability services. Several SHAs and many PCTs have taken no notice of this letter. **All NHS organisations (including acute hospitals) must ensure they possess expertise and leadership as required in David Nicholson's earlier letter.**
6. Every report on healthcare and learning disabilities identifies staff education and training as a problem. Mainstream health staff are not trained to understand and work with people with learning disabilities in their daily jobs. **A root and branch review of health professional education and training is needed to promote disability equality.**

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7. The single most important thing the group felt should happen is that **every element of the review's recommendations – SHA workstreams, central themes of work etc - should be tested to ensure that those recommendations will result in effective change for the most excluded sections of society.** This need not explicitly be in relation to adults with a learning disability, but we know that if you get it right for people with a learning disability, you get it right for most people – because of the range and complexity of the barriers and obstacles that learning disabled people face in society. If recommendations do not pass this test, they should not be accepted.
8. Finally, **the Review's conclusions must be tested by a Disability Equality Impact Assessment and against the provisions of the Disability Equality Duty.** The participants are clearly of the view that, given the process failings described above, such an appraisal would show non-compliance. Rapid engagement with the learning disability sector and a response to the points outlined here would help and the final report should contain explicit recommendations to meet DED requirements e.g. instigating double GP appointment times for people with learning disabilities as 'reasonable adjustment.'

The notes that your officials took at the meeting contain many other practical suggestions for actions and change.

The participants at the meeting hope that these suggestions help and can be taken forward. They also wanted to note that there is much good work taking place across the country – varying from small local initiatives to the work being led by Ben Dyson in the DH in response to the DRC report. In particular, the commitment to introduce comprehensive health checks for adults with learning disabilities is strongly welcomed and will have a significant impact if done properly. However, the underpinning problem of the Review process to date having not engaged the learning disability sector needs to be rapidly addressed and SHA vision statements referred back to them to deal with their shortcomings.

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On a personal note, you may be aware that I am leaving the DH at the end of this month after six years as National Director for Learning Disabilities - leading the delivery of the Valuing People policy. Whilst there has been some progress over that period in relation to engaging the NHS in this agenda, it is a matter of significant regret that, across all the 'whole life' programme of the Government's Valuing People policy, the weakest progress is almost certainly with the NHS. I will retain a significant interest in these issues in my new role as Chief Executive of the National Development Team and hope that I can continue to help and support both the DH and the NHS to modernise and improve outcomes for people.

I look forward to receiving your response to this letter. My office will ensure that it is communicated to participants at the Breakfast meeting. In the event of your response being after my departure on April 30th, I would be grateful if it could also be copied to me at rgreig@ndt.org.uk

With best wishes for the success of your review,

Yours sincerely,

Rob Greig
National Director: Learning Disabilities

c.c. *David Nicholson CBE, NHS Chief Executive*
David Behan CBE, Director General, Social Care
Breakfast discussion participants
Darzi Review Team