



Department  
of Health

Government response to No  
voice unheard, no right ignored  
– a consultation for people with  
learning disabilities, autism and  
mental health conditions





# Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions

Presented to Parliament  
by the Secretary of State for Health  
by Command of Her Majesty

November 2015



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# Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions

## Ministerial foreword

Our vision of a civilised society is one in which we take more responsibility for ourselves and our neighbours as part of thriving communities working together, and with less dependence on remote bureaucracies. One area where we are still not making enough progress to realise our vision is for those with learning disabilities, autism and mental ill health.

All too often the rights of people with learning disabilities or autism or mental health conditions have not been respected fully. I recognise that since the previous Government's response to what happened at Winterbourne View, there have been some improvements, but they've not gone far enough or been made fast enough.

The consultation – *No voice unheard, no right ignored* – looked at how to strengthen these rights, focusing on how people can live independently in their communities and make choices in their lives. Many of the responses we received were about the fundamentals of how to treat people, how to involve them, and how to enable people to challenge decisions in the system. It is clear that, as well as suggestion of more challenging and aspirational ideas, there was also an emphasis on getting the basics right. That is why you will find that this response is phased so that we can make progress urgently by building on existing momentum and implementing change quickly as well as setting out a longer term plan that will

tackle some of the most difficult and complex challenges. The package of proposals we set out here is intended to enable system-wide changes that make it easier to do the right thing for people and their families.

With both our early and longer term proposals we are working to ensure that people have high quality care and support in a range of community settings so that they can live in a home of their choice with the care and support they need. For those who need care in hospital we want to ensure that they also receive high quality care.

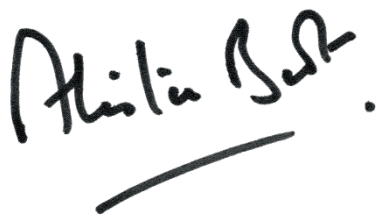
To do this, we need to be much better at making sure people with learning disabilities are properly assessed and that any physical or mental health conditions they have are identified and properly treated. This means more of a focus on integrated and personalised care and support, for people with a learning disability and also for those with autism.

Our aim is that people lead as fulfilling and independent lives as they can, and that they have the support to live independently when possible. This requires a step change. Services, and wider society, should first and foremost see the person and their potential. This means a profound shift from focussing on what people can't do – to enabling and supporting what they can. For some people, being in employment will be a key indicator of success.

Many people and organisations at all levels have key parts to play in making our vision

happen. At the local level, Health and Wellbeing Boards need to ensure they have good plans to tackle the challenges ahead. I appreciate your engagement, and look forward to your continued efforts and support in helping improve the lives of the most vulnerable among us.

We expect to see a significant change in the experience of care and in outcomes for people with learning disabilities, autism and mental health conditions between now and 2020. As a country, a key measure of our success will be how we care for the weakest and most vulnerable in our communities. I want to thank all of the people who use services, carers, professionals and advocates who responded to the consultation, and I would wish to encourage you to continue to hold me and our system to account for making more progress using the proposals in this response.

A handwritten signature in black ink that reads "Alistair Burt." The signature is written in a cursive style and is underlined with a single horizontal stroke.

**Rt Hon Alistair Burt MP**  
**Minister of State for Community and Social Care**





## Introduction

1. *No voice unheard, no right ignored: a consultation for people with learning disabilities, autism and mental health conditions* was presented by the previous (coalition) Government because not enough progress had been made to transform their care – principally to relocate them from inpatient units to community-based care – as promised in the wake of the Winterbourne View scandal. Reducing inpatient numbers, and reliance on inpatient care, remains a key goal of the revitalised Transforming Care Programme for system-wide change shared by NHS England, Local Government Association (LGA), Association of Directors of Adult Social Services (ADASS), Care Quality Commission (CQC), Health Education England and the Department of Health.

2. The consultation recognised stark variability in commissioning approaches and in resulting outcomes across the country. This reflected the fact that some commissioners have failed to grasp and act on the urgency of putting in place suitable community provision. Too many have not changed their behaviour, in part because the system is not set up to make it easy for them to do so or to make it hard for them *not* to do so. As well as the impact on individuals and their families, this represents a failure to act on strategic imperatives to plan, design and deliver the right services now. These imperatives include:

- growing evidence that, over time, the right care and support in the community can reduce the incidence of behaviour that challenges services and, in turn, reduce costs to the NHS and other parts of the public sector, such as the criminal justice system, and
- increasing demand – by 2030 the number of adults aged 70+ with learning disabilities using social care (and also

very likely to be using health services) is expected to double.

3. The consultation accordingly set out to explore views on a range of proposals intended to strengthen or build upon existing policies, and sought views on those likely to have most impact. It posed 50 questions primarily related to:

- assessment in mental health hospitals for people (all age) with learning disability or autism
- adult care and support, primarily for those with learning disability but also for adults with autism (and the links to support for children and young people), and
- all those to whom the Mental Health Act 1983 currently applies (including children and young people).

## What we propose

4. The Government has listened to the views expressed in response to the consultation. We agree there is a need for further action to realise the vision of everyone being treated with dignity and respect by health and care services and enjoying the same rights as everyone else.

5. Our proposals are set out below, and comprise a number of phases of activity. The overall aim is to make sure that the rights, incentives, responsibilities and duties in the system ensure that change is delivered everywhere. The expectation and focus will be on delivering better outcomes for individuals and families, alongside greater efficiency and value for the taxpayer.

6. The proposed actions are clustered into three implementation phases, namely:

- early actions that seek to sustain momentum generated, chiefly through the

use of existing powers and building on work currently underway

- further changes, including proposed legislative changes that cannot be achieved via existing powers (and which relate principally to the Mental Health Act 1983), and
- a third phase, which explores more radical solutions to longer-term issues, as well as ongoing monitoring and review, and a commitment that the Government will intervene further, including through legislation if necessary, if the improvements sought continue not to be realised in practice.

7. These proposals for action are put forward in the context of, and are subject to, the Government's comprehensive spending review. They are not intended to be the final word on initiatives to improve the life chances of vulnerable people, and should be seen as part of an ongoing and evolving dialogue. Some of the measures proposed will need further consultation, and some relevant proposals are already being consulted on.<sup>1</sup> We will continue to engage with stakeholders and those with expertise by lived experience in a spirit of co-production as we take these proposals forward.

8. Several of the proposals relate to giving guidance. The Secretary of State and some statutory agencies have a range of powers in statute to give guidance including wide-ranging general powers as well as specific powers to give guidance in relation to specific duties. These are likely to give options as to how to achieve the desired effect. In each case, we will rapidly determine the most appropriate powers under which to act to have the best and strongest effect, taking account of practical issues such as planning cycles for local services.

9. The three implementation phases are not intended to be rigidly sequential. Exploratory and preparatory work on actions which feature in later phases can begin concurrently with actions in earlier phases. Similarly, actions undertaken in earlier phases will be kept under review to inform later actions.

#### *Transforming Care*

10. Under the aegis of the Transforming Care Programme, and building on the previous Government and NHS England's commitments to significantly reduce the use of inpatient hospital care to support people with learning disabilities, autism and mental health conditions, a range of important initiatives are underway. These include:

- Care and Treatment Reviews (CTRs), which aim to reduce unnecessary admissions and lengthy stays in specialist hospitals, and have been rolling out since October 2014; by mid-September this year, over 2,020 CTRs had been completed. CTRs bring around the same table those responsible for the care of people who are in, or are at risk of being admitted to, specialist hospitals, with those individuals themselves and their families, and independent clinicians and experts by experience, in order to ensure that people's individual care needs are being met. CTRs are being embedded as business as usual from September this year
- a service model for commissioners of health and social care services, *Supporting people with a learning disability and/or autism who have a mental health condition or display behaviour that challenges*, along with extra support for local areas to draw up plans to transform services, spearheaded by six 'Fast Track' areas

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<sup>1</sup> <http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/#mental-capacity-and-deprivation-of-liberty-consultation>

- work on improving the quality of data for the Transforming Care cohort. Since February 2015, data about inpatients (the Assuring Transformation Data Set) has been collected by the Health & Social Care Information Centre on a live Clinical Audit Platform. Data is now published monthly and quarterly, and includes inpatient numbers; admissions, transfers and discharges; age, gender and ethnicity; discharge planning; and length of stay. Work continues to refine these figures, using local areas' own data, an annual Census collected by providers, and the Mental Health & Learning Disability Data Set. From January 2016, the new national Mental Health Services Data Set will provide richer data about the cohort
- further work on issues such as developing the workforce we need to realise sustained change; and on funding flows, including work to expand the local offer of personal health budgets and integrated personal budgets to give more choice and control over support services, and
- continued work with key partners such as Mencap and the Challenging Behaviour Foundation, and with self-advocates and families, to understand the concerns of people with learning disabilities and their families and to support the development of resources to enable them to exercise their rights.

11. Across the system, work is also continuing to reduce practices of physical restraint, whilst the need for urgent action to prevent the inappropriate use of medication has been clearly highlighted in several recent reports.<sup>2</sup>

12. NHS England, the LGA, and ADASS have set out plans for the next steps in

this transformation programme.<sup>3</sup> These are centred on planning assumptions which will result in a reduction in total inpatient numbers nationally of 35 to 50 per cent by the end of 2018/19 (from around 2,600 to around 1,300 to 1,700). These plans include a new service model that is designed to increase the opportunities for people to be cared for in the community in which they want to live and make meaningful choices about their care and support, and to reduce the reliance on inpatient beds.

13. At a national level, this work will continue to be overseen by the Transforming Care Assurance Board. Many of the proposals in response to the consultation are intended to build on and augment this work, to achieve faster and more comprehensive change. In some instances, the Government proposes to take the learning from Transforming Care initiatives and consider actions to benefit a wider cohort of people, recognising the pervasive impact of poorer life chances and outcomes – including premature mortality – for people with learning disabilities and/or autism.

## A phased approach

14. Informed by responses to the consultation, the Government intends to take forward the following:

### Implementation Phase 1

*Early actions that seek to sustain momentum generated, chiefly through the use of existing powers and building on work currently underway:*

- **guidance for commissioners of health and social care services on:**
  - **promoting wellbeing, and factors to take into account when considering living arrangements, including**

<sup>2</sup> <https://www.england.nhs.uk/2015/07/14/urgent-pledge/>

<sup>3</sup> <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

how to support people to live independently, in the community and respecting their wishes and desires

- involving people with learning disabilities/autism/mental health problems in the design, development and delivery of services
  - exercise of Care Act 2014 local 'market-shaping' duties to further aid the development of a diverse market of community-based provision, and
  - the need to ensure sufficiency of supply of community-based provision
  - responsibilities for ensuring physical healthcare needs are met alongside mental health needs
  - pilot access to a named social worker who will provide professional advice and support, be the primary point of contact for the service user and their family/carers wherever the person is being supported, and provide a professional voice across the system
  - amend Mental Health Act regulations to change the information required on admission so that Approved Mental Health Professionals have to consider and record whether assessment and treatment could be provided without detention in hospital
  - strengthen work being undertaken as part of the Transforming Care Programme's 'empowering people' workstream and/or the Department's strategic partner programme to:
    - build on the new accessible information standard to ensure that people receive information in formats that they can understand, and that they receive appropriate support to help them to communicate
- build on the proposal of a (non-statutory) 'Charter of Rights' to provide definitive and accessible information on their rights, and how to access support to exercise them, and promote use of advance statements
  - work with NHS England and the Local Government Association to develop guidance and tools (e.g. consent templates) to ensure information is shared legitimately and in accordance with professional standards and good practice, and
  - consider what further actions are required to embed solutions to generic data governance issues, especially where data sharing is currently impeded in relation to the care of people with learning disabilities, autism and mental health conditions, where this would meet aims of good commissioning practice and improved patient care
  - review data available for local and national transparency and accountability with metrics including:
    - delayed discharges
    - personal budgets/integrated budgets
    - integrated personal commissioning
  - recognising the issues for people with learning disabilities, autism and mental health conditions in the criminal justice system:
    - an end to the use of police cells as a place of safety for children and young people detained under sections 135 or 136 of the Mental Health Act 1983

- no one detained under sections 135 or 136 to be held in a ‘place of safety’ for more than 24 hours without being assessed by a relevant professional and either discharged or admitted (this and the above to be achieved via the Policing & Criminal Justice Bill together with other changes resulting from the review of sections 135/136)

15. We intend to take forward the above actions during the current financial year (2015/16) and into 2016/17.

### Implementation Phase 2

*Further changes, including proposed legislative changes that cannot be achieved via existing powers:*

- consider how CTR principles/ processes can (i) be extended to local authority-led and other placements and (ii) be strengthened, including if necessary by statutory force
- consider how learning from implementation of CTRs can inform the Care Programme Approach (CPA), and whether this guidance could helpfully be updated/expanded
- (subject to successful pilot) roll-out access to a named social worker who will provide professional advice and support, be the primary point of contact for the service user and their family/carers wherever the person is being supported, and provide a professional voice across the system
- subject to further consultation, make changes to the Mental Health Act 1983:
  - enabling patients and families to challenge whether their wishes and feelings were appropriately considered when making applications for detention
- amending provisions regarding “nearest relative” to ensure this meets the wishes and needs of people subject to the Act
- making the Mental Health Act Code of Practice statutory guidance for NHS commissioners as it is for professionals, local authorities and providers
- clarify responsibility to ensure physical care needs are met for mental health inpatients/ detained patients to ensure the individual is registered with a general practitioner and is able to benefit from programmes such as individual health checks, screening tests and health action plans.
- review safeguards regarding renewals of detention (e.g. expansion of requirement for an independent second doctor’s opinion)
- propose amending the Act to make provisions about the discharge of patients to community placements amounting to a deprivation of liberty
- (subject to the Law Commission’s consultation in the context of Deprivation of Liberty safeguards) consider introduction of a single advocacy model bringing together existing statutory schemes (including Independent Mental Health Advocates and Independent Mental Capacity Advocates) and to providing these on an opt-out (rather than opt-in) basis for patients who lack capacity.

16. This phase will involve further consultation with stakeholders, with any resulting legislation to be introduced as soon as parliamentary time allows.

### Implementation Phase 3

*Explore more radical solutions to longer-term issues, including ongoing monitoring and review, and a commitment that the Government will intervene further, including through legislation if necessary, if the improvements sought continue not to be realised in practice:*

- **monitor implementation of the new service model for commissioners of health and social care services, and of CTRs on care planning, admissions, transfers and discharges and consider the need for further legislative proposals in response to review of impact**
- **further consideration in principle of whether and how the Mental Health Act should apply to people with learning disabilities and/or autism and if this remains appropriate.**

17. This phase is ongoing, with the transformation of the system being kept under review, including reviewing the impact of implementation of measures proposed under phase 1. We will take a decision on further intervention in due course, using a basket of key indicators tracking progress on important issues such as personalisation, the right care in the right place, and support for independent living. We are developing a dashboard of key metrics as part of the work of the National Learning Disability Board, and will ensure this enables progress to be monitored to inform future decisions on further intervention.

18. Any proposals that would significantly alter the scope of the Mental Health Act would need very careful consideration and consultation.

### *The package of proposals*

19. The Government believes that the combined package of proposed measures will work together to drive the required scale and pace of changes envisaged, improve outcomes for individuals and their families, and deliver greater efficiencies for the system, so that people are more regularly treated at home or in the community, where people tell us they want to be, rather than in hospital. We appreciate there will always be a small number of people who need care and support in hospital, especially in crisis situations, but we would expect that this will be for no longer than clinically necessary, and wherever possible located closer to where the individual lives or wishes to be.

20. We consider legislative and non-legislative proposals to be mutually reinforcing. Whilst some proposals require legislative changes, others will work within the existing system. Some actions are possible now within existing systems and processes, and will enable faster progress. Others, because they will require new legislation or further development – or rely on wider actions such as workforce development – will take longer.

21. The rationale for the proposals listed above, and further information on their intended impact, is set out in the following sections, which draw on what we heard as part of the consultation exercise.

22. These proposals for the most part apply to England, but as the Mental Health Act applies across England and Wales, changes to the law in Wales would have to be agreed by the National Assembly for Wales.

## What we heard during the consultation and what we propose

23. *No voice unheard, no right ignored: a consultation for people with learning disabilities, autism and mental health conditions* stated the clear vision that all disabled people, including those with learning disability, autism or mental health conditions, have a right to lead their life like everyone else, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same rights as others, and all services should first and foremost see the person and their potential.

24. It recognised that a lot has been done to advance towards this vision. This includes a renewed and refreshed Autism Strategy; the Children and Families Act 2014 and the Care Act 2014, which set an important new legal framework of support from an early age right into adulthood; and the Care Quality Commission's transformation of the way it inspects mental health and learning disability services. However, despite all of this, the scale and pace of changes for individuals and their families that we all wanted to see has not yet happened, especially for those with 'hidden impairments' such as learning disabilities, autism and mental health conditions.

25. The consultation was aimed at accelerating progress to achieve four things, namely:

- people in charge, supported by family and friends
- inclusion and independence in the community
- the right care in the right place, and

- very clear accountability and responsibility throughout the system.

26. Respondents were clear that whilst many rights do exist for people with learning disabilities, autism and mental health conditions, these are not universally understood and individuals are not supported and enabled to exercise these effectively. These include both well-established rights, such as those under the Human Rights Act 1998, Mental Health Act 1983 and Equality Act 2010, and more recently introduced rights under the Care Act 2014 and the Children and Families Act 2014. The consultation put forward a range of ideas to address these concerns, improve practice locally, strengthen existing safeguards and ensure that mechanisms worked effectively.

27. This response sets out proposals to sustain the momentum generated by embedding changes achieved, for example, as a result of the Care Act, current and planned initiatives under the Transforming Care Programme, and proposals for further change that may take longer to achieve. This includes legislative proposals where we do not think the required change is possible within the current system or where stakeholders do not have confidence that existing arrangements will deliver the required changes, especially during a period of fiscal restraint. In these areas there may be an argument that further legislation is needed, and the Government will consider intervening further if the expected scale and pace of change is still not delivered on the ground. Some issues will need further consideration before determining the best approach.

### How will things be different?

28. The proposals in this document, coupled with the substantial programmes of work being put in place by key national agencies and system delivery partners, aim to deliver significant progress starting now,

making real differences between now and 2020 so that people should:

- expect to be supported to live independently as part of a community and in a home they have chosen
- know their views will be listened to and be able to challenge decisions about them and about their care
- have clearly stipulated rights within the Mental Health Act
- be able to exercise control over the support they receive with a personal budget, and expect that different health and local services will organise themselves around their needs, and
- know that professionals are looking out for their physical health needs as well as their mental health needs.

29. In short, people should expect to enjoy as good a life as any other member of the community, with an end to institutional care by default.

30. This is one part of a bigger journey. Although prompted initially by events at Winterbourne View, we also know that many people with learning disabilities who are not in hospitals or residential care also do not feel they have enough choice and control over their own lives and in how they are supported and enabled to live independently.

31. We think it is right to focus initially on the people who need most help, but at the same time to consider and seize opportunities to tackle wide systemic issues, and to spread the learning to benefit the wider population of people needing help and support. This is expected to yield benefits in terms of preventing people becoming ‘at risk’ of admission as well as helping them to lead fulfilling and independent lives.

32. We intend that this will mark a step change, and help to secure the rights for

*everyone* that they deserve. We also intend this to strengthen further the drive for parity of esteem for all those with mental health conditions.

### *Children and Young People*

33. Children and young people with learning disabilities, autism and mental health conditions and their families are equally impacted by these issues, and it is important that they too are given the opportunity to be fully included in decisions about how and where their care is delivered. The Transforming Care Programme acknowledges this, and children and young people are included in both NHS England’s Care and Treatment Reviews and its service model of care for people with a learning disability and/or autism who have a mental health condition or display behaviour that challenges. In addition, in the work we will take forward in relation to the Mental Health Act and in ensuring individuals and their families know their rights, we will also ensure that where appropriate the guidance we produce includes children and young people.

34. However, as identified by a number of stakeholders who responded to the consultation, children and young people have specific needs, and the landscape in which they receive services is very different to that of adults. The new arrangements for children with special educational needs and disabilities (SEND) introduced by the Children and Families Act 2014 will help to ensure that children, young people and their families are involved fully in decisions about the care and education services that are available to them. The requirements for integrated working will provide, on a local level, a framework to support the adequate provision of community care through the development of the local offer. On an individual level the arrangements provide a framework for joined-up person-centred care that is outcomes-focused,



supports early intervention and effective transition and is developed with the input of children and their families. This framework will involve children's and adult services working together.

35. These new provisions have only recently been introduced. It will take time for the long term benefits of the new system to materialise, and this is acknowledged by both Ofsted and CQC, who are planning to pilot joint inspections of local commissioning arrangements.

36. We are also taking further steps which address specific issues raised in response to the consultation. Local authorities are considering Education Health and Care plans for children and young people in Assessment and Treatment Units and 52 weeks residential placements. We are seeking to improve the information we hold through the development of the Maternity and Children's Data Set, which will provide comparative, mother and child-centric data that will be used to improve clinical quality and service efficiency, and to commission services in a way that improves health and reduces inequalities. In addition we are investing £1.25 billion in the next five years to improve children and young people's mental health services, and have committed to developing guidance on minimising the use of restrictive practices on children and young people in healthcare settings.

I expect to be supported to live independently as part of a community and in a home I have chosen

37. The consultation posed questions to do with supporting people to live independently, at home or in the community, rather than in inpatient settings. To achieve this, care needs to be provided out of hospital, and the amount of good quality, locally available community-based provision, together with stable and appropriate housing, needs to increase.

38. Some people may still need to go into hospital (e.g. to support them when they are in crisis), but that this should be in far smaller numbers, for the shortest possible duration, in the least restrictive setting, and as close as possible to home taking into account the wishes of individuals about where people live and how they are supported. This includes for individuals subject to the Mental Health Act. Equally, the system needs to be geared to supporting people so that they do not enter crisis and become at risk of admission in the first place.

39. Under this heading, the consultation considered four main and interrelated issues: how best to promote people's wellbeing; what should be considered in determining living arrangements and how this should occur; how to ensure sufficient community provision; and the role of professionals in making decisions about whether to admit someone to hospital under the Mental Health Act.

### What we heard

40. It was clear from responses to the consultation that enabling people to live independently was a key priority, especially for individuals, their families and carers. There

was generally strong support for all four issues consulted on. Provision of good quality community-based solutions and choice in what was available locally was considered a prime driver in delivering the required changes and improving the lives of people affected. Concerns were raised about the community services available, both what was available and its quality.

### *Promoting wellbeing and inclusion in the community*

41. There was strong support for proposals about NHS commissioners sharing duties to promote individual wellbeing in the Care Act 2014 with local authorities. We agree it is important that both the NHS and local authorities promote the wellbeing of all citizens in their localities. Taking into account wider social determinants of health and care, including housing and employment, will enable people to live independent and more fulfilling lives and reduce the likelihood of admission to hospital.

42. Preparing for adulthood is an essential element of the new arrangements for children and young people with special educational needs and disability, to support the transition from education to employment for 16-25s, and from the outset improve the likelihood of these young adults finding a job, through programmes such as Supported Internships.<sup>4</sup>

43. Local authorities and clinical commissioning groups (CCGs) should be working together and planning for supporting the transition to adulthood, through Education and Health Care (EHC) plans, identifying

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<sup>4</sup> Supported Internships are a structured study programme based primarily at an employer. They enable young people aged 16-24 with a statement of special educational needs, an Learning Difficulty Assessment or an EHC plan to achieve sustainable paid employment by equipping them with the skills they need for work, through learning in the workplace.

pathways into employment, independent living, participation in society and good health. The published Local Offer must include support in preparing for adulthood.

44. Since September 2013, all post-16 providers are expected to offer all students a study programme that is coherent, appropriately challenging, and supports the progression of the individual. Study plans are based on a young person's prior attainment and designed to meet clear educational and career aspirations. Post-16 providers which offer courses that are designed to provide pathways to employment should have a clear focus on preparing students with SEND for work. This includes identifying the skills that employers value, and helping young people to develop them.

45. Proposals on promoting inclusion in the community were favourably received, particularly with regard to ensuring that community inclusion was considered in determining living arrangements, both in the community and in hospital. People agreed this would help ensure that non-clinical factors were considered in reaching decisions about where people received care and support, and help maintain contact with family and friends and promote independence, ensuring solutions met people's wishes.

46. The current system already allows holistic considerations to be taken into account, yet it was reported that professionals did not routinely do this. Further action was needed to ensure this happened, and that NHS commissioners and local authorities worked together to do this. On both taking account of wellbeing, and ensuring that community inclusion is taken into account in determining living arrangements, we propose to give guidance to commissioners of health and social care services.

47. In addition, the Department of Health is in the process of commissioning a strategic research initiative to evaluate and inform implementation of the Care Act 2014. We want research that can help us to know more about how the Act is being implemented locally, and how effectively it is achieving its underlying aims. We would also like to know what lessons can be derived as to what works in implementation, to help drive up performance, quality and choice nationally. We will ensure that this includes improving care for those with learning disabilities, autism and mental health conditions.

#### *Sufficient community provision*

48. Ensuring sufficient community provision was seen as both a major enabler and a major risk to supporting people to live independently and in the community. Respondents were clear that one of the most significant challenges to supporting people to live in the community was the lack of available community services in some areas. If people are to be given good quality local choices, a more diverse provider market with a range of options and choices needs to be enabled and that this needs to be sustainable.

49. The market-shaping duty in the Care Act to promote an efficient and effective market for adult social care and support and the Community Right to Challenge to enable staff, voluntary and community sector organisations and parish councils to challenge commissioning decisions in the Localism Act 2011 were generally appreciated as key ways of diversifying adult social care markets. We received mixed feedback about the potential benefits of extending these provisions to the NHS. A number of significant concerns were raised, given the different nature and funding of the NHS-funded provider market. Many respondents replied that the new arrangements under the

Care Act needed sufficient time to bed in before further change was considered.

50. Since this consultation was launched there have been significant developments such as the joint NHS England, Local Government Association and Association of Directors of Adult Social Services' stakeholder engagement on the new service model and NHS England's commitment to decommission inpatient facilities and close beds. Taking account of these new developments, we propose statutory guidance on exercise of Care Act 2014 local 'market-shaping' duties to further aid the development of a diverse market of community-based provision. In framing that guidance we will explore further how we can give effect to the need to ensure sufficiency of supply of community-based provision.

*Assessment for detention and treatment under the Mental Health Act 1983*

51. Regulations set out what information is required in approving applications for detention under the Mental Health Act. The majority of respondents supported the idea of changing the information required in the secondary legislation and for this to be documented. Whilst the default was already that alternatives to detention should be considered, and that people should be supported in the least restrictive setting, we know that this does not always happen. Individuals, their families and carers were particularly supportive of these ideas, considering them key to ensuring alternatives were considered and their wishes taken into account. Requiring this to be recorded would improve transparency and accountability. Many professionals and professional organisations also agreed that it was important clinicians explain why they felt an individual could not be treated in the community, not just why they needed to be

detained. They saw this as a helpful shift in presumptions.

### **What we propose**

52. In response, we propose the following actions:

- **guidance for commissioners of health and social care services on:**
  - **promoting wellbeing, and factors to take into account when considering living arrangements, including how to support people to live independently, in the community and respecting their wishes and desires**
  - **exercise of Care Act 2014 local 'market-shaping' duties to further aid the development of a diverse market of community-based provision, and**
  - **the need to ensure sufficiency of supply of community-based provision**
- **amend Mental Health Act regulations to change the information required on admission so that Approved Mental Health Professionals have to consider and record whether assessment and treatment could be provided without detention in hospital.**

I know my views will be listened to and I am able to challenge decisions about me and about my care

53. A range of consultation questions were designed to explore issues related to involving the individual, and as appropriate their family, carer or advocate in decisions that affect them and to ensure that decisions reflect their needs, wants and aspirations. Questions focused on what rights people have and should have and how they could be enabled to exercise them, including what could be done when they disagreed with a decision made by professionals or if something went wrong.

### What we heard

54. We know from individuals, their families, friends and supporters, that being involved, listened to and empowered to participate fully in decisions about their care and support were viewed as key ways of effecting change and delivering the outcomes that people want. We also know that people feel strongly that knowing whom to speak to and when is important, with clear accountability for their care and support.

55. Themes from responses focused on:

- the need for high quality and accessible information and advocacy
- the importance of a clear and transparent process for admissions to hospital and to be able to challenge at key points
- having a single professional who champions the individual's rights, provides professional challenge, and is a point of contact wherever an individual is supported

- involving those with lived experience in commissioning decisions, governance and oversight, and
- ensuring people subject to the Mental Health Act are effectively supported.

### *Information, advocacy and support*

56. Responses were clear that individuals, families, carers and advocates needed to be empowered to effectively have choice and control and be involved in all decisions, including individuals subject to the Mental Health Act. Respondents considered that whilst many rights already existed, in practice they were not universally applied. This often resulted in people not receiving good quality care and support in line with their wishes and needs.

57. Feedback also acknowledged that there was already much good work in progress to meet the new accessible Information Standard. Since June this year, all health and social care organisations are required by law to follow an accessible information standard to ensure that people with a disability receive information in formats that they can understand, and that they receive appropriate support to help them to communicate. The Transforming Care Programme will enable people to be confident that they have information in a format they can understand and have access to independent advocacy and support to enable them to make decisions about their care and support.

58. We heard how important advocacy is to people and about the need for this to be independent, as well as problems with how statutory advocacy currently operates. As the consultation document set out, statutory advocacy provision commissioned by the local authority can work effectively hand-in-hand with self-advocacy, community advocacy and peer support, and a culture where self-advocacy is valued and supported

should flow through the entire system. Self-advocates and their families are critical both in drawing up plans and in monitoring their effectiveness, and local structures and local partnerships to facilitate this are very important.

59. There was support for exploring more radical and potentially more efficient and cost-effective proposals. Since this consultation ended, the Law Commission has undertaken a separate consultation on the Mental Capacity Act 2007 and Deprivation of Liberty Safeguards. This considered a range of issues related to the effective provision of independent advocacy services for vulnerable people, and included a proposal to rationalise existing independent advocacy provisions under the Mental Health Act, Mental Capacity Act and Care Act. It expects to publish a final report with its recommendations and a draft Bill in 2016. We are working with the Law Commission to ensure a consistent approach to these issues.

#### *Admission to hospital, transfers and discharge*

60. Consultation responses reconfirmed concerns about the numbers of people with learning disabilities, autism and mental health conditions being admitted to hospital, often a long way from their home or family and friends, and against their wishes, and the negative impacts this can have. We heard about delays in transfers (e.g. as part of a step-down programme), and the impact this has on people and the costs to the system. We are clear that it is not acceptable for people to be cared for in places where they do not wish to be, especially long-term, and that culture and practice in this area has to change.

61. A significant development has been implementation of CTRs to reduce unnecessary admissions and lengthy stays. CTRs bring those responsible for the care of

those who are in, or at risk of being admitted to, specialist hospitals around the table with the individual themselves and their family to ensure that the care needs of that individual are being met

62. NHS England has already included provision for CTRs in planning guidance for 2015/16 and is expecting these to become embedded as 'business as usual'. We heard strong feedback about the expected impact this will have in reducing admissions, particularly how it involves individuals, commissioners and clinicians in coming to a joint decision.

63. We intend to gather learning from the introduction of CTRs, including about the costs of implementation, and

- consider how best to ensure that the core elements of these processes are mandatory in future, whilst also enabling personalisation for individual circumstances, and
- consider how to extend CTR principles beyond those in or 'at risk' of admission and to people covered by local authority-funded placements.

64. Our aim is to ensure that local commissioners follow these principles in the longer term, apply them more widely, and ensure this good practice is sustainable. We intend that this will both radically reduce admissions and facilitate quicker transfers and discharges, especially when individuals or their families and carers request it.

65. We will consider how learning from implementation of CTRs can inform the Care Programme Approach (CPA), and whether this guidance could helpfully be updated/expanded.

66. Evidence shows that being part of the community and being able to live near family and friends is a key contribution to physical and mental health wellbeing. The

issue of delays to discharge is therefore very important. People should only remain in hospital when strictly necessary for clinical reasons: any undue delay in transfers when they are assessed as fit for discharge into the community is unacceptable. We will consider taking further steps if necessary to ensure services meet their responsibilities for timely discharge.

*Professional challenge, accountability and single point of contact*

67. Respondents were clear that, as well as individuals and their families and advocates being able to challenge decisions, there was need for greater professional challenge. This needed to be independent but professionally-based so that challenge could be made across the health and care system. Ensuring sufficient transparency and accountability for individuals and families was also a key change requested.

68. Questions on a named single named social worker and single professional responsible for providing information were seen as key means of achieving this. This would enable professional challenge and a single point of contact for individuals and their families regardless of where care is being delivered and in particular when things go wrong.

69. The Government intends that people at risk of being admitted to hospital will have access to a single named social worker who is accountable for their care and support. We expect that this will be a named social worker rather than a named health professional, given the need for challenge to and independence from clinical teams and for the individual to benefit from this role whether they are living in the community or hospital.

70. It is currently envisaged that this would work in a similar way to Approved Mental Health Professionals (AMHPs)

who are professionally responsible for delivering functions for a local authority and provide professional challenge in relation to the Mental Health Act. We see the role as championing the rights and views of vulnerable people, listening to people, understanding their wishes and desires, supporting them to live independently and in the least restrictive setting, and challenging other professionals in the system whilst being a partner in the system.

71. We appreciate that this will take some time to put into effect, and will require increases in workforce capability and capacity. Given concerns about people being located out of area it is important that we have a single nationally applied system. We will introduce a pilot scheme with a view to phased roll-out and consider possible legislative underpinning based on evaluation and resourcing. However, we will encourage localities to put this into practice themselves where this can be achieved more quickly.

*Involving experts by experience in governance and oversight*

72. A number of responses pointed to the need for greater involvement of service users and carers in governance and oversight and commissioning decisions. Different ways were suggested as to how this could best be achieved. For example, NHS England intends to develop guidance to promote the involvement of experts by experience and to explore whether further provisions can be incorporated into the NHS standard contract.

73. However, we do believe that guidance for commissioners could helpfully reinforce the need to involve people with learning disabilities/autism/mental health problems in the design, development and delivery of services, in a spirit of co-production, as the best way to ensures services meet requirements.

74. At local level, we encourage Health and Wellbeing Boards, CCGs and local authorities to ensure that learning disabilities are included in their joint strategic needs assessments (JSNAs) and local plans, to involve those with lived experience in meaningful ways in drawing these up, reviewing and reporting on progress, and to ensure the outcomes are publically available.

### **What we propose**

75. In response, we propose the following actions:

- **consider how Care and Treatment Review principles/processes can (i) be extended to local authority-led and other placements and (ii) be strengthened, including if necessary by statutory force**
- **consider how learning from implementation of CTRs can inform the Care Programme Approach (CPA), and whether this guidance could helpfully be updated/expanded**
- **(subject to the Law Commission’s consultation in the context of Deprivation of Liberty safeguards) consider introduction of a single advocacy model bringing together existing statutory schemes (including Independent Mental Health Advocates and Independent Mental Capacity Advocates) and providing these on an opt-out (rather than opt-in) basis**
- **pilot access to a named social worker who will provide professional advice and support, be the primary point of contact for the service user and their family/carers wherever the person is being supported, and provide a professional voice across the system**
- **strengthen work being undertaken as part of the Transforming Care**

### **Programme’s ‘empowering people’ workstream and/or the Department’s strategic partner programme to:**

- **build on the new accessible information standard to ensure that people receive information in formats that they can understand, and that they receive appropriate support to help them to communicate**
- **build on the proposal of a (non-statutory) ‘Charter of Rights’ to provide definitive and accessible information on their rights, and how to access support to exercise them, and promote use of advance statements**
- **guidance for commissioners of health and social care services on involving people with learning disabilities/autism/mental health conditions in the design, development and delivery of services**
- **monitor implementation of the new service model for commissioners of health and social care services, and of Care and Treatment Reviews on care planning, admissions, transfers and discharges and consider the need for further legislative proposals in response to a review of impact.**



## I have clearly stipulated rights within the Mental Health Act

76. Questions under this heading reflected concerns that, despite the rights, protections and safeguards that the Mental Health Act affords, these were not being applied in practice, and that in some areas changes were required to ensure people were adequately protected.

### What we heard

77. Overall, we received a range of responses to these questions. In some areas there was strong support for change, and in other areas this was more mixed. Respondents were clear that any proposed changes needed to be worked through and the impacts fully considered to ensure there would be no adverse or unintended consequences.

78. It should be noted that many of the proposals will not apply to those mental health patients, including those with learning disabilities or autism, detained under Part 3 of the Mental Health Act, who may also be subject to Secretary of State for Justice restrictions under that Act.

### *Rights under the Mental Health Act 1983*

79. There was strong support for making the Code of Practice statutory guidance for NHS commissioners, as it is for NHS-funded providers, local authorities and professionals. This was seen as important for culture change and to improve practice, and we intend to amend the legislation accordingly.

80. Respondents commented that the impact of the new Code of Practice should be evaluated to see whether it delivers the required changes to culture and practice. In many of these areas, we intend to review the effects of implementation of the Code – informed by the Care Quality Commission's

inspections and annual report – once it has been in force for a year, and determine then what further changes may be necessary. In the meantime, we will work with stakeholders to explore those areas where it is felt that change is required but more work is needed to determine how.

### *Learning disabilities/autism and the Mental Health Act*

81. Responses in relation to questions about removing people with learning disability and autism from the scope of the Mental Health Act (so they could not be detained unless they also had a separate diagnosable mental health condition) received a very mixed response. Whilst some stakeholders, especially individuals, their families and supporters, and the voluntary and community sector were keen on the principle that some sort of change was needed, far fewer expressed a strong preference for any of the options put forward. A range of responses highlighted the risks of potential unintended consequences for each option, including how this might affect options for treatment for people who had committed offences. It is clear from the range of responses that there was no clear mandate for changing existing legislation in any particular direction. There was a desire to consider further the potential impacts of each of the possible changes and the specific effects that the new guidance in the Code of Practice is having on workforce practices.

82. These are important issues and considerations. We are convinced that these proposals will require much more exploratory work before moving on to any form of legislative change. We propose to undertake that work, making full use of the suggestions and advice given to us in responses to this consultation, and having taken full account of the range of possibilities and impacts. We will consider the best way to achieve this.

83. Likewise, we received a very mixed response in relation to the question about whether a single gateway or admissions process should be introduced, replacing or combining the existing sections 2 and 3. There were concerns raised about what this would mean in practice and how the safeguards of both systems could be ensured and costs maintained. Based on this feedback we are not inclined to pursue this idea, although we will ensure that it is considered as part of further work.

*Supporting people to exercise their rights under the Mental Health Act*

84. The provisions consulted under this heading received a range of different responses. Respondents were broadly supportive of proposals to change the default position for people lacking capacity, so that they would automatically be offered the support of an Independent Mental Health Advocate (which they would have the option to refuse), rather than having to actively request it.

85. Giving people more say in determining who their nearest relative can be also received strong support from service users, carers and advocacy groups, although some professionals raised concerns about how this might work in practice and about possible unintended consequences. Several of these issues and interfaces with other initiatives (e.g. on supporting and involving carers) require further thought.

86. A range of views were provided on improving decision-making processes and Community Treatment Orders, with comments reflecting two broad themes: how to improve participation of the individual, their families and carers and how to make decision-making processes clearer, more consistent and effective. The latter especially referred to the disparity between safeguards

on decisions to renew detentions and perceived conflicts of interest under current arrangements.

87. Given the breadth of views, and the risks that were raised, in particular the need to avoid unintended consequences, we consider that further work is needed before we can offer specific proposals. As a first step, we will use the feedback gained from the consultation to develop a clearer picture of the risks and issues that need to be considered. We will then engage with stakeholders on how best to ensure an effective set of proposals can be put forward.

*Supporting implementation of the Mental Capacity Act*

88. The individuals this work seeks to support may lack the mental capacity to make decisions about aspects of their care, treatment, where they wish to live and potentially other life choices, big and small.

89. The Mental Capacity Act 2005 (the MCA) provides the legal framework for such decision-making. It emphasises the need to support individuals to make their own decisions wherever possible and provide the least restrictive care. Where an individual lacks the capacity to make a decision, the MCA emphasises the importance of their previously expressed wishes and preferences, and of consulting with family in reaching a best interests decision.

90. Evidence shows that MCA implementation is not of an acceptable standard and as such the Department of Health has a programme of work in place to address this – working closely with its partners. We have recently published an update on progress in this area.<sup>5</sup>

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<sup>5</sup> <http://www.scie.org.uk/mca-directory/keygovernmentdocuments.asp>

91. Our major initiative for the next year is the establishment of a new National Mental Capacity Forum. Bringing together a wide range of organisations with responsibility for implementing the MCA, the new Forum will develop tangible actions to boost awareness of individuals' rights under the Act. This will be crucial in supporting our ambitions for those with learning disabilities. The Forum will contain specific learning disability expertise.

*Interactions with the police and criminal justice system*

92. Building on previous feedback, we received very strong messages of support on not using police cells as places of safety for under-18s and that no one should be held in a place of safety under sections 135 and 136 for more than 24 hours.<sup>6</sup> We know that there has also been significant progress in how sections 135 and 136 operate since the consultation document was published in March and are keen to ensure this is maintained. Some responses also highlighted practical issues of implementing the recommendations, including ensuring there were suitable alternatives. Very few responses supported extending powers to paramedics. We received some strong opposition to this suggestion, with the main concern being that this would fundamentally change the purpose of these sections which are about powers of the police.

93. The Home Secretary has reaffirmed the Government's commitment to taking forward the recommendations of the s135 and s136 review in 2014 involving legislative change as quickly as possible, subject to the outcome of this consultation. She also announced up to £15million would be available to improve and increase the availability of health-based places of safety. Because these changes relate specifically to police powers, there is

scope for the necessary amendments to be taken forward through the Policing & Criminal Justice Bill announced in the Queen's Speech.

94. We heard concerns about circumstances that have arisen where a person detained as a restricted patient under Part 3 of the Mental Health Act via the criminal justice system no longer requires hospital inpatient treatment and could be accommodated in a less restrictive setting subject to conditions that amount to a deprivation of liberty. Approximately two-thirds of those who responded to these questions were in favour of amending the Act to allow for these individuals to be discharged from hospital in some way and moved to a less restrictive setting, but where that setting would still amount to a deprivation of liberty, provided any changes were compatible with wider human rights and equality legislation, and provided there were no unintended consequences.

95. In July, the Upper Tribunal issued its decision on the case of *the Secretary of State for Justice vs. KC*. This case gave further clarification about the circumstances in which a restricted patient lacking capacity could lawfully be discharged from hospital into a community setting on conditions amounting to a deprivation of liberty. There is ongoing litigation following on from the decision in KC which may further change the position.

96. We will need to consider whether similar concerns arise in the case of unrestricted patients detained pursuant to Part 3 of the Mental Health Act, and whether and how any changes should apply to such patients.

97. Much more preparatory work is needed before we can progress with legislative changes. However, we recognise the desirability of amending the Mental Health Act to deal with patients in these circumstances.

<sup>6</sup> <http://www.scie.org.uk/mca-directory/keygovernmentdocuments.asp>

The Department of Health will need to work with the Ministry of Justice on this issue.

98. The Law Commission's consultation on the Mental Capacity Act 2005 and the Deprivation of Liberty safeguards (DoLS), which closed on 2 November, also considered relevant issues and proposals we will need to consider alongside proposals for changes to the Mental Health Act.

### **What we propose**

99. In response, we propose the following actions:

- **recognising the issues for people with learning disabilities, autism and mental health conditions in the criminal justice system:**
  - an end to the use of police cells as a place of safety for children and young people detained under sections 135 or 136 of the Mental Health Act 1983
  - no one detained under sections 135 or 136 to be held in a 'place of safety' for more than 24 hours without being assessed by a relevant professional and either discharged or admitted (this and the above to be achieved via the Policing & Criminal Justice Bill together with other changes resulting from the review of sections 135/136)
- **subject to further consultation, make changes to the Mental Health Act 1983:**
  - enabling patients and families to challenge whether their wishes and feelings were appropriately considered when making applications for detention
- **amending provisions regarding "nearest relative" to ensure this meets the wishes and needs of people subject to the Act**
- **making the Mental Health Act Code of Practice statutory guidance for NHS commissioners as it is for professionals, local authorities and providers**
- **review safeguards regarding renewals of detention (e.g. expansion of requirement for an independent second doctor's opinion)**
- **propose amending the Act to make provisions about the discharge of patients to community placements amounting to a deprivation of liberty**
- **further consideration in principle of whether and how the Mental Health Act should apply to people with learning disabilities and/or autism and if this remains appropriate.**

I am able to exercise control over the support I receive with a personal budget, and I expect different health and local services will organise themselves around my needs

100. Under this heading, the consultation looked at issues to ensure accountability, transparency, integration, funding and responsibility across the system, especially for individuals and their families. The overarching aim of the proposals in the consultation was to put people and their families at the heart of the health and care system. They know and understand their needs and circumstances better than any commissioner, provider or professional. At local level, people should have a greater role in service commissioning, planning, delivery and oversight. For individuals, we need to empower people to make informed choices and decisions about the support they need, and when and who should provide that support. Integration between health and social care and other sectors is a key part of this.

101. Since the consultation was launched there has been considerable progress, including implementation of the Care Act 2014, introduction of the Integrated Personalised Commissioning (IPC) programme, and development of a new service model to address many of the issues raised. In most areas, responses to the consultation indicated that the impacts of recent and planned developments need to be built on, with greater promotion and cultural change and transparency through data collection, reporting and monitoring to ensure compliance.

## What we heard

### *Integration and funding of services*

102. Three questions considered how best to integrate the commissioning and funding of services, including whether to do this at a locality or population level or to do this around individuals.

103. Organisations need to work together to develop joined-up and holistic solutions that work for and around the individual rather than along system lines. This includes making decisions earlier in the care pathway, and, where possible, including wider social determinants including housing, education and employment. Addressing these in isolation will not bring about the required results.

104. People and their families told us that what matters to them is getting high quality care locally, not who commissions their care or funds it, and that services should work effectively together in a seamless way. People tell us that this works best where services are integrated and co-commissioned across health and social care where budgets are pooled or combined to do this. Responses were clear that this needed to be accompanied by further integration of the commissioning and delivery of services to be effective. Lack of funding, especially in certain parts of the system, and integration were consistently cited as major obstacles to progress.

105. However, we know that fewer than a third of localities currently do this voluntarily for people with learning disabilities and that there are considerable disincentives to their doing so. Whilst the Government has enabling powers through section 121 of the Care Act to mandate CCGs to pool funds, given that significant proportions of care for these groups is currently directly commissioned by NHS England, the relatively

small amount of CCG spend and emerging evidence from the existing Better Care Fund, coupled with moves to devolve power to localities to devise their own solutions, means we are not convinced that making pooled funds mandatory is the best way to meet the needs of local people.

106. There would be significant issues in ring-fencing social care contributions in practice, including the small numbers in each locality, such that this might make such a scheme non-viable in practice. Moreover, in many cases, needs are complex and require highly personalised approaches. This points towards integration around the individual, rather than at the level of organisations.

107. We will work with NHS England, the LGA and ADASS to encourage localities to pool budgets where they consider this is right for their local populations, including for people with less complex needs, but we do not propose to mandate that this must happen everywhere.

108. As described earlier, for children and young people the new system for SEND provides a framework for joint working across health, social care and education introduced in 2014. It requires local authorities and health commissioners to jointly plan and agree the services which will be provided for children with SEND needs. The Department of Health will continue to work with Department for Education to support local authorities and CCGs in implementation, providing guidance on how they can tackle local challenges together.

109. The Department of Health will also work with the Department for Business, Innovation and Skills (BIS) to ensure that young people and adults with learning difficulties and/or disabilities and mental health conditions are able to access good quality further education (FE) and skills training to help them gain the skills they need to secure sustainable

employment, participate in their communities and lead more independent lives.

110. Many FE colleges and local authority adult education services have developed innovative ways of responding to the needs of disabled learners and are working with a wide range of partners. 62 BIS-funded Community Learning providers are currently trialling courses specifically targeted at adults aged 19 and above with mild to moderate mental health problems such as depression, anxiety and sleep disorders. At national level, the project is working closely with the Department of Health and the Department for Work and Pensions. At the local level, learning providers are developing courses in partnership with their local Jobcentre Plus and mental health services in order to complement interventions such as Improving Access to Psychological Therapies (IAPT), Recovery College courses and other locally-commissioned activities to support and improve mental health.

#### *Personal budgets*

111. Personal health budgets were seen as a strong way of giving individuals choice and control about decisions affecting them, enabling people within an agreed care plan to commission services they considered would best meet their needs and wishes. This is firmly in line with the remit of this consultation to support and develop the rights of people with learning disabilities, autism and mental health conditions, building on existing rights in the Care Act and for those in receipt of NHS Continuing Health Care.

112. NHS England has set a clear expectation for CCGs to expand the use of personal budgets, with a requirement that the local offer specifically includes people with learning disabilities by April 2016, and has put a support programme in place for local areas to achieve this.

113. We will take steps to promote transparency and accountability to show how many personal health budgets are offered so we can tell what progress is being made. CCGs are already required to set out the expanded offer in the local Joint Health and Wellbeing Strategy. At the centre we are currently considering how to develop official data collection measures – likely to be via the CCG scorecard and/or integration scorecard – to give a realistic picture of what is happening. In addition, we also expect the information from the pilot IPC programme to include information on how areas might be able to implement a joined up approach, how many budgets were offered/given, and outcomes. This is a key area in which the Government will intervene further, including via legislation if necessary, if the improvements sought are not being realised in practice.

#### *Information sharing*

114. There was strong support for ensuring information was shared appropriately but there were concerns about how this was being applied in practice. An individual's personal information and confidentiality should be protected, but legitimate sharing of information for a variety of purposes should also not be impeded unduly.

115. Respondents were clear that difficulties encountered by CCGs in accessing patient-level data have served as a major obstacle to reducing the admission of those with learning disabilities to inpatient settings. In particular, when dealing with people with complex care needs, a deficit of information on the part of CCGs means that they are unable to effectively plan for a reduction in the level of care provided when a person moves from an inpatient setting back into the community.

116. The PMIU review *Admissions to Inpatient Learning Disability Beds* made two recommendations with regard to improving

information sharing: (i) NHS England should provide template information sharing agreements and associated guidance to CCGs, and (ii) new legislation concerning information governance should be introduced.

117. In light of this, the Department of Health is helping to develop guidance on ensuring that information is shared and that, where possible, consent for information sharing is obtained, in accordance with the law, professional standards and good practice. This will be shared with provider organisations and commissioners. Further, in addition to generic guidance, the Department is designing a consent template which can be used by organisations. The guidance and the consent template will be trialed across the six 'Fast Track' sites and then updated in accordance with lessons learned. The resource for this project is being jointly provided by the Department of Health, NHS England and the LGA.

118. In terms of wider work being done in the Department of Health to overcome systemic barriers to information sharing, many of the work streams feed into the proposals arising out of the National Information Board (NIB) framework for action, *Personalised Health and Care 2020: Using data and technology to transform outcomes for patients and citizens*, which was published in November 2014. It was recognised that better integration of patient information will mean that patients do not have to tell their story repeatedly in different care settings. This will result in more efficient working, improved care, and support that is better-tailored to the patient. In particular, work stream 4 arising out of the framework for action, 'build and sustain public trust', is playing an important role in promoting safe and appropriate information sharing.

119. Our aim is to demonstrate to the public that information is held and used securely,

giving them confidence that this information should be available in both health and care settings. Accordingly, the following actions are being taken:

- a review of the effectiveness of current approaches to cyber-security in NHS organisations in relation to patient data will be carried out by the CQC. The National Data Guardian for Health and Social Care, Dame Fiona Caldicott, will contribute to this review by developing clear guidelines on data security against which every NHS and care organisation will be held to account. She will also provide recommendations on a new consent model which will make it absolutely clear to patients, and users of care, when data about them will be used, and in what circumstances they can opt out. The work will be completed in January with recommendations on how the new guidelines can be assured through CQC inspections and NHS England commissioning processes
- the Department of Health is also consulting on the role of the National Data Guardian to identify what issues the role should prioritise and the extent of its remit, and
- the Information Governance toolkit (which provides a roadmap for achieving excellent information governance) is to be refreshed and relaunched.

120. Further work related to overcoming barriers to information sharing has arisen out of work stream 1 from the framework for action, 'Enable me to make the right health and care choices'. Specifically, nhs.uk is being developed into a new integrated health and care digital platform, which will include access to personal health records. In addition, the MyNHS data service on nhs.uk will be expanded to include new scorecards, expanded coverage of patient

experience and regular themed reports. This will help people to make informed choices about where they get their health care from.

121. We will consider what further actions are required in relation to the care of people with learning disabilities, autism and mental health conditions, in order to embed these solutions to generic data governance issues, especially where data sharing is currently impeded, where this would meet aims of good commissioning practice and improved patient care.

#### *Accountability and transparency*

122. Whilst existing health and care legislation sets out responsibilities across the system, respondents felt that in some circumstances greater clarity on the roles of individuals and organisations would be beneficial. Much of the feedback received related to existing systems and processes to ensure appropriate local accountability. To address these concerns it is important that local health and care organisations:

- ensure that information is available locally to individuals and their families, including in accessible formats, about the responsibilities of local organisations and how they can seek redress for concerns
- encourage and ensure delivery, and expand existing arrangements providing joint accountability across health and social care with greater involvement of voluntary sector partners
- promote and encourage greater involvement of individuals and family carers in informing service commissioning, development and delivery
- involve experts by experience in monitoring and inspecting services, and
- ensure greater transparency and reporting of issues and decisions relating



to people with learning disabilities, autism and mental health conditions.

123. These proposals are designed to ensure greater and more robust accountability at a local level and to involve those with lived experience as the people who know best what matters most. One way of doing this is by being transparent with clearly published plans, audits and reports, enabling local people to hold statutory bodies to account.

124. Local Health and Wellbeing Boards have a particularly important role to play in this process including giving oversight and support to their member agencies to take forward the reshaping of services, and by providing local accountability.

### **What we propose**

125. In response, we propose the following actions:

- **review data available for local and national transparency and accountability with metrics including:**
  - **delayed discharges**
  - **personal budgets/integrated budgets**
  - **integrated personal commissioning**
- **work with NHS England and the Local Government Association to develop guidance and tools (e.g. consent templates) to ensure information is shared legitimately and in accordance with professional standards and good practice, and**
- **consider what further actions are required to embed solutions to generic data governance issues, especially where data sharing is currently impeded in relation to the care of people with learning disabilities, autism and mental health conditions,**

**where this would meet aims of good commissioning practice and improved patient care.**

I know that professionals are looking out for my physical health needs as well as my mental health needs.

126. Everyone has exactly the same entitlements to receive good physical and mental healthcare, and existing legislation sets out responsibilities across the health and care system. Potential lack of clarity relating to who is responsible for a people's physical health when they are admitted is a particular concern for people with a learning disability or autism where symptoms of physical problems could be misunderstood to be related to the learning disability or autism.

### What we heard

127. Respondents were clear that in some circumstances there is a need for greater clarity on the responsibilities of organisations and of individuals to ensure that an individual's physical and mental health care needs are fully considered and supported, wherever they are located.

128. This is particularly true in supporting the physical health needs of individuals in long-term mental health hospitals, especially out of area, where access to their local GP (e.g. because they are located in hospital some distance away) means they effectively become de-registered when being admitted to hospital. Some physical healthcare services may not be readily available, particularly when an individual is in some secure services.

129. Overall, two thirds of responses said that responsibilities should be clearer, but there were a range of comments on where responsibility should lie and how services could be provided. Our aim is to ensure more areas get better at identifying and addressing people's needs by ensuring they have regular

care reviews or checks and have a care plan which includes all issues that need to be addressed.

130. We wish to promote improvements in practice within the current system, to ensure that all needs of an individual are effectively supported. We do however consider that more needs to be done especially when people are located out of area or for a significant period of time, to ensure that this always happens. Everyone should have access to a GP. This is an important right in the NHS and one that people in hospital should not be denied.

131. The Care Act statutory guidance clarified responsibilities in relation to social care in prisons, and the new MHA Code of Practice gives guidance to promote the support of physical needs for people under the Mental Health Act, including diet, nutrition, screening, check-ups and reasonable adjustments.

132. We intend to clarify the roles and responsibilities in guidance for commissioners in relation to supporting people with learning disabilities, autism and mental health conditions. We think that, combined with the recent changes, this will significantly address issues of premature mortality, co-morbidities, diagnostic overshadowing and lower satisfaction with services.

### What we propose

133. In response, we propose the following actions:

- **guidance to commissioners of health and social care services to clarify responsibilities for ensuring physical healthcare needs are met alongside mental health needs**
- **subject to further consultation, make changes to the Mental Health Act 1983 regarding responsibility to ensure**

physical care needs are met for mental health inpatients/detained patients to ensure the individual is registered with a general practitioner and is able to benefit from programmes such as individual health checks, screening tests and health action plans.

## Conclusion

134. Disabled people, including those with learning disabilities, autism, mental health conditions and/or behaviour that may be challenging have the same rights as everyone else. Our expectation is that people should be supported and empowered in securing these rights and that this should already be happening. This should be within the power of people, their families, carers and advocates, but we know that too often people are not enabled to access these rights and do not know always what they are. Staff, whether they be health and care professionals, commissioners, regulators, or policy makers, should all be doing everything they can to ensure this is a reality.

135. We all have a vital role in making change happen. This requires a profound power shift to help people move from being passive recipients to active citizens, treated with dignity and respect.

136. We encourage everyone working in health and care to prioritise these issues and address the concerns of local people. The consultation reflected clear messages on the need to support people to be included and to live independently in their community, rather than in hospital. Not only is care in hospital not what people tell us they want, we also know that care in the community can cost the system less. The proposals in this document are therefore a key feature of the Secretary of State's priorities to deliver better quality of care with better outcomes for individuals, to improve out-of-hospital care and also to achieve, but also to deliver greater efficiency and value for the tax payer.

137. We look to commissioners, providers, local authorities, the voluntary sector, professionals and experts by experience to drive these changes forward locally, enabling people to live independent and fulfilling lives.

People who use services, their families, carers and advocates know best what is important to them and what will make a difference. We need to listen to people and ensure that we work together to realise our shared ambition.

## Annex: Consultation process and key themes

The consultation ran from 6 March to 29 May 2015.

It covered potential measures in England, but noted that as the Mental Health Act applies across England and Wales, any changes to the law in Wales would have to be agreed by the National Assembly for Wales.

The Department sought responses from a wide-ranging audience, disseminated information to organisations and stakeholder groups, and publicised the consultation using social media and blogs.

An Easy Read version of the consultation document was also available. In addition the Department supported a number of meetings and events for individuals and families to discuss the issues raised. We are grateful to everyone who took part or contributed their views directly.

The Department asked an independent organisation, the Evidence Centre, to analyse every response to the consultation and draw together the main themes from all of the responses. The detailed analysis is published alongside this Government response.

Overall there were 481 responses from 468 different individuals, groups or organisations. 47% these came from individuals and 53% from organisations or groups. Responses were received from across England.

Of the 219 responses from individuals, 198 provided details about who they were. Half of these identified as a service

user or carer, friend of a service user or family member. Half of the responses from individuals (54%) also stated that the person providing feedback had either a mental or physical health issue, or disability. Responses were also received from health and social care professionals, support workers, advocates and others. The main groups who responded were the voluntary sector (54%) including larger national and smaller more regional organisations, local authorities (18%) and NHS organisations (12%).

Across the consultation, four key themes emerged as priorities. Proposals in the following areas were considered to have the most benefits:

- increased provision of services in the community.
- better engagement of service users and families in discussion.
- joint commissioning between health and social care; and
- ensuring accountability and transparency across the system for individuals and their families.





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