

<b>Title:</b> Transforming care: A national response to Winterbourne View Hospital. <i>Department of Health Review: Final Report</i> <b>IA No:</b> 7071  <b>Lead department or agency:</b> Department of Health  <b>Other departments or agencies:</b> NHS Commissioning Board, Department for Communities and Local Government	<b>Impact Assessment (IA)</b>
	<b>Date:</b> 4/2/2013
	<b>Stage:</b> Development/Options
	<b>Source of intervention:</b> Domestic
<b>Type of measure:</b> Other	

**Summary: Intervention and Options** **RPC Opinion:** RPC Opinion Status

Cost of Preferred (or more likely) Option				
Total Net Present Value	Business Net Present Value	Net cost to business per year (EANCB on 2009 prices)	In scope of One-In, One-Out?	Measure qualifies as
£/	£1.2m	£0.14m	No	NA

**What is the problem under consideration? Why is government intervention necessary?**  
 Commissioners of services for people with learning disabilities or autism who also have mental health conditions or challenging behaviour can demonstrate weak or risk averse commissioning behaviour and are subject to perverse incentives in planning and investing in local services which could prevent admission into NHS funded inpatient services. This is compounded by asymmetric information as commissioners lack knowledge about good quality care and there is little feedback or information, including poor regulatory oversight, about poor quality provision. As a result, too many people are in inappropriate, poor quality and expensive inpatient services. Government intervention can help overcome some of the organisational barriers discussed in this document, disseminate best practice and ensure the existence of comparable data, which is necessary to overcome asymmetric information.

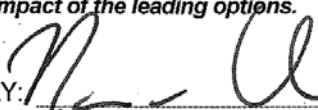
**What are the policy objectives and the intended effects?**  
 The proposed actions aspire to ensure people with learning disabilities or autism who also have mental health conditions or challenging behaviour receive inpatient care only where this is appropriate and for a reasonable length of time. If this is achieved, it will result in fewer admissions to inpatient services for assessment and treatment and shorter length of stay while in those services.

**What policy options have been considered, including any alternatives to regulation? Please justify preferred option (further details in Evidence Base)**  
 The following options have been considered:  
  
 Option 1: do nothing – continue implementing existing policies, which address some of the identified problems.  
 Option 2: implement all the actions in the Department of Health review or, where appropriate, look into implementing the actions subject to further analysis  
  
 Option 2 is preferred. Option 1 would not achieve the objective of reviewing the care of patients in specialist hospitals and returning them into community settings.

**Will the policy be reviewed?** It will be reviewed. **If applicable, set review date:** 12/2013

Does implementation go beyond minimum EU requirements?	N/A				
Are any of these organisations in scope? If Micros not exempted set out reason in Evidence Base.	<b>Micro</b> Yes/No	<b>&lt; 20</b> Yes/No	<b>Small</b> Yes/No	<b>Medium</b> Yes/No	<b>Large</b> Yes/No
What is the CO <sub>2</sub> equivalent change in greenhouse gas emissions? (Million tonnes CO <sub>2</sub> equivalent)	<b>Traded:</b>		<b>Non-traded:</b>		

*I have read the Impact Assessment and I am satisfied that, given the available evidence, it represents a reasonable view of the likely costs, benefits and impact of the leading options.*

Signed by the responsible SELECT SIGNATORY:  Date: 24/2/13

# Summary: Analysis & Evidence

# Policy Option 2

Description: Improving outcomes for people in inpatient services for learning disabilities (DH review on Winterbourne View) - PARTIAL ECONOMIC ASSESSMENT

Price Base Year 2012	PV Base Year 2012	Time Period Years 10	Net Benefit (Present Value (PV)) (£m)		
			Low: Optional	High: Optional	Best Estimate:

COSTS (£m)	Total Transition (Constant Price) Years	Average Annual (excl. Transition) (Constant Price)	Total Cost (Present Value)
Low	Optional	Optional	Optional
High	Optional	Optional	Optional
Best Estimate	/	£3.3m	£31m

### Description and scale of key monetised costs by 'main affected groups'

Costs to NHS and social care commissioners of care reviews for all inpatients in specialised learning disabilities hospitals.  
 Costs to the Department of Health and data burden on commissioners and providers of new data collections.  
 Potential opportunity costs to commissioners from improved commissioning.

### Other key non-monetised costs by 'main affected groups'

Costs to providers of assessment and treatment services of adapting to the changing demand for their services.  
 Provision of alternative local services, which is likely to be funded by joint NHS and social care commissioning. This cost cannot be fully monetised yet, as Clinical Commissioning Groups will need to develop the details of their proposals with local authorities to move people into community settings.

BENEFITS (£m)	Total Transition (Constant Price) Years	Average Annual (excl. Transition) (Constant Price)	Total Benefit (Present Value)
Low	Optional	Optional	Optional
High	Optional	Optional	Optional
Best Estimate	NOT QUANTIFIED	NOT QUANTIFIED	NOT QUANTIFIED

### Description and scale of key monetised benefits by 'main affected groups'

### Other key non-monetised benefits by 'main affected groups'

Potential cost savings to the NHS if people move out of inpatient care. This cannot be fully monetised yet, as Clinical Commissioning Groups and local authorities will need to develop the details of their proposals to move people into alternative settings;  
 Potential increase in quality of life if people move into less restrictive care settings.

### Key assumptions/sensitivities/risks

Discount rate (%) 3.5

Any costs and benefits are contingent on further policy development, in particular by Clinical Commissioning Groups and local authorities.  
 As set out in DH Impact Assessment guidance, this summary sheet does not present financial costs only. Instead, it presents total costs to society, which also include an estimate of the opportunity cost of government spending. For details, please see paragraphs 83 – 85 in the main body of the assessment.

### BUSINESS ASSESSMENT (Option 2)

Direct impact on business (Equivalent Annual) £m:	In scope of OIOO?	Measure qualifies as
Costs: £0.14m      Benefits:£0m      Net: £0.14m	No	NA

# Evidence Base (for summary sheets)

## I - INTRODUCTION

1. Winterbourne View was a private hospital in Bristol owned by Castlebeck Care Ltd for adults with learning disabilities and autism. It was designed to accommodate 24 patients aged 18 and over, to provide assessment, treatment and rehabilitation. People at Winterbourne View experienced serious and sustained abuse, ill-treatment and neglect. These events represented an extreme failure of the health and care system. Subsequent Care Quality Commission (CQC) inspections<sup>1</sup> showed that people with learning disabilities or autism who also have mental health conditions or challenging behaviour in specialist hospital or residential care settings continue to be at high risk of poor quality care.
2. It should be noted that some actions are already in place which address some of the most urgent problems identified at Winterbourne View (see Annex A for a list of actions already implemented).
3. The Department of Health (DH) set up a review to establish any systemic issues in the provision of inpatient care for people with learning disabilities and identify necessary action for Government. The negative outcomes identified in the review can be summarised as:
  - too many people with learning disabilities are inappropriately admitted to specialist learning disabilities and autism hospital services, such as assessment and treatment units;
  - they stay in those facilities for too long;
  - while people are in those facilities they are at risk of receiving poor quality care; and
  - at a high cost to the health and social care system, when compared to equivalent community provision.
4. Section II sets out the underlying causes of the issues identified in the review. Sections III and IV set out an initial assessment of the all **new** actions proposed to address these issues. It should be noted that some of the proposed actions are at a very early stage of policy development. Where this is the case, this impact assessment will provide the **best evidence available at the moment, but further assessment will be needed** as the policy develops.

## II - THE UNDERLYING PROBLEM: POOR INCENTIVES AND LACK OF INFORMATION IN THE COMMISSIONING AND PROVISION OF LEARNING DISABILITIES SERVICES

5. This section sets out the underlying causes of the poor care outcomes experienced by people with learning disabilities or autism who also have mental health conditions or challenging behaviour at specialist inpatient facilities such as Winterbourne View.
6. *Firstly, perverse incentives may* result in under-provision of appropriate alternatives to hospital services.
7. *Secondly, a lack of commissioning knowledge, monitoring and information* on the quality of care may result in the continued commissioning of poor quality services.

### A - Poor commissioning, contracting and perverse incentives

8. Commissioners responsible for patients at Winterbourne View did not have “comprehensive policies and strategic thinking (...) within the NHS or across health and social care on how best to respond to patient needs and prevent continued escalation”<sup>2</sup>. Such lack of planning often results in a shortage of suitable local services, including accommodation and support<sup>3</sup> and step-down services allowing people to leave inpatient facilities and return to the community<sup>4</sup>. Even with joint commissioning, individual care plans are usually not joined up and a “lack of clarity around

transition points between child and adult social care, and between social care and the NHS”<sup>5</sup> results in poor transition planning.

9. In the case of specialist services for people with learning disabilities, there is often more than one commissioner responsible for the patient’s care. *Social care commissioners* may avoid commissioning alternative local services for people with learning disabilities or autism who also have mental health conditions or challenging behaviour if they think that those people will receive NHS funded care otherwise. The costs of hospital treatment are likely borne by the NHS, while costs of supporting people in community settings would fall on social services. Thus, social care commissioners may have little incentive to provide step-down or crisis intervention services, in particular for complex services. After all, “(...) if a person they support can be argued successfully to need health care, then the cost of that will be borne by the health service rather than the local authority.”<sup>6</sup>
10. *NHS commissioners* themselves may avoid investing in preventative services because of:
  - pressure on financial and staff resources leading to prioritisation of immediate, acute needs over longer term prevention;
  - avoidance of double running of (investment) costs in the short-run;
  - lock-in of funding streams in out-of-area secure placements<sup>7</sup>;
  - difficulties in measuring the impact of early intervention.
11. In addition, commissioners may avoid commissioning certain services for people with very complex needs out of **risk aversion**. Even where community provision is possible in principle, commissioners might avoid commissioning such a service based on the perception that inpatient care is safer for the person, but may also reduce risks to staff and the wider community.
12. Importantly, the next section shows that information problems prevent commissioners from ensuring the best possible care. *Firstly*, commissioners often lack knowledge about what constitutes good practice for the high-cost but low caseload care for people with learning disabilities or autism who also have mental health conditions or challenging behaviour. *Secondly*, a lack of information about the quality of services provided reduces incentives to invest in local services to prevent inpatient admission and poor quality care.

## **B - Lack of knowledge, monitoring and feedback**

13. The poor outcomes at Winterbourne View and elsewhere also reflect information problems. Indeed, any care system is subject to a double problem of **asymmetric information**:
  - the provider knows more about the quality of services provided than the care recipient and the commissioner;
  - the care recipient may know more about their needs and the outcomes of care than either the provider or the commissioner.
14. This is a general problem that may occur in commissioning. However, it may be particularly important in the case of learning disabilities services, where there are multiple limitations regarding the availability of information on the quality of services.
15. *First*, given the highly specialised, but low volume nature of services for people with learning disabilities or autism who also have mental health conditions or challenging behaviour, local **commissioners may lack the knowledge and expertise required**, reinforcing the problem of asymmetric information<sup>8</sup> and presenting the risk that they may not commission the right services for the patient.
16. *Second*, individual commissioners may lack good summary information about services provided in their area: “people with learning disabilities are not visible or identifiable to health services and hence the quality of their care is impossible to assess. **Data and information on this sub-set of the population and their [care pathways] is largely lacking** and what exists is inadequately co-ordinated or understood.”<sup>9</sup> Not knowing who receives what care, in what setting, with what outcome reinforces commissioning failures. In the NHS, financial incentives are often used to improve the outcomes of commissioning (e.g. in the context of Payment by Results). Lack of

information means that the quality of outcomes is difficult to measure and therefore, it is difficult to apply financial incentives. In addition, it means that:

- there are few clear warning signs where the quality of care is poor;
- there is little accountability for services provided;
- commissioners cannot benchmark their own performance;

17. *Third*, the lack of basic information is further compounded by insufficient recognition of feedback to commissioners when there is poor quality care. Although patient control and choice can contribute to the prevention of abuse and neglect of people with learning disabilities<sup>10</sup>, **people with learning disabilities are often not involved in the care planning process.**<sup>11</sup> At an extreme, as at Winterbourne View, abuse and poor quality care may continue, because complaints are not addressed and concerns are dismissed<sup>12</sup>.
18. *Fourth*, in such an environment, advocacy services should empower service users and their families and facilitate their involvement. Good quality advocacy can help uncover abuse and neglect<sup>13</sup>. In practice, however, **poor quality advocacy has been observed**<sup>14</sup> meaning that adverse incidents may go unnoticed.
19. *Fifth*, **commissioners fail to assure the quality of the care**, which they have commissioned. For instance, at Winterbourne View, some commissioners agreed to use Castlebeck Ltd's contract in over half of cases even though this contract did not contain quality features such as the reporting of quality measures and clinical outcomes, which might have offered an opportunity to identify issues of concern. In addition, a "lack of any effective contract monitoring by commissioners meant that, whatever type of contract was in place, they were not used as an effective commissioning tool"<sup>15</sup>.
20. *Sixth*, there was no appropriate mechanism in place to follow through on **safeguarding procedures**. The CQC inspections noted safeguarding concerns, such as inappropriate non-referral of incidents to the safeguarding team, at 18% of inspected locations. Often providers were unclear about the relevant provisions with no mechanism in place to address that knowledge gap<sup>16</sup>.
21. *Finally*, in the absence of direct user feedback and appropriate safeguarding procedures, commissioners relied on **regulatory agencies** to pick up poor quality of care. CQC registration and inspection reports were taken as a sign of sufficient quality.<sup>17</sup> However, the inspection regime was found to be ineffective and too focussed on 'big level abuse'.<sup>18</sup> In addition, the roles and responsibilities of regulatory agencies were unclear, leading to confusion and a lack of cooperation and information sharing.<sup>19</sup>
22. Figure 1, summarises the problems identified in this section, which affect the outcomes in the commissioning of specialist services for people with learning disabilities or autism who also have mental health conditions or challenging behaviour.

**Figure 1:** Problems affecting commissioning of specialist services

- |  |
|--|
| <p>1) <b>Incentives and disjointed commissioning</b></p> <ul style="list-style-type: none"><li>• Financial incentives</li><li>• Risk aversion</li></ul> <p>2) <b>Lack of information, knowledge and feedback</b></p> <ul style="list-style-type: none"><li>• Lack of commissioning expertise</li><li>• Lack of information and reliable data</li><li>• Lack of service user involvement</li><li>• Lack of good quality advocacy services</li><li>• Poor quality assurance through contracts</li><li>• Lack of good safeguarding policies</li><li>• Poor regulatory oversight</li></ul> |
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### III - POLICY OBJECTIVES AND SUMMARY OF ACTIONS

23. In *Transforming care: A national response to Winterbourne View*, the Department of Health presents a number of actions addressing the problems set out in Figure 1. In particular, it highlights that the Government's Mandate to the NHS Commissioning Board<sup>20</sup> sets out:
- "The NHS Commissioning Board's **objective** is to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people."
24. The proposed actions, as set out in the Concordat accompanying the review report, aspire to:
- reduce the number of people who are inappropriately in specialist learning disabilities and autism hospitals and services;
  - reduce the length of stay in these services (where appropriate); and,
  - improve the quality of care in those services.
25. Government intervention is required to overcome organisational barriers (perverse incentives, disjointed commissioning) as well as knowledge and information gaps which make it difficult for many commissioners to achieve these objectives themselves. Furthermore, it is likely to be more efficient for Government to disseminate best practice and ensure the existence of comparable data and information, which is necessary to overcome asymmetric information.
26. **Do nothing:** It should be noted that some of the measures mentioned in the review report and Concordat are already being developed or implemented. They contribute to the improvement of outcomes for people with learning disabilities and behaviour that challenges, but they are not new actions resulting from the review. As such, for the purpose of this impact assessment they are part of the 'do nothing' scenario. The table in **Annex A** provides an overview of these actions.

### IV - IMPACTS OF GOVERNMENT INTERVENTION

27. It should be noted that the policy development for many of these actions is at a very early stage, so that there is not enough information yet to fully assess the costs and benefits resulting from the new actions. Where appropriate, the impact assessment will provide **indicative analysis** supporting the principle of the action proposed, i.e. set out that the proposed actions can be beneficial. Further impact assessments will be needed to fully assess the costs and benefits of these actions. For instance, until the initial case-finding and reviews have been completed, it is difficult to assess the extent of the financial impact. The costs of people placed in inappropriate settings could vary widely: some may need more costly packages in the community; for others it may be possible for them to return to the community with additional input and, for some, NHS mental health services may be more appropriate.
28. It should be noted that some of the new actions proposed in the review represent commitments to look into a specific action, rather than firm commitments to implement (see Annex B for a list of commitments to look into a policy, which will not be assessed in this impact assessment). This means that these actions are still subject to **separate decision-making, including further analysis and consultation**, as appropriate.
29. The main proposed actions are a work programme led by the NHS Commissioning Board to reduce the number of inappropriate placements in specialist inpatient settings as well as a sector-led improvement programme to increase the quality of commissioned services. These actions will be supported by new data sources commissioned by the Department of Health as well as a range of new resources for commissioners.

## A – Costs

### A1 - NHS Commissioning Board work programme to reduce the number of inappropriate placements – subject to further analysis

30. The NHS Commissioning Board has committed to lead on a range of actions to reduce the number of people in specialist hospitals, where better alternatives are available.
31. It should be noted that the aspiration of the proposed action is to ensure that all inappropriately placed people are brought back into community-based settings as soon as possible, and no later than 31 May 2014. However, it is not possible to determine the likely impact of this policy, as decisions will be made on a case by case basis in view of identifying the appropriate care for each individual. **This will be kept under review as the policy is taken forward.** In particular, the NHS Commissioning Board will assess any potential costs on local authorities.
32. While the NHS Commissioning Board has not yet fully scoped the components of the work programme, it should be noted that the Board will:
  - Ensure by 1 April 2013 that all Primary Care Trusts develop local registers of all people with learning disabilities or autism who have a mental health condition or challenging behaviour in NHS-funded care;
  - Make clear to Clinical Commissioning Groups in their handover and legacy arrangements what is expected of them in maintaining the local register from 1 April 2013;
  - Review individuals' care with the Local Authority and identify who should be the first point of contact for each individual;
  - Ensure that, by 1 June 2013, health and care commissioners working with service providers, people who use services and families will review the care of all people in learning disability or autism inpatient beds and agree a personal care plan for each individual based around their and their families' needs and agreed outcomes. People with challenging behaviours and their families will have the support they need to ensure they can take an active part in these reviews being provided with information, advice and independent advocacy, including peer advocacy;
  - Ensure that plans are put into action as soon as possible, and all individuals should be receiving personalised care and support in the appropriate community settings no later than 1 June 2014.
33. From April 2013, the NHS Commissioning Board will hold Clinical Commissioning Groups to account for their progress in transforming the way they commission services for people with learning disabilities or autism who also have mental health conditions or challenging behaviour.
34. The NHS Commissioning Board and ADASS will develop by March 2013 practical resources for commissioners of services for people with learning disabilities, including model service specifications to support Clinical Commissioning Groups in commissioning specialist services for people with challenging behaviour, a joint health and social care self-assessment framework, and a way of rewarding best practice through the NHS Commissioning for Quality and Innovation (CQUIN) framework. The objective of this is to ensure that payments are more clearly linked to patient outcomes and create a more positive environment to encourage investment in supported living arrangements in local communities.
35. At the current stage of policy development, the proposed actions **cannot be fully costed**. Where we have information on potential costs, we present them in this impact assessment. However, the impact will be kept under review as the NHS Commissioning Board develops these proposals further and, in particular, assesses any potential costs to local authorities.
36. As a broad indication of costs, it should be considered that the NHS commissioners will have to:
  - a. set up and maintain a register; and,
  - b. implement reviews of the care received by any inpatient in specialist learning disabilities and autism hospitals.

37. **Cost of Reviews:** For the purpose of this impact assessment, it is assumed that the establishment of a register can effectively follow from the reviews of the care individuals receive. The impact assessment on “Assessment, eligibility and portability for care users and carers”<sup>21</sup> estimates that an average community care assessment costs about £450 in 2010/11 prices. This is about £460 in 2012/13 prices (=£450 in 2010/11 \*1.023 to adjust for headline inflation using the HM Treasury GDP deflator).
38. However, it should be noted that reviewing the care of people in inpatient services may be more difficult as their care needs are more complex. For similar reasons, the provision of care in community based living settings for people with learning disabilities is estimated to be 60% higher when residents have low levels of ability<sup>22</sup>. If the same uprate applied to the cost of care reviews, this would result in a cost of approximately £740 in 2011/12 prices per review (=£460 \*1.6). We take this to be a reasonable upper bound estimate for the cost of a review.
39. Annex C sets out that there are about 3,400 people in specialist inpatient services for learning disabilities. Therefore, we estimate the cost of individual care reviews for all patients in specialist inpatient services for people with learning disabilities or autism who also have mental health conditions or challenging behaviour to be up to **£2,500,000** in 2012/13 (=3,400 \* £740). These costs are likely to fall onto social care and health commissioners in joint commissioning arrangements.
40. **Cost of changes to commissioning arrangements:** It should be noted that the true costs of reviews could be lower if some of these reviews took place regardless of the proposed NHS Commissioning Board actions. However, it should also be noted that there may be additional costs where commissioners change the way they work to ensure people receive appropriate care and that any progress made through the review of care provided is maintained as new people enter services in the future. These costs include, for instance, the costs of establishing new evidence-based strategic plans and changing commissioning patterns. These costs cannot be quantified at this stage, as they will depend on further policy development by Clinical Commissioning Groups and local authorities.
41. **Cost of relocation to commissioners:** where, upon review, people move from inpatient care into alternative provision, costs will incur to the commissioners of those services. If people move back to their communities we expect that services in question will be commissioned under joint commissioning arrangements between the NHS and social care commissioners.
42. It should be noted that, at the present stage of policy development, it is not clear how many people can be relocated out of assessment and treatment units into the community, into what kind of provision, at what cost and under what kind of funding arrangement. The details of the proposed policy will be developed by the NHS Commissioning Board and will be subject to further analysis as appropriate.
43. Therefore, we cannot fully quantify the costs of alternative provision. However, it should be noted that Annex C estimates that about 300 people in assessment and treatment have finished treatment, but have not been discharged. Further, as an illustration, Annex D provides estimates of costs of alternative provision for these people.
44. The NHS Commissioning Board will need to consider arrangements if people need to relocate, such as joint funding arrangements for people moving back to the community, to ensure that there is no unfunded pressure on local government and that health and social care commissioners work together to achieve relocation where appropriate.
45. **Cost of relocation to providers / double running of services:** In addition, there will be some transitional costs to providers of assessment and treatment services as they will need to restructure their supply in response to changing demand.

## **A2 – Sector-led improvement - subject to further analysis**

46. As set out in section II of this impact assessment, commissioners may lack the expertise and knowledge to ensure the quality of commissioned services.



47. To address this, the Local Government Association and NHS Commissioning Board will establish a joint improvement programme to provide leadership and support to the transformation of services locally. They will involve key partners including DH, ADASS, ADCS and CQC in this work, as well as people with challenging behaviour and their families. The programme will be operating within three months with the Board and leadership arrangements being in place by the end of December 2012. The Department of Health will provide funding to support this work, which may include funding to the regions to co-ordinate local action and sharing of good practice. This will be a sector-led improvement initiative based on the Towards Excellence in Adult Social Care (TEASC) initiative to improve commissioner knowledge and skills.
48. The details of the proposed work programme for sector-led improvement for learning disabilities services have not been developed yet. Therefore, at this stage, only an **indicative assessment** of the costs and benefits of the work programme is possible. As an indication of the scope of the proposed work programme, we can consider the activities currently covered under TEASC<sup>23</sup>:
- regular self-assessment (although not mandatory, most councils do this);
  - provision of comparable data on key outcomes and productivity based on data collection; and
  - subsidised peer challenge for councils with recognised problems.
49. Other potential components of sector-led improvement initiatives include:
- knowledge sharing events; and
  - provision of syntheses of existing good and emerging practice, e.g. through online resources.<sup>24</sup>
50. This action addresses the identified knowledge and skills gap and promotes the exchange of good practice. The objective is to ensure that commissioners have the knowledge and support to plan care for people with learning disabilities or autism who also have mental health conditions or challenging behaviour to ensure that the reduction in usage of assessment and treatment units can be sustained in the long run. In addition, spreading good practice aims to ensure the quality of commissioned services, in particular inpatient services.

#### Costs

51. At the current stage, this proposal **cannot be fully costed**. No decision has been made about the details of the initiative, both in terms of content and in terms of structure. Furthermore, there may be potential opportunity costs associated with improved commissioning as commissioners will shift resources (time etc) towards commissioning services for people with learning disabilities and challenging behaviour.
52. In order to provide some indication of potential costs we looked at similar initiatives run by the Department and their associated costs. The three-year Valuing People Now (VPN) strategy, which promotes the government's policy towards people with learning disabilities, addresses a similar audience to the proposed sector-led initiative.
53. The cost of promoting the VPN strategy is estimated at around £5,000,000 per year. About 30% of this was spent on the regional promotion of VPN, while 70% was spent on the national delivery.
55. However, VPN covered a wider range of issues affecting all people with learning disabilities, while the proposed sector-led initiative will be focussed on the commissioning issues affecting people with learning disabilities or autism who also have a mental health condition or challenging behaviour. Research indicates that 10-15% of learning disabled users of educational, health or social care services show challenging behaviour.<sup>25</sup> Thus, overall, the costs of the proposed initiative are likely to be substantially less than £5,000,000 per year for two years.
56. As an approximation, we assume that costs of national delivery will be lower in line with the lower number of people covered by the initiative, while the cost of regional promotion will be approximately the same. This would suggest that costs would be around 40% of those of VPN (=30% + 70% \*15%). Under the above assumption, the costs of the proposed initiative are approximately **£2,000,000 per year** (until 2014/15) and about £500,000 for the remainder of 2012/13.

#### Effectiveness of intervention

57. Sector-led improvement is a relatively new concept. An initial evaluation of the impact of sector-led improvement initiatives across local government will be published in 2013.<sup>26</sup> However, some local authorities have acted as early adopters to a sector-led improvement exercise in children's services. Their experience shows that such initiatives can be tools to spread knowledge and best practice in a way that is adapted to the needs of individual local authorities.<sup>27</sup>
58. Further evidence supporting the potential of sector-led improvement comes from the evaluation of earlier programmes promoted by the Department for Education, which were not sector-led improvement initiatives as such, but share similar objectives and mechanisms, such as knowledge sharing events and generation of emerging good practice from the sector:
- C4EO (Centre for Excellence and Outcomes in Children and Young People's Services) is an organisation delivering knowledge sharing events and producing syntheses of existing best practice to create a single and comprehensive picture of effective practice in delivering children's services.
  - the CSP (Commissioning Support Programme) provides commissioning support such as online resources, regional and national events as well as bespoke support on an opt-in basis.
59. An evaluation of these initiatives by PricewaterhouseCoopers<sup>28</sup> analysed questionnaire responses by 354 officers working in children's services and 50 Directors of Children's services (for C4EO) as well as 53 Commissioning Champions, 50 Directors and 276 commissioners from local areas. The evaluation found that, over the first two years of their operation,
- There was high awareness in the sector of both initiatives.
  - They were said to positively affect skills, knowledge and culture – especially in smaller local authorities.
  - More than a third (C4EO) and more than half (CSP) of commissioners reported that the respective interventions had a specific positive impact on service delivery;
  - Over a quarter (C4EO) and over a third of commissioners confirmed improvement of outcomes as a result of the respective initiatives.
60. There are limitations to this study, in particular it did not consider the degree to which the initiatives improved cost-effectiveness in service delivery, and were cost-efficient themselves. In addition, the evaluation may overstate the benefits of the programmes in question, as those less convinced / less involved in the programme will have been most likely to respond. The more engaged the commissioners, the higher the impact of any initiative relying on sector input.

### A3 – Department of Health data collections

61. Section II sets out that there is a lack of good quality summary data about services provided to people with learning disabilities.<sup>29</sup> Not knowing who receives what care, in what setting, with what outcome reinforces commissioning failures. It means that:
- there are few clear warning signs where the quality of care is poor;
  - there is little accountability for services provided;
  - commissioners cannot benchmark their own performance;
  - it is more difficult to identify problems and hold commissioners to account for poor performance.
62. Basic and transparent information about services helps to ensure accountability, locally and nationally. The Department proposes to address this issue by commissioning new data collections.
63. **Key performance indicators:** Key performance indicators will aim to address the fundamental asymmetry of information identified in section II. They define organisational goals, which reflect good quality care, and measure progress towards these goals. In addition, they enable commissioners, the government and stakeholders to benchmark commissioning performance. By

comparing indicator outcomes, differences in performance can be identified encouraging the search for improved practices that lead to superior performance.<sup>30</sup>

64. The Department of Health, the Health and Social Care Information Centre (HSCIC) and the NHS Commissioning Board will develop measures and key performance indicators from April 2013 to support commissioners in monitoring their progress in future.
65. Comparatively few initiatives so far have used performance indicators with regard to non-acute social services.<sup>31</sup> As a result, there is a lack of evaluations of the impact of performance indicators. Benchmarking has been found to improve performance in a wide range of industries<sup>32</sup>, while evidence suggests that public reporting of performance, as exemplified by key performance indicators, can improve performance in care systems<sup>33</sup>. However, indicators need to be carefully designed to avoid setting unintended incentives and to ensure that the indicators encourage good outcomes.<sup>34</sup>
66. **Audit:** The Department of Health will commission an audit of current services for people with challenging behaviour by March 2013 to take a snapshot of the provision, numbers of out of area placements and lengths of stay. The audit will be repeated one year on to enable the Learning Disability Programme Board to assess what is happening.
67. The audit would collect information on the care and experience of people with challenging behaviour, who are in receipt of publicly funded health care services. The type of questions asked need to be defined, but could include *“How many people with learning disabilities receive what type of service? What are the outcomes of the care delivered? What is the variation in provision and outcomes across different?”*
68. The audit has two objectives:
  - support the implementation of key performance indicators by providing baseline information about the services provided in different areas.
  - provide information about variation in the provision of specialist learning disability services beyond what can be captured in the narrow scope of key performance indicators.
69. **Extending the Mental Health Minimum Data Set:** The Department will look to extend the Mental Health Minimum Data Set to cover people with learning disabilities to be collected through the HSCIC from 2014/15. Detailed work on the scope of the data set will be done over the next few months but it is intended that some changes to allow the inclusion of people with learning disabilities would be implemented to allow collection from 2014 (version 4.5). A bigger set of changes to allow the collection of more learning disability specific data items would be mandated from 2015 (version 5).
70. At the present time, those with a learning disability and a mental health condition are in scope of the MHMDS. Changes would be made in version 4.5 to allow those with (i) a mental health condition (ii) a learning disability condition (iii) a mental health and learning disability condition to be distinguished.
71. In a second step, version 5 of the MHMDS, which is planned to be mandated from 2015, is planned to include more detailed information on learning disability services which can be used for a variety of reporting purposes.
72. Data would be collected from providers on a monthly basis. All providers of NHS commissioned services are required to submit data to the MHMDS, including independent sector and Any Qualified Providers. A requirement exists to have a N3 connection to submit data. Connecting for Health are working on processes to improve the mechanism of gaining the required connectivity.
73. Compared to one-off collections such as the audit the main benefits of an extension of the MHMDS are:
  - the profile of patients across a whole year can be captured;
  - the data set can cover both community and hospital services and includes a wide range of information about the demographic, clinical and socioeconomic characteristics of individual patients;

- The data includes information about contact with services, uses of the Mental Health Act, and the Care Programme Approach for each individual patient. All these details enable the use of services, patterns of care and patient outcomes to be tracked, including along pathways of care. The MHMDS therefore provides a robust basis for ongoing monitoring of access to and outcomes of care for users of specialist – both community and hospital – mental health services.”<sup>35</sup>

74. Table 1 summarises the costs of developing and collecting DH data requirements as estimated by the HSCIC. Table 2 summarises indicative estimates of the burden the collections will put on providers and commissioners submitting data. The true burden will depend on the exact specifications of the data collections.

75. As noted earlier, we assume that about one third of the data burden on providers will fall on the independent sector. This is in line with the share of all inpatients in learning disabilities services, which are in independently provided services.<sup>36</sup> As a result, the burden falling on the independent sector is approximately £150,000 (=£400,000/3) in 2013/14 and 2014/15 and approximately £50,000 per year thereafter (in 2011/12 prices) – figures rounded to the nearest £50,000.

*Table 1 – Costs of developing and collecting DH data requirements, rounded to the nearest £100,000*

	2012/13	2013/14	2014/15	2015/16 and after
<b>KPI</b>	£100,000	£100,000	£100,000	/
<b>Audit</b>	/	£300,000	£300,000	/
<b>Minimum Data Set</b>	/	£300,000	£500,000	£500,000

*Table 2 – Data burden of proposed collections*

	2012/13	2013/14	2014/15	2015/16 and after
<b>KPI</b> - cost on NHS commissioners	£100,000	£100,000	£100,000	/
<b>Audit</b> – cost on providers of NHS funded LD services	/	£300,000	£300,000	/
<b>Minimum Data Set</b> – cost on providers of NHS funded LD services	/	£100,000	£100,000	£100,000

#### **A4 – Commissioning best practice and guidance**

76. Table 3 summarises a range of other actions, which involve the commissioning of best practice and guidance in areas of concern identified in the Winterbourne View Review.

77. Based on discussions with the parties carrying out the proposed action, the Department currently estimates that it will cost about **£150,000** to the Department, **£25,000** to the NHS Commissioning Board and about **£100,000** to third sector partners to carry out these actions.

78. It should be noted that further and more substantial costs may result if the outcome of the commissioned best practice results in changes to service delivery. However, these cannot be fully assessed in this assessment for two reasons: firstly, the exact content of the guidance and recommendations is not known yet, as the actions, in the main, constitute commissioning for further best practice. The rationale presented in the table as well as section II of this impact assessment suggests that improvements in these areas can be achieved, but, at this stage, we

do not know which components of good practice will be identified and, in particular, cannot assess the cost-effectiveness of the proposed interventions.

Table 3 – best practice and guidance commissioned

Guidance/ piece of best practice	Description	Rationale
<b>Service specification and other resources</b>	<p>The NHS Commissioning Board will also work with ADASS to develop practical resources for commissioners of services for people with learning disabilities, including:</p> <ul style="list-style-type: none"> <li>• model service specifications to support CCGs in commissioning specialist services for children, young people and adults with challenging behaviour built around the model of care (in the report)</li> <li>• new NHS contract schedules for specialist learning disability services</li> <li>• models for rewarding best practice through the NHS Commissioning for Quality and Innovation (CQUIN) framework</li> <li>• a joint health and social care self-assessment framework to support local agencies to measure and benchmark progress</li> </ul>	<p>As set out in section II, commissioners often lack the tools to hold providers to account and assure the quality of services. The service specification can be used by commissioners to ensure the quality of the contracts they use.</p>
<b>Identifying market barriers in the housing market</b>	<p>The national market development forum within the <i>Think Local, Act Personal</i> (TLAP) partnership will work with the Department of Health to identify barriers to reducing the need for specialist hospitals and by April 2013 will publish solutions for providing effective local services.</p>	<p>Relocation into the community is only possible if local services are available. This report will help to identify and address any market barriers that prevent the emergence of such services.</p>
<b>Positive behavioural support and restraint</b>	<p>With external partners, the Department of Health will publish by the end of 2013 guidance on best practice around positive behaviour support so that physical restraint is only ever used as a last resort where the safety of individuals would otherwise be at risk and never to punish or humiliate. This will include a set of agreed values to promote change and raise standards, looking at different methods of restraint, a training framework for commissioners, and identification of information and data needs.</p>	<p>Staff training and competence can complement a purely compliance based approach which is “unlikely to uncover the more subtle abuses which appear in people’s everyday lives”<sup>37</sup> There is some evidence that positive behavioural approaches can bring about very substantial changes in the occurrence of challenging behaviour.<sup>38</sup></p>
<b>Good practice guidance on personalisation</b>	<p>DH, with the National Valuing Families Forum, the National Forum of People with Learning Disabilities, ADASS, LGA and the NHS to identify and promote good practice for people with learning disabilities across health and social care</p>	<p>As set out in section II, lack of service user involvement is one of the reasons why inadequate services can go unnoticed.</p>

<b>Advocacy</b>	<p>The Department of Health will work with independent advocacy organisations to:</p> <ul style="list-style-type: none"> <li>• identify the key factors to take account of in commissioning advocacy for people with learning disabilities in hospitals so that people in hospital get good access to information, advice and advocacy that supports their particular needs.</li> <li>• drive up the quality of independent advocacy, through strengthening the Action for Advocacy (A4A) Quality Performance Mark (QPM) and reviewing the Code of Practice for advocates to clarify their role.</li> </ul>	<p>Advocacy is crucial to reduce abuse. A system based on compliance with guidelines and auditing alone may be “unlikely to uncover the more subtle abuses which appear in people’s everyday lives, due to its concentration on the measurement of the existence of policy and procedure at the expense of measuring individual satisfaction with the quality of services.”<sup>39</sup> “The abuse and neglect of highly marginalised people (...) is less likely to be uncovered within a complaints based system, unless that person has a staunch advocate.”<sup>40</sup></p>
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## A5 – Cost summary

79. Table 4 summarises the costs identified in this section. It is important to note that it is not possible, at the moment, to quantify the cost resulting from Clinical Commissioning Groups and local authorities relocating inpatients into the community. This will be kept under review as the policy develops. It should also be noted that Clinical Commissioning Groups and local authorities will need to consider arrangements if people need to relocate, such as joint funding arrangements for people moving back to the community, to ensure that there is no unfunded pressure on local government and that health and social care commissioners work together to achieve relocation where appropriate.
80. **Costs to the independent sector:** the total cost to business over ten years is £1,400,000 resulting from new data collections and the costs of adjusting to a change in demand (sum of line 11 in table 4). The **present value of costs to the private sector is £1,200,000** (using a 3.5% discount rate; sum of line 14 in table 4).
81. Over ten years, this is equivalent to costs of **£140,000 per year (annual equivalent cost)**.<sup>i</sup>
82. **Costs to the public sector:** the total, undiscounted cost to the public sector is £13,500,000 over ten years (sum of line 12 in table 4).
83. **Opportunity cost:** It should be noted that the National Institute for Health and Clinical Excellence (NICE), estimates that an increase of expenditure of £20-£30,000 will on average force the NHS to make economies (e.g. on staff or on drugs or on procedures) that will lead to a loss of a QALY. DH methodology for assessing policies is designed to ensure that we observe the same budget constraint as NICE does. Therefore, we compare the benefits of a policy with the costs, in terms of the health benefit, that could have been generated through funding to the NHS (at a rate of £25,000 per QALY). At the same time, the Department of Health assigns a value of £60,000 to a QALY, consistently with similar valuation of policies that mitigate mortality or morbidity risk by other government departments, based upon studies of what members of the public are on average willing to spend to reduce their own mortality risk, or to improve their own health outcomes.
84. A policy proposal that costs £25,000 to the NHS is therefore presented with an opportunity cost of £60,000 on the assumption that it would force an economy that would displace a QALY, and therefore lead to a drop in overall health benefits that would be valued by the public at £60,000. As a rule of thumb, the true opportunity cost of funding in the health and social care system is assumed to be £2.4 for every £1 lost (=£60,000/£25,000).

<sup>i</sup> The Equivalent Annual Cost is calculated by dividing the net present value through an annuity rate. This rate can be calculated using the formula:  $a = (1+r)/r * [1 - 1/(1+r)^t]$ , where r is the interest rate (3.5%) and t is the number of years over which the NPV has been calculated. See BIS guidance to calculate the appropriate annuity rate (<http://www.bis.gov.uk/assets/biscore/better-regulation/docs/o/11-671-one-in-one-out-methodology>)

85. The valuation of public sector expenditure taking into account opportunity costs is presented in lines 13, 16 and 17 of table 4. The net present value of public sector costs, including opportunity costs, is about £32,000,000 over ten years (sum of line 13).
86. **Total cost, including opportunity cost:** The undiscounted cost to the independent and public sector (including opportunity cost), over ten years, is £33,000,000 (= £32,000,000 public sector opportunity cost + £1,200,000 private sector). The average annual cost is £3,300,000 (= £33,000,000/10).
87. **Total present value of costs:** the total present value of costs to the independent and public sector, discounted at 3.5% and including opportunity costs, is **£31,000,000** (sum of line 17).

Table 4 – Costs in £000s (2011/12 prices), rounded

	Cost	Borne by	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	TOTAL
1	Care Reviews	Local commissioners (health and social care)	£2,500	£0	£0	£0	£0	£0	£0	£0	£0	£0	£2,500
2	Sector-led improvement	Department of Health	£500	£2,000	£2,000	£0	£0	£0	£0	£0	£0	£0	£4,500
3	Best practice and guidance	NHS Commissioning Board	£25	£0	£0	£0	£0	£0	£0	£0	£0	£0	£25
4	Best practice and guidance	Department of Health	£150	£0	£0	£0	£0	£0	£0	£0	£0	£0	£150
5	Best practice and guidance	Third sector	£100	£0	£0	£0	£0	£0	£0	£0	£0	£0	£100
6	Data Collections	Department of Health	£100	£700	£900	£500	£500	£500	£500	£500	£500	£500	£5,200
7	Data Collections	NHS Commissioners	£100	£100	£100	£0	£0	£0	£0	£0	£0	£0	£300
8	Data Collections	Independent sector providers	£0	£150	£150	£50	£50	£50	£50	£50	£50	£50	£650
9	Data Collections	NHS providers	£0	£300	£300	£100	£100	£100	£100	£100	£100	£100	£1,300
10	<b>TOTAL</b>		<b>£3,475</b>	<b>£3,250</b>	<b>£3,450</b>	<b>£650</b>	<b>£650</b>	<b>£650</b>	<b>£650</b>	<b>£650</b>	<b>£650</b>	<b>£650</b>	<b>£14,700</b>
11	<b>TOTAL (independent and third sector)</b>		<b>£100</b>	<b>£300</b>	<b>£300</b>	<b>£100</b>	<b>£100</b>	<b>£100</b>	<b>£100</b>	<b>£100</b>	<b>£100</b>	<b>£100</b>	<b>£1,400</b>
12	<b>TOTAL (public sector)</b>		<b>£3,375</b>	<b>£2,950</b>	<b>£3,150</b>	<b>£550</b>	<b>£550</b>	<b>£550</b>	<b>£550</b>	<b>£550</b>	<b>£550</b>	<b>£550</b>	<b>£13,300</b>
13	<b>Public sector including opportunity cost</b>		<b>£8,100</b>	<b>£7,080</b>	<b>£7,560</b>	<b>£1,320</b>	<b>£1,320</b>	<b>£1,320</b>	<b>£1,320</b>	<b>£1,320</b>	<b>£1,320</b>	<b>£1,320</b>	<b>£32,000</b>
14	Discounted private and third sector		£100	£290	£280	£90	£87	£84	£81	£79	£76	£73	£1,241
15	Discounted public sector		£3,375	£2,850	£2,941	£496	£479	£463	£447	£432	£418	£404	£12,305
16	Discounted public sector including opportunity cost		£8,100	£6,841	£7,057	£1,191	£1,150	£1,111	£1,074	£1,038	£1,002	£969	£29,532
17	<b>TOTAL discounted (including opportunity costs)</b>		<b>£8,200</b>	<b>£7,130</b>	<b>£7,337</b>	<b>£1,281</b>	<b>£1,237</b>	<b>£1,196</b>	<b>£1,155</b>	<b>£1,116</b>	<b>£1,078</b>	<b>£1,042</b>	<b>£30,773</b>



## B – Potential benefits

88. As set out in **Annex C**, we estimate that about 300 people in assessment and treatment have finished treatment, but have no plan for discharge. About **650 people** have been in assessment and treatment units for more than six months. Reviewing the care of these people may result in changes to their care packages, including relocation into the community or a different inpatient setting. When Winterbourne View closed, the range of resulting placements including living in one's family home, residential care homes, supported living settings as well as low- and medium secure placements.
89. **Poor quality of life due to inappropriate care:** Without detailed case studies it is not possible to determine, whether in each individual case this type of placement is in the best interest of the patient or not. In particular, any benefits from moving patients into alternative services are contingent on the quality of these services.<sup>41</sup>
90. Self-determination is a core domain of quality of life for people with learning disabilities<sup>42</sup> and evidence suggests that less restrictive care settings can lead to an improvement in quality of life.<sup>43</sup> Correspondingly, long stays in hospitals have been reported to lead to loss of crucial skills, which are needed to live a self-determined life outside hospital.<sup>44</sup>
91. There is also evidence that resettlement of patients from inpatient settings into community settings can improve their and their family carers' quality of life. For example, with out of area inpatient placements, family carers may have to travel long distances to visit their family member, which also imposes an additional cost on them. Sines et al (2012)<sup>45</sup> study the quality of life, as reported by their main carers, of 39 service users with severe learning disabilities leaving the Orchard Hill long stay hospital<sup>i</sup> in between 2007 and 2009. They found a substantial improvement in their quality of life from 36% of the potential maximum on the QoL scale used to 68%.
92. It should be noted that this scale cannot be readily translated into assessment tools such as the EQ5D scale or the Quality Adjusted Life Year. Given this limitation, we cannot monetise the benefit from moving people into community settings.
93. In addition, spreading commissioning expertise will also improve the quality of services commissioned, allowing commissioners to be more proactive in using commissioning tools and quality assure the services they provide. Winterbourne View and the following investigations have revealed the poor quality of care in some assessment and treatment facilities leading to adverse impacts on individual's health and wellbeing. The CQC inspections<sup>46</sup> show that 58% of people in assessment and treatment were in services that were non-compliant with at least one out of the CQC requirements regarding the care and welfare of service users and safeguarding. Crucially, in some cases, behaviour management approaches were punitive and involved restrictions<sup>47</sup>. In other words, often care is overly reliant on restraint. Restraint, even if appropriate, has negative impacts on people's quality of life: firstly, it may lead to anxiety, fear and panic<sup>48</sup> as well as anger and mental distress.<sup>49</sup>
94. The potential benefits of improving quality of care are not quantified here, as they will be contingent on several other factors:
- The content of the sector-led programme, which has not yet been decided.
  - How effectively the actions proposed in section A succeed in reducing the usage of assessment and treatment and similar facilities.
  - The interaction between the sector-led programme and the resources that will be developed to improve commissioners' skills and knowledge (see section D).
95. However, it should also be noted that as well as having a positive impact on patients and family carers, there is the potential to have a positive impact on the wider system. For example, there will be reduced costs to the criminal justice system in dealing with serious criminal abuse such as at Winterbourne View.

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<sup>i</sup> Note that this is not an assessment and treatment unit, but, given the length of stay observed in assessment and treatment, these often almost operate as a long-stay hospital.

96. **Net cost savings from moving people into alternative provision:** despite concerns about the appropriateness and quality of care, placements in specialist hospitals could potentially be more expensive when compared to equivalent placements in alternative provision.<sup>50</sup>

### *Risks and Limitations*

97. Overall, health benefits notwithstanding, the financial benefits of the proposed course of action have the potential to outweigh the costs. However, whether and how this outcome can be achieved, cannot at present be assessed. This will depend on the details of the actions proposed by Clinical Commissioning Groups and their local authority partners and is subject to considerable risks.
98. It should also be noted that there may be a difference between who bears the costs and who benefits from potential savings; cost savings fall on NHS commissioners, while if people go back to the community the resulting costs of alternative provision are likely to be borne within a joint commissioning arrangement. These additional costs of local provision could be very high. Therefore, the NHS Commissioning Board's work programme will need to address the coordination problem resulting from costs falling on social care commissioners (in joint commissioning agreements), but cost savings falling on the NHS alone.
99. Improvements in commissioning expertise and the use of collaborative commissioning will be essential to ensure that planning of services for people with learning disabilities improves, and to overcome the coordination problem resulting from the fact that costs and cost savings do not fall on the same commissioners.
100. It should also be noted any positive outcomes are contingent on a number of factors.
101. *First*, they depend on whether people can be easily moved into alternative provision and whether there is an appropriate offer of services. The Department is commissioning best practice into the barriers to the development of local housing markets, which aims to facilitate the development of appropriate offers and how these can overcome.
102. *Second*, where new services are set up, there may be additional costs, if these run in parallel to the existing assessment and treatment placements while transfer into the new care setting is prepared. In other words, "pump-priming of monies may be required in the short-term as, in effect, (new and old services) will need to operate in tandem for a period of time."<sup>51</sup> However, it should be noted that placements in assessment and treatment are likely to be spot purchases, often for nominally short periods. Given this, and given the purpose of assessment and treatment, it is likely that placements can be terminated quickly, when alternative provision is in place.
103. *Third*, there may be cases, in which assessment and treatment is genuinely the preferable placement option.
104. *Fourth*, the durable success of these measures will depend, to a large extent, on the prevention of inappropriate admissions to assessment and treatment in the first place. For this, better local planning is needed. This is promoted through other actions in the Review and Concordat such as sector-led improvement and improving the availability of good quality data set out above.

## V – SUMMARY AND CONCLUSION

105. This impact assessment has presented the underlying causes of poor outcomes in the commissioning of services to people with learning disabilities or autism who also have mental health conditions or challenging behaviour. Due to poor incentives and a lack of knowledge, too many people are in inpatient services for too long and when in these services, they often receive poor quality care (see section II).
106. The assessment has then looked at the main actions proposed to reduce the number of people in assessment and treatment and improve the quality of care. Reducing the number of

people in assessment and treatment has been shown to have the potential to increase quality of life and reduce the overall costs to the health and social care system.

107. However, whether these cost savings can be achieved is contingent on future policy development which needs to overcome the coordination problem stemming from the fact that cost savings and costs fall on different commissioners.

## **Equality**

108. The Department has paid due regard to the Equality Act 2010 and the public sector equality duty in undertaking the Winterbourne View Review. We have tried to:
- Make sure that the review is conducted in a way that includes and involves people who are affected and those with an interest in learning disability services
  - Identify how the suggested actions will allow the Department and others to demonstrate how they are meeting the requirements of the Act and the public sector equality duty.

## **Patients at Winterbourne View Hospital**

109. The NHS Review looked at 48 patient placements at Winterbourne View. More than 40% of patients were under 25 years old when they were admitted to the hospital and 94% were under the age of 50. Data was not available to show how these figures compared with other facilities specialising in challenging behaviour.<sup>52</sup>
110. The gender of patients at Winterbourne View was well balanced. The NHS Review found that there were 50% men and 50% women among the 48 placements it analysed. Nationally, 70% of patients in inpatient learning disability services and 58% in mental health services were men.
111. The majority of patients had a mild or borderline learning disability, with just over 25% having a moderate or severe learning disability. A small minority had no learning disability. Around a third of the patients had a diagnosis of some form of autism and around 10% a diagnosis of Asperger Syndrome.
112. The NHS Review found that whilst most commissioners had identified the general needs of learning disabled people as part of population needs assessments, only a minority seemed to have developed more detailed policy and strategy around challenging behaviour.<sup>53</sup> It also found that there was inconsistent use of contracts by commissioners as an effective commissioning tool.
113. In the 28 placements commissioners looked at in detail, there was no evidence of a signed contract in two cases; six cases were covered by a local authority standard contract; the rest were covered by the standard Castlebeck contract or a signed contract provided by them. This led to a lack of focus on quality and outcomes, for example, there was no requirement for Castlebeck to report serious incidents to commissioners. Using the standard NHS contract may have provided some additional safeguards relating to meeting quality, safety and equality standards.

## **Involving people with experience of services**

114. The reviews into events at the hospital have recognised the importance of getting, and including input from a wide range of people, including self advocates, families and carer representatives either through reference groups or through interviews with individuals. For example, the NHS Review Panel was supported in its work by a Reference Group of self-advocates, families and carer representatives. It also contacted and interviewed some former patients of Winterbourne View Hospital, and their families and carers. This has ensured that the views and experiences of people using services and facilities have informed the review and suggested recommendations and actions.

115. The CQC's programme of inspections of 150 services providing care for people with learning disabilities and challenging behaviours was supported by an external advisory and reference group. Each inspection team included an 'expert by experience' (a person who had experience of using services), their supporter, and a family carer together with a professional adviser. CQC's overview report identified that more needed to be done to make sure that people with learning disabilities are not discriminated against and that they and their families should have higher expectations of the services that are commissioned and provided for them.

116. The Department has undertaken its review with input from:

- The DH Learning Disability Programme Board, which includes people with learning disabilities and family carers of people with learning disabilities as well as organisations representing the interests of people with learning disabilities and their families and carers, for example the National Forum of People with Learning Disabilities, the National Valuing Families Forum and Mencap.
- The DH Valuing People Health Steering Group which was established to oversee progress in improving the quality of healthcare for people with learning disabilities.
- A diverse range of stakeholders at stakeholder events that were organised between December 2011 and August 2012.<sup>54</sup> Feedback from these events has informed the final report.
- Extensive engagement across the health and care sector and across government to make sure there is a consistent approach to addressing potential discrimination and inequalities.

117. The Department also supported a meeting held on 9 November 2012, run by the British Institute of Learning Disabilities and the Association for Real Change, which examined the current situation in relation to support for people with learning disabilities from minority ethnic communities and their families and to ensure good practice in the future. A number of issues were identified, including the need for:

- provision of information about services and good practice to BME communities;
- better ways of identifying and supporting people with learning disabilities from BME communities; and,
- organisations and bodies like the NHS Commissioning Board, clinical commissioning groups, Healthwatch and others to recognise and address the issues facing people with learning disabilities from BME communities.

## Conclusion

118. The overall aim of the Review is to eliminate unlawful discrimination and harassment; advance equality of opportunity and to foster good relations. The Concordat which has been agreed with key partner organisations, represents a commitment to a programme for change to transform health and care services and improve the quality of care for people with learning disabilities and autism and challenging behaviour. The aim of the Concordat is to make sure that:

- people can access high quality local support near their family and friends and can live fulfilling lives in the community
- people are not sent to inpatient services where it is not necessary, and they spend the minimum time in inpatient services where they need assessment and treatment
- the quality of care improves and that progress is monitored and measured

119. The Review report includes a number of actions, which could have a positive impact on equality, including:

- Improving training and awareness in the health and care workforce about learning disabilities and autism and challenging behaviour. This will help professionals and staff to recognise and respond more appropriately to people's needs.

- Introducing a code of conduct, minimum training standards and a voluntary register for healthcare support workers. This will help to make sure there are appropriately qualified staff able to provide good quality care, who can be held to account for their actions.
- Developing resources for commissioners including model service specifications. This will give commissioners a better understanding of people's needs, services that are more aligned with best practice and evidence, to allow more effective monitoring of outcomes and encourage participation of service users and family carers in the process.
- Putting in place ways of measuring and monitoring progress and improvements in services, through key performance indicators, an audit and the development of a minimum data set. Taken together these will provide information about services to ensure local and national accountability, for example telling us how many people are in care, who commissioned the care and with what outcomes. They will also allow benchmarking, for example for local stakeholders to use to assess outcomes and processes across localities against good quality care and outcomes. They will also provide clear information where commissioning arrangements are less effective or are failing. The minimum data set would include information on people's protected characteristics and allow in time for differential impact on different groups to be measured and any unacceptable variations to be identified and addressed.
- Giving people with learning disabilities a voice in local Healthwatch. This will allow them to make an impact locally on the quality of services, for example through Health and Wellbeing Boards and JSNAs.
- Identifying and disseminating good practice in providing personalised care according to people's needs in all settings. This will allow commissioners and providers to see how different organisations are successfully delivering quality outcomes and encourage spread of good practice.
- Strengthening and clarifying guidance on whistleblowing to identify issues where things are not going well. Together with the commitment in the NHS Constitution to support all staff in raising concerns about safety, malpractice and wrongdoing and to respond to and investigate concerns, this will give staff the confidence that where they identify serious problems these will be addressed. It will also provide a further safeguard for patients against poor care as well as abuse.
- Regulating and inspecting providers more robustly and placing reporting requirements on providers' boards. This will encourage a culture of greater openness and transparency so that there is external scrutiny of the quality of care for people who are in vulnerable circumstances.
- Driving up the quality of advocacy services to provide support to people with learning disability who are at risk of admission to inappropriate settings. This will give people in vulnerable circumstances a voice to make sure that their interests and needs inform decisions about their care.

120. We have considered whether the recommended actions or the way they are implemented will affect people who share relevant protected characteristics in different ways from people who do not share them, and have concluded that they will not.

121. The Department is also developing an indicator for the NHS Outcomes Framework on excess under 60 mortality rate in adults with a learning disability compared with the rate in the general population. Reducing premature mortality is a priority area for the Secretary of State for Health. This will help to focus on improving the quality of care for people with learning disabilities so that they have better outcomes.

122. The Department has also recently published its corporate equality objectives action plan.<sup>55</sup> These include a specific objective to "Provide greater choice and control for people with learning disabilities and people with autism and their families and carers, as part of our drive to improve outcomes for people with learning disabilities and autism". The Department is committed to publishing updates on progress towards meeting the objectives annually.

## Annex A – Actions covered in the review that have already been decided/implemented independently of the review ('do nothing')

Title	Summary	Previous assessment (where available)
Carry out a refresh of Challenging Behaviour guidance	By December 2012, the professional bodies that make up the Learning Disability Professional Senate will refresh <i>Challenging Behaviour: A Unified Approach</i> to ensure clinicians in community learning disability teams to deliver the best outcomes.	
Skills for Care framework and guidance	Skills for Care will develop by February 2013, a framework of guidance and support on commissioning workforce solutions to meet the needs of people with challenging behaviour.	
Code of conduct and minimum training	Skills for Health and Skills for Care will develop by January 2013 national minimum training standards and a code of conduct for healthcare support workers and adult social care workers. These can be used as the basis for standards in the establishment of a voluntary register for healthcare support workers and adult social care workers in England.	
Professional standards, core principles, statements of ethics	By April 2013, the Academy of Medical Royal Colleges and the bodies that make up the Learning Disability Professional Senate will develop core principles on a statement of ethics to reflect wider responsibilities in the health and care system	
Whistleblowing	<p>The Department of Health has asked the LGA and the NHSCB to take account of the recommendations of the Serious Case Review on whistleblowing.</p> <p>Commissioners should ensure that organisations contracting with the NHS or a local authority include a condition of employment on its workers to report concerns.</p>	
Safeguarding	<p>DH will revise statutory guidance and good practice guidance to reflect new legislation and address findings from Winterbourne View, to be completed in time for the implementation of the Care and Support Bill. In particular,</p> <ul style="list-style-type: none"> <li>• local authorities will be empowered to make safeguarding enquiries, and Boards will have a responsibility to carry out safeguarding adults reviews;</li> <li>• the Safeguarding Adults Board will publish an annual report on the exercise of its functions and its success in achieving their strategic plan; and,</li> <li>• the Safeguarding Adults Board core membership will consist of the LA, NHS, and</li> </ul>	<a href="http://www.dh.gov.uk/health/files/2012/07/IA-Annex-D-Quality-providers-workforce.pdf">http://www.dh.gov.uk/health/files/2012/07/IA-Annex-D-Quality-providers-workforce.pdf</a>

	<p>Police organisations, convened by the LA. Individual boards will be able to appoint other members in line with local need.</p> <p>The Department for Education is revising <i>Working Together to Safeguard Children</i>, statutory guidance on how organisations, agencies and individuals working with children should work together to safeguard and promote their welfare. The guidance will be published in due course.</p> <p>Ofsted, CQC, Her Majesty's Inspectorate of Constabulary (HMIC), Her Majesty's Inspectorate of Probation and Her Majesty's Inspectorate of Prisons will introduce a new joint inspection of multi-agency arrangements for the protection of children in England from June 2013.</p>	
Healthwatch	<p>The Department of Health will work with the LGA and Healthwatch England to embed the importance of local Healthwatch involving people with learning disabilities and their families. A key way for local Healthwatch to benefit from the voice of people with learning disabilities and families is by engaging with existing local Learning Disability Partnership Boards. LINKs (local involvement networks) and those preparing for Healthwatch can begin to build these relationships with their Boards in advance of local Healthwatch organisations starting up on 1 April 2013.</p>	<p><a href="http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/Publications/PublicationPublications/PublicationPublications/DH_123583http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_129917.pdf">www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationPublications/PublicationPublications/DH_123583http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_129917.pdf</a></p>
Care Quality Commission ongoing improvements	<p>The CQC is committed to delivering on the recommendations set out in:</p> <ol style="list-style-type: none"> <li>1) the evaluation of the inspection of 150 learning disability services;</li> <li>2) the findings of the Serious Case Review;</li> <li>3) their Internal Management Review; and</li> <li>4) any relevant matters from the consultation on their strategy for 2013-2016.</li> </ol> <p>CQC will use existing powers to seek assurance that providers have regard to national guidance and the model of care at Annex A (of the review report).</p> <p>CQC will take action to ensure the model of care is included as part of inspection and registration of relevant services from 2013, when CQC's new regulatory model is implemented.</p> <p>CQC will also include reference to the model of care in their revised guidance about compliance, which is also to be published in 2013</p> <p>CQC will continue to make unannounced inspections of providers of learning disability and</p>	

	<p>mental health services, employing people who use services and families as vital parts of the inspection team</p>	
<p>NICE Quality Standards and clinical guidelines</p>	<p>By Summer 2015, NICE will publish quality standards and clinical guidelines on challenging behaviour and learning disability.</p> <p>By Summer 2016, NICE will publish quality standards and clinical guidelines on mental health and learning disability</p> <p>NICE will also develop new quality standards on child maltreatment. They will focus on the recognition and response to concerns about abuse and neglect and effective interventions</p>	
<p>Monitoring and measuring progress</p>	<p>At a national level, from November 2012, the cross-government Learning Disability Programme Board chaired by the Minister of State for Care and Support will lead delivery of the programme of change by measuring progress against milestones, monitoring risks to delivery, and challenging external delivery partners to deliver to plan, regularly publishing updates</p> <p>The cross-government Learning Disability Programme Board will measure progress against milestones, monitor risks to delivery, and challenge external delivery partners to deliver to the action plan of all commitments. CQC, the NHSCB, the head of the LGA, ADASS will with other delivery partners, be members of the Programme Board, and report on progress.</p> <p>Regular updates to the Programme Board will be published on the DH webpage with all other papers and minutes for that Board.</p> <p>DH will work with the joint improvement team to monitor and report on progress nationally. We will publish a follow up report, including data comparing progress between localities, by December 2013 and repeat this in December 2014.</p>	



## Annex B – Actions covered in the review that are subject to further analysis and a separate decision making process

Title	Summary
Progress report on learning disabilities nursing	By end 2013 there will be a progress report on actions to implement the recommendations in <i>Strengthening the Commitment</i> , the report of the UK Modernising Learning Disability Nursing Review.
Children and transition	<p>Through the Children and Families Bill, the Department of Health and the Department for Education will work together to introduce from 2014 a new single assessment process for every child and young person up to 25 with special education needs or a disability with an Education, Health and Care Plan (subject to parliamentary approval). This will be supported by a statutory code of practice.</p> <p>The Department of Health and Department for Education will work with the independent experts on the Children and Young People's Health Outcomes Forum to consider how to prioritise improvement outcomes for children and young people with challenging behaviour and how best to support young people with complex needs in making the transition to adulthood. This will report by June 2013.</p>
Mental Health Act	During 2014, the Department of Health will update the Mental Health Act Code of Practice and this will take account of findings from the Winterbourne View review
Deprivation of Liberty Safeguards  Restraint	<p>DH will work with CQC to agree how best to raise awareness of and ensure compliance with Deprivation of Liberty Safeguards (DOLS) provisions to protect individuals and their human rights and will report by Spring 2014.</p> <p>The Department of Health will, together with CQC, consider what further action may be needed to check how providers record and monitor restraint</p>
Review funding arrangements and consider joint commissioning	<p>CCGs and local authorities, working as part of the local Health and Wellbeing Board, will set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area.</p> <p>The strong presumption will be in favour of supporting this with pooled budget arrangements with local commissioners offering justification where this is not done. The NHSCB, ADASS and ADCS will promote and facilitate joint commissioning arrangements.</p> <p>The joint plan will be developed and agreed during 2013-14 and will be part of the Joint Health and Well-being Strategy for implementation from April 2014.</p>

Guidance on children in long-term residential care	The Department of Health and the Department for Education will develop and issue statutory guidance on children in long-term residential care in 2013.
Health Education England	From April 2013, Health Education England will have a duty to ensure we have an education and training system fit to supply a highly trained and high quality workforce. HEE will work with the Department of Health, providers, clinical leaders and other partners to improve skills and capability of the workforce to respond to the needs of people with challenging behaviour. HEE are committed to ensuring that non-professional members of the workforce (i.e. bands 1-4) receive continuing development and training to provide a skilled and highly motivated workforce.
Safeguarding	NHS A&E staff need to be alert to adult safeguarding issues and have a clear understanding of what to do with any safeguarding concerns. DH will highlight to A&E departments the importance of detecting incidences of re-attendance from the same location / individual in their annual review of Clinical Quality Indicators.
Commissioning guidance	By March 2013 the Joint Commissioning Panel of the Royal College of General Practitioners and the Royal College of Psychiatrists will produce detailed guidance on commissioning services for people with learning disabilities who also have mental health conditions.
Use of medication	<p>The Royal College of Psychiatrists, the Royal Pharmaceutical Society and other professional leadership organisations will work with ADASS and ADCS to ensure medicines are used in a safe, appropriate and proportionate way and their use optimised in the treatment of children, young people and adults with learning disabilities. This should include a focus on the safe and appropriate use of antipsychotics and antidepressants.</p> <p>The Department of Health will explore with the Royal College of Psychiatrists and others whether there is a need to commission an audit of use of medication for this group. As the first stage of this DH will commission a wider review of the prescribing of antipsychotic and antidepressant medicines for people with challenging behaviour.</p>
Health and Wellbeing Boards	DH will ensure Health and Wellbeing Boards have guidance and information to support them to understand the complex needs of people with challenging behaviour.

<p>Strengthening accountability and corporate responsibility for quality of care</p>	<p>We expect Directors, management and leaders of organisations providing NHS or local authority-funded services to ensure that systems and processes are in place to provide assurance that essential requirements are being met and that they have governance systems in place to ensure they deliver high quality appropriate care.</p> <p>The Department of Health will explore with the National Skills Academy and the NHS Leadership Academy options to develop proposals on Board leadership development by March 2013.</p> <p>CQC will explore with the Department of Health how enforcement action can be taken against a board which fails to meet its legal obligations to service users.</p> <p>CQC will take steps to strengthen the way it uses its existing powers to hold organisations to account for failure to meet legal obligations to service users. CQC will meet with executives of provider organisations when there are serious concerns about quality and safety issues to discuss their plans to deliver safe and effective care.</p> <p>The Department of Health will immediately examine how corporate bodies and their Boards of Directors can be held to account for the provision of poor care and harm, and set out proposals during Spring 2013 on strengthening the system where there are gaps.</p> <p>We will consider both regulatory sanctions available to CQC and criminal sanctions, We will determine whether CQC's current regulatory powers and its primary legislative powers need to be strengthened to hold Boards to account.</p> <p>CQC will also consider whether it is able to use its existing powers to carry out a fit and proper person test of Board members as part of the registration of providers.</p> <p>Monitor will consider including internal reporting requirements for the Boards of licensable providers to strengthen the monitoring of outcomes and clinical governance arrangements at Board level. Monitor and CQC are required to co-operate with each other and share information.</p>
<p>Health and social care self assessment framework</p>	<p>ADASS will implement a joint health and social care self assessment framework to monitor progress of key health and social care inequalities from April 2013. The results of progress from local areas will be published.</p>
<p>Criminal records checks</p>	<p>From 2013, arrangements for checking criminal records will become quicker and simpler with the introduction of a new service that will make criminal records certificates more portable. The Department of Health will review the regulatory requirements in respect of criminal records checks and whether providers should routinely request a criminal record certificate on recruitment once the impact of the new service is understood.</p>

## Annex C - How many people with learning disabilities and challenging behaviour are in inpatient care?

- C1. There is no up-to-date information on the number of people in assessment and treatment units and similar specialist hospitals.
- C2. The 2010 *Count me in* census<sup>56</sup> shows that, in March 2010, about 3,400 people were in inpatient wards for patients with learning disabilities.

### How many people with LD are in assessment and treatment units?

- C3. *Count me in* data also shows that there were **1,250 inpatients** for assessment and treatment in learning disabilities wards.
- C4. Of all learning disabilities inpatients, including those in residential care, 33% were in services provided by independent sector providers. If a similar rate applied to inpatients in assessment and treatment, this would suggest about **400 people** (=1,250 \*33%) with learning disabilities and challenging behaviour **in independent sector** assessment and treatment units.

### Are too many people in assessment and treatment units?

- C5. A study found that 25% of patients in assessment and treatment units had finished treatment but had no plan for discharge.<sup>57</sup> This would suggest that, in 2010, **about 300 people** (=1250 \*25%) with learning disabilities were in assessment and treatment although they **could be discharged**.
- C6. Another consideration is length of stay. Only in exceptional circumstances are assessment and treatment units appropriate for long stays. As an approximation, we can consider a stay in excess of six months to be inappropriately long. The CQC summary report has shown that length of stay in (NHS and Independent) assessment and treatment services and secure services was generally long (from 6 weeks to 17 years) and inconsistent with the descriptions of assessment and treatment.<sup>58</sup> At Winterbourne View, the average length of stay at the time of its closure, was around 19 months.
- C7. *Count me in* data shows **at least 650 patients in assessment and treatment units for learning disabilities for more than 6 months**.<sup>59</sup>
- C8. It should be noted that we do not know the alternative course of treatment for all of these patients and, in particular, it may be that any alternative provision would need to contain an element of mental health treatment.

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<sup>i</sup> The 2010 census counts 755 people with a length of stay of less than six months. Even if all of these short-stay patients had been in assessment and treatment, there still would have been about 500 patients (=1,251 – 755) in A&T for more than 6 months. The higher estimate of 650 accounts for the fact that, by definition, some of the short stays will be in respite care (130 patients) and patients in short-stay wards (an unknown fraction of 60 patients with a stay of less than a year), not assessment and treatment. This is a lower bound estimate as it does not take into account that some patients in other ward types (e.g. long stay wards) will also have been recently admitted into care.

# Annex D - What is the cost of A&T provision relative to the alternative?

## 1 - What is the cost of A&T provision?

D1. Table D1 summarises publicly available information about the average cost of assessment and treatment services in eight localities. This information has been published by commissioners in response to freedom of information requests.

**Table D1 – Assessment and treatment costs in October 2012**

Commissioner	Average cost per week
NHS Cornwall + Isles of Scilly PCT <sup>60</sup>	£2,563
Barnet PCT <sup>61</sup>	£3,745
Camden PCT <sup>62</sup>	£3,750
Islington PCT <sup>63</sup>	£2,753
Haringey PCT <sup>64</sup>	£3,745
Enfield PCT <sup>65</sup>	£3,745
Derbyshire Cluster NHS <sup>66</sup>	£2,916
Heywood, Middleton and Rochdale PCT <sup>67</sup>	£3,000
Milton Keynes <sup>68</sup>	£3,000

D2. There is not enough published data to derive a national picture of the costs of placements in assessment and treatment units. The available information covers less than 10% of the estimated total population in assessment and treatment. Furthermore, most of the sample is from London and the East Midlands. These limitations notwithstanding, it should be noted that the average costs per week in assessment and treatment range from £2,563 in Cornwall and the Isles of Scilly to £3,745 in Barnet, Haringey and Enfield. The weighted average across all sites is about £3,100 per week (about £3,250 in London, £2,850 outside of London). Based on the information from the freedom of information requests, the costs of assessment and treatment provision appears to be broadly similar to low secure services.<sup>69</sup> This suggests costs of about £160,000 per patient-year (=£3,100 \*52) spent in assessment and treatment.

## 2 - What is the cost of the alternative provision?

D3. However, the above savings need to be compared to the costs of the alternative services for those moved out of assessment and treatment. It should be noted that patients discharged from Winterbourne View went on to a range of different care arrangements, including supported living (about 20%), residential care (about 50%) as well as low (15%) and medium secure hospitals (5%).

D4. The costs of the potential alternative arrangements are summarised in table D2. It should be noted that those in assessment and treatment units are likely to have higher needs, which are correlated to higher costs. Where appropriate, the cost estimates in the right hand column are adjusted for higher care needs of people with lower levels of ability, as proposed by PSSRU<sup>ii</sup>. This is likely to be a better representation of the patients in question. It should be noted that there may be cases in which people will be moved out of assessment and treatment and into more secure settings, which would be more expensive. At the same time, it may well be that patients currently in assessment and treatment could be moved into semi-independent living or group home arrangements, which would generate higher savings.

<sup>ii</sup> The PSSRU proposes to derive the unit cost of provision for people with low levels of ability by multiplying the unit costs (except for capital costs) by a factor 1.6. Annuitised capital costs are £73 per week for group homes, £81 for fully – living settings and £59 per week in semi-independent living.

**Table D2 – Unit costs for alternative provision, in 2011/12 prices**

	<b>Average ability – weekly full care package cost (incl capital allowance)</b>	<b>Lower levels of ability – weekly all-in cost</b>
<b>Community</b>		
Supported living: semi-independent living <sup>70</sup>	£824	£1,222
Supported living: Group homes <sup>71</sup>	£1,475	£2,240
Supported living: Fully staffed <sup>72</sup>	£1,790	£2,731
<b>Residential</b>		
Nursing care <sup>73</sup>	£1,223	
Residential care <sup>74</sup>	£1,306	
Low-secure hospitals <sup>75</sup>	£3,185	
Medium-secure hospitals <sup>76</sup>	£3,570	

- D5. The above figures suggest that, in some case, the costs of the alternative care provision may be lower than the costs in assessment and treatment centres (around £3,100 per week); for example, if they are based in the community, in residential or nursing care homes. Conversely, costs in low and medium secure services seem similar (or slightly more expensive) than in assessment and treatment centres.
- D6. We currently do not have sufficient information to estimate the cost of community care packages for this group of people but we believe that it will be quite high. Furthermore, it should be noted that they may also have mental health problems and therefore require some continuing NHS mental health provision if they are moved into the community; up to 350 out of 1,250 people in assessment and treatment have been admitted for mental health reasons. This will result in further costs, which implies that the cost of the alternative provision in the community may be expensive. As an indication, it should be noted that the mean cost of community mental health consultant contacts is about £135 per contact<sup>iii</sup>.
- D7. In conclusion, it is very difficult to estimate if there will be potential cost savings from moving people from assessment and treatment centres to alternative provision unless we have more information on what type of provision and what kind of packages of care they would require.

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<sup>iii</sup> PSSRU Unit Costs 2011-12

## Annex E - Endnotes

- <sup>1</sup> **Care Quality Commission 2012 (I)**: Learning disability services inspection programme. National overview. June 2012. Care Quality Commission. <http://www.cqc.org.uk/public/reports-surveys-and-reviews/themed-inspections/review-learning-disability-services>
- <sup>2</sup> Report of the **NHS Review** of commissioning of care and treatment at Winterbourne View, pg 26 paragraph 5.7 <http://www.southofengland.nhs.uk/wp-content/uploads/2012/03/Final-Report-for-publication-Report-of-the-NHS-Review-of-Commissioning-of-Care-and-Treatment-at-Winterbourne-View-30-July-2012.pdf>
- <sup>3</sup> **Mansell et al 2006**, People with learning disabilities in 'out-of-area' residential placements: I. Policy context, Journal of Intellectual Disability Research, 50(11), p837-844
- <sup>4</sup> see **Burns, Mc Cann and Silberman 2010**
- <sup>5</sup> see **NHS Review**, p28, para 5.14
- <sup>6</sup> see **Mansell et al 2006**
- <sup>7</sup> see **Burns, Mc Cann and Silberman 2010**
- <sup>8</sup> see **Burns, Mc Cann and Silberman 2010**
- <sup>9</sup> **Department of Health 2008**: Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities, Sir Jonathan Michael and the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. July 2008 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099255](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255)
- <sup>10</sup> see **Chenoweth and Robinson 2011**
- <sup>11</sup> see **Care Quality Commission 2012 (II)**: Internal management review of the regulation of Winterbourne View; This was confirmed by contributors to the DH engagement with people with learning disabilities. One of the attendees concluding remark was *"there must be so many other people up and down the country that are not getting listened to. It's important that people are listened to, and know what their rights are within the place"*. **Care Quality Commission 2012 (II)**: Internal management review of the regulation of Winterbourne View; [http://www.cqc.org.uk/sites/default/files/media/documents/20120730\\_wv\\_imr\\_final\\_report.pdf](http://www.cqc.org.uk/sites/default/files/media/documents/20120730_wv_imr_final_report.pdf)
- Department of Health 2012**: Winterbourne View review engagement: *Summary of response*
- <sup>12</sup> **South Gloucestershire Safeguarding Adults Board 2012**: Winterbourne View Hospital, The Serious Case Review, page iv
- <sup>13</sup> see **Chenoweth and Robinson 2011**
- <sup>14</sup> see **Care Quality Commission 2012 (I)**, p31
- <sup>15</sup> see **NHS Review**, p33 - 36
- <sup>16</sup> see **NHS Review**, p33 - 36
- <sup>17</sup> see **NHS Review**
- <sup>18</sup> see **Department of Health 2012 - Winterbourne View Review Engagement**
- <sup>19</sup> see **South Gloucestershire Safeguarding Adults Board 2012**, page iv
- <sup>20</sup> **Department of Health 2012**: The Mandate. A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015. <https://www.wp.dh.gov.uk/publications/files/2012/11/mandate.pdf>
- <sup>21</sup> **Department of Health 2012 (II)**: Assessment, eligibility and portability for care users and carers, Accompanying IA for the White Paper "Caring for Our Future: reforming care and support." <http://www.dh.gov.uk/health/files/2012/07/IA-Annex-C-assessment-and-eligibility.pdf>
- <sup>22</sup> **PSSRU 2011**: Unit Costs of Health and Social Care 2011. <http://www.pssru.ac.uk/project-pages/unit-costs/2011/index.php>
- <sup>23</sup> **Local Government Association 2012 (I)**: Sector-led improvement in local government. [http://www.local.gov.uk/c/document\\_library/get\\_file?uuid=f19c68ea-368d-4be9-b1c8-7d085324436e&groupId=10171](http://www.local.gov.uk/c/document_library/get_file?uuid=f19c68ea-368d-4be9-b1c8-7d085324436e&groupId=10171)
- <sup>24</sup> **Pricewaterhouse Coopers 2011**: Joint Evaluation of the Commissioning Support Programme (CSP) and Centre for Excellence and Outcomes (C4EO) <https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR107.pdf>
- <sup>25</sup> Mansell J, Ritchie F and Dyer R: Health Service Inpatient Units for People with Intellectual Disabilities and Challenging Behaviour or Mental Health Problems. Journal of Applied Research in Intellectual Disabilities 2010, 23, 552-559.
- <sup>26</sup> **Local Government Association 2012 (II)**: Evaluation of Sector-led improvement. [http://www.local.gov.uk/web/guest/research-performance-and-improvement/-/journal\\_content/56/10171/3771375/ARTICLE-TEMPLATE](http://www.local.gov.uk/web/guest/research-performance-and-improvement/-/journal_content/56/10171/3771375/ARTICLE-TEMPLATE)
- <sup>27</sup> **Easton et al 2012**: Evaluation of the early adopter sector-led improvement programme pilots, LGA research report.
- <sup>28</sup> **Pricewaterhouse Coopers 2011**: Joint Evaluation of the Commissioning Support Programme (CSP) and Centre for Excellence and Outcomes (C4EO) <https://www.education.gov.uk/publications/eOrderingDownload/DFE-RR107.pdf>
- <sup>29</sup> **Department of Health 2008**: Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities, Sir Jonathan Michael and the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. July 2008 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099255](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255)
- <sup>30</sup> **Korne et al 2010**: Evaluation of an international benchmarking initiative in nine eye hospital, Health Care Management Review 35 (1), p23-35
- <sup>31</sup> see **Korne et al 2010**

- <sup>32</sup> see **Korne et al 2010**
- <sup>33</sup> **Hogg 2011**: Improving measurement of primary health care system performance
- <sup>34</sup> **Freeman 2002**: Use of performance indicators to improve health care quality in the public sector: a review of the literature, *Health Service Management Research*, 15(2), 126 – 137.
- <sup>35</sup> **Care Quality Commission 2011**: Count me in 2010 - Results of the 2010 national census of inpatients and patients on supervised community treatment in mental health and learning disability services in England and Wales [http://www.cqc.org.uk/sites/default/files/media/documents/count\\_me\\_in\\_2010\\_final\\_tagged.pdf](http://www.cqc.org.uk/sites/default/files/media/documents/count_me_in_2010_final_tagged.pdf)
- <sup>36</sup> see **Care Quality Commission 2011**
- <sup>37</sup> **White et al 2003**: The Identification of Environments and Culture that Promote the Abuse of People with Intellectual Disabilities: a Review of the Literature, *Journal of Applied Research in Intellectual Disabilities*, 16, p1-9; see also **Chenoweth and Robinson 2011**: Preventing abuse in accommodation services: from procedural response to protective cultures, *Journal of Intellectual Disabilities* 15(1), p63-74
- <sup>38</sup> **Carr et al 1999**, Positive Behavioural Support for People with Developmental Disabilities, A research synthesis
- <sup>39</sup> see **Chenoweth and Robinson 2011**
- <sup>40</sup> see **Chenoweth and Robinson 2011**
- <sup>41</sup> summarised in **Chowdhury and Benson 2011**, Deinstitutionalisation and Quality of Life of Individuals with Intellectual Disability: A Review of the International Literature, *Journal of Policy and Practice in Intellectual Disabilities* 8 (4), p256-265;
- <sup>42</sup> **Strnadova and Evans 2011**: Subjective Quality of Life of Women with Intellectual Disabilities: The Role of Perceived Control over their Own Life in Self-determined Behaviour, *Journal of Applied Research in Intellectual Disabilities* 25, p71–79
- <sup>43</sup> **Chenoweth and Robinson** summarise the evidence against the “against the congregation of people in groups when the routines, structures and operation of the group are determined by staff and managers”. **Chowdhury and Benson 2011** summarise the literature on the benefits of deinstitutionalisation. See: **Chenoweth and Robinson 2011**: Preventing abuse in accommodation services: from procedural response to protective cultures, *Journal of Intellectual Disabilities* 15(1), p63-74
- <sup>44</sup> **Burns, Mc Cann and Silberman 2010**: ‘It’s what happens when you’re ready to leave the hospital that’s really important’ – commissioning secure services for people with learning disabilities, *Journal of Learning Disabilities and Offending Behaviour* 1(1), p17-28.
- <sup>45</sup> The study finds an increase in reported QoL scores from 35% to 68% on the instrument used, which comprises seven domains. Note that this is not comparable with other instruments of self-reported QoL, such as the QALY. See **Sines, Hogard and Ellis 2012**, Evaluating quality of life in adults with profound learning difficulties resettled from hospital to supported living in the community, *Journal of Intellectual Disabilities*, p1-17
- <sup>46</sup> **Care Quality Commission 2012**: Learning disability services inspection programme (June 2012) p33
- <sup>47</sup> see **Care Quality Commission 2012**
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- <sup>58</sup> see **Care Quality Commission 2012 (I)**
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- <sup>62</sup> **NHS North Central London 2012**
- <sup>63</sup> **NHS North Central London 2012**
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<sup>65</sup> **NHS North Central London 2012**

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<sup>70</sup> **PSSRU 2011**

<sup>71</sup> **PSSRU 2011**

<sup>72</sup> **PSSRU 2011**

<sup>73</sup> **PSSEX1** data on the average gross weekly expenditure per person with learning disability in nursing or residential care

<sup>74</sup> **PSSEX1** data on the average gross weekly expenditure per person with learning disability in nursing or residential care

<sup>75</sup> NHS reference costs 2011/12

<sup>76</sup> NHS reference costs 2011/12