Learning Disability Programme Board

Note of the Meeting
Date - 19 November 2013
Time - 1.30-4.30pm
Venue - The Boardroom, Richmond House

Chair:

Jon Rouse, Director General for Social Care, Local Government and Care Partnerships at the Department of Health

Board members who were at the meeting:
Craig Hart - National Forum of People with Learning Disabilities (Supported by Catherine O'Byrne)
Vicki Raphael - National Valuing Families Forum (NVFF)
Viv Cooper - NVFF and the Challenging Behaviour Foundation (CBF)
Beverley Dawkins – Mencap (standing in for Jan Tregelles)
Ciara Lawrence – Mencap (supported by Ailis Hardy)
Julie Hankin – CQC (standing in for Alan Rosenbach)
Alick Bush - The Learning Disability Professional Senate
Zandrea Stewart - Joint Improvement Programme (standing in for JIP director – vacant)
Ivan Ellul - NHS England
Dominic Slowie – NHS England
Sam Cramond – NHS England
Andrea Pope-Smith – ADASS
Katie Hall – Local Government Association
Ann Marie Connolly – Public Health England
Helen Nix - Department for Education

Paper authors / presenters who were at the meeting:
Gyles Glover – Public Health England (to present item)
Tessa Ing - Department of Health (for first half to present item)
Linda Jordan – NDTi (for second half to present item)

Department of Health policy and secretariat who were at the meeting:
Frances Smethurst - Department of Health
Gareth James - Department of Health
Ben Thomas - Department of Health
Zawar Patel – Department of Health
Anita Wadhawan – Department of Health (for first half)
Emily Runcorn – Department of Health (secretariat)

People who could not come to the meeting (apologies):
Tim Breedon - NHS Confederation
Rosy Pope – ADASS
Bill Mumford - Providers Forum and TLAP
Karen Flood - National Forum of People with Learning Disabilities
Bill Bentley – Local Government Association
Chris Welsh – Health Education England
Nicolett Divecha/ Berenice Napier / Jill Lindley - Department for Business, Innovation and Skills
Jacqui Hansbro – Department Work & Pensions

	1. Introductions and welcome

1.1 The Minister said he was very sorry as he was not able to make the meeting and so Jon Rouse chaired. Jon said that in response to feedback, the meeting will not only focus on Winterbourne View work, but look at broader issues.

1.2 The Department of Health had published the response to the Francis report about Mid-Staffordshire hospital earlier in the day. Jon said that the main conclusions from the Francis report would also have consequences for people with learning disabilities, for example there will be a consultation on a new crime of wilful neglect and the introduction of a fit and proper persons test. He said there will be work on a single care certificate for all health and social care assistants to ensure staff are trained to correct levels, but this would not include personal assistants as they are not regulated.

1.3 It was agreed there should be an easy read version of the Francis response.

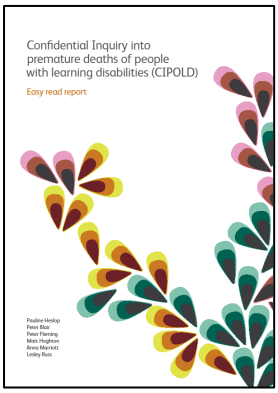
ACTION 28: DH Policy team to speak to officials in DH who lead on Francis about getting an easy read version of the Francis response.

2. Minutes of meeting on 4 July 2013

What has happened on the actions we agreed at the last meeting?

2.1 The minutes of the last meeting held on 4 July 2013 were agreed.

2.2 Jon went over some of the action points from the last meeting. Updates can be found at the end of these minutes and any further comments can be sent to the secretariat.



3. Update on Reducing Premature Mortality

3.1 Zawar Patel introduced this item together with the paper LDPB (13)31. He said the Government response to the Confidential Inquiry report had been published on 12 July 2013. The response included over 40 actions and commitments to the Inquiry's recommendations (paper LDPB(13)32).

ACTION 29: Any feedback on the Reducing Premature Mortality action plan should be emailed to Zawar Patel.

3.2 Gyles Glover said there was work underway to give better data about early deaths of people with learning disabilities. This involved linking data in General Practice systems, which keep a register of people with learning disabilities and their health problems, to Office of National Statistics (ONS) mortality data. This should be available in 2014 and should provide better data on age and cause of death, including showing how each area is doing.

3.3 Other key recommendations identified by the Confidential Inquiry included introducing named care coordinators for people with severe and complex needs and those living with two or more long term conditions, and developing a national learning disability mortality review body.

3.4 Dominic Slowie told members that NHS England was holding a workshop on 26th November to bring together key stakeholders. He said it was his number one priority to reduce avoidable early deaths. NHS England was looking at a national learning disability mortality review

body, but all possibilities were being considered and would be discussed at the workshop.

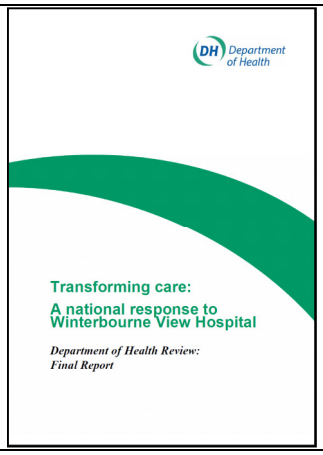
3.5 Andrea Pope-Smith said some of these actions were similar to ones in the Winterbourne View action plan. Jon said we should check both plans to make sure work is not being duplicated. Some Board members wanted to be involved in the workshop so Dominic agreed to check with the organisers and let them know.

ACTION 30: Dominic to check if the Forums and ADASS are involved with the NHS England workshop on 26th November and to make sure they can be invited.

3.6 Ciara Lawrence asked why it had taken so long to decide what to do about the results of the Confidential Inquiry. Zawar said that a response had been published three months after the inquiry, and an action plan had been set up immediately after that. He said work has been as fast as possible in the middle of lots of changes in the healthcare system and other big programmes of work.

ACTION 31: Premature mortality will be discussed again at the February LDPB, and PHE to present their work at that meeting.

3.7 Zawar said there would be an update on all of the actions in the Government response by the end of March 2014.



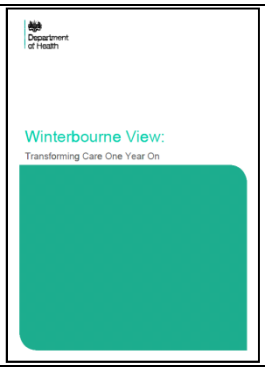
4. Transforming Care Progress

4.1 Jon Rouse introduced this item saying that 11 months after publication of Transforming Care, there had been progress but not as much as should have been made. He said that lots of people had done a lot of work and that many actions were on track. The "One Year On" progress report was due to be published in December and Jon said that it would be transparent and honest. Jon said there was a formal process starting shortly to bring in new leadership of the Joint Improvement Programme and the programme would accelerate.

	4A. Report back from Concordat event on 5th November 2013

4.2 Frances Smethurst explained that many of the Board members attended the Concordat event on 5th November so knew what happened, but that the Board had a paper (LDPB (13)33) so it could be uploaded to the Gov.uk website along with all the Board papers so anyone could see. The event included collecting updates from Concordat signatories and a presentation on the Joint Improvement Programme's stocktake of local areas. Frances said that suggested actions are being taken on board, and feedback is being used in quotes for the One Year On report.

ACTION 32: DH secretariat to amend the NVFF section of Concordat Event paper LDPB(13)33 to make clear it was not just about two families but about progress.



4B. Outline for One Year On report

4.3 Tessa Ing, who was writing the One Year On report, spoke about the outline for the report, paper LDPB(13)34. She said that it will be a short report of about 20 pages with annexes, one of which will be an update on all the actions. She asked the Board if this was the right approach and if the key things that are important to members are contained within the body of the report. Tessa said the introduction was very important, including picking up the care that the ex-Winterbourne View residents are receiving.

4.4 Katie Hall said the honest and transparent approach was correct and asked how many more versions would be shared with the Board. Tessa said she definitely wanted to seek the Board's view before the final version, but there were very tight deadlines as publication is due before Christmas. Frances said it was very important to get input but that depending on how it goes with comments and clearance, it may not be possible to share every draft. She said this was not about hiding things, just practicalities. Andrea Pope-Smith thought that asking specific questions to the Board would help focus the comments received. Tessa also said she would let members know when the Board would see drafts so members could try to ensure they have time available in their diaries to look over it.

ACTION 33: Tessa to share with the Board so they know when they would get a draft for comment.

4.5 Vicki Raphael asked if there would be a breakdown included of how Joint Improvement Programme money has been spent. Tessa advised this will be included as an appendix.

4.6 Craig Hart said the challenges on advocacy should be noted. Viv Cooper thought the report should focus on what is happening to real people, and not just about process. Beverley Dawkins suggested including case studies which show good practice in challenging circumstances.

ACTION 34: Members to send in case studies for the One Year On report to Tessa Ing.

4.7 Alick Bush suggested that in the vision there should be 5 key actions about how it will look and feel to people. Ivan Ellul thought the role of Health and Wellbeing Boards should be in the report.

ACTION 35: Members to send back any further comments on the draft One Year On report to Tessa Ing as soon as possible.

4C. Summary of workstrand updates

4.8 Frances said that the paper LDPB (13) 35 gives updates on all the workstrands. She said that in order not to focus just on process, Board members from the National Forum of People with Learning Disabilities, the National Valuing Families Forum and Mencap are working on a RAG (red/amber/green) rating for outcomes. They are meeting on 15 January 2014 and will report to the February Learning Disability Programme Board.

ACTION 36: National Valuing Families Forum, National Forum of People with Learning Disabilities and Mencap to present to February LDPB on outcomes.

4D. Highlight report from the Winterbourne View Joint Improvement Programme

4.9 Zandrea Stewart told the Board about what the Joint Improvement Programme is working on (paper LDPB (13)36). It included the next stage of the stocktake which is getting local status reports which will be published on the same day as the One Year On report. Jon Rouse said that if areas were not cooperating, it would still be possible for the Minister to use section 48 powers although these powers are very rarely used. This would trigger the Care Quality Commission to do a review of the local authority and make recommendations.

4.10 Viv Cooper emphasised the need for both faster progress and better planning going forward. She said that if actions are done at short notice, then there is a risk of not engaging with people with learning disabilities and their families, but also said that progress needed to be made quickly.

4.11 Jon Rouse said that things need to go faster. Beverley Dawkins said it would be bad to rush people into moving, but that the “too complex” label can be used to delay progress unless it is the individuals and their families saying that.

4.12 Zandrea said that the June 2014 deadline would be used as a guideline, and the Joint Improvement Programme has lots of expertise to probe areas to give explanations of any delays. Dominic Slowie noted that sometimes providers tell commissioners that people are not ready to move, but now Clinical Commissioning Groups have clinical expertise to see if the environment is hindering the person from moving. He said that we must support commissioners.

4.13 Zandrea went on to describe the big issues that the Joint Improvement Programme is working on (paper LDPB(13)37). Jon Rouse said it looked like the JIP had now got a grip on the issues.

4.14 Viv Cooper said that the first issue "Buying the right services" assumes there are services there to buy, but really there is a need to develop services. Andrea Pope-Smith said TEASC have produced market position statements for learning disability and a framework for standardisation. Jon Rouse said the programme should definitely tie in with the work of ADASS.

ACTION 37: Joint Improvement Programme to link with Andrea Pope-Smith and ADASS on market development work so they can support / signpost local areas.

NHS England	**4E. NHS England update**

4.15 Ivan Ellul gave an update from NHS England covering papers LDPB (13)38 & 39. He said there was more progress needed and people still need to challenge. He said there was improved clinical leadership with appointments such as Dominic Slowie (National Clinical Director for Learning Disability), Hazel Watson and David Harling (Enhanced Quality Assurance Programme (EQAP) lead). Ivan said that work had been done on definitions, but that there was further work to do when the numbers are received from the census and can be matched up with other pieces of work.

4.16 Ivan described the EQAP programme as a joint programme with ADASS to ensure the quality of reviews of people's care packages. The priorities are the former patients of Winterbourne View and also places

that the Care Quality Commission (CQC) has concerns about. He said that there had been a constructive meeting that morning, and one thing that came out of it was that a number of families are worried about the media intrusion and that it could be felt as threatening.

4.16 Ivan also updated the Board on information collected on the former patients of Winterbourne View (no patient identifiable data). This is detailed in papers LDPB (13)40A & 40B. 12 out of the 47 former patients are still in out-of-area assessment and treatment (A&T) units, although this is not static as people can rightly be in units for short spells. 24 are in residential care homes and 10 are in supported living. NHS England has written to ask for consent from the Winterbourne View families so that Respond can contact them so they can receive additional support.

4.17 Jon Rouse asked what was happening with the 12 people in out-of-area A&T units. Ivan said that the EQAP team will be working on their cases as a priority. Beverley said the out of area placements should be prioritised first. She also said she was concerned about the 24 in residential care homes as it was unclear what type of care they were receiving. Viv wanted to know how many of the people were in CQC compliant services, and how people in CQC non-compliant services will be prioritised. Ivan said that there will be link up with the Joint Improvement Programme and Andrea also offered to speak to the local areas involved.

ACTION 38: NHS England to prioritise the ex-Winterbourne patients who are in A&T units through EQAP and link with Andrea at ADASS on speaking to local areas.

5. Housing

5.1 In response to the Board's feedback to include wider strategic issues, Frances prepared a paper LDPB (13)41 which was about housing. This is an important concern to ensure change can happen for the Winterbourne View programme. There had been a meeting with people from DH, Department of Work & Pensions (DWP), Department of Communities and Local Government (DCLG) and the Joint Improvement Programme to share information, including impact from exempt accommodation and benefits reform.

5.2 Katie Hall said that there was a lot in the paper for Local Authorities, and that the LGA needs to talk to ADASS. Andrea Pope-Smith said that ADASS were monitoring the situation closely, but that benefit changes were having a negative impact on people with learning disabilities, together with the recession. Andrea said that it was helpful to have incentives for private sector, for example, affordable housing. She said that money must follow the person.

5.3 Craig Hart said there some people who are living on their own were dependent on their personal assistants (PAs) and were vulnerable to financial abuse.

ACTION 39: It was agreed to look at the PA framework at a future Board meeting, if possible in February.

5.4 Ciara Lawrence said that families have to do a lot of work to find the right house and make sure it is accessible to move into. She thought this would be really hard for people who do not have a family doing this for them.

5.5 Jon Rouse said there was no excuse for commissioners and they should jointly look at the whole life cost, for example, reusing money that was spent on assessment and treatment units.

5.6 Beverley said that for people with profound and multiple learning disabilities, their families have a constant battle to explain what is needed as it is usually bespoke. They might not have big pots of money to follow them and so the support becomes unaffordable. Beverley also

touched on the practical details of housing that make all the difference, for example making sure sockets are covered.

5.7 Andrea said that lots of architects are experts in building these specialist environments. Jon gave the example of PlaceShapers group which specialises in community based solutions. Zandrea said that the JIP is working with the Housing and Support Alliance so they have expertise in this area.

ACTION 40: Joint Improvement Programme to follow up suggestions from Jon Rouse and Andrea Pope-Smith of experts on building specialist housing so they can support/signpost local areas.

5.8 Viv made the point that even if people are living with their families, this might not be through choice. Ciara supported this saying that she wanted to be independent and move out from her family and has successfully done this. Frances said she thought it was hard to separate out people who live with their families by choice and those who live separately in the data. Frances said she would talk to data experts in DH about this.

ACTION 41: Frances to speak to Adult Social Care Outcomes Framework (ASCOF) leads on learning disability housing indicator.

Department for Education	**6. Special Educational Needs (SEN) and Integrated Care Pathways**

6.1 Helen Nix said the Children and Families Bill was being taken through Parliament at the moment, and hopefully will become law in September 2014. Helen went through the update paper LDPB (13)42. There were 7 key highlights including a more coordinated assessment

process called an education, health and care plan that will apply from 0-25 years old.

6.2 Gareth James talked about integrated care pathways. He said the reforms provide statutory frameworks and is backed up by a Code of Practice. A draft is out for consultation but closes on 9 December.

ACTION 42: DH secretariat to provide link to consultation of Special Educational Needs Code of Practice to Board members.

6.3 Gareth said that success will depend on outcomes, and that local authorities and clinical commissioning groups will work together on "shared intentions". He said that there will be person-centred coordinated care with all services in one room designing a local offer and individual plans for children.

6.4 Linda Jordan from the National Development Team for Inclusion (NDTi) spoke about her work on the Preparing for Adulthood Pathfinder programme. The programme helps young people so they move into adulthood smoothly, for example getting employment. She said the Pathfinder programme was now in phase two, and will be ready for implementation in September 2014. She said that less than a quarter of children with special educational needs (SEN) are eligible for adult social care. The 75% who do not qualify for adult social care will still get plans from age 14/15 to see what other support is available, for example priority for housing and Access to Work.

6.5 Zandrea said that the Joint Improvement Programme has already made connections with DfE, Council of Disabled Children (CDC) and NDTi to dovetail these programmes.

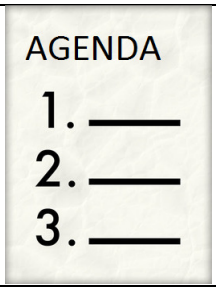
ACTION 43: DH secretariat to provide Preparing for Adulthood link to Board members.

7. Forward Look on Strategic Issues

7.1 Frances said paper LDPB (13)43 showed what work the Department of Health was doing, some thoughts about other strategic issues and looked ahead to the next 6-12 months. Frances asked if anyone had any comments to let her know.

8. Any other questions for delivery partners and stakeholders?

8.1 There were no other questions.



9. Forward Look

9.1 Frances said that paper LDPB (13)44 lists the possible agenda items for the next Learning Disability Programme Board (LDPB) in February. She said there are already too many items, so Board members should tell the secretariat which ones are most important to them.

ACTION 44: Board members to send preferred agenda items for February LDPB to Emily Runcorn by January 13th 2014.

	10. Anything else?

10.1 Jon Rouse thanked both the National Forum of People with Learning Disabilities and the National Valuing Families Forum for providing their update reports to the Board and thanked all members for their contributions.

10.2 Board members were asked to fill out the feedback forms.

10.3 Next meeting is on 25 February 2014 at 1.30-4.30pm, Cathedral Room, Richmond House.

10.4 Updates on the outstanding action points from 4 July meeting:

No.	Action	Owner	Update
1	Members are requested to suggest visits to projects/programmes for Jon Rouse.	All members	Awaiting update from Jon's office on LD visits.
2	Make changes to ToR and re-circulate to the Board	Frances Smethurst	Not circulated due to possible changes with Joint Improvement Programme. This will be circulated for the LDPB in February.

5	Board members to send a photo to the Secretariat.	All members	Some photos were taken at November Board meeting. DH secretariat will email members without a photo to ask for one.
6	Add both Forums to the Statement of Accountability, information on Health and Wellbeing Boards and Healthwatch, and include the Learning Disability Professional Senate.	Frances Smethurst	Not circulated due to possible changes with Joint Improvement Programme. This will be circulated for the LDPB in February.
7	Request someone from LDPB to sit on Children's Partnership Board when relevant issues are discussed.	Anne Spence	To be raised at LDPB in February.
9	Involve Respond in results from deep dive for former Winterbourne View residents.	Chris Bull, Ivan Ellul	Discussed at November LDPB. NHS England is seeking consent to ensure Respond is available to all if they wish.
15	CQC to work up a proposal on how they plan to make more use of experts by experience in the new registration process and will circulate	Alan Rosenbach	Proposal worked up but using Expert Reference

	to the Board.		Group for first piece of work with possibility of merging group (Julie Hankin)
16	CQC to follow up with Mencap about training people with learning disabilities	Alan Rosenbach	Alan spoken internally at CQC about Mencap and will be in touch (Julie Hankin). Viv said not to talk to one organisation alone.
19	Include advocacy as an item on the next Joint Improvement Programme Board meeting.	JIP	Advocacy was an item on 7 Nov JIP Board meeting that was cancelled. It will be considered in future.
22	Submission to be sent to MS(CS) giving information on the Scottish learning disability policy and for a paper on how we look at wider strategic issues to be discussed at the next Learning Disability Programme Board meeting.	Frances Smethurst	Reflected in the Forward Look on Strategic Issues paper for Nov LDPB.
23	DWP to inform Board members about changes to the Access to Work scheme and how this supports disabled people when information is	Nicola Lomas	Disability Employment Strategy will be an item at the February Board

	available.		meeting.
24	A representative from the LDPB should be involved in the DWP Stakeholder group	John Skinner / Nicola Lomas	Change of personnel at DWP – DH secretariat to inform new DWP members, letter from Jon Rouse / MS(CS) to escalate if required.
25	Howard and Andrea to link up outside the meeting to discuss a pilot of a bespoke apprenticeship scheme for people with learning disabilities.	Howard Bines / Andrea Pope-Smith	Howard put Andrea in touch with the scheme, but there was no room in their thinking to have a bespoke programme for LD. In fact, Andrea said they are increasing the qualifications which makes it harder for people with LD. Skills for Care have secured funding exploring what reasonable adjustments and a bespoke programme would look like so the pilot

			programme will go ahead. DH Director to write to BIS counterpart on this issue.

10.5 New actions from this meeting:

28	DH Policy team to speak to officials in DH who lead on Francis about getting an easy read version of the Francis response.	DH Policy team	
29	Any feedback on the Reducing Premature Mortality action plan should be emailed to Zawar Patel.	All members	
30	Dominic to check if the Forums and ADASS are involved with the NHS England workshop on 26th November and to make sure they can be invited.	Dominic Slowie	
31	Premature mortality will be discussed again at the February LDPB, and PHE to present their work at that meeting.	Zawar Patel	
32	DH secretariat to amend the NVFF section of Concordat Event paper LDPB(13)33 to make clear it was not just about two families but about progress.	DH secretariat	Complete – amended version will be uploaded with all the LDPB papers to gov.uk website.
33	Tessa to share with the Board so they know when they would get a draft for comment.	Tessa Ing	Complete

34	Members to send in case studies for the One Year On report to Tessa Ing.	All members	Complete
35	Members to send back any further comments on the draft One Year On report to Tessa Ing as soon as possible.	All members	Complete
36	National Valuing Families Forum, National Forum of People with Learning Disabilities and Mencap to present to February LDPB on outcomes.	Viv Cooper, Vicki Raphael, Craig Hart, Karen Flood & Ciara Lawrence	Meeting took place on 15 January 2014
37	Joint Improvement Programme to link with Andrea Pope-Smith and ADASS on market development work so they can support / signpost local areas.	JIP team	
38	NHS England to prioritise the ex-Winterbourne patients who are in A&T units through EQAP and link with Andrea at ADASS on speaking to local areas.	Ivan Ellul	
39	It was agreed to look at the PA framework at a future Board meeting, if possible in February.	DH secretariat	
40	Joint Improvement Programme to follow up suggestions from Jon Rouse and Andrea Pope-Smith of experts on building specialist housing so they can support/signpost local areas.	JIP team	
41	Frances to speak to Adult Social Care Outcomes Framework (ASCOF) leads on learning disability housing indicator.	Frances Smethurst	
42	DH secretariat to provide link to consultation of Special Educational	DH secretariat	Link: https://www.go

	Needs Code of Practice to Board members.		v.uk/government/consultations/special-educational-needs-sen-code-of-practice-16-to-25 Note – consultation closed on 20 December
43	DH secretariat to provide Preparing for Adulthood link to Board members.	DH secretariat	Link: http://www.preparingforadulthood.org.uk/
44	Board members to send preferred agenda items to Emily Runcorn by January 13th 2014.	All members	DH secretariat requested in email to Board members.

Ongoing actions for all members:

- Board papers should be in easy read format.
- Reports should reflect terminology should be "people whose behaviour is challenging / can challenge" and not "people with challenging behaviour".
- Membership lists to be kept updated in the Statement of Accountability (NHS England Winterbourne Steering Group, Joint Improvement Programme Board, CQC Learning Disability Advisory Group, Learning Disability Professional Senate) – email DH secretariat with any changes.