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# **Summary: Intervention and Options**

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, Measure of Two-Out?								
£3.7m	£0m	£0m	No	NA				

**RPC Opinion:** RPC Opinion Status

#### What is the problem under consideration? Why is government intervention necessary?

There is a need to improve commissioning and provision of appropriate community services for people with learning disabilities or autism who may also have a mental health condition and behaviour that can challenge services. This cohort of vulnerable people currently spend long periods of time in inpatient hospital settings far from home where they often receive poor quality care and experience poor outcomes. People and their families do not feel that they have a voice or are involved in decisions about their care and this has a significant negative impact on them. Inappropriate models of care in over restrictive settings also represents an inefficient use of public money.

# What are the policy objectives and the intended effects?

The consultation paper includes a suite of proposals to effectively involve people and their families in care; strengthen existing, and give people new, rights to be included and live independently in the community; incentivise commissioners and providers to develop appropriate models of care in less restrictive settings; and have stronger accountability for decisions at professional and organisational level. Together, these should help shape the local market of care, improve and strengthen key elements of the Mental Health Act, and develop community provision to allow people to exercise choice of independent living focusing on outcomes that matter to them.

# What policy options have been considered, including any alternatives to regulation? Please justify preferred option (further details in Evidence Base)

Do Nothing: Although the Transforming Care programme, on which the consultation proposals build on, has helped to develop new models of care and service specifications, identify and share good practice and support sector and peer led improvement in commissioning and provision of care, there has been limited success to bring transformational change to services for people with learning disabilities and behaviours that challenge services. This has not achieved the expected substantial reduction in inpatient provision, development of community provision and improved outcomes for people.

Option A) Consult on potential ways to strengthen existing regulation and statutory guidance and ways to incentivise compliance with expected models of care and quality of services.

Will the policy be reviewed? It will be reviewed. If applicable, set review date: 08/2015									
Does implementation go beyond minimum EU requirements?		Yes / No /	N/A						
Are any of these organisations in scope? If Micros not exempted set out reason in Evidence Base.	Micro Yes/No	< 20 Yes/No	Small Yes/No		<b>dium</b> s/No	Large Yes/No			
What is the $CO_2$ equivalent change in greenhouse gas emissi (Million tonnes $CO_2$ equivalent)	Traded:		Non-t	raded:					

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:	
Signed by the responsible SELECT SIGNATORT.	Dale.	

# **Summary: Analysis & Evidence**

#### **Description:**

#### **FULL ECONOMIC ASSESSMENT**

Price Base	PV Base	Time Period	Net Benefit (Present Value (PV)) (£m)					
<b>Year</b> 2015	<b>Year</b> 2015	Years 10	<b>Low:</b> £1.2m	High: £12.4m	Best Estimate: £3.7m			

COSTS (£m)	Total Tra (Constant Price)	nsition Years	Average Annual (excl. Transition) (Constant Price)	Total Cost (Present Value)
Low	n/a		£0.6m	£5.2m
High	n/a		£6.1m	£51.6m
Best Estimate	n/a		£1.8m	£15.5m

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

The key cost of moving people into a community setting is the cost of the care package they receive when outside of inpatient setting. High and low estimates are based on Group Home settings, and a more comprehensive package of Fully-Staffed living settings. At the central estimate the annual cost is £144,000 per person. There is a small cost in the setting up of, and providing information about, personal health budgets. These costs will fall upon both NHS and Social Care .

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

No other non-monetised costs are expected.

BENEFITS (£m)	<b>Total Tra</b> (Constant Price)	ansition Years	Average Annual (excl. Transition) (Constant Price)	<b>Total Benefit</b> (Present Value)
Low	n/a		£0.8m	£6.4m
High	n/a		£7.6m	£64.0m
Best Estimate	n/a		£2.3m	£19.2m

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

The key benefit of extending Personal Health Budgets to people with learning disabilities in inpatient settings is the cost saving of no longer providing care in such institutions. This is equal to a cost saving of £183,000 per year, per person. Savings are expected to accrue to Social Care but predominantly to the NHS.

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

Quality of life improvements due continuity of care and reuniting with family and social network. According to evidence, social isolation can lead to the development of later mental health problems and premature mortality.

Key assumptions/sensitivities/risks

Discount rate (%)

3.5

Take-up rate for PHBs similar as the NHS CHC cohort, and it will take three years to reach this state. PHBs will enable people to move into the community 12 months quicker than traditional care pathways. It also assumes that the cost of each individual's community care package is less than the cost of care in inpatient settings, (although this is tested in the sensitivity analysis). The savings are dependent upon funds being transferfrom inpatient to community settings

# **BUSINESS ASSESSMENT (Option 1)**

Direct impact on bus	siness (Equivalent Annu	In scope of OITO?	Measure qualifies as	
Costs: 0	Benefits: 0	Net: 0	No	NA

# Introduction

- 1. The Department of Health published the final report of its review into Winterbourne View Hospital in December 2012. The report and accompanying Concordat included actions to improve the quality and safety of care and commitments to move people inappropriately in hospital to community based placements leading to a permanent reduction in the reliance on inpatient provision. We know that many people with learning disabilities or autism who also have mental health conditions and behaviours that challenge services are still experiencing poor quality care in inappropriate settings far from their homes, families and loved ones.
- 2. In 2013, the <u>Learning Disability Census</u> identified 3,250 people in NHS or independent sector hospitals many of whom were 'out of area'. In 2014, 3,230 people were in hospital, so we have not seen the expected substantial reduction in inpatient care. Census data shows that the mean length of stay for a continuous period of care is 5.43 years and 1,165 people are in inpatient settings more than 50km from home. The average weekly cost of inpatient care is £3,426 per person (£178,152 a year). The lack of significant change in the data shows that there has not been much progress and provides the rationale for the changes we are consulting on.
- 3. Being placed at a distance from families or friends is likely to put additional strain on relationships with family members and other social contacts, thus limiting the opportunities for people with learning disabilities (LD) to integrate with their community.<sup>1</sup>
- 4. We are seeking views on the proposals in the consultation paper and our cost and benefit assumptions in this impact assessment. We aim at characterising what appropriate community provision for people with learning disabilities and challenging behaviour looks like, what appropriate community provision is already in place and how much additional investment to set up appropriate services would be required. Therefore, we welcome any feedback and additional evidence to inform the final impact assessment.

# **Problem under Consideration**

5. There are various factors both individual- and service-related that contribute to the likelihood of an individual being placed out-of-area in inpatient settings. Previously highlighted factors have included the growing population of people with LD, lack of volume of local accommodation, increasing house prices in cities, lack of competence of staff in LD services to manage complex cases, social attitudes towards people with LD and shortage of National Health Service-funded step-up and step-down provision for individuals with challenging behaviours and more severe LD<sup>2</sup>. In addition to these, there is

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<sup>1</sup> Social Care Institute for Excellence 2004; Beadle-Brown et al. 2005; Chinn et al. 2011

<sup>&</sup>lt;sup>2</sup> Mansell et al. 2006a

great regional variability in expenditure<sup>3</sup> and the provision of places made available by local authorities for individuals with LD.<sup>4 5</sup>

- 6. The Transforming Care impact assessment discussed these problems in detail, including the potential reasons that lead to many people being referred inappropriately to inpatient care when they could and should be treated in the community. In summary, the impact assessment identified underlying causes of the poor care outcomes experienced by this group of people, including: perverse incentives which may result in under-provision of appropriate alternatives to hospital services (specifically the poor commissioning of community services); and, a lack of commissioning knowledge, monitoring and information on the quality of care which may result in the continued commissioning of poor quality services.
- 7. A report by the National Audit Office published in February 2015 <sup>6</sup> investigated the challenge of discharging people with learning disabilities and challenging behaviour faced by the government by analysing how its commitments were met and the barriers to transforming care services. They do acknowledge that this is a complex process which defies short-term solutions that requires all parts of the health and social care systems work effectively together and, particularly, it requires mechanisms for systematically pooling resources to build sufficient capacity in the community for this to happen.
- 8. Social care commissioners may avoid commissioning alternative local community services for this cohort of people if they think that the people will receive NHS funded care otherwise. The costs of hospital treatment are mainly borne by the NHS, while costs of supporting people in community settings would fall on both health and social care services. Therefore, social care commissioners may have little incentive to provide stepdown or crisis intervention services.
- 9. NHS commissioners may avoid investing in community 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 inpatient block contracts;
- difficulties in measuring the impact of early intervention.
- 10. In addition, commissioners may avoid commissioning least restrictive community services for people with very complex needs out of risk aversion. Even where community provision is possible and there is capacity, commissioners might avoid commissioning such a service based on the perception that inpatient care is safer for the person and may also reduce risks to staff and the wider community.
- 11. Information problems prevent commissioners from ensuring the best possible care.
  Commissioners often lack knowledge about good quality care for this group of people. A

<sup>&</sup>lt;sup>3</sup> Forsyth & Winterbottom 2002

<sup>&</sup>lt;sup>4</sup> Emerson & Hatton 1998

<sup>&</sup>lt;sup>5</sup> Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality, D. Andrea Barron et al. 2011

http://www.nao.org.uk/report/care-services-for-people-with-learning-disabilities-and-challenging-behaviour/

lack of information about the quality of services provided reduces incentives to invest in local services to prevent inpatient admission and poor quality care.

# Lack of empowerment, monitoring and feedback

12. The poor outcomes that people experience also reflect information problems:

- The highly specialised low volume services for people with learning disabilities or autism who also have mental health conditions or behaviour that challenges may mean local commissioners may lack the knowledge and expertise required presenting the risk that they may not commission the right services for the patient.
- Individual commissioners may lack good summary information about services provided in their area. Data and information on this group of people is improving but is still inadequately co-ordinated or understood by all commissioners.
- In the NHS, financial incentives are often used to improve the outcomes of commissioning (e.g. 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.
- 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 people with learning disabilities are often not involved in the care planning process. At an extreme, abuse and poor quality care may continue, because complaints are not addressed.
- Commissioners fail to assure the quality of the care, which they have commissioned.
- There is no appropriate mechanism in place to follow through on safeguarding procedures.
- In the absence of direct user feedback and appropriate safeguarding procedures. commissioners rely on regulatory agencies to pick up poor quality of care. CQC registration and inspection reports are taken as a sign of sufficient quality. In some case, it has been be ineffective. The roles and responsibilities of regulatory agencies can also be unclear, leading to confusion and a lack of cooperation and information sharing.
- Advocacy services should empower people and their families and facilitate their involvement. Good quality advocacy can help uncover abuse and neglect. In practice, however, poor quality advocacy has been observed meaning that adverse incidents may go unnoticed. Sometimes family members, at best, only have a vague understanding of the care the service users receive. Furthermore, some of the families from minority ethnic backgrounds felt that the service users' progress was being hampered by language and cultural issues. Social isolation and exclusion have previously been identified as concerns for this group<sup>8</sup> and there is growing acknowledgement of the importance of cultural competence to improve quality of care and outcomes<sup>9</sup>. <sup>10</sup>

Question 1: Do you agree with our assessment of the problem? Are there other challenges which contribute to poor experience and outcomes? Are there examples of appropriate community provision and evidence of the costs of this provision?

Out of Area, Out of Sight: Review of Out-of-Area Placement Arrangements made by Social Services and Health for People with Learning Disabilities from the West Midlands Nicholas Goodman Jane Nix Fiona Ritchie 2006 Hubert 2006

People with Intellectual Disabilities in Out-of- Area Specialist Hospitals: What Do Families Think? Simon Bonell 2011

# **Policy Objectives**

- 13. The proposed actions, as set out in accompanying consultation document aspire to keep people as close to home as possible. This consultation seeks your views on ways to:
- Increase empowerment of people to challenge service and system decisions about them.
- Strengthen people's rights to enable them to make effective choices about being included in their communities including the right to determine where they live.
- By strengthening people's rights and choices reduce the number of people who are inappropriately in mental health hospitals and services.
- reduce the length of stay in these services for people who appropriately there.
- 14. We are consulting on proposals for a range of measures to:
- Actively involve patients and their families in their care so that commissioners and providers listen and respond to their choices and decisions.
- Strengthen people's rights to be included and live independently in the community with or close to family and friends.
- Design and develop incentives for appropriate models of care, where possible in the community and in the least restrictive setting possible.
- Strengthen accountability and responsibility at professional, management and organisational level with an emphasis on integration and joint working.

# **Costs and Benefits**

- 15. Many of the costs and benefits attributed to the proposals presented in the accompanying consultation document, have already been considered in other published impact assessments, for example, the <a href="Care Act">Care Act</a>, <a href="Mental Health Act Code of Practice">Mental Health Act Code of Practice</a> and <a href="Transforming Care">Transforming Care</a>. Furthermore, some proposals we are consulting on do not have any additional costs, or we have assumed they have negligible costs based on the evidence available to us. These are therefore not considered in this impact assessment. Appendix A sets out, for each proposal; where the costs and benefits have been covered; if costs are assumed negligible; or if there are no additional costs. We also ask questions in a number of areas where we are seeking more evidence.
- 16. Please note that the detail of what might be achieved from the 2015/16 financial year will be subject to the next Spending Review and the next Government, and therefore all details are aspirations only and do not represent agreed future policy or an explicit commitment to implementing these proposals.

# **Personal Health Budgets**

- 17. Section 6 of the consultation paper 'Securing Independence and Inclusion for all' proposes introducing a right to have a personal health budget for those with learning disabilities.
- 18. All CCGs are able to offer personal health budgets to their population if they choose to. Patients eligible for the NHS Continuing Healthcare have, since October 2014, had a 'right to have' a Personal Health Budget. Extending this 'right to have' to people with

- learning disabilities in inpatient settings would require new regulations, and careful consideration of how the eligibility criteria are defined.
- 19. Introducing a right to have a PHB for people with learning disabilities in inpatient settings will place the burden of proof on CCGs not the individual. This is likely to lead to an increase in the uptake of personal health budgets by people with learning disabilities in inpatient settings.
- 20. The consultation document considers extending the right to have a PHB to two cohorts:
  - a. People with learning disabilities who are in institutions, where there is no longer a justifiable clinical or legal reason for them to be there; or
  - b. People with learning disabilities who have mental health needs or challenging behaviour and are subject to a Care Programme Approach (CPA).
- 21. Whilst data exists on the first cohort, we cannot determine enough about the second cohort to conduct and complete and robust evaluation. The Health and Social Care Information Centre (HSCIC) have conducted analysis outside of the published datasets which shows there were 3,831 people who were in contact with both mental health and learning disability services whilst on CPA at the end of October 2014. However there is a lack of data on the care these people are receiving, what the alternative could be if using a PHB, and the costs associated with these. Therefore the following analysis only examines the impact on the first cohort those with learning disabilities who are in institutions.

**Question 2** How many people are in cohort b? What does their care package currently look like, and how might we expect to see this change if they were given a PHB?

## **Target Population**

- 22. In response to 'Transforming Care: A national response to Winterbourne View Hospital' the HSCIC undertook an audit of current services for people with challenging behaviour to take a snapshot of provision, numbers of out of area placements and lengths of stay. The annual Learning Disabilities Census is collected on 30 September and contains information about the 3,230 service users (in 2014) who were in receipt of treatment from NHS and independent Learning Disability service providers on that day.
- 23. Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information Systems (POPPI)<sup>12</sup> have estimated the total number of people with learning disabilities in England at approximately 1.0m. This shows that a very small percentage of people with learning disabilities are in inpatient settings at any one point in time (circa 0.3%).

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<sup>11</sup> https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/213215/final-report.pdf

<sup>12</sup> http://www.pansi.org.uk/ & http://www.poppi.org.uk/

- 24. Assuming this rate remains constant, and applying to the PANSI and POPPI learning disability population projections gives an average annual figure of 3400 people with learning disabilities in inpatient settings over the 10 year period.
- 25. We are aware that this figure may be an over-estimate. In the last few months NHS England have undertaken a major programme of Care and Treatment Reviews for people who were inpatients on 1 April 2014 and did not have a discharge plan and date. As at mid-January NHS England had undertaken 1,032 reviews, discharged 566 people, and were anticipating that the CTRs would continue to speed up discharges in the coming months.<sup>13</sup>
- 26. Of the 3,400 people a proportion are unable to move into a community setting, and would therefore be unlikely to benefit from a Personal Health Budget. In 2014 a number of people were recorded in the census as "need[ing] inpatient care for treatment reason" which included patients who were in ongoing inpatient care programmes, or for whom their security level could not be reduced.
- 27. This IA assumes the people who might benefit from a PHB are those who were recorded as having a Step-down or Community placement sought (430) or who were in inpatient care as a result of a residential funding dispute (10). These categories equate to 14% of the people in inpatient settings. It is assumed the same proportion applies over the 10 years, and so 14% of the identified population are included in the following analysis.

**Question 3.** Do you agree that this is the correct cohort of people to use in the analysis?

Table 1. Potential number of people in receipt of PHB

	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
LD Population (aged 18+)	1,013,000	1,021,000	1,028,000	1,035,000	1,042,000	1,050,000	1,057,000	1,065,000	1,073,000	1,080,000
People with LD in inpatient settings	3,300	3,300	3,300	3,300	3,300	3,400	3,400	3,400	3,400	3,500
Target cohort	440	450	450	450	460	460	460	470	470	470
Take - up rate	1%	2%	3%	3%	3%	3%	3%	3%	3%	3%
Number of people taking up a PHB	4	9	13	14	14	14	14	14	14	14

Please note that figures have been rounded

28. Of the people in inpatient settings not all will take up the opportunity to have a personal health budget. Evidence from the take-up of PHB for people on NHS Continuing Healthcare suggests a take-up rate of 3% would be challenging but feasible (this is tested in the sensitivity analysis). Assuming that the policy takes three years to reach a steady state we would expect to see around **14 people** taking up a PHB each year.

# **Benefits**

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<sup>&</sup>lt;sup>13</sup>http://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf

- 29. A review commissioned by the Social Care Institute for Excellence reported the following as main disadvantages associated with out-of-are placements: cost 14, effect of dislocation from family and social network, loss of continuity of care and incomplete or irregular reviews of the standards and quality of care of those services<sup>15</sup>. Of particular importance is location or the distance from family and friends. There is some evidence that these experiences in themselves may contribute to later mental health problems<sup>16</sup>, especially in situations where individuals are made even more vulnerable by experiences of deprivation and social exclusion. Furthermore, individuals with adequate social relationships have a 50% greater likelihood of survival compared to those with poor or insufficient social relationships<sup>17</sup>.
- 30. The evaluation of the national PHB pilot found that across a range of long-term conditions personal health budgets improve care-related quality of life and the psychological wellbeing of PHB holders<sup>18</sup>. In addition, the cost of their services increased at a slower rate than among people without personal health budgets. These positive findings were particularly strong for mental health, although there were no specific findings relating to learning disabilities. The pilot concluded that personal health budgets were cost-effective, and the higher the value of the personal health budgets the higher the savings. Based on this, the evaluation suggested that personal health budgets should initially be targeted at people with the greatest need.
- 31. By taking up a personal health budget, people with learning disabilities in inpatient settings are expected to have more control over their package of care. This is expected to lead to a greater proportion of them leaving inpatient settings and receiving care in the community, sooner than they would otherwise have done.
- 32. As a result of centralised inpatient services many service users are placed a considerable distance from home. In 2014 the average distance from home was 60km, which places considerable stress on both the individual and the families of the people in institutions. As a result of moving into community care we would anticipate for individuals to move closer to home, and therefore reduce this burden.
- 33. As the evaluation did not estimate the effects of personal health budgets for people with learning disabilities, the following does not assume any direct costs or benefits from this. Instead it estimates the indirect costs and benefits of the personal health budget enabling more people to move into the community, where the cost of providing care will be different to in inpatient settings.
- 34. On average, caring for a person with learning disabilities in an inpatient setting costs approximately £178,000 per annum. They remain within these settings for 5.43 years<sup>19</sup>. There is substantial variability within this, with some individuals staying for less than three

<sup>&</sup>lt;sup>14</sup> Robertson et al. 2004; Knapp et al. 2005; Mansell et al. 2006b; Allen et al. 2007

<sup>&</sup>lt;sup>15</sup> Jaydeokar & Piachaud 2004; O'Hara 2006

<sup>&</sup>lt;sup>16</sup> Mueser et al. 1998

<sup>&</sup>lt;sup>17</sup> Social Relationships and Mortality Risk: A Meta-analytic Review Julianne Holt-Lunstad 2010

<sup>&</sup>lt;sup>18</sup> Walsh, P. N., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R. L. and Moseley, C. (2010), Supported Accommodation for People With Intellectual Disabilities and Quality of Life: An Overview. Journal of Policy and Practice in Intellectual Disabilities, 7: 137-142

<sup>&</sup>lt;sup>19</sup> HSICIC; Learning Disabilities Census Report, England – 30 September 2014

months, while others remain for over ten years. We do not know how a PHB will alter the length of stay in inpatient settings, and so have assumed it will reduce by 12 months (this is tested in the sensitivity analysis).

**Question 4.** Do you agree with our assumption of a 3% take-up rate? How much quicker could people with learning disabilities move out of inpatient settings into the community if they have greater control over their package of care? What could be done alongside this to promote the use of PHBs to these individuals?

35. Reducing the length of stay by one year equates to a potential saving of £1.9m per year, or £19.2m discounted (at 3.5% per year) over ten years. Please note that this is based on an annual cost of approximately £183,000 (2015/16 figures) for people who ready to be discharged or are already delayed transfers of care.

Table 2. Potential savings associated with a reduction in length of stay

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	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
Number of people taking up a PHB	4	9	13	14	14	14	14	14	14	14
Total Benefit (£m)	0.8	1.6	2.5	2.5	2.5	2.5	2.5	2.6	2.6	2.6
Total Discounted Benefit (£m)	8.0	1.6	2.3	2.2	2.2	2.1	2.1	2.0	2.0	1.9

Please note that figures have been rounded

36. A large proportion of this saving will fall onto the NHS. However some inpatient services for people with learning disabilities are commissioned by Local Authorities. At the time of the LD census 5% of service users (for whom the commissioner was known) had their care commissioned by a Local Authority. We therefore expect this benefit to be shared between Local Authorities and NHS commissioners roughly according to this proportion.

#### Costs

- 37. As these people move into the community their care package will change, and whilst the care and costs of people in inpatient settings is known, there is a high degree of uncertainty around they type of care they would require when in the community.
- 38. We anticipate that the average package of care for people with learning disabilities in the community will not fully support the people who are currently in inpatient settings. This is an assumption that people with learning disabilities who are currently being cared for in the community are not representative of people with learning disabilities who are in inpatient settings.

**Question 5.** What type of package of care might these individuals require once in the community? Would we expect for some of these people to be eligible for NHS Continuing Healthcare when they are outside of the inpatient setting?

39. While the cost of care in the community will vary from person to person it is likely that they have a high level of need and will therefore require comprehensive packages of care. The Personal Social Services Research Unit (PSSRU) produce costings of different packages of community care for people with learning disabilities, of which the most comprehensive

- is for Fully-Staffed Residential services for people with lower levels of ability. This gives a central estimate of the cost of community provision of £144,000 per person per year<sup>20</sup>.
- 40. There will also be an administrative cost associated with setting up a personal health budget. This is not a set-up cost (as most CCGs already offer PHBs to people on NHS Continuing Healthcare) but will cover ongoing costs from providing support and information to people in receipt of a personal health budget.
- 41. Evidence from the pilot sites suggests this cost may be around £670 per person21 for people on NHS Continuing Healthcare. The average package of care for people in the pilots was £22,600<sup>22</sup>, and so the administrative cost represents around 3% of total service costs. This is assumed to be proportionate to the cost. Therefore, with an average service cost of £144,000, the administrative cost would be £4,300.
- 42. As an increasing number of people take up the offer of a personal health budget we would expect to see this cost fall, however until this is evidenced we assume a constant cost over the ten years. This implies a total cost of £148,000 per person with a personal health budget in the community per year. This is the central estimate and is tested in the sensitivity analysis.

Table 3. Potential costs associated with community care provision

	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
Number of people taking up a PHB	4	9	13	14	14	14	14	14	14	14
Total Cost (£m)	0.7	1.3	2.0	2.0	2.0	2.0	2.1	2.1	2.1	2.1
Total Discounted Cost (£m)	0.7	1.3	1.9	1.8	1.8	1.7	1.7	1.6	1.6	1.5

- 43. At the central estimate of around 14 people taking up a PHB, the total costs equates to around £1.5m a year, or £15m discounted over ten years.
- 44. Just as the benefits are shared between Local Authorities and NHS commissioners so are the costs. However as individuals are likely to have a high level of need for social care once in the community, the share of the cost on Local Authorities is likely to be higher than the share of the savings. There is currently no information available on the likely split of funding once in the community, so it is not possible to calculate the exact share of the costs by sector.

**Question 6.** What proportion of these people's needs will be met by social care once they are in a community setting?

#### **Net Benefit**

45. Based on the package of community care described above, there may be a net benefit of around £0.4m per year from extending the right to have a personal health budget to people with learning disabilities in inpatient care. Over ten years, the discounted net benefit is approximately £3.7m. The table below gives the net benefit in each year based

https://www.phbe.org.uk/index-phbe.php

<sup>&</sup>lt;sup>20</sup> http://www.pssru.ac.uk/project-pages/unit-costs/2014/

<sup>21</sup> https://www.phbe.org.uk/

on the best estimate of costs and benefits as set out above. As there is a high degree of uncertainty, **Appendix B** presents Sensitivity Analysis.

Table 4. Discounted net benefit

	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25
Total Benefit	0.8	1.6	2.3	2.2	2.2	2.1	2.1	2.0	2.0	1.9
Total Cost	0.7	1.3	1.9	1.8	1.8	1.7	1.7	1.6	1.6	1.5
Net Benefit	0.2	0.3	0.4	0.4	0.4	0.4	0.4	0.4	0.4	0.4

# **Sensitivity Analysis**

- 46. There is a high degree of uncertainty in this analysis, primarily around three key assumptions:
  - a. The cost of care in the community
  - b. The take-up rate
  - c. The reduction in length of stay in inpatient settings)
- 47. The potential costs of caring for these people in the community are based upon unit costs published by the PSSRU. It is conceivable that the cost per person may be lower than this. For example Group-Home residential services for people with learning disabilities averages £118,000 per person per year. However, there is a strong possibility that the unit costs will be greater than this, as people in inpatient settings are likely to have greater care needs than those in the community. The upper estimate is based upon the Fully-Staffed residential services (used for the central estimate) but with an additional £25,000 per annum which would cover 50% more staff than covered by package used in the central estimate.
- 48. At the lower estimate we would expect to see a discounted net benefit of £6.4m over the ten years. If the average cost in the community reaches the upper estimate of £170,000 then we would see a net benefit of £1.0m.
- 49. The take-up rates are based on feedback from the rollout of a right to have a PHB for people on NHS Continuing healthcare, from which 1% was considered feasible, 3% challenging and feasible, and 10% possible but not feasible.
- 50. At a 1% take-up rate we would expect to see a discounted net benefit of £1.2m over the ten years. If take-up reached 10% we would expect to see it rise to £12.4m.
- 51. Different lengths of stay have an equivalent effect to different uptake rates. For example, if taking up a personal health budget only reduces people's length of stay by 4 months (instead of 12 months), this has the equivalent effect of a 1% uptake rate (instead of a 3% uptake rate).

# **Monitoring & Evaluation**

52. The HSCIC publish an annual snapshot of people with learning disabilities in inpatient settings, taken on the night of the 30 September, and published in January. This data publication will be used to monitor the attainment of the policy.

Consultation Proposal	Reiteration of existing proposal / No additional cost / New cost	Questions (that we are asking specifically in this impact assessment or in the consultation document on evidence for cost and benefit of the proposals)
Improve commissioning		
Promote inclusion in the community  Reduce inpatient admissions far from home and family  Extend new Care Act LA duties on individual wellbeing to the NHS in certain specified circumstances e.g. where joint care planning requirement and people at particular risk of inpatient admission in relation to lifelong needs.  LA and NHS commissioner in determining living arrangements or longer inpatient stays to have regard for the need to ensure people remain in or close to the community that matters to them	Care Act impact assessment considered the costs and benefits of promoting an individual's wellbeing when taking steps or making decisions and concluded that it reflects current practice in local authorities.  Integrated funding and intelligent commissioning would address any potential increase in costs on local authorities. This should be seen alongside those proposals. Therefore, no additional overall cost or burden is expected.	What level of support does this cohort of people need in the community? How much would it cost for the NHS/LAs?  How far away are we from achieving appropriate community provision?  What are your views on how this might impact on LAs and the NHS?
Treatment or support closer to home and in less restrictive settings  Duty set out in statutory guidance for NHS and LAs to provide care for people as close to home as possible and in the way and setting that is least restrictive.	Transforming Care includes expectation that local areas should be doing this already. The impact assessment considers the costs and benefits of the NHS and LAs working more closely together.  Organisations are already aware of need to develop joint strategic needs assessment and joint health and wellbeing strategies at population level to be able to	Do you agree that this does not place any additional costs or burdens on LAs or the NHS?

reduce unnecessary and costly inpatient admissions	the costs of promoting diversity and quality in	such a duty on the NHS?
Ensure sufficient community provision to	The Care Act impact assessment considers	What is your view on the likely costs or burdens of
		M/legt in accounting to the
Providers of specialist inpatient services and residential care services to be either explicitly permitted to or have a duty to share confidential patient information with case managers, to support case managers to make or monitor commissioning arrangements. Should include requests from other commissioner who is also, or who will subsequently become, responsible for commissioning their care.  Ensure sufficient supply of censure sufficient	ommunity services The Care Act impact	or burdens on LAs or the NHS?  What is your view on the
Clear responsibility and accountability for physical healthcare in mental health provision  Clarify that the local CCG where a unit is located is responsible for commissioning the physical health care of anyone who is de facto resident in their geographic area because they are in an inpatient mental health setting there.  Information shared appropriately to support	Patients' physical health needs should already be being met by NHS organisations. Clarifying who is responsible for this when an individual is admitted to a hospital for mental health needs would mean distribution of costs between NHS organisations. There would not be additional costs associated with this.	Do you agree that this would not introduce additional costs for organisations?  Would such a duty impose additional costs
Statutory Code of Practice for Mental Health Act fully effective  Clarify that the Mental Health Act Code of Practice also applies to CCGs and NHS England commissioning.	Partially covered by the Code of Practice Consultation IA	Can you please tell us what are the potential costs and benefits associated with this?
	respond to the needs of individuals.  Organisations are already developing EHC plans for children and young people up to age 25.	

Building on Care Act market shaping duties for LAs, health and social care commissioners both to have to have regard for sufficient supply of community based support and treatment the market of care and support providers. The duty on local authorities is intended to codify existing practice and provide further guidance for local authorities on issues for them to consider.

Following earlier reforms local authorities already commission services from a range of providers. There may be some additional, though not significant, for local authorities that do not have existing market shaping measures.

There is also support from the £700,000 Developing Care Markets for Quality and Choice programme to help local authorities to shape local markets using local information to produce Market Positioning Statements.

There is already a general duty on CCGs to arrange services necessary to meet reasonable requirements.

Long-term we do not expect there to be additional costs. It should mean overall costs savings as people move out of expensive inpatient settings.

What level of support this cohort of people need in the community? How much would it cost for the NHS/LAs?

How far away are we from achieving appropriate community provision?

# Align financial incentives

More control and choice for individuals through personal health budgets

Right to have a personal health budget for either:

People with learning disability

Potential Costs and savings are discussed as part of this consultation IA

Questions are set as part of the main body of the IA

and/or autism who are currently in specialist inpatient care, but have been assessed as able to be supported in the community with the right package. The budget would not be used to pay for their institutional care. except in exceptional circumstances. Or People with learning disabilities who have mental health needs or challenging behaviour and are subject to Care Planning Approach whether that is in the community or institutional

# More integrated/pooled budgets across health and care

care.

Integrated budget set up with a NHS mandate requirement for a ring-fenced amount within the NHS England budget to be used for specific service integration purposes with a set of specific conditions attached in order to secure the set-up of appropriate community based care and treatment options to enable discharge and to reduce the number of future admissions.

Legal basis for pooling budgets is already well established. A number of health and social care organisations already pool budgets.

Local areas already expected to develop joint health and care plans. Purpose of this proposal would be to clarify for organisations and to enable pooling of budgets in areas where this is not already happening.

No additional cost implications, but would mean distribution of existing costs between the NHS and social care.

Do you agree that this would not mean additional costs for LAs and NHS organisations?

# Reduce unnecessary admissions in inpatient settings

# Reduce detentions under the Mental Health Act (via behavioural nudge)

Change the information required on the form for detention under the Mental Health Act to nudge clinical behaviour so have to explain why the person could not be treated in the community (not

Partly covered by Mental Health Act Code of Practice impact assessment:

 consideration of better joint working between professionals, providers and health and care commissioners. Some redistribution of costs Do you agree that this would, at worst, be cost neutral and could reduce costs?

just why they need to be detained).	<ul> <li>expected from NHS.</li> <li>costs training of staff who use the Mental Health Act. Any additional training requirement would be picked up as part of CPD or regular refresher training so no significant costs anticipated.</li> <li>Organisations updating policies, procedures and documentation. Total opportunity cost of £0.5m</li> </ul>	
Ensuring that the MHA includes or excludes people with learning disability and/or autism appropriately		What are the potential costs and benefits associated with these two options?
Either (i) Excluding learning disability and autism from the MHA;(ii) amending the definition of "mental disorder" by tightening "learning disability qualification" and adding a new "autism qualification" (iii) excluding learning disability and autism from the civil sections of the MHA but not criminal justice sections.		
Simplified Mental Health Act detention  A single gateway, or one set of criteria for detention (for both assessment and treatment) which could reinforce the least restriction principle for all patients, while providing equity.	Covered by Mental Health Act Code of Practice impact assessment:      consideration of better joint working between professionals, providers and health and care commissioners. Some redistribution of costs expected from NHS.      costs training of staff who use the Mental Health Act. Any additional training requirement would be picked up as part of CPD or regular	Do you agree that this will not raise additional costs?

refresher training so no significant costs anticipated.  Organisations updating policies, procedures and documentation. Total opportunity cost of £0.5m	
	Would this have any cost implications for the NHS or LAs?
The Code of Practice consultation IA and the Care Act IA refer to costs and savings of accessible information	Do you agree that this would not mean additional costs for LAs and NHS organisations?
Covered by Mental Health Act Code of Practice impact assessment. Anticipated costs of £0.8m over 5 years.  Professionals are already expected to involve people in decisions about their care. Could include this in regular refresher training or CPD. No significant additional cost expected.	Do you agree that asking organisations to seek and record consent will not place additional costs on them?
	no significant costs anticipated.  Organisations updating policies, procedures and documentation. Total opportunity cost of £0.5m  The Code of Practice consultation IA and the Care Act IA refer to costs and savings of accessible information  Covered by Mental Health Act Code of Practice impact assessment. Anticipated costs of £0.8m over 5 years.  Professionals are already expected to involve people in decisions about their care. Could include this in regular refresher training or CPD. No significant additional cost

for the mean and to require to		
for them and to request a		
move, transfer or discharge.	For people under the	Do you garee that this
Discharge can take place as	Mental Health Act, the	Do you agree that this proposal should not
soon as possible as it is	Code of Practice impact	mean <b>additional</b> costs?
planned from the point of admission	assessment considers	inean additional costs?
aumssion	costs associated with:	
All patients to receive		
discharge and after-care	<ul> <li>better joined up working between NHS</li> </ul>	
planning from the point when	and local authorities	
the patient is admitted to		
hospital and that CCGs and	<ul> <li>increasing transparency and</li> </ul>	
local authorities take	greater involvement of	
reasonable steps to identify	patients and carers	
appropriate after-care	<ul> <li>training of staff</li> </ul>	
services for patients well	<ul><li> training of stan</li><li> organisations</li></ul>	
before their actual discharge	updating policies,	
from hospital. Individuals and	procedures and	
their families/carers or other	documentation	
advocates should be involved	cover this proposal. No	
in this process with	additional costs are	
information provided in an	anticipated.	
accessible format.	, , , , , , , , , , , , , , , , , , ,	
	Some costs might arise	
	in expanding this	
	principle to people not	
	under the Mental Health	
	Act, although they should	
	already be subject to	
	similar discharge	
	planning.	
	It is standard practice for	
	discharge planning to	
	start from admission and	
	so no significant	
	additional costs are	
	anticipated.	
	Applying a fixed	
	timeframe in which to	
	produce a care plan may	
	increase the potential	
	cost. However, most	
	areas in practice would	
	be able to manage this	
	as part of their local processes.	
People more able to	Covered in part by the	Do you agree that this
challenge decisions about	Mental Health Act Code	will not raise additional
them taken under the	of Practice impact	costs?
Mental Health Act and	assessment	
stronger safeguards of their	consideration of the costs	
interests	and benefits of greater	

Individuals and families (or advocates) to have the right to challenge immediately on or prior to inpatient admission under the Mental Health Act if they think the AMHP has not properly taken into account the patient's wishes and feelings in the pre-application interview.

involvement of patients and carers and the use of least restrictive practices.

Any additional costs would be considered as part of further consultation on how this could be applied. At this stage, we do not expect that this would have any impact on costs of providing mental health services.

However, we would need to clarify the proportion of people who would be eligible for S117 aftercare. Our commitment to further consultation includes a full cost assessment when the proposal is more specific and defined.

# Self-advocates actively engaged in the governance of providers

To boost the role of self and family advocates in the system we propose that guidance should set out that providers of learning disability or autism services should include people with learning disabilities or autism and families directly in governance, for example, on the Boards of the organisation.

# Better access to advocacy in inpatient mental health settings for people who lack capacity

Increasing uptake of Independent Mental Health Advocates by making the service opt-out rather than opt-in for people who lack capacity.

The Care Act impact assessment considers the costs and benefits of independent advocacy in detail. A large proportion of the people considered as part of that will include those with learning disabilities and autism. Therefore, no significant additional costs are expected.

Issuing guidance or formalising arrangements through contracts would ensure that advocacy is provided.

There could be costs of employing learning disabled people in organisations. These would be offset by savings in benefits payments to those who would otherwise be unemployed. CQC is

Do you have any information or evidence on whether these proposals would mean additional costs or benefits to LAs or NHS organisations?

	already looking at employing customers in assessing whether organisations are well led.  There may be some costs of ensuring advocates understand complex needs.	
Ensure people's "nearest	This is covered partially	Do you have any views
relative" under the Mental Health Act is someone who	by the Mental Health Act Code of Practice impact	on whether this would mean <b>additional</b> costs
is meaningful to them	assessment	or lead to savings?
3	consideration of greater	5
People to be able to choose	involvement of family	Do you agree that this
their own "nearest relative"	carers. Costs are unlikely	should <b>reduce</b> the cost
(who has specific legal responsibilities/duties/powers)	to be significant. Also, benefits of greater	of displacement and disputes?
under the Mental Health Act.	involvement could mean	dioputes:
Current hierarchical list	fewer legal challenges	
remains as default if	and lower tribunal costs.	
necessary only.	Costs of tracing nearest	
	relative currently can be	
	quite high. This could	
	therefore achieve some	
	cost savings if implemented properly.	
	Risks of costs increase if	
	there are disputes about	
	people's choices. There	
	are also potential Mental Capacity Act costs if	
	there is a need to make	
	additional decisions on	
	capacity to determine the	
	nearest relative. This proposal needs to be	
	looked at in the context of	
	those related issues.	
Ensure people have a	Covered in part by	Do you have any views
named social worker with clear responsibilities	consideration in the Mental Health Act Code	on whether this would mean <b>additional</b> costs
Cieai responsibilities	of Practice impact	for LAs?
Responsible, named social	assessment of costs and	
worker to ensure that the	benefits of:	
individual plan is based on the least restrictive, least	Retter joint working	
institutional setting and to	Better joint working between	
have a primary professional	professionals, NHS	
responsibility to ensure that	and local authority	
non-residential or community	commissioners and	
based options have been fully	providers	

considered. Also responsible for ensuring a co-productive approach with individuals and their families in agreeing their care and support arrangements and ensuring they are kept informed and involved. People have right to choose someone else to carry out this role if they want to.

- Increasing transparency and accountability and greater involvement of patients and families.
- Training of staff who use the Mental Health Act.
- Reviewing and revising existing policies to reduce restrictive practices.
- Organisations reviewing and updating policies, procedures and practices.

Would build on social workers existing case work so no additional recruitment costs anticipated.